

AN ABSTRACT OF THE DISSERTATION OF

Deborah Padgett Coehlo for the degree of Doctor of Philosophy in Human Development and Family Studies on June 8, 1999. Title: Residential Placement of Patients with Dementia: Relationship to Care Recipient and Caregiver Variables.

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The occurrence and timing of residential care of patients with dementia is impacted by several care recipient and caregiver variables. Previous research has shown a strong relationship among residential placement and marital status, cognitive decline, deterioration in functional abilities, and presence of behavior problems in the care recipient. Research on caregivers has shown that, as the stress of caregiving increases and the well-being of the caregiver decreases, residential care is more likely to occur. Previous studies, however, have not explored the impact of problem behaviors over time or the impact of caregiver variables on the timing of residential placement. This study was designed to examine the relationship among care recipients' change in behavior over time and caregivers' physical and mental well-being and the occurrence and the timing of residential placement.

The sample used for this study was derived from a larger sample identified as having dementia at the Oregon Alzheimer's Disease Center at Oregon Health Sciences University. The caregivers of these patients were sent a questionnaire

asking about physical and mental well-being and the current placement of the care recipient. From the returned questionnaires ($n = 100$), a subset of caregivers ($n = 23$) identified as having chosen residential care for their relatives were interviewed regarding the timing and reasons for residential care.

Relationships among residential placement of patients with dementia and several care recipient and caregiver variables were shown in this study. Multiple regression equations indicated a significant relationship between the caregiver scores on the CES-D, caregiver employment status, Activities of Daily Living (ADL) scores, and behavior change over time of the care recipient and the occurrence of residential care of the care recipient. Further, a Cox proportion model illustrated that depression and employment status of the caregiver, type of relationship between caregivers and care recipients, and ADL and behavior change scores in the care recipients were significantly related to the timing of residential care.

**Residential Placement of Patients with Dementia:
Relationship to Care Recipient and Caregiver Variables**

by

Deborah Padgett Coehlo

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Residential Placement of Patients with Dementia: Relationship to Care Recipient and Caregiver Variables

Introduction

The decision to place a loved one in a residential care facility is often one of the most difficult decisions made in families. This decision is fraught with guilt, concern over the care and safety of the loved one, and concern over personal well-being. Research designed to identify variables that predict when a patient will be admitted into a residential care facility has grown over the past two decades. This trend is largely due to a societal belief that home care is preferable to residential care and to the increasing concern over the cost of institutional care in an aging population (Meek, McKeithan, & Schumock, 1998).

Many of the previous studies on residential placement have been limited to caregiving of patients with dementia. This trend can be linked to the increased numbers of aging adults with dementia-related illnesses in our population, and the pattern of patients with dementia being the most likely to be placed in residential care when compared to any other diagnosis (Brody, Powell, Lawton, & Liebowitz, 1984; Snowden, 1993).

Although many factors enter into the decision of where to care for an aging relative, problem behaviors may be an important factor in increasing the burden of caregiving to the point that home care is no longer possible. The purpose of this study

was to examine the relationship between characteristics of a person with dementia and the caregiver, and the likelihood and timing of residential placement.

Previous research on variables influencing residential care for persons with dementia has had mixed results. Many variables have been considered when attempting to explain why some, but not all, persons with dementia are placed in residential care and when the transition between home and residential care occurs. The variables studied in the past can be divided into three main areas of interest. These include looking at (a) care recipient or patient variables, (b) caregiver variables, and (c) societal variables. Many theoretical frameworks have been used. Two theoretical models used often include the stress-adaptation model and models of health care utilization. The results from these studies have varied depending on the focus and the theoretical framework used, with several researchers finding caregiver variables more influential than care recipient variables, and other researchers finding the opposite pattern. The results, however, have emphasized how complex and interactive the variables are that influence residential placement decisions.

Problem behaviors have been investigated by several researchers as part of the web of interacting variables that influence residential placement. The problem behaviors examined include aggression, wandering, poor sleep patterns, delusions and hallucinations, and apathy. Aggression has been the most common problem behavior investigated, largely due to the difficulty both caregivers and residential care staff have coping with this kind of behavior. The investigation of problem behaviors, however, has rarely been the focus of these studies. Further, longitudinal studies

looking at change in behaviors and the impact on caregivers over time have not been done. Nevertheless, these studies have identified the negative influence of these behaviors on caregiver's well-being and the effect on early residential placement. Further, problem behaviors have been identified as a key factor hindering residential placement as many facilities refuse to accept patients with aggressive or disruptive behaviors.

This study will use longitudinal data on care recipients' behaviors over time to assess the impact of change in problem behaviors on whether residential care was used. The study utilizes a theoretical framework based on ideas from the stress-adaptation model. This model was chosen to illustrate the interactive effect of behaviors on the care recipient, the caregiver, and the transition from home care to residential care. The goal of this study is to provide information for clinicians, caregivers, and residential facilities on the extent to which problem behaviors may influence placement of care recipients in residential care thereby guiding interventions to (a) assist families in coping with or decreasing problem behaviors, or (b) assist families and residential staff in caring for a patient with problem behaviors in the best environment possible.

Miller and McFall (1991) suggested that an essential factor to investigate in future research on residential placement is the impact of change in care recipients' abilities and caregivers' capabilities on admission risk. Schulz and Williamson (1994), in their review of the caregiving literature, emphasized the need to investigate further the impact of caregiving tasks on the physical and mental health of caregivers. These

and other researchers support the idea that predicting when a patient with dementia will be admitted to residential care continues to be a growing need. Looking more closely at the relationship of problem behaviors over time and whether residential care is used and the timing of the transition from home to residential care will address these needs.

Research Questions

1. Do the severity and frequency of problem behaviors in the care recipient over time significantly affect the likelihood and timing of admission into residential care?
2. Are there differences in caregiver or care recipient characteristics, including age, sex, marital status, relationship, education level, and hours of outside employment between those families choosing residential care and those families choosing to care for their relative at home? Further, do these variables affect when the transition from home to residential care occurs?
3. Does caregiver well-being, as measured by both physical and mental health scales, affect the likelihood and timing of residential care for the care recipient?

Definition of Terms

Care recipient. Care recipient refers to patients diagnosed with dementia who require care from others to assist with activities of daily living (Stone, Cafferata, & Sangl, 1987).

Caregiver. Caregiver, in this study, refers to individuals who assist patients with dementia in activities of daily living. This assistance is unpaid and the care recipient is dependent on that aid, and generally includes some degree of dressing, feeding, bathing, and assuring the safety and health of that individual (Walker, Pratt, & Eddy, 1995). The caregiver is generally a relative or close friend of the patient.

Residential Care. Residential care refers to any living arrangement outside of the patient's home where care is paid to provide assistance with activities of daily living. This arrangement can include foster care, an assisted living facility, group home, and/or nursing home.

Problem Behaviors. Behaviors that are disruptive to the relationship between the care recipient and caregiver, and have been shown to affect caregivers' well-being negatively, including aggressive, delusional, apathetic, and irritable behaviors, and changes in sleep and appetite.

Chapter Two: Literature Review

This literature review provides a summary of previous research on when and why caregivers place a relative in residential care. Although a majority of the studies included in this review were done on patients with dementia, several studies investigating caregiving and/or residential care placement included other chronic illnesses requiring extended caregiving such as cerebral vascular accidents, myocardial infarctions, and cancer. This summary will be followed by a description of important theoretical models utilized in both caregiving literature and in studies focused on residential care use. These two areas will then be synthesized to outline the importance of the present study.

The Decision for Residential Placement

The decision to place a loved one diagnosed with dementia into residential care is a difficult, but an increasingly likely judgment many families have to face. Our population is an aging one, and the incidence of dementia grows with age (Meek, McKeithan, & Schumock, 1998). It is estimated that approximately 4 million Americans have Alzheimer's Disease and other related dementias (Meek, McKeithan, & Schumock). Further, it is estimated that up to 75% of those diagnosed with dementia will spend some time in a residential care facility (Meek, McKeithan, & Schumock). Walsh, Welch, and Larson (1990) found that out of 123 patients diagnosed with Alzheimer's Disease, 92 (74.8%) required nursing home care for an average of 2.75 years. During a comprehensive, longitudinal study of 555

caregiver/recipient dyads involving patients with dementia, Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch (1994) found that 43% of their sample were placed in residential care within three years after entering the study.

This trend is costly to both families and society. Although many options are now available for out-of-home placements, nursing homes continue to be the most likely residential care facility chosen for patients with dementia (Meek, McKeithan, & Schumock, 1998). The cost of nursing home care for patients with dementia for one year is estimated at \$36,230 compared to \$18,931 if cared for at home, based on the direct cost of services provided (Meek, McKeithan, & Schumock). Critics of these estimates point out that care at home is more costly than residential care if indirect costs (e.g., lost wages, and increased health care needs of the caregiver) and unpaid labor (e.g., cost of unpaid caregiving) are considered. Nevertheless, residential care often places a significant financial burden on families and society (Meek, McKeithan, & Schumock). Further, approximately 15% of residential care residents are believed to be placed needlessly in high levels of care, and could, if support was available, be cared for at home (Spector, Reschovsky, & Cohen, 1996). Because of this cost, many researchers and clinicians have attempted to identify factors that predict residential placement in order to identify interventions that may delay or prevent this placement. Previous studies have focused on variables in three main areas care recipient, caregiver, and societal.

Care Recipient Variables. Care recipient or patient variables investigated include age, gender, marital status, cognitive ability, ability to care for daily needs,

and presence of problem behaviors. The age of the care recipients entering residential care is generally older than those remaining at home, which is consistent with reports of diminishing cognitive ability with age in patients with dementia (Aneshensel et al., 1994; Jagger & Lindesay, 1997; Montgomery & Kosloski, 1994; Pruchno, Michaels, & Potashnik, 1990). Research into gender has had more mixed results, with most studies indicating women are more likely to spend time in residential care than men (Colerick & George, 1986). This gender difference is dependent somewhat on the marital status of the women, with single, older women with few family contacts being more likely to enter residential care than are married women. In general, married persons are more likely to be cared for at home than single persons and spouses are less likely than other relatives to choose residential care. This partially explains the trend of women being more likely to spend time in residential care, as women and men care for their spouses at home, but women are more likely to outlive their spouses. Once women are living alone or with children, their risk for institutionalization increases (Colerick & George, 1986; Freedman, Berkman, Rapp, & Ostfeld, 1994).

Cognitive impairment in the care recipient alone was not found to be the most influential factor predicting admission into residential care in several studies (Cohen et al., 1994; Lieberman & Kramer, 1991). The relationship between cognitive impairment and behavioral problems, however, is common, with as high as 71% of those in nursing homes having both cognitive impairments and behavioral disturbances (Jagger & Lindsey, 1997). Functional ability, however, has appeared to

be one of the most important predictive factors, with urinary and bowel continence reported by many as one of the most important factors predicting residential care (Johanson, Irizarry, & Doughty, 1997; Newens, Foster, & Kay, 1995; Pruchno, Michael, & Potashnik, 1990; Wolinsky, Callahan, Fitzgerald, & Johnson, 1993). Finally, several behaviors common in patients with dementia have been investigated as to their effect on caregiving and residential placement. Disruptive and aggressive behaviors have been found to be predictive of nursing home placement. This trend is slightly higher for men than women (Cohen et al., 1993; Colerick & George, 1986; Jagger & Lindsey).

Caregiver variables. Studies on caregivers can be divided into those on caregiver characteristics and those on caregiver burden or stress affecting residential placement decisions. Caregiver characteristics that predict residential placement include employment, with those employed being more likely to choose residential care; and relationship to the patient, with spouses being less likely to choose residential care (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1994). Also of interest is the caregiver's financial status, which has had mixed predictive results on decisions to use residential care. These mixed findings are thought to be a result of variable state support for caregiving families versus indirect financial burdens of home care versus residential care (Aneshensel et al., 1994; Miller et al., 1998).

Caregiver burden or stress studies have examined several outcomes of caregiving that may influence caregiver well-being. This stress or burden has been

shown to have a negative impact on the caregiver's physical and mental health. These negative outcomes in caregiver well-being may in turn have an indirect effect on caregivers' desire to place or actual placement of persons with dementia in residential care. When considering levels of stress or burden alone and not associated with residential care placement decisions, the duration of caregiving has been found to be less important than the amount or complexity of caregiving (Given, Given, Strommel, & Azzouz, 1999; Townsend, Noelker, Deimling, & Bass, 1989; Walker, Acock, Bowman, & Li, 1996). The Given, Given, Strommel, and Azzouz study of 628 caregivers of recently discharged older hospital patients with increased dependency after discharge found that the adding new dependencies over time negatively impacted depression scores in caregivers. Other variables investigated in an attempt to identify factors increasing caregiver burden include caregiver physical and mental health, stress, family conflict, value placed on caregiving, and previous quality of relationship to the patient.

When stress or burden is investigated as a precursor to residential placement decisions, the degree of caregiver burden has been shown to have an indirect influence on the decision for residential placement, but to varying degrees (Newens, Forster, & Kay, 1995; Pruchno, Michaels, & Potashnik, 1990; Townsend, Noelker, Deimling, & Bass). Part of the difficulty in determining the amount of caregiver burden affecting residential care decisions may be related to the fact that some caregivers continue care in spite of high levels of burden while others choose residential care in spite of low levels of burden.

Societal variables. Finally, researchers have identified social variables or constraints and barriers to caring for a patient with dementia at home. These studies, however, have been limited in scope to the cost of care and the availability and impact of services. The cost of residential care is considered one of the biggest concerns facing our aging society. Residential care can be as much as two to three times the cost of home care (Coughlin & Liu, 1989; Meek et al., 1998). Further, home care is felt to be preferable to residential care, due to quality and safety factors. Therefore, many investigators have examined societal factors that can delay or prevent residential care. Societal factors found to delay placement include availability of appropriate medical care and community services for patients including pharmaceutical agents and home health services. Further, the availability and use of paid and unpaid support to caregivers have been found to delay residential placement (Cohen, Gold, Shulman, Wortley, McDonald, & Wargon, 1993; Collins, King, & Kokinakis, 1994; Miller, et al., 1998; Mittelman et al., 1993). Collins, King, and Kokinakis found that, of 38 caregivers, 40% stated they would have delayed residential placement of their relative if one more service was available to them.

Theoretical Models

Several theoretical models have been used to examine when and why a person with dementia is likely to be placed in residential care. For example, decision-making theories have been used to examine why residential care is used by some, but not all caregivers of persons with dementia (Johnson, Schwiebert, & Rosenmann, 1994). These theories attempt to examine what factors influence decision-making processes, and the timing of decisions. For example, many families make the decision to transfer a relative to residential care during a crisis, and use crisis decision-making processes to make that transition. Another model used in studies on residential care is the health care utilization model. This model considers the interaction among characteristics of the caregiver and care recipient, the perceived need for residential care by caregivers, and the availability of residential care centers as the salient variables affecting transfer of care recipients from home to residential care (Miller et al., 1998). These and other models have assisted researchers in separating out important variables influencing the complex decision to place a family member in residential care. For the purposes of this study, the theoretical model best illustrating the importance of studying the relationship between care recipients' problem behaviors and caregiver's well-being on the placement of the care recipient and timing of that placement in residential care is the stress-adaptation model.

Stress-adaptation model. The stress-adaptation model was first considered by many researchers to explain how each person copes with stress differently depending

on the type of stress and the availability of external and internal resources. Hans Selye was one of the earliest researchers in this century to describe the general stress adaptation theory. Early publications of Selye's work promoted literally thousands of studies on the physiology of stress (Lazarus & Folkman, 1984). From this research, concepts grew to explain the dynamic interplay between stress and the body's reaction to the stress in an attempt to maintain equilibrium. The body's reaction to stress has been termed adaptation. Further, these studies enhanced the understanding that stress and adaptation result in both benefits and costs to each person. For example, the stress of finding residential care for a relative may result in negative psychological outcomes from feelings of fear and guilt, and at the same time, positive psychological outcomes from feelings of relief and accomplishment (Aldwin, 1994; Lazarus & Folkman).

The types of stress have been quantified in an attempt to determine events causing low, moderate and high levels of stress (Aldwin, 1994; Lazarus & Folkman, 1984). Stress has been further divided into primary stressors and secondary stressors. Primary stressors have a direct impact on a person. For example, a fall (the stressor) causes a direct impact on the person's health (e.g., a fractured hip). Secondary stressors, in contrast, have an indirect impact on a person. For example, a fall can cause a fracture that in turn may cause the indirect loss of employment and financial instability. Further, each person adapts to these different kinds of stress differently dependent on internal resources or coping strategies, and external support. When considering caregiving, the quality of the relationship between the caregiver and the care recipient and the amount of outside support are examples of resources mediating

or balancing stress levels, that in turn lead to or hinder adaptation. Finally, each individual perceives and uses resources differently depending on past coping strategies or adaptations developed over time (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Light, Niederehe, & Lebowitz, 1994; Pearlin, 1989; Pearlin, Lieberman, Menaghan, & Mullan, 1981).

Several studies have examined the process of caregiving using the stress-adaptation model. The general theory is that caregivers choose residential care when their ability to adapt to the growing levels of stress involved with caregiving exceeds their adaptation or coping skills (Aneshensel et al., 1995; Light, Niederehe, & Lebowitz, 1994; Zarit, Orr, & Zarit, 1985). Stress processes affecting caregivers involve the many interrelated factors that affect the caregiver's well-being, including the amount of hours working outside of the home, age, health status, amount of support available, and the functional level of the care recipient (Colerick & George, 1986; Cohen et al., 1993; Collins, King, & Kokinakis, 1994; Freedman, Berkman, Rapp, & Ostfeld, 1994; Jagger & Lindsey, 1997). As these variables negatively affect caregivers, changes have been documented in caregivers' physical and mental health. For example, several studies have documented increased depression for caregivers when compared to noncaregiver controls, and increased depression is felt to be influenced by a combination of the level of stress experienced by the caregiver and how the caregiver interprets that stress (Alspaugh, Zarit, Stephens, & Townsend, 1999; Coppel, Burton, Becker, & Fiore, 1985; Drinka, Smith & Drinka, 1987; Gallagher-Thompson, 1995; Schulz & Williamson, 1994; Whitlatch, Feinberg, &

Sebesta, 1997). For example, in the Alspaugh et al. study of 188 caregivers of patients with dementia, depression levels were higher and more chronic for those caregivers expressing feelings of role captivity. Likewise, caregivers have been found to use more self-medication and to perceive their health to be poorer than matched controls, which illustrates other symptoms of altered health (Light, Niederehe, & Lebowitz, 1994).

The stress experienced by caregivers has been studied extensively for two primary reasons. First, the chronicity of stress experienced by caregivers is felt to be more harmful than short-lived or self-contained and temporary stress. Not only the duration of care, but the complexity of care adds to this chronic state of stress commonly referred to as the “wear and tear theory” (Townsend, Noekler, Deimling, & Bass, 1989). Aneshensel and colleagues (1995), in their study of 555 patients with dementia and their caregivers, found that the average length of time in the caregiving role was 2 to 4.5 years, with a range of 1 to 11 years. In other studies, the complexity of care was found to be even more important than the duration of care (Townsend et al., 1989; Walker et al., 1996). This complexity has been related to the numerous changes a patient with dementia experiences over time, and the effect these changes have on the caregiver. These changes in the patient not only include cognitive decline with loss of short-term memory, but decline in personality and health as well. Studies emphasizing personality changes in the care recipient have found patients with dementia are often described by their caregivers as having more neuroticism and less

openness, agreeableness, conscientiousness, and extraversion than before diagnosis (Hooker et al., 1998b).

Although many clinicians attempt to assist caregivers to continue caregiving in the home, the level of support for caregivers is often felt to be inadequate to prevent placement of relatives in residential care or to decrease the burden on caregivers who continue to provide care (Brody, Lawton, & Liebowitz, 1984). In spite of this feeling, the identification of the chronicity and complexity of stress found in caregivers and the effect stress on residential placement has prompted many pilot programs aimed at intervening to reduce the stress or burden (Gallagher-Thompson, 1995; Sherrill, Reifer, & Henry, 1995). For example, studies using community services and home visits are aimed at helping caregivers reduce their stress, thereby reducing their perceived burden (for a recent example of this model see Mittelman et al., 1993). This increase in community services, however, has not yet been shown to reduce the use of residential care consistently (O'Conner, Politt, Brook, Reiss, & Rothm, 1991). In contrast, use of community services has been shown to decrease the time from diagnosis to residential care. One theory for this trend is that caregivers become more aware of caregiving options as support services become involved with the family, and caregivers realize alternative support, short of residential care, is inefficient to meet their needs (Lawton, Powell, Brody, Saperstein, & Grimes, 1989).

The second reason stress is explored in caregivers is that stressful events occurring because of caregiving often beget other stresses. Further, the combination of stresses affects not only the care provided, but also the ability to use outside resources

(Aneshensel et al., 1995). This succession of stresses in caregiving literature, as with other research on the effect of stress, is often divided between primary and secondary stresses (Aneshensel et al.; Pearlin, 1994).

One primary stressor found to be present at some level in all caregivers is concern over the care recipient's disruptive behaviors (Aneshensel, et al., 1995; Brody et al., 1990; Miller et al., 1998; Raskind, 1998). Behaviors included in most investigations included major categories of aggression, sleep disturbance, change in moods, and emergence of delusions and/or hallucinations. When behaviors were included in the study design, they were found to be associated with negative outcomes. For example, Miller and colleagues found aggressive behaviors and wandering to be the most influential factors in deciding on residential care for patients with dementia. Further, depression in caregivers is often linked to the level of problem behaviors in care recipients, particularly aggressive and wandering behaviors (Biegel, Sales, & Shulz, 1991; George & Gwyther, 1986).

Secondary stressors found to impact caregivers' decisions to place relatives in residential care are their own deteriorating physical and mental health because of the strain of caregiving. Brody, Dempsey, and Pruchno (1990) found that for 311 children of parents residing in nursing homes, caregivers' poor health was significantly related to nursing home placement. Colerick and George (1986) found caregiver well-being in general affected residential placement more than care recipient variables.

The goal of many clinicians is to identify interventions that will minimize the negative impact of stresses. Yet, in spite of problem behaviors being identified as

stressful to caregivers, few studies have identified specific behaviors causing the most stress. Further, of those studies recommending interventions for behavior problems, most are directed at environmental changes and behavioral therapy for the care recipient, rather than at assisting the caregiver. This lack of assistance for caregivers may be linked to the relatively high rate of violence by caregivers against patients with dementia. The incidence of violence against care recipients by caregivers is higher in patients with dementia when compared to patients with normal cognitive functioning, and not related to the level of dependence. Rather, risk factors for this type of abuse include care recipients with aggressive and disruptive behaviors and caregivers who live alone with the care recipient. This pattern supports the idea that caregivers who face high levels of stress from care recipients' problem behaviors, and who have little support to assist them in adapting to this stress, may resort to violence against the care recipient as a maladaptive coping strategy (for a thorough review of this literature, see Pillemer & Suitor, 1995).

The stress-adaptation model is valuable for evaluating and designing further research into this area. Problem behaviors in care recipients emerge repeatedly as an important variable affecting caregiving stress and adaptation. Although behaviors have been investigated in a general sense, few research studies have looked specifically at behaviors over time and the impact of these behaviors on caregiver's well-being. Seen from the stress-adaptation theory, the influence of the behaviors could affect the decision to place a relative with dementia in residential care, not so much as a direct stressor, but as a precursor to significant secondary stresses (e.g., physical and mental

well-being of the caregiver). Further, more than any other quality, problem behaviors are associated with caregiver physical injury, caregiver embarrassment and frustration, and care recipient abuse (Aneshensel et al., 1995; Cummings & Miller, 1990). During the caregiving career, problem behaviors tend to get worse over time as the diseases causing dementia progress (Cummings & Miller, 1990). This increase in stress and change in relationship may also affect the caregiver's well-being, and the eventual decision to choose outside care.

The factors outlined using the stress-adaptation model to examine caregiving emphasize the need to investigate more closely how problem behaviors in care recipients over time influence caregivers' well-being and decisions regarding residential care. If problem behaviors cause the most stress in a caregiver, and that stress leads to negative outcomes, the relationship will deteriorate, and residential placement will be sought. Understanding how much problem behaviors affect caregivers, and using this knowledge to identify effective strategies for interventions, can be a key factor in preventing or delaying residential care without further straining caregiver well-being.

Figure 1 illustrates the conceptual model of problem behaviors over time directly impacting the stress caregivers experience that, in turn, impacts caregiver physical and mental well-being. This direct effect of stress on caregivers' well-being has an indirect effect on residential placement. As caregivers experience a decline in well-being, they are less able to adapt to the strain of caregiving. This decline in

adaptation results in the need to increase outside support, which may mean residential care.

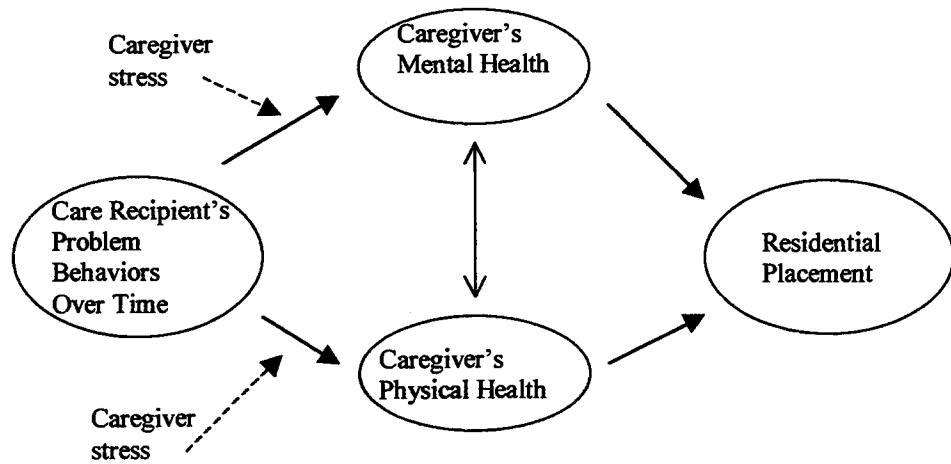


Figure 1. Conceptual Model of current study illustrating the direct and indirect relationship among care recipients' problem behaviors over time, caregivers' well-being, and residential placement of the care recipient.

Overall Goal of the Study

The overall goal of this study is to determine how much caregiver and care recipient characteristics, especially well-being in caregivers and problem behaviors in care recipients, are related to whether residential care is used by caregivers and when, after the diagnosis of dementia, care recipients are at highest risk for placement in a residential care facility.

Research Questions

1. Do the severity and frequency of problem behaviors over time in the care recipient significantly affect the likelihood and timing of admission into residential care?
2. Are there differences in caregiver or care recipient characteristics, including age, sex, type of relationship, education level, and hours of outside employment between those families choosing residential care and those families choosing to care for their relative at home?
3. Is caregivers' well-being, as measured by both physical and mental health scales, related to whether the care recipient remains at home or is placed in residential care?

Chapter Three: Methods

Overview of Study Design

This exploratory research study employs a multivariate longitudinal design. Although this type of study design is complex, the complexity is needed to explain the relationship between care recipients and caregivers, and the factors influencing these roles over time. This study utilized data collected by both the Oregon Alzheimer's Disease Center (OADC) and researchers at Oregon State University (OSU) over a six-year period (Hooker et al., 1998a). A letter indicating permission to use these data is included as Appendix A. The data collected were from care recipients with Alzheimer's Disease and other dementias, and their caregivers, and included extensive information on care recipients' behavioral changes over time and caregivers' physical and mental well-being. The data included information gained from face-to-face and telephone interviews conducted by trained personnel.

The plan for the analysis of results of this study was to use the following statistical processes:

1. Intercorrelation analysis to determine relationships between care recipient and caregiver variables and residential care for care recipients.
2. Comparison analysis using T-Test to assess differences between those caregivers choosing residential care versus home care for the care recipient and to assess differences between those caregivers who chose residential who were interviewed versus those not interviewed.

3. Regression analysis to determine which variables significantly affected transfer into residential care and the weight of that affect.
4. A survival model design to determine when a patient with dementia is at the highest risk for residential placement after diagnosis (a change in State A = home placement to State B = residential care).

Sample Population

This study utilized data obtained through a larger study with OADC and OSU examining the relationship between the behaviors of patients with dementia and caregivers' well-being (Hooker et al., 1998b). The original data set included patients diagnosed with dementia and evaluated for behavioral changes through the OADC over a six-year period (1992 to 1998).

Following diagnosis and inclusion in the OADC study, caregivers of these patients were asked to participate in a collaborative study with OSU to examine the relationship between problem behaviors in the care recipient and caregiver well-being. Criteria for participation in this study met three main criteria. These included:

1. The caregiver had to be the primary caregiver, responsible for the overall health and well-being of the care recipient at the start of the original OADC study.
2. The patient had to be diagnosed with probable or possible dementia at the start of the study.
3. The patient had to have visited the OADC and have a behavioral

measurement completed.

The caregiver had to return a signed consent form with the Caregiver Questionnaire. One hundred care recipient-caregiver dyads participated in an evaluation at OADC and the caregiver questionnaire. Of these 100 participants, 92 (92%) participated in a supplemental phone interview to assess behavioral changes using the Neuropsychiatric Inventory (NPI). The average time from diagnosis to the telephone interview on behavioral changes was 1.9 years, with a range of less than one year to six years. Table 1 illustrates the number of participants divided by the year of diagnosis.

Table 1.

Number of Participants by Year Entering the Study

Number of Participants by Year Entering the Study (n=100)		
<u>Year of Diagnosis</u>	<u>Frequency</u>	<u>Percent</u>
1992	6	06
1993	12	12
1994	14	14
1995	10	10
1996	53	53
1997	5	05
Totals	100	100

To examine the factors influencing the occurrence and the timing of residential placement, caregivers identified as having chosen residential care for the care recipient at the time of the caregiver questionnaire were chosen to be interviewed by phone a second time. This phone interview occurred approximately one year after the caregiver questionnaire was completed. From the 100 caregivers participating in the caregiver questionnaire, 39 (39%) were identified as having used residential care for their relative. Of these 39 caregivers, 25 (64%) were interviewed on when, what kind of care, and why outside care was used for the care recipient. Two of these caregivers did not use residential care, but did not care for the care recipient in their home. One cared for her mother in a trailer behind her home, and one cared for her mother in a separate residence. These two were eliminated from the data analysis on caregivers using residential care for the care recipient, leaving 23 interviews for analysis. Of the remaining 14 caregivers indicating residential care was used on the Caregiver Questionnaire but not interviewed, 6 were unreachable after five attempts and 8 had disconnected phone numbers.

Summary of Sample Selection Procedures

The following procedures were used to identify participants for this study:

1. All caregivers of patients identified at OADC as having a diagnosis of dementia and having been evaluated for behavior were sent the caregiver questionnaires during the larger study conducted by Hooker and colleagues (1998a). From this original sample, 100 caregivers returned the questionnaire. Of the 100 caregivers

with returned questionnaires, 92 were interviewed by telephone regarding behavior changes using the NPI. The data from the 100 caregivers was used in the analysis for this study.

2. Of the 100 caregivers with returned questionnaires, 39 were identified as having placed their relative in residential care.
3. Of the 39 identified as placing their relative in residential care, 25 were interviewed to determine why and when this transition occurred. Two of these participants were eliminated from the data analysis on residential placement due to the care recipient living apart from the caregiver, but not in residential care. Fourteen caregivers indicated they had transferred their care recipient to residential care were unavailable by phone. Therefore, 23 participants participated in the telephone interview regarding residential care. Figure 2 illustrates the flow of participants in this study.

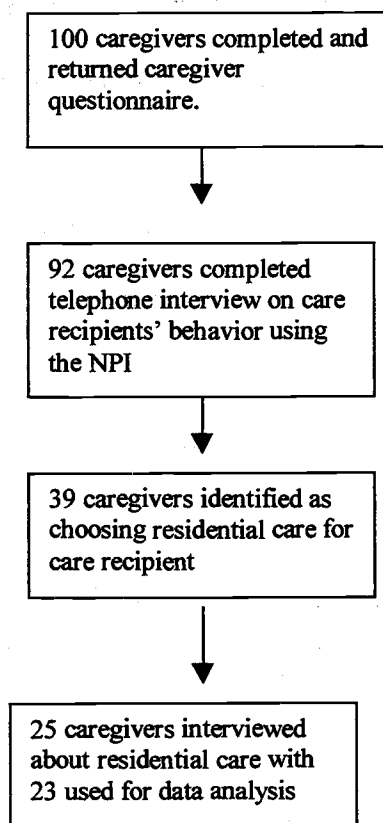


Figure 2. Flow of participation in study.

Description of care recipients. At the time of diagnosis, the care recipients were an average of 72 years of age and most (84%) were married. Those not married, were either divorced or separated ($n = 4$), single and never married ($n = 4$), or other relationships not specified ($n = 3$). Five subjects did not have data on marital status at the time of diagnosis. Fifty-six percent of the care recipients were men and 44% were women. Eighty of the care recipients were at home at the time of diagnosis, and 19

were living in residential care (missing data=1). This pattern shifted over the course of time between diagnosis and the caregiver study, leaving 54 at home and 39 in residential care (missing data= 7), indicating an increase of 21 care recipients transitioning from home to residential care over the course of this study. Table 2 summarizes the sex and marital status of care recipients at the time of diagnosis and Figure 3 illustrates the transition from home care to residential care between the time of diagnosis to the time of the caregiver study.

Table 2

Frequencies of Sex and Marital Status of Care Recipients at Time of Diagnosis.

Frequencies of Care Recipients		
(n=100)		
	Frequency	Percent
Sex		
Men	56	56.0
Women	44	44.0
Marital Status		
Married	84	84.0
Divorced or Separated	4	4.0
Single/Never Married	4	4.0
Other	3	3.0
Missing	5	5.0

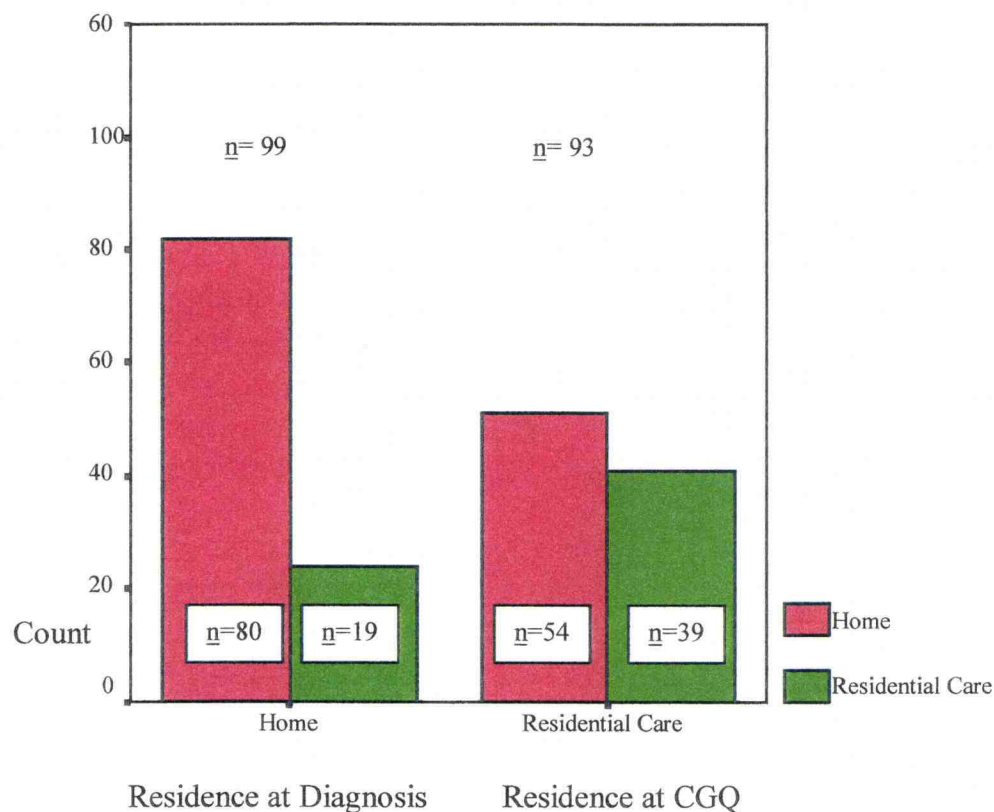


Figure 3. Place of Residence at Time of Diagnosis Compared to Time at Caregiver Questionnaire illustrating a higher number of care recipients in residential care at the time of the caregiver questionnaire than at the time of diagnosis. CGQ= Caregiver Questionnaire.

Description of caregivers. At the time of the caregiver questionnaire, the caregivers were, on average, 66 years old, with a range from 29 to 99 years old. Thirty (30%) of the caregivers were men and 65 (65%) were women (missing data= 5). Eighty-three percent of the caregivers were married, and caring for their spouse. Ninety-four percent of the caregivers were White with two Native Americans and the remaining four caregivers not identifying their race. The average education level of

caregivers was between high school and two years of college. Most (76%) of the caregivers were not employed, but 24% remained employed. The average length of time as a caregiver at the time of the caregiver study was 5.5 years, with a range of less than one year to 22 years. Most of the caregivers indicated their health was good to excellent (58%) with an average of two to three chronic conditions.

Table 3 illustrates the means and frequencies of sex, ethnic background, marital status, relationship, and employment status of caregivers at the time of the caregiver questionnaire.

Table 3.

Frequencies of Selected Variables of Caregivers at the Time of the Caregiver Questionnaire

Frequencies of Sex, Ethnic Background, Marital Status, Relationship, and Employment Status of Caregivers at the Time of the Caregiver Questionnaire (n=100)		
	Frequency	Percent
Sex		
Men	30	30.0
Women	65	65.0
Missing	5	5.0
Ethnic background		
White	94	94.0
Native American	2	2.0
Missing	4	4.0
Marital status		
Married	83	83.0
Not married	13	23.0
Missing	4	4.0
Relationship to care recipient		
Spouse	83	83.0

Table 3, Continued

Frequencies of Sex, Ethnic Background, Marital Status, Relationship, and
Employment Status of Caregivers at the Time of the Caregiver Questionnaire

(n=100)

Other	13	13.0
Missing	4	4.0
Employment status		
Employed	22	22.0
Not employed	69	69.0
Missing	9	9.0

Measurements

Patients with Dementia. The patients with dementia were measured for cognitive status, activities of daily living, and problem behaviors using three separate measurement tools at the time of diagnosis. The behavior measurement tool was repeated soon after the caregiver questionnaire was received using a telephone interview. The measurements used included the following:

Folstein Mini Mental Scale. The cognitive status of these patients was measured using the Mini Mental State Evaluation (MMSE) at the time of diagnosis (Folstein, Folstein, & McHugh, 1975). This is a 16-item scale with both questions and activities used to assess a person's memory and cognitive ability. The scores range

from 0 to 30, with high scores indicating higher levels of mental functioning. Scores below 24 indicate cognitive impairment.

Activities of Daily Living (ADL) and Instrumental Activities of Daily Living. The ADL is a 9-item questionnaire used to measure the ability of individuals to perform common activities of daily living such as dressing, feeding, toileting, and walking. This tool was given to care recipients at the time of diagnosis. The individual's ability was rated on a three-point scale, with higher scores indicating lower skill level. Cronbach's alpha for the ADL in this study was .87.

Neuropsychiatric Inventory (NPI). The NPI is a 91-item measurement scale used to assess behavioral changes in individuals with dementia (Cummings, 1997; Cummings et al., 1994). Information on each item is gained through an interview with caregivers of patients with dementia. This scale was used at the time of diagnosis and during the telephone interview with caregivers following return of the caregiver questionnaires. During the interview, each behavior, within 12 sub-scales, was rated as present or absent. The subscales included (a) irritability, (b) agitation and aggression, (c) anxiety, (d) depression and dysphoria, (e) elation and euphoria, (f) inhibition, (g) apathy and indifference, (h) aberrant motor behavior, (i) delusions, (j) hallucinations, (k) sleep disturbances, and (l) appetite and eating disorders. Each subscale was rated on a four-point scale for frequency and a three-point scale for severity, allowing for the calculation of a frequency times severity score. During the

telephone interview, caregivers were given verbal instructions and a “Cue Card” to refer to for responses to each question. Although face to face interviews would have been ideal, reliability between face-to-face interviews and telephone interviews have been shown to be comparable (Cummings, 1997). Higher scores indicated more frequent and/or severe behavior problems. Cronbach’s alpha levels for this scale have been as high as .88 (Cummings et al., 1994). Cronbach’s alpha for the NPI in this study was .78.

Caregiver Measurements. The caregivers of the patients with dementia completed questionnaires pertaining to demographic information, perception of physical health and chronic conditions, caregiver experiences, personality trait of optimism, affect balance, and perceived stress. The final phase of this study included a second telephone interview (the first telephone interview was the NPI) with those caregivers who used residential care. The original caregiver questionnaire included the following measurements:

Caregiver Questionnaire. This questionnaire included 20 items asking about caregiver demographics such as age, marital status, employment status, education level, and ethnic background. Information was also obtained regarding hours of help obtained, kinds of support, and perception of quality of relationship to the patient with dementia.

Health Perception Questionnaire (HPQ). The Health Perception Questionnaire was derived from the subscale of the Health Perception Questionnaire used in the Rand Health Insurance Experiment. This subscale includes nine items designed to provide close discrimination at higher levels of health. Cronbach's alpha for this scale has been shown as high as .89 (Davies & Ware, 1981). Cronbach's alpha in this study was .79, indicating adequate internal consistency reliability. Items were coded so that high scores indicated poorer health perception.

In addition to the above scale, questions were added to the Health Perception Questionnaire derived from commonly used questions from health research. These included (a) In general would you say your health was excellent, good, fair, or poor.(b) During the past 12 months, about how many days did you spend in the hospital, (c) During the past 12 months, about how many times did you see any type of doctor?, and (d) During the past 12 months, about how many days have you been sick in bed all or most of the day. Items on this scale were examined individually rather than summed as an index (Hooker et al., 1998a).

Chronic conditions. The questions on health perception were followed by a checklist of 20 health conditions reportedly diagnosed by a doctor, such as diabetes, hypertension, heart trouble, and/or arthritis. These conditions were derived from a subscale of the Multi-level Assessment Index (MAI) (Lawton, Moss, Fulcomer, & Kleban, 1982). Respondents were asked to indicate whether or not each condition existed in the past year, and if any other chronic conditions were diagnosed

but not listed. The MAI was designed for use with older adults and the psychometric properties of each of its domains and subscales are well-documented (Lawton, Moss, Fulcomer, & Kleban). A total score was derived by summing all yes responses to the questions. Higher scores indicated poorer health

Center for Epidemiological Studies Depression Index (CES-D). The CES-D is a 20-item scale used to assess the overall level of depression experienced in the past week (Radloff, 1977). Psychometric properties reported in previous studies have been strong, with Cronbach's alpha levels as high as .89 (Hooker, Monahan, Shifren, & Hutchinson, 1992; Pruchno & Resch, 1989). For this study, four items were reverse coded so that a higher total score indicated higher levels of depressive signs and symptoms in the caregiver. Cronbach's alpha for the CES-D in this study was .91 (Hooker et al., 1998a).

Perceived Stress Scale (PSS). Perceived stress of caregivers was assessed using the PSS, which is a 14-item questionnaire designed to assess the degree to which situations are appraised as stressful (Cohen, Karmack, & Mermelstein, 1983; Hooker et al., 1992). Psychometric properties have been strong for this questionnaire, and it has been used successfully with caregivers of patients with dementia. Responses to questions regarding common stresses are rated on a four-point scale, with higher scores indicating more perceived stress. Cronbach's alpha for the PSS in this study was .75 (Hooker et al., 1998a).

Bradburn Affect Balance Scale (ABS). The ABS was another tool used to assess mental health of caregivers. This tool is especially useful because it includes both positive and negative affect subscales. Bradburn's (1969) procedure of subtracting negative affect scores from positive affect scores and then adding a constant of 5 to derive a single score was reversed so that a high score indicated low levels of mental well-being. Cronbach's alpha for the ABS in this study was .70 (Hooker et al., 1998a).

Caregiver Experiences. The Caregiver Experiences Questionnaire is a 25-item questionnaire used to assess thoughts and feelings of a caregiver based on a four-point scale (Zarit, Stephens, Townsend, Greene, & Ferraro, 1996). This questionnaire was designed to be used specifically with dementia patient caregivers, and previous psychometric testing has been good (Zarit et al., 1996). All items were coded so that a high score indicated negative caregiver experiences. Cronbach's alpha for the Caregiver Experiences Questionnaire in this study was .70 (Hooker et al., 1998a).

Caregiver Phone Interview: Final Phase. The Caregiver Phone Interview: Final Phase was a 4-item telephone interview designed for this study to obtain additional information on the care recipient's place of residence over time, and when and why residential care was used.

A copy of all measurement tools used for this study can be found in Appendix B.

Data Analysis Procedures

The initial step in the data analysis included descriptive data on all care recipients' and caregivers' measurement scales, including functional, cognitive, and behavioral measurements for the care recipient and physical and mental health of the caregivers. The descriptive data also included descriptions of the 39 caregivers choosing residential care for the care recipient at the time of the caregiver questionnaire. These descriptive data assisted in describing this population for comparison with previous studies and in identifying any variables different from the general population. Further, comparing descriptive statistics between the 100 participants versus the 39 participants choosing residential care assisted in comparing these two groups of caregivers for this study.

The next step in the data analysis involved comparing means among those caregivers choosing residential care and interviewed and those choosing residential care and not interviewed. Variables chosen for analysis included sex, marital status, age, behavior score, cognitive status, and functional status of care recipient as these variables were identified as important through the review of literature and available at the beginning of the study. This comparison was done to determine if these groups were significantly different, and if that difference might influence results.

The next phase of the data analysis included evaluating intercorrelations between variables identified through the review of literature as important in studies examining residential placement and whether or not residential care was used. The variables used during this phase included age, sex, education level, employment, relationship to care recipient, marital status of care recipient, and scores on the measurements used for behavior problems in the care recipient and mental and physical health of the caregiver. This analysis was done to first determine relationships between residential care and important variables, and second to assess for multicollinearity concerns.

The next phase of the data analysis included multivariate regression analysis to determine which variables significantly affected transfer into residential care, choosing the variables with the strongest relationship to residential care and consistent with variables identified as salient through the review of literature. The regression analysis was used to determine how much influence each variable had on the dependent variable, and how much variance was explained by these variables. A hierarchical design was used starting with the variables demonstrating the highest intercorrelation with residential placement, including ADLs and behavior change scores on the care recipient, employment status and CES-D scores on the caregiver. Other variables were added one at a time, including MMSE score at the time of diagnosis, and aggression scores at the time of diagnosis and at the time of the NPI Telephone Interview, evaluating the change in R^2 with each addition to assess whether or not other variables had an effect on the variance. The regression analysis was

limited to a portion of variables measured in accordance with the sample size (Grimm & Yarnold, 1995). Further, tests for multicollinearity were performed, including tolerance levels and variance inflation factors, to examine whether any two variables had shared, or redundant variance (Grimm & Yarnold).

The final phase of the data analysis was to examine the data using a Cox Proportion Model for survival assessment to determine which factors affected the timing of residential care after the diagnosis of dementia. The analysis used the state change between home and residential care as the dependent variable and factors that may influence this timing based on previous studies and the results of the intercorrelation analysis, including age, sex, and marital status of the care recipient, and employment status of the caregiver as the independent variables. Finally, three covariates were added to this model to examine the effect of these variables on the timing of residential care. These covariates were chosen based on the results of the regression analysis and the primary research questions, and included (a) the NPI change score from the point of diagnosis to the caregiver study, (b) the CES-D total scores, and (c) ADL Scores of the care recipient at the time of diagnosis. The Cox Proportion Model was chosen because this model accounts for subjects entering the study at different times, calculating for left censoring, or those participants already in State B (residential care) at entry into the study, and right censoring, or those participants still in State A (home care) at the end of the study.

Each phase of the data analysis used different data sources on the subjects dependent on the research question being addressed. Variables measured on the care

recipients were used from data obtained at the time of diagnosis ($n=100$), and data on the caregivers were obtained from the caregiver questionnaire ($n=100$). The behavioral change score was obtained from data collected at the time of diagnosis ($n=65$) and at the first telephone interview ($n = 92$). Finally, data on the caregivers using residential care was obtained from the final telephone interview ($n=23$). All data groupings were used for the descriptive data on the care recipients and caregivers, intercorrelations, regression analyses, and Cox Proportional Model, whereas only data from the final telephone interview was used for descriptive data on caregivers choosing residential care for their care recipients. Table 4 illustrates the different time points used for the different analyses and the different groupings of data used for the different analyses.

Table 4.

Different Time Points Used for the Different Analyses

Different Time Points Used for the Different Analyses				
	DX	CG	FiTINPI	FTI
	(n=100)	(n=100)	(n = 92)	(n=23)
	CR	CG	CHGSCNPI	CGR
Descriptive	X	X		X
Intercorrelations	X	X	X	
Regression	X	X	X	
Cox Proportion	X	X	X	

Note. DX= Time of Diagnosis; CG= Caregiver Questionnaire; FiTINPI= First telephone interview using the NPI; FTI= Final Telephone Interview on caregivers using residential care; CR= Care recipient; CG= Caregiver; CHGSCNPI= Change Score on the NPI from diagnosis to first interview; CGR= Caregivers choosing residential care.

Handling Missing Data. One of the most challenging questions to answer when planning this research study was how to address the problem of missing data. Because of the longitudinal study design, missing data were expected to be larger than what would be found in other design models. For descriptive data analysis of both the care recipients and the caregivers' data, pairwise deletion was used to replace missing data for categorical variables. The largest amount of missing data was present in the

NPI scores at the time of diagnosis. This was due to the OADC using two behavioral assessments at the time of diagnosis, resulting in several participants ($n = 35$) having missing NPI scores at the time of diagnosis. Because of this large percentage (35%) of missing data for the NPI score at diagnosis, the common approach of estimation modeling (EM) procedure available in SPSS (SPSS 8.0, 1998) was used to replace this missing data (Li, 1998). EM uses the means, covariances, and correlations with quantitative data to replace values using iterative methods based on the assumption that the missing data are not randomized (SPSS 8.0).

Chapter Four: Results

The results of this study indicated several significant relationships exist between variables examined and residential placement of persons with dementia. The results are divided into descriptive data, comparison data, regression analysis, and the survival model.

Descriptive Data

Care Recipient Measurement Scales. The measurements used to assess the cognitive ability and behavior problems of care recipients showed moderate levels of cognitive decline, as well as moderate levels of behavior problems at the time of diagnosis. A mean score on the MMSE of 19.01 was found and the mean total score on the NPI was 15.95. The mean score on the ADL, in contrast, showed mild levels of decline at the time of diagnosis. Table 5 illustrates the means and frequencies of important care recipient measurement scores at the time of diagnosis.

Table 5

Means of Selected Measurements on Care Recipients

Means of Selected Measurements on Care Recipients								
(n=100)								
Measurements	N		Mean	Median	SD	Min	Max	
	Valid	Missing						
Age at diagnosis	100	0	72.52	74.00	9.08	44.00	90.00	
MMSE	97	3	19.01	21.00	7.00	.00	30.00	
ADL total score	100	0	2.59	2.00	2.96	.00	14.00	
NPIDX	63	37	15.95	12.00	17.37	.00	80.00	
NPICG	89	3	26.96	96.00	23.80	0.00	96.00	

MMSE= Mini-Mental State Evaluation at the time of diagnosis; ADL= Activities of Daily Living Total Score at the time of diagnosis; NPIDX= Neuropsychiatric Inventory total score; NPICG= Neuropsychiatric Inventory total score at time of telephone interview.

Description of caregiver measurement scales. The scores on the measurements used to assess physical and mental well-being of the caregiver indicated low levels of chronic health conditions (average of two conditions per caregiver), and moderate levels of perceived poor health, stress, affect balance, and negative caregiver experiences. The score on the CES-D, however, was above average for the general population and above the level of 16, the cutoff score indicating symptoms of

depression (Pruchno & Resch, 1989). Table 6 summarizes the mean, minimum, maximum, and standard deviation for each of the scales used to measure physical and mental well-being of caregivers.

Table 6.

Mean Scores of Selected Measurements on Caregivers

Descriptive Statistics on Caregiver Measurement Scales					
(n=100)					
	<u>N</u>	<u>Min</u>	<u>Max</u>	<u>Mean</u>	<u>SD</u>
<u>Physical Well-Being</u>					
Rating of health	87	.00	4.00	2.05	.89
HPQ Score	78	13.00	41.00	23.67	7.10
Total COND	61	.00	9.00	2.40	1.73
<u>Mental Well-Being</u>					
CESD Score	86	.00	43.00	16.77	11.30
ABS Score	80	1.00	9.00	4.98	1.73
PSS Score	90	4.00	18.00	9.88	3.15
CGEXP Score	68	34.00	87.00	56.79	9.27

Note. HP= Health Perception Questionnaire; COND= Number of Chronic Conditions in the Caregiver; CESD= Center for Epidemiological Studies- Depression Scale; ABS = Affect Balance Scale; PSS= Perceived Stress Scale; CGEXP= Caregiver Experiences Questionnaire.

Caregivers making the transition from home to residential care. Twenty-three caregivers who had transferred the care recipient to residential care by the time the caregiver data were collected were interviewed to determine specifics of that transition. All of the caregivers contacted agreed to the interview and willingly answered all questions, adding information freely as they told their stories of caregiving at home and transferring their loved one to residential care. Of these 23 caregivers, 7 were men and 16 were women. The average age of these caregivers was 70 years old at the time of the interview with a range from 53 to 83 years. Seventy-seven percent of the caregivers were spouses, and 19% were children indicating a higher percentage of nonspouse caregivers than the larger sample. One caregiver was a friend of the care recipient. Eighty-nine percent ($n = 21$) of caregivers reported that they were emotionally close or very close to the care recipient. The number of chronic conditions, and mean scores on the physical health measurement tools remained consistent with the larger sample population. The mean scores on the mental health measurements, especially the CES-D, were higher for those caregivers participating in the phone interview (20.65) when compared to the mean found for all participating caregivers (16.77). Likewise, the NPI Total Score at the time of the NPI telephone interview was higher for this group, with an average of 34.88 compared to 27.44 for all participating caregivers.

Caregivers' Stories. The most common reason cited for the transfer from home care to residential care was aggressive and/or violent behavior. Thirty-nine percent ($n = 9$) of caregivers noted aggression towards themselves and/or family members as being the main factor in deciding residential care was needed. Caregivers told stories of being chased, physically restrained, or held captive by the care recipient, including threats of homicide. In three cases, the transfer to residential care occurred after the caregiver had called 9-1-1 due to fear of personal safety. One women stated, "my husband became quite mean; he would chase me off our own property thinking I was a robber." Another women stated, "my husband tried to kill me and his sister." This patient was then transferred to three different care centers due to his violence. Another women described her husband as accusing her of having "orgies", and one day grabbing her by the wrist and dragging her back in the house, keeping her hostage for two days. She found residential care as soon as she escaped her own home. Others described being unable to care for the care recipient because of their aggressive behaviors.

Another common reason for transfer was the deterioration in the care recipients health ($n = 4$). One care recipient suffered from three seizures, each one leaving her with more pronounced deterioration in abilities. Other care recipients suffered from other life threatening illnesses, including heart disease, diabetes, circulatory problems and cancer, along with their diagnosis of dementia.

The next most common reason for residential placement was wandering behavior ($n = 3$) of the care recipient. The wandering behavior caused a combination

of exhaustion from constant surveillance and chronic stress from fear for the care recipients' safety. Two caregivers noted they found residential care when they found the care recipient wandering away from home at night.

The remaining caregivers noted exhaustion and their own health and/or inability to continue caregiving because of physical limitations that led to residential placement of the care recipient. One spouse explained that his children transferred his wife to residential care while he spent two weeks in intensive care recovering from heart disease and cancer. He noted his physician told him that caregiving was killing him. Another woman explained she planned to care for her husband "for the duration," but he began falling out of bed, and she could no longer lift "170 pounds of dead weight off the floor."

In spite of the high average scores on the CES-D for this group of caregivers, none of the caregivers mentioned sadness or depression as a major factor in their decision to place their family member in residential care. As they talked, they continually mentioned chronic stress from exhaustion and lack of sleep, concern over personal safety, and family stress, but not their own sadness.

The cost of caregiving was raised by two caregivers. One caregiver noted her insurance was wonderful, but without it, she would have spent an average of \$67,000.00 per year on care for her husband not including the cost of medications. Another woman noted she worked two jobs for several years to pay for the care her husband needed.

The course of the transfer from home to residential care varied from family to family, but the average time caring for the care recipient at home was 6.72 years with a range of 2 to 22 years. The care recipient then spent an average of 2.12 years in residential care until death ($n=12$) or the time of the final interview. The transfer was not always limited to one transfer, with the average care recipient transferring two to three times between residential care centers and/or hospital care. One care recipient was transferred seven times. The most common reason for transfers was care recipient health problems, followed by dissatisfaction with care or the residential facility asking for a psychiatric evaluation due to aggressive behavior. One woman told her story of desperately trying to find care for her husband while he begged her not to send him away. She put him in three different foster homes, only to bring him home again as she feared for his happiness. His aggressiveness eventually led to permanent placement in a nursing home. This story was an exception to most stories, in that once a care recipient left home they usually stayed in residential care.

The other major change occurring during the time between the caregiver questionnaire and the final interview was that over half ($n=12$) of the care recipients had died between the time the caregiver data were collected and the date of the final telephone interview on residential care. The cause of death was deteriorating physical health directly related to the dementia in most cases. One man, however, died from choking, and another man died from cancer.

The caregivers also talked freely about who supported them during the caregiving years and specifically during the transition from home care to residential

care. They reported using their family the most for support. Many described their children as the ones encouraging the transfer from home to residential care. One woman noted her children said “I just wasn’t making any sense anymore!” Surprisingly, few mentioned receiving support from professionals with the exception of one caregiver who described an aide taking her mother home to care for her. She stated this person “took the burden right off of me.” One man noted he used himself for support, and found care for his wife through “luck.” Two caregivers said they attempted to use daycare first, but this service did not relieve chronic exhaustion from lack of sleep at night. Another problem mentioned regarding daycare was the limited variety of activities. For example, one woman told the story of her Jewish husband spending one day making Christmas cards. Overall, the support used did not alleviate the long hours and stress associated with caregiving, or the risk to the health and safety of the care recipients and caregivers. Rather, the support used assisted the caregivers in clarifying why residential care was needed.

Comparison of Groups

Comparison of caregivers choosing home care versus residential care for care recipients. One important research question is whether there were any differences between those caregivers keeping the care recipient at home versus choosing residential care. This question was addressed first by comparing the means of important variables between these two groups, including age, sex, marital status, relationship, education level, NPI change score, and mean measurements for physical

and mental well-being of caregivers. Significant differences in mean scores were found between the age of the two groups, with older caregivers more likely to choose residential care, and employment status, with employed caregivers more likely to choose residential care. The CES-D scores showed remarkable differences, with the mean score for those caregivers choosing residential care being 22.37 compared to a mean of 12.98 for caregivers choosing home care. Other caregiver well-being measurements showed significant differences in the mean, including the HPQ, PSS and the Caregiver Experiences Questionnaire. Likewise, the mean NPI change score was 22.42 for those caregivers choosing residential care compared with 10.61 for those caregivers choosing home care. Nonsignificant differences were found between gender, marital status, education level, Table 7 summarizes the comparison of means for the two groups of caregivers.

Table 7

Comparison of Means on Variables for Caregivers Choosing Residential Care versus Caregivers Choosing Home Care.

Comparison of Means on Variables for Caregivers Choosing Residential Care versus Caregivers Choosing Home Care.						
Variable	Residence	N	Mean	SD	Mean Diff	t score
Employment	Home	53	.15	.36	-.23	-2.53*
	Residential	37	.37	.49		
HPQ	Home	45	21.91	6.11	-2.49	-3.88*
	Residential	34	25.79	7.73		
PSS	Home	52	9.21	2.95	-1.68	-2.63**
	Residential	38	10.89	3.07		
Caregiver	Home	49	55.04	8.49	-5.81	-2.46*
Experiences	Residential	20	60.85	9.84		
NPICS	Home	36	10.61	13.23	-11.80	-2.35*
	Residential	19	22.42	24.23		
CES-D	Home	51	12.98	9.56	-9.39	4.15***
	Residential	35	22.37	11.33		

Note. Only variables showing a significant difference in means are included. Mean Diff = Mean Difference; HPQ = Health Perception Questionnaire; PSS = Perceived Stress Scale; NPICG = Change in Neuropsychiatric Score from time of diagnosis to first telephone interview; CES-D = Center for Epidemiology Scale on Depression.

*** $p < .000$ ** $p < .01$ * $p < .05$

Comparison of Caregivers Choosing Residential Care and Interviewed versus Choosing Residential Care and Not Interviewed. One challenge of this study was the high percentage of caregivers not available to be interviewed who had placed their family member in residential care. In order to evaluate the differences between those caregivers interviewed about residential care versus those not interviewed, a comparison of means between groups on important variables was done, using t-test for independent groups.

Fourteen caregivers who indicated the care recipient was not cared for at home were not interviewed due to disconnected or changed phone numbers or inability to contact caregivers by phone. When comparing this group to the group of caregivers that were interviewed, the only significant difference was in age, with younger caregivers being less likely to be interviewed, years as caregiver with newer caregivers being less likely to be interviewed, and affect balance score, with those not interviewed having higher mean scores on this scale. Although more women than men were interviewed, the mean difference between sexes was not significant. Other nonsignificant differences included marital status, employment, education, mean scores on other measurements for caregiver well-being, care recipient age, cognitive level and functional level at diagnosis, and NPI change scores. Table 8 illustrates the comparison of means between those participants interviewed and those not interviewed.

Table 8

Comparison of Means on Variables for Caregivers Choosing Residential Care and Interviewed versus Caregivers Choosing Residential Care and Not Interviewed.

Comparison of Means on Variables for Caregivers Choosing Residential Care and Interviewed versus Caregivers Choosing Residential Care and Not Interviewed.						
Variable	Interview Status	N	Mean	SD	Mean Difference	t score
Age	Interviewed	19	69.34	8.45	4.84	3.66***
	Not Interviewed	21	57.14	12.10		
Years as Caregiver	Interviewed	19	5.58	4.57	2.08	1.77*
	Not Interviewed	19	3.50	2.35		
ABS	Interviewed	15	3.67	1.23	-1.81	-3.35**
	Not Interviewed	19	5.47	1.78		

Note. Only variables showing a significant difference in means are included. ABS= Affect Balance Scale.

*** $p < .000$ ** $p < .01$ * $p < .10$

Intercorrelations Between Residence of Care Recipient and Caregiver Variables

The next phase of the data analysis was to compute intercorrelations between place of residence of care recipients at the time of the caregiver study and select variables drawn from the literature as salient to predicting residential placement. Using care recipient variables, significant positive relationships were found between place of residence and MMSE scores, ADL scores and NPI change score between the first and last evaluation. Using caregiver variables, significant relationships were found between place of residence and employment status, health perception, depression score, level of optimism score, perceived stress score, caregiver experiences, and positive aspects of caregiving.

Of interest is a lack of relationship between place of residence and caregiver age or sex, quality of relationship between caregiver and care recipient, years as caregiver, NPI scores at any one evaluation time, marital status of caregiver, number of chronic health conditions in the caregiver or the affect balance score was not found. Table 9 shows the correlation matrix for these variables, listing only those variables demonstrating a significant relationship.

Table 9

Intercorrelations of Care Recipient and Caregiver Variables with Residence of Care Recipient

	CRRES	NPICG	EMPLO	HPQ	CES-D	LOT	PSS	CGEXP	MMSE	ADL
Y										
(n=100)										
CRRES	1.00	.21*	.23*	.27*	.39**	.24*	.24*	.29*	-.35**	.42**
NPICG		1.00	-.04	-.04	.04	-.14	.38**	.37*	-.17	.19
EMPLOY			1.00	-.07	-.04	-.06	-.05	.01	-.02	.09
HPQ				1.00	.58**	.35**	.55*	.32*	.05	.08
CES-D					1.00	.53**	.70**	.55**	-.12	.22*
PSS							1.00	.52**	-.13	.15
CGEXP								1.00	-.07	.09
MMSE									1.00	-.58**
ADL										1.00

(table continued)

Note. CRRES = Care Recipient Place of Residence; NPICG = NPI change score; EMPLOY = Caregiver employment status; HPQ = Health Perception Questionnaire; CES-D = Center for Epidemiological Scale on Depression; PSS = Perceived Stress Scale; CGEXP = Caregiver Experiences Questionnaire; MMSE = Mini Mental State Evaluation; ADL = Activities of Daily Living Scale. CRRES = 0= Home; 1= Residential Care; EMPLOY = 0 = Not Employed; 1 = Employed.

*p < .05 **p < .01

Regression Analysis

Linear regression was used to identify the strength of variables that relate to the transfer from home to residential care for care recipients. As shown in Table 8, caregivers' level of depression and employment status and the care recipient's change in behavior score between the first and last evaluation and ADL score showed a strong relationship with the place of residence of the care recipient. Other variables thought to be related to residential placement were also entered, using a hierarchical design to determine the influence of other caregiver and care recipient variables. These other variables included MMSE levels and aggression scores as a subscale of the NPI at the first and last evaluations. All other variables had nonsignificant t values and R^2 changes were less than 5% when these variables were removed. Therefore, CES-D total scores, NPI change scores, employment status of caregivers, and ADL Total Scores at the time of diagnosis were the only variables retained for the final equation. The model was significant with an F value of 12.94 and R^2 level of .36. Unstandardized beta, standardized beta, and t values are shown in Table 10.

Table 10

Summary of Hierarchical Regression Analysis using CES-D score, NPI Change Score, Employment Status and Activities of Daily Living as Predictor Variables.

	Variable	<u>B</u>	<u>SE B</u>	<u>B</u>
Step 1				
	CESD	.02	.00	.40***
	NPICS	.01	.00	.18*
	Employment Status	.29	.10	.25**
	ADL	.05	.01	.30**
Step 2				
	CESD	.02	.00	.36***
	NPICS	.05	.00	.15
	Employment Status	.30	.01	.26**
	ADL	.04	.02	.25*
	MMSE	-.00	.01	-.14
	NPI Aggression	-.00	.02	-.08
	NPI Aggression 2	.00	.02	.03

Note. $F = 12.94^{***}$ $R^2 = .36$ for Step 1; Change $R^2 = .38$ ($ps < .05$); CESD = Center for Epidemiological Depression Scale Total Score; NPICS = Neuropsychiatric Inventory Change Score from first to last evaluation; ADL = Activities of Daily Living at time of diagnosis; MMSE = Mini Mental Scale; NPI Aggression Subscale of NPI at diagnosis and at the time of the caregiver questionnaire.

* $p < .05$; ** $p < .01$; *** $p < .001$

Tests for multicollinearity indicated tolerance levels above .99 and variance inflation factors all below 2. These values indicate all variables used were independent of each other.

Survival Model

The question of when a patient with dementia is at risk for residential placement following diagnosis was analyzed using survival distribution curves for the entire sample. The date of entry into the study was used as the date of the initial diagnostic evaluation obtained from OADC. Although this date may not coincide with the exact date of onset of dementia, researchers agree that this is the optimal date to use to avoid ambiguity (e.g., Miller et al., 1998). The state change considered was when a care recipient entered residential care. In other words, survival time was considered home care and the hazard was considered entry into residential care. The Cox Proportional Hazard Model was employed using covariates shown in the literature to impact the timing of residential care (i.e., sex, marital status, relationship to care recipient, and employment status). Additionally, NPI change scores, CES-D scores, and ADL scores were added as covariates because of their strong relationship to residential placement with earlier statistical tests. This model provided the benefit of analyzing the influence of predictor values closest to the change in states (Miller et al., 1998; Parmer & Machin, 1996).

The results of this analysis indicated that once care recipients were diagnosed with dementia and then cared at home for more than four years, their risk for residential care increased. The CES-D score proved to be a significant

covariate, with caregivers whose scores were above the mean of 16.55 having an increased risk of placing the care recipient in residential care. Further, care recipients with an NPI Change Score above the mean of 14.96 were at increased risk for residential care as soon as two years after diagnosis. ADL scores also showed a significant relationship to the timing of residential care with those care recipients having a mean score above 2.74 having an increased risk of residential placement 3 years after diagnosis. These patterns are consistent with earlier findings indicating (a) higher scores on the CES-D for caregivers, (b) higher NPI change scores, and (c) higher scores on the ADL for care recipients increase the risk for residential placement, and add that the risk for residential placement is earlier when the scores on these measures are higher. Other variables were added to this model to compare groups, including gender of the caregiver, marital status of the care recipient, relationship of the caregiver to care recipient, and employment status of the caregiver. All but gender proved to be significant covariates, indicating a difference between groups. This pattern is consistent with earlier research indicating that those other than a spouse who remain employed and care for an unmarried care recipient are at highest risk for placing the care recipient in residential care earlier than other groups. Further, single care recipients enter residential care earlier than married care recipients. In summary, depression scores and employment status in caregivers, and behavior change in care recipients increase the risk of whether or not care recipients are placed in residential care, and depression scores, employment status of the caregiver, and the sex, marital status and behavior change in the care recipient, and the type of relationship between the

caregiver and care recipient decrease the time between diagnosis of dementia and residential care placement.

Figures 4 through 10 illustrate the survival curves for residential placement first by the difference in sex and employment status of caregivers and marital status of care recipients followed then by each of the covariates analyzed.

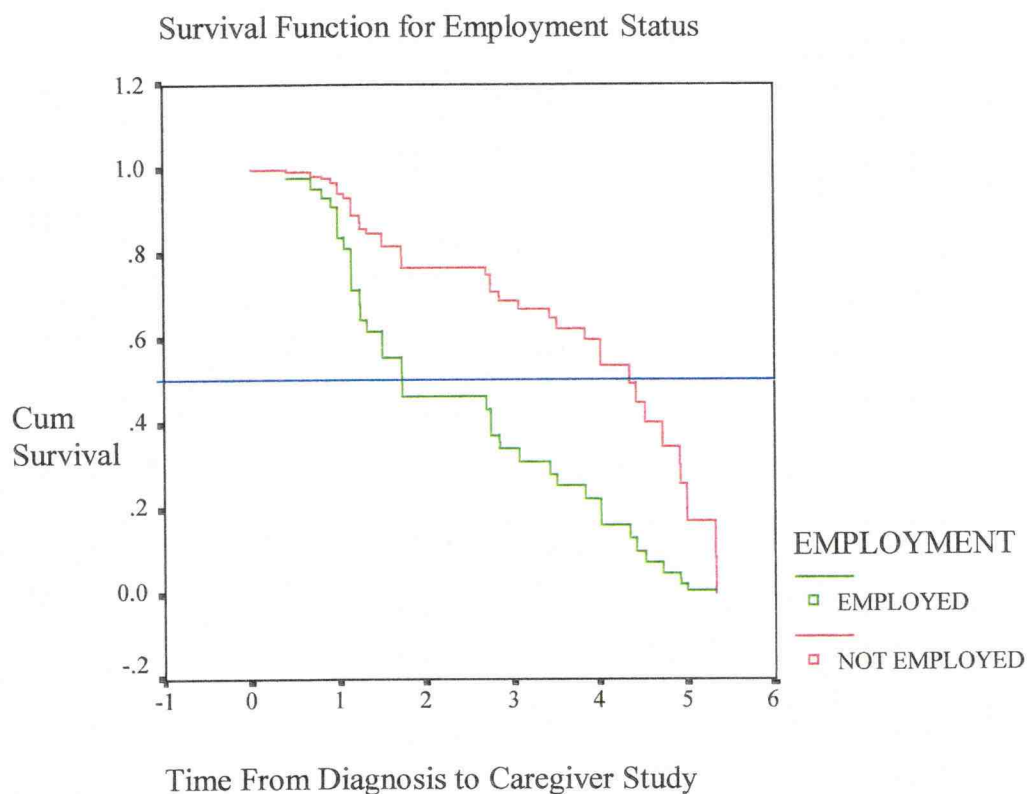


Figure 4. Survival curve for residential placement using employment status of the caregiver as the covariate illustrating a significant effect of employment on the timing of residential placement. This figure illustrates care recipients of employed caregivers enter residential care significantly earlier than unemployed caregivers, with about half entering residential care as early as two years after diagnosis. The blue line marks when .50 proportion of care recipients enter residential care.

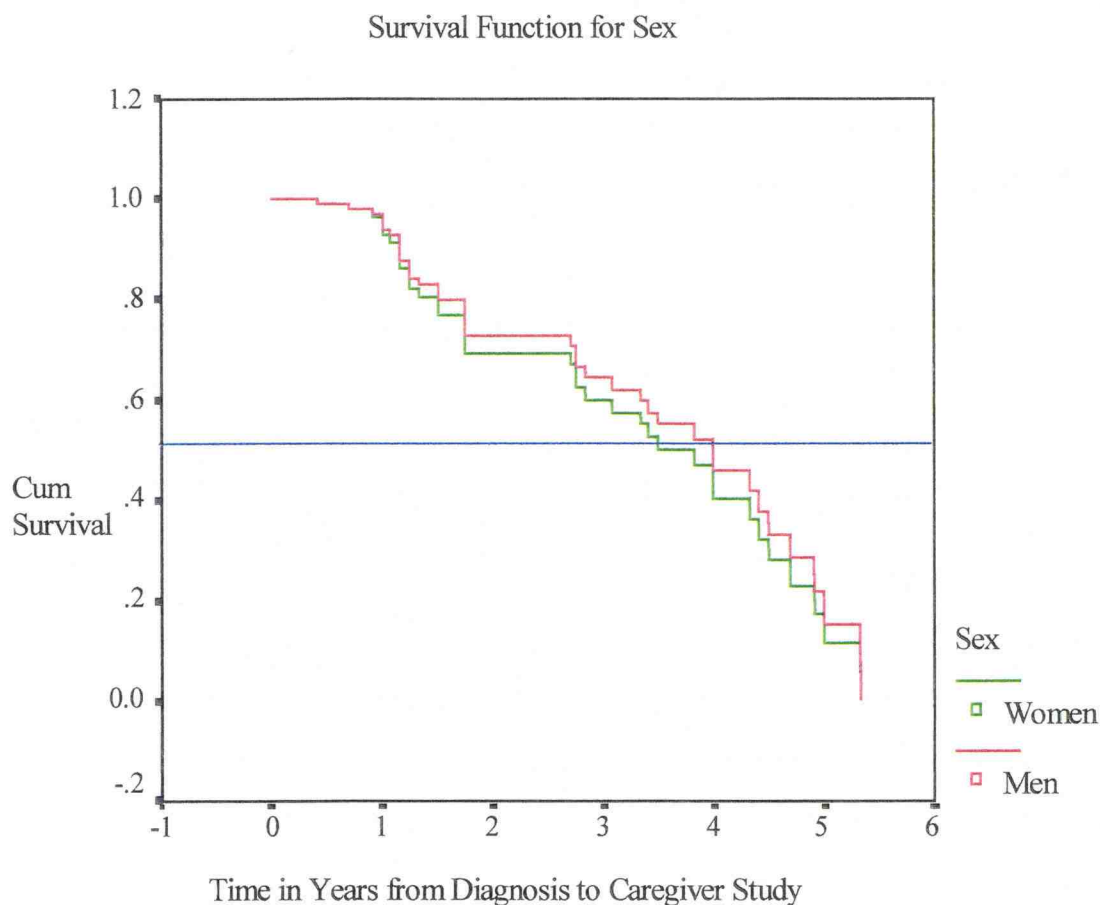


Figure 5. Survival curve for Residential Placement using sex as the covariate illustrating no significant effect of sex on the timing of residential placement. Blue line is drawn at the point where .50 proportion of care recipients enter residential care, indicating about half of the care recipients enter care by year four after diagnosis.

Survival Function for Marital Status of Care Recipients

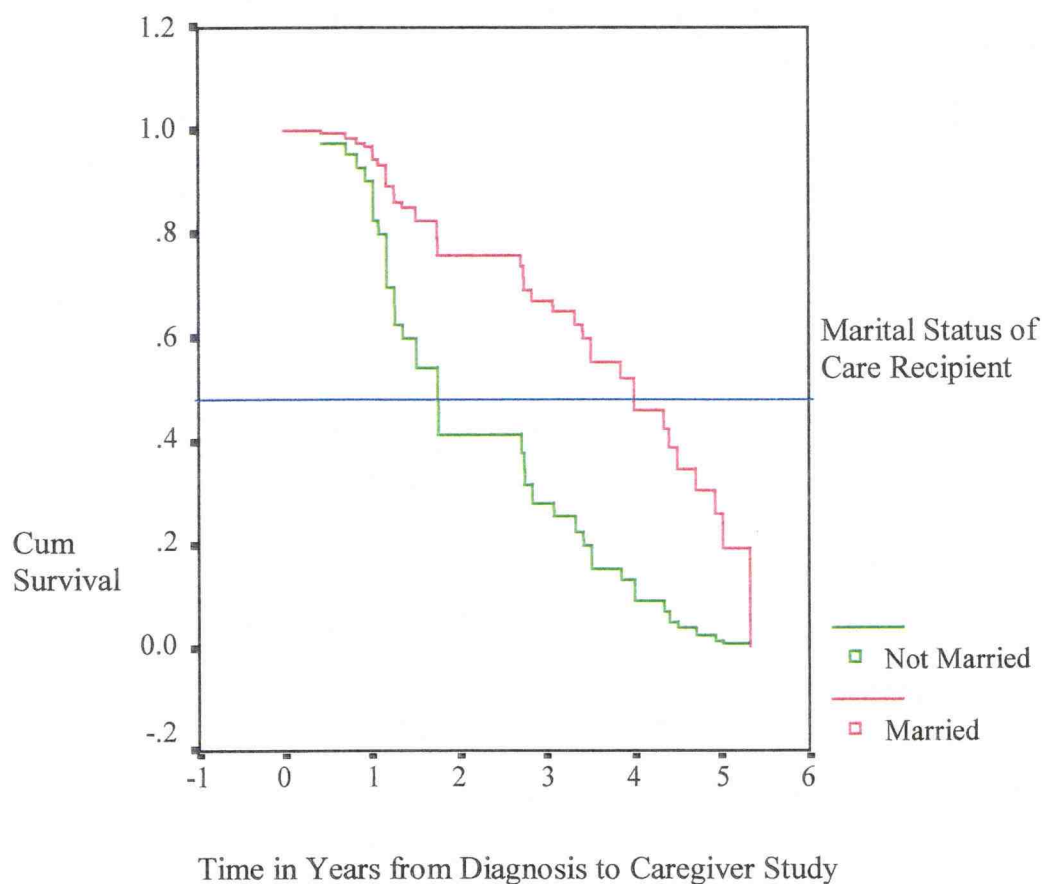


Figure 6 . Survival curve for residential placement using marital status of the care recipient as the covariate illustrating a significant effect of marital status on the timing of residential placement. This figure illustrates unmarried care recipients enter residential care significantly earlier than married care recipients, with about half entering residential care as early as two years after diagnosis. The blue line marks when .50 proportion of care recipients enter residential care.

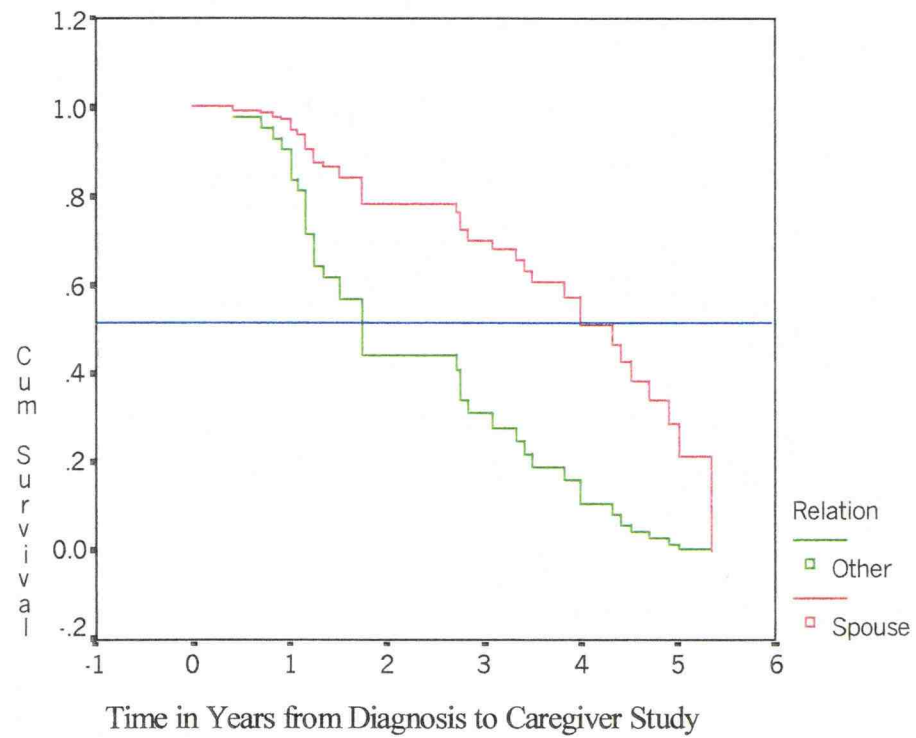


Figure 7. Survival curve for residential placement using relationship to of the care recipient to the caregiver as the covariate illustrating a significant effect of type of relationship on the timing of residential placement. This figure illustrates that over half of the care recipients cared for by other than a spouse enter residential care earlier than those care recipients cared for by a spouse. The blue line marks when .50 proportion of care recipients enter residential care, indicating about half of the care recipients cared for by other than a spouse enter residential care as early as two years after diagnosis.

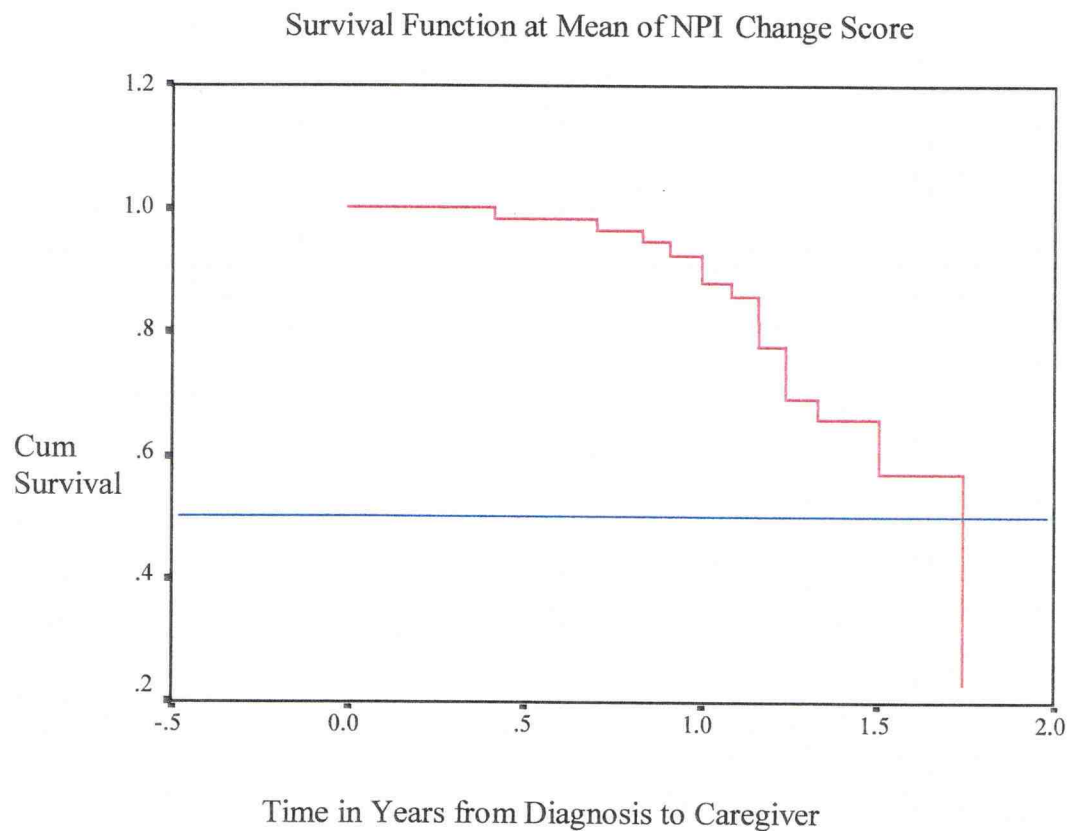


Figure 8. Survival curve for residential placement using NPI Change Score as the covariate illustrating a significant effect of the change in NPI score on the timing of residential placement. This figure illustrates that about half of the care recipients with a score above the mean (14.96) entered residential care less than two years after diagnosis. The blue line marks when .50 proportion of care recipients entered residential care after diagnosis.

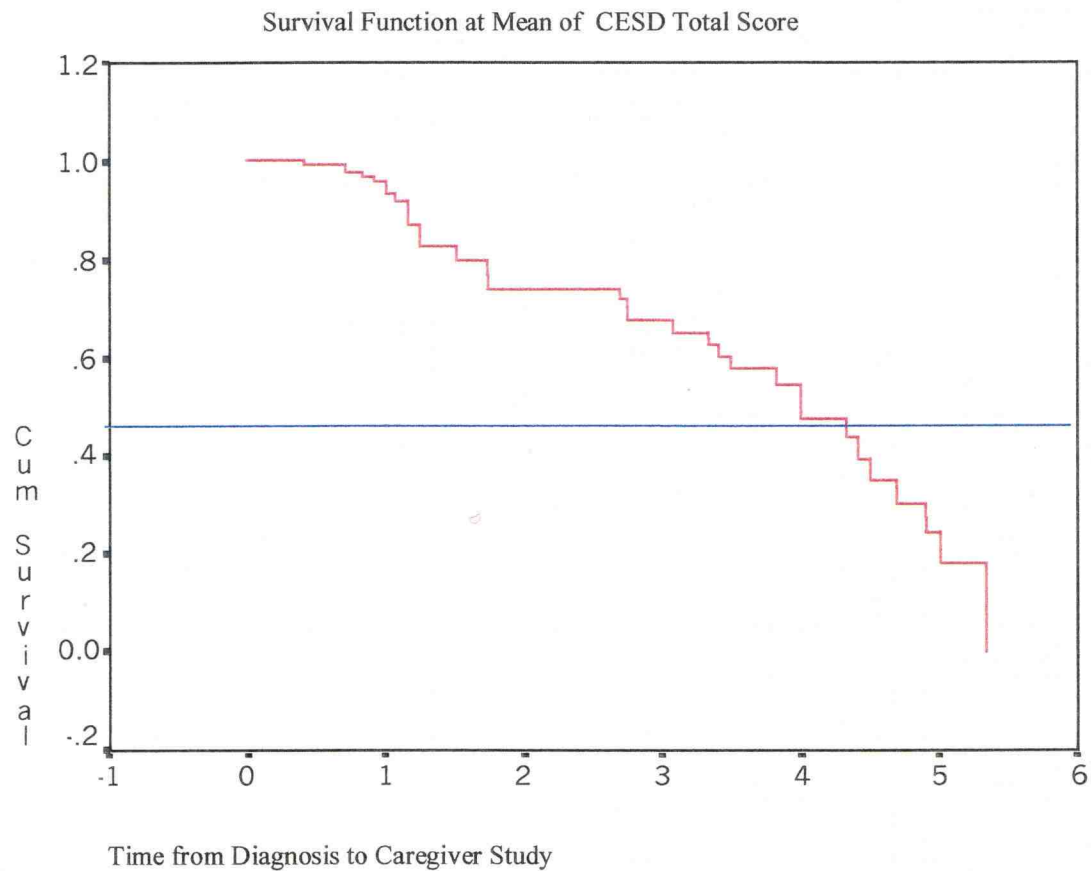


Figure 9. Survival curve for residential placement using CES-D Total Score as the covariate illustrating a significant effect of the CES-D Total score on the timing of residential placement. This figure illustrates that about half of the care recipients with a score above the mean (16.55) entered residential care approximately four years after diagnosis. The blue line marks when .50 proportion of care recipients entered residential care after diagnosis.

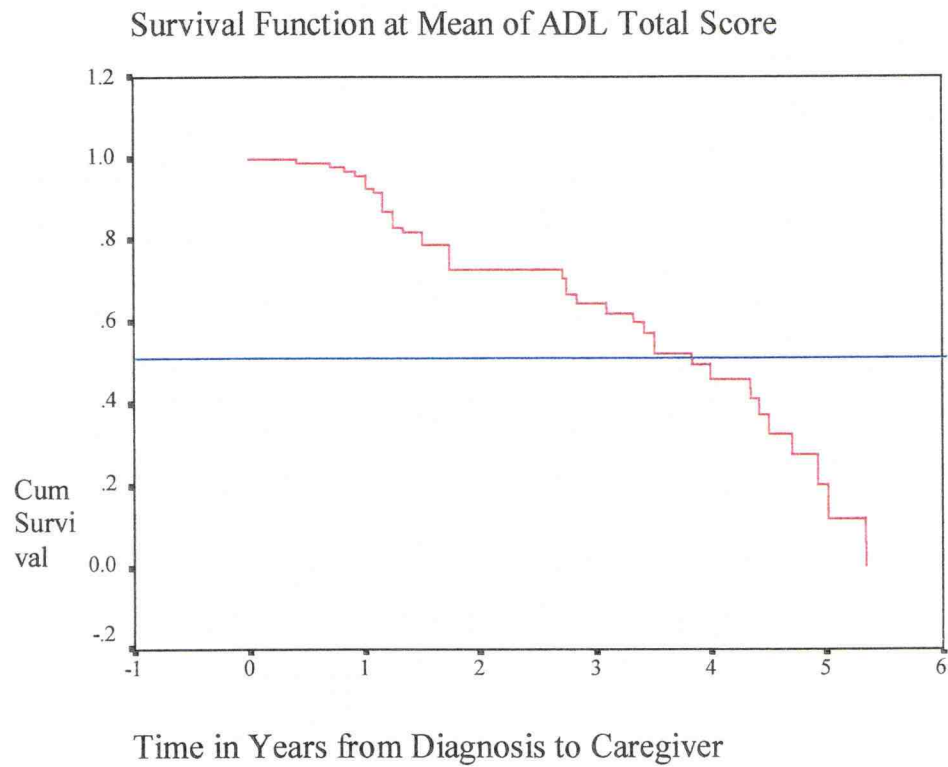


Figure 10. Survival curve for residential placement using ADL Total Score as the covariate illustrating a significant effect of the ADL Total Score on the timing of residential placement. This figure illustrates that about half of the care recipients with a score above the mean (2.74) entered residential care less than four years after diagnosis. The blue line marks when .50 proportion of care recipients entered residential care after diagnosis.

Chapter Five: Discussion

The primary research questions for this study were how much impact do behavior problems in patients with dementia have on the occurrence and timing of residential care and whether other characteristics in the care recipient and/or caregiver influence the change from home care to residential care. The primary findings related to these questions were that the employment status and depression scores in the caregiver and negative behavior change over time and activities of daily living scores at the time of diagnosis in the care recipient influenced the change from home care to residential care more than any other variables analyzed. Further, negative behavior change over time had a stronger relationship with whether a patient with dementia was placed in residential care than any one behavior score at diagnosis or at the time of the caregiver questionnaire. These findings not only emphasize the growing importance of screening all caregivers for symptoms of depression, but also emphasize the importance of longitudinal studies. Because change in behaviors over time was a better predictor for residential care than scores at one time, the belief is supported that stress over time from increasing problem behaviors in care recipients impacts caregivers' need to choose residential care.

Several surprising findings also emerged from these data. The strong relationship between depression scores from caregivers and residential placement supported the idea that depression may trigger residential placement by caregivers. It remains unclear from this study whether or not caregivers were depressed before taking on the caregiving role, or if their depressive symptoms changed as their

caregiving role changed, but it is clear that higher scores on the CES-D were strongly related to residential care. The mean CES-D score for all participating caregivers was 16.55, but was 22.37 for those caregivers choosing residential care for their loved one. The finding that depression scores were high for caregivers is consistent with previous research (Alspaugh, Zarit, Stephens, & Townsend, 1999; Coppel, Burton, Becker, & Fiore, 1985; Drinka, Smith, & Drinka, 1987; Gallagher-Thompson, 1995; Schulz & Williamson, 1994; Whitlatch, Feinberg, & Sebesta, 1997), but previous studies have not shown the relationship between depression scores and residential placement. In this study, over one-third of the variance in residential care was accounted for by the caregivers' depression score and employment status and care recipients' behavior change score and ADL scores at the time of diagnosis. The combination of increasing problem behaviors and caregiver depression has been shown in caregiver literature (Shultz, O'Brien, Bookwala, & Fleissner, 1995), but the combination of these variables has not yet been discussed as a predictor for residential placement.

The relationship between functional abilities at the time of diagnosis and residential placement has been repeatedly reported in the literature.(Johanson et al., 1997, Newens et al., 1995, Pruchno et al., 1990; Wolinsky et al., 1993). This variable not only had a strong correlation with residential placement, but also demonstrated a relationship to the timing of placement. ADL scores did not, however, show a strong relationship to behavior change scores. This lack of relationship between ADL scores and behavior change scores may be linked to a pattern of patients with poorer functional abilities presenting less stressful behavior problems at diagnosis and being

less likely to manifest disruptive behaviors over time due to their physical limitations.

Employment of caregivers was also shown to have a strong relationship with residential placement consistent with previous studies (Cohen et al., 1993; Colerick & George, 1986). When the relationship between caregiver and care recipient, marital status of the care recipient, and the employment status of the caregiver were examined together, it appears that those caregivers caring for other than a spouse have the added stress of maintaining employment, family, and caregiving. This additional burden appears to decrease the time caregivers are able to care for the care recipient at home.

Several variables previously shown as important to residential placement failed to show any relationship or predictive qualities. Although activities of daily living on a whole was significant, incontinence alone was not found to be a salient variable in predicting residential care in this study. Several previous studies have found incontinence to be one of the most important factors in predicting residential care (Johanson, Irizarry, & Doughty, 1997; Newens, Forster, & Kay, 1995; Wolinsky, Callahan, Fitzgerald, & Johnson, 1993). The difference in findings in this study may indicate that these caregivers were able to handle difficulties with toileting easier than behavior problems and personal stress. Further, overall deterioration in ADL's logically adds more burden to the caregiver than any one difficulty such as incontinence. During the interviews with caregivers, it was noteworthy that incontinence was mentioned only as a secondary factor and not as a primary factor in transferring care recipients to residential care. Given et al. (1999)

supported the idea that stress from caring for a person with behavior problems is different from caring for a person with dependency needs from deteriorating activities of daily living. The difference in the effect of specific ADLs needs further investigation. Another possibility for the difference in findings regarding incontinence is that previous studies citing incontinence as a strong predictor used data obtained from care centers. Caregivers may tell nursing home staff that incontinence is the reason for admission when in fact behavior problems may be a more compelling reason. The reluctance to reveal information on behavior problems may be due to fear that the problem behaviors may hinder residential placement and may not be covered by certain insurance programs as reasons necessitating residential care. Incontinence may be more acceptable as a diagnosis needing skilled nursing services and insurance coverage may be easier to obtain (Cohen et al., 1993). Indeed, several caregivers noted transfers from one residential care to another were prompted by staff struggling with increasing behavior problems in the care recipient and not from deteriorating dependency needs.

The other area showing a moderately strong relationship to residential placement was caregivers' health perception. Although this measure did demonstrate a significant relationship to residential care, other measures, including the number of health conditions and health rating failed to demonstrate any relationship to residential placement. This may indicate caregivers are choosing alternative care for the care recipient as they perceive their health to be deteriorating, but before their physical health shows measurable decline. In Colerick and George's (1986) study, caregiver well-being was found to be a predictive factor for residential placement,

but mental and physical well-being was not separated. When looking at the impact of caregiving on caregiver well-being, other studies have shown a stronger relationship with negative outcomes of caregivers' mental health than physical health (Schulz & Williamson, 1994). This supports the importance of measuring these two concepts separately, as mental health proved far more powerful than physical health as a predictor of residential placement in this study.

Finally, previous studies have found a strong relationship between cognitive decline and behavior problems, with as high as 71% of patients with dementia also having behavior problems (Jagger & Lindsey, 1997). In this study, however, a strong relationship between cognitive decline and behavior scores at any one time or the change score was not found. Again, this may be related to the setting used for previous studies, with nursing homes being the most common site. Dementia patients cared for at home may have far fewer behavior problems than those cared for in nursing homes. This idea is supported by the higher NPI Change Scores found for those care recipients in residential care when compared to those still living at home.

By examining study results, the question of which characteristics may predict residential placement continues to yield conflicting outcomes. By considering the stories of the caregivers themselves, however, some compelling evidence arises that the combination of problem behaviors, especially aggression, with the exhaustion and depression so common to the role of caregiving, leads to the critical need for finding assistance outside the home. The caregivers in this study repeatedly talked of the long hours of caring for their relative with little relief from outside help. The nights seemed the longest, as many caregivers talked of only getting an hour or two

of uninterrupted sleep per night. The help caregivers did receive was often short, ill-fitted to their needs, and/or expensive. These comments are consistent with previous studies indicating support services are used by caregivers, but do not necessarily delay or prevent residential placement (Lawton, et al., 1989; O'Connor et al., 1991). In spite of these hardships, many caregivers continued their efforts to care for their loved one. Only when their life was threatened by physical harm, exhaustion, or physical illness did these caregivers finally relinquish care. Many were pleased with the care they found, describing the professional care providers as a "life saver." Others told stories of their relative lying in feces, or left unattended and unfed for days. All caregivers continued to provide care regardless of whether the care recipient was at home or in residential care. One caregiver noted he spent an average of six hours per day caring for his wife after placing her in foster care. In support of earlier studies indicating efforts to prevent residential care through increased daycare and respite services for care recipients in fact increased residential care admission, these caregivers indicated respite care was often inadequate to meet the needs of the caregiver or the care recipient and turned out to be a temporary stop on the way to residential care (Lawton et al., 1989; O'Conner et al., 1991).

I ended each interview with the final question, "Is there anything else you would like to tell others about being a caregiver?" Several offered the advice of not waiting too long to transfer a relative to residential care. One women noted she visits her husband daily, and can "enjoy him now that I'm not exhausted." A man caring for his wife offered the suggestion that caregivers "have to be honest. You want the best care, and care at home may not be the best care. Nursing home care can be

better for the caregiver and the patient.” All caregivers offered something to try to help the next person.

Because of the results of this study, evidence for a change in approach in how researchers and clinicians support caregivers and care recipients with dementia may be indicated. Several researchers indicated the purpose in studying residential care admission predictors was to identify ways to decrease admissions and thereby reduce costs to society. Johanson, Irizarry, and Doughty (1997) indicated that providing more services for caregivers on ways to control incontinence could reduce nursing home admissions and costs. These solutions can only add to, rather than relieve the burden of caregiving so many adults face. Rather than pressure caregivers to provide more complex care, without relieving the stress they already face, clinicians may serve caregivers better by assisting them in finding residential care that meets everyone’s needs.

Although the change in the caregiving role following residential placement was not the focus of this study, it was clear through the conversations with caregivers that caregiving changed in positive more than negative ways when residential care was used. This improvement seemed to be largely because the caregiver had help in the caregiving tasks once residential care was used resulting in more energy to provide quality care rather than situational care given by an exhausted, sad, and sometimes ill caregiver. Support for partnerships in caregiving between residential care facilities and caregivers may prove to be the best option for many. By supporting this option more openly, funding may become more accessible, thereby

improving the quality and quantity of residential care so needed by so many caregivers.

Limitations

As with all social science research, there are many limitations to this study. The limitations include both the small sample size and the amount of missing data. Although missing data are typical for longitudinal studies over similar periods, the need to impute missing data and or limit the selection of cases analyzed weakens the statistical power of the analysis. The small sample size also limited the number of variables used in the regression model, again limiting the ability to generalize findings.

Another limitation of this study is the over-representation of White caregivers with more than a high school diploma. Thus, results cannot be generalized to other populations. Further, this study was limited to subjects in and around the northwest section of the United States. Therefore, results may be altered by geographical and cultural variables not yet considered. In spite of these limitations, the rate of residential care use by caregivers of patients with dementia was similar to that in other larger studies (Aneshensel et al., 1994).

A third limitation to this study is the lack of longitudinal data on other important variables including ADLs and caregiver data. Because these variables were measured cross-sectionally, it is impossible to identify causation for placement decisions clearly. For example, there is little evidence to support whether depression symptoms preceded or increased with the diagnosis of dementia. As Miller and

McFall (1991) emphasized, examining change in capabilities, in addition to risk factors, is an important need for future research.

Strengths

A major strength of this study is the use of longitudinal behavioral data to examine the relationship between behavior problems and residential care. Because these data illustrated change across time, a more powerful regression model emerged. This change score and its relationship to residential care had not yet been reported in previous studies. Another strength of having longitudinal data was the ability to use a survival model to assess the timing of residential care, and to examine how that timing changed with certain covariates. The change in behavior and the increase in depression in caregivers and their influence on residential care was clearly illustrated due to the availability of longitudinal data.

Another strength of this study was the opportunity to talk directly with caregivers during the final interview. This information supplemented and enriched the quantitative data. By talking directly to the caregivers, important variables were better understood, and possible reasons for differences between this study and previous studies emerged. Because of the conversations with caregivers, application of this information to others can be more personal, and may be more appropriate to the needs of caregivers.

Implications

The implications of the results of this study are many. Clinicians may use this information to look towards changes in problem behaviors when assessing caregiver burden and stress. Further, by assessing behavior problems and caregiver depression during early diagnostic tests for dementia, clinicians can better identify those caregivers who may struggle with caregiving. Specifically, screening for aggressive behaviors may assist in preventing serious injuries to both care recipients and caregivers. Further, better screening tools are needed to identify which care recipients and/or caregivers may benefit from residential care, which may in turn assist in decreasing negative outcomes of caregiving such as caregiver depression. Violent and aggressive behavior and/or caregiver depression may be important items to include in this screening. If residential placement is an option considered earlier in the caregiving career, then caregivers may be more likely to receive the support and guidance they need to find the best setting for all concerned and to work as partners with residential care providers to provide, in the end, the best possible care for persons with dementia. Finally, these results are very important to consider in multidisciplinary professional educational curriculums. For example, nursing students need to be educated about the reasons caregivers chose residential care, ways to screen for caregiver stress and depression and care recipient behavior problems and functional abilities, and ways to support caregivers in finding timely and appropriate residential care.

Directions for Future Research

Although important trends emerged from the data, caregiving is an individual experience with multiple, interacting variables. Combining data from different sources, such as information from residential care staff and caregivers would enrich our knowledge of variables affecting placement. Further, more longitudinal data with complete data at three or more waves could open up possibilities for more powerful data analysis. Techniques such as structural equation modeling and latent growth curve modeling used with larger sample sizes across more time points could strengthen the findings explored in this study, and assess the variability so common in caregivers.

Several variables were not included in this data set that may be very important to the timing of residential placement. For example, decision-making processes and reactions to stress may delay or hasten transitions to residential care. Further, availability of resources were not explored in this study, and could have influenced the decisions. Two of the caregivers interviewed mentioned finances as a concern with finding and keeping residential care. The idea of cost versus benefits of both home and residential care needs more exploration.

Finally, longitudinal data on caregivers is an important need. Finding out the status of mental and physical well-being at the time of diagnosis of dementia in a loved one, and how these states change over time and affect residential planning and implementation is a salient necessity.

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Appendices

Appendix A

Permission Letter to Use Data from Larger Study

**OREGON STATE UNIVERSITY
CORVALLIS, OREGON 97331**

February 16, 1999

Deborah Padgett Coehlo
8037 NW Mitchell Drive
Corvallis, Oregon 97330

Re: Dissertation entitled "Residential Placement of Patients with Dementia:
Relationship to Care Recipient and Caregiver Variables".

Dear Ms. Coehlo:

This letter is written to grant you permission to use data collected for the study entitled "Behavioral Changes in Dementia Patients: Relationship to Caregivers' Well-Being" over the period from June 1998 through June 1999. These data include both care recipient and caregiver data from both the Oregon Alzheimer's Disease Center and Oregon State University Study. Permission includes use of all data using the following measurement tools:

- Mini Mental State Examination
- Activities of Daily Living
- Neuropsychiatric Inventory
- Caregiver Questionnaire
- Health Perception Questionnaire
- Bradburn's Affect Balance Scale
- Perceived Stress Scale
- Center for Epidemiological Studies- Depression Scale
- Caregiver Experiences Questionnaire

These measurements are all considered public domain, and used extensively in research and clinical settings. Please do not hesitate to contact either of us if any questions arise regarding use of these data with your dissertation. Thank you for your interest in using our data. We fully support your efforts, and feel your topic will add to our understanding of caregiving patients with dementia.

Sincerely,

Karen Hooker, Ph.D.
Associate Professor: Department of Human Development and Family Sciences
Co-Principal Investigator

Sally Bowman, Ph.D.
Assistant Professor: Extension Services
Co-Principal Investigator

Appendix B

Care Recipient Measurement Scales

- **Mini-Mental State Examination**
- **Activities of Daily Living**
- **Neuropsychiatric Inventory**

ADCO

MINI-MENTAL STATE EXAMINATION (MMSE)

Patient's Name _____ Medical Record# _____
 Evaluation Date _____ Evaluating Clinician _____
 Name of Person Completing Form _____ Date Completed _____

Instructions: To facilitate consistent administration of the MMSE, the examiner should pose questions as worded below. Please note Instructions specific to each test Item in *Italics*. Please record subject's responses.

Max Correct	Score	ORIENTATION
	(5)	What is the (year) (season) (date) (day) (month)? (Draw line through each correct answer. Accept exact year, date, day, month. Season will be scored correct if within a week either way of - 912 1 - Fall, 1212 1 - Winter, 312 1 - Spring, 6121 - Summer)
	(1)	What state are we in? (Oregon)
	(1)	What city are we in? (Portland)
	(1)	What is the name of this hospital/office/clinic? (Accept Oregon Medical School, OHSU, University Hospital, or similar variations. Do not accept Multnomah County Hospital, Pill Hill)
	(1)	What county do you live in? (County where patient lives)
	(1)	What floor are we on? (exact)
		REGISTRATION
	(3)	I am going to name 3 things, and I want you to say them after me. Are you ready? The Three things are (1 second per word) iceberg, lion, and cactus. Now you say them. (Score 1 For each item correctly repeated on the first trial) Repeat as often as necessary until patient can say all three. Record number of trials here
		ATTENTION AND CALCULATION
		Spell "world" backwards. Have patient spell WORLD forward (correct if necessary), prior to spelling it backward. Score is the number of letters in correct order. Count 1 error for each omission or letter transposition (switching adjacent letters) (e.g., dirow = 5, dlrw = 4, diorw = 4, dolw = 3) Please record patient's response
		RECALL
		Now name those 3 things I asked you to remember earlier. (Score 1 for each correct object)

(3)

LANGUAGE

(1)

What is this Called? Show the patient a pencil. Must be a pencil. A pen is not acceptable.

(1)

What is this called? Show the patient a watch. (If patient has trouble with a digital watch, show an analog watch.)

(1)

Repeat the following: "No ifs, ands, or buts." (Must be repeated verbatim on the first trial (e.g., "No if ("s" dropped) ands or buts" L's not accepted). Allow only one trial. Score 0 or 1

(3)

Give the patient a piece of plain blank paper and repeat the three step command-

(Ask all at once. Draw line through each step correctly executed. Score 1 for each.) "Take this paper in your right hand, fold it in half, and put it on the floor."

For the next three items, use the back of this form. Fold in thirds so that patient can perform each task without being distracted by text or drawings in the other two sections.

(1)

Read this and do what it says. (Hand patient the paper (folded as noted above) with the words 'Close your eyes.' Can repeat entire instruction if needed. Score only if patient actually closes eyes.)

(1)

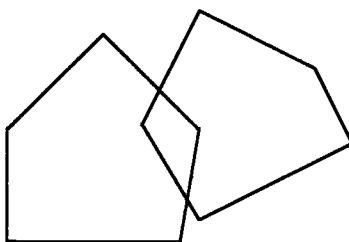
Write a sentence. (Do not dictate-must be written spontaneously. Must have a subject, a verb and make sense. Correct grammar and punctuation are not necessary

(1)

Copy this design. (All 0 angles must be present and the intersection of the two open diagonals must be rhomboid (four-sided). Tremor and rotation are ignored.)

(30) Total Score

Close your -eyes.



ADCO

MODIFIED ACTIVITIES OF DAILY LIVING

Patient Name _____	Medical Record# _____
Evaluation Date _____	Evaluating Clinician _____
Name of Person Completing Form _____	Date Completed _____

Activities of Daily Living - ADL

Tester may need to evaluate what subject is functionally capable of doing,

Assistance

not what(s)he actually does. *Special instructions in Italics below.*

Needed

Unless otherwise specified, Score:

0	None
1	Slight
2	Full

- | | |
|--|---|
| 1. Eating (<i>needs food cut up reminder to eat?</i>) | <input style="width: 50px; height: 20px;" type="text"/> |
| 2. Dressing and undressing (<i>needs clothing set out for him/her. 7</i>) | <input style="width: 50px; height: 20px;" type="text"/> |
| 3. Combing hair and shaving (<i>needs to be reminded?</i>) | <input style="width: 50px; height: 20px;" type="text"/> |
| 4. Walking | <input style="width: 50px; height: 20px;" type="text"/> |
| 5. Getting in and out of bed | <input style="width: 50px; height: 20px;" type="text"/> |
| 6. Bathing or showering (<i>needs prompting or reminders, needs assistance with part of task (i.e., washing hair)</i>) | <input style="width: 50px; height: 20px;" type="text"/> |
| 7. Toileting (<i>needs reminders or help with cleaning self after toileting?</i>) | <input style="width: 50px; height: 20px;" type="text"/> |
| 8. Incontinence | |

Score:

0	Never
1	Once or twice/ week
2	Three or more times/ week

- | | |
|---|---|
| 9. Needs help with shopping, bathing, housework, and/or getting around? | <input style="width: 50px; height: 20px;" type="text"/> |
|---|---|

Total ADL Score

ADCO
MODIFIED NEUROPSYCHIATRIC INVENTORY
 Adapted from the UCLA Neuropsychiatric Inventory

Office Use Only

Patient Code Number: _____

Patient Name _____	Medical Record # _____
Evaluation Date _____	Evaluating Clinician _____
Name of Informant _____	Relationship to patient _____
Name of person completing form _____	Date Completed _____

Instructions: SCORE behaviors present since onset of illness, NOT present throughout patient's life. If behavior HAS occurred in the LAST MONTH, check off all subquestions that apply and mark the overall frequency and severity of the behavior. OTHERWISE, go to the next behavior.

A. IRRITABILITY/LABILITY: Does (S) get irritated and easily disturbed? Are his/her moods very changeable? Is he/she abnormally impatient? We do not mean frustration over memory loss or inability to perform usual tasks; we are interested to know if (S) has abnormal irritability, impatience, or rapid emotional changes different from his/her usual self.

- ☐ N/A, unable to assess, e.g. too impaired.
- ☐ NO, Not since illness began. **GO DIRECTLY TO NEXT BEHAVIOR- ITEM B**
- ☐ YES, since illness began but not in the last month.

☐ **YES, HAS OCCURRED IN THE LAST MONTH: If any of these behaviors have occurred, please indicate as a group how often (frequency) and how severe these behaviors have been.**

Behavior	Frequency	Severity
<input type="checkbox"/> 1. Does (S) have a bad temper, flying "Off the handle" easily over little things?	<input type="checkbox"/> 1. Occasionally- less than once per week	<input type="checkbox"/> 1. Mild- irritability or lability is notable but usually responds to redirection and reassurance.
<input type="checkbox"/> 2. Is (S) Stubborn, having to have things his/her way?	<input type="checkbox"/> 2. Often- about once per week	<input type="checkbox"/> 2. Moderate- irritability and lability are very evident and difficult to overcome by the caregiver.
<input type="checkbox"/> 3. Does (S) have sudden flashes of anger?	<input type="checkbox"/> 3. Frequently- several times per week but less than every day.	<input type="checkbox"/> 3. Marked- irritability and lability are very evident, they usually fail to respond to any

intervention by the caregiver, and they are a major source of distress.

- | | | | |
|--------------------------|---|--------------------------|--|
| <input type="checkbox"/> | 4. Is (S) impatient, having trouble coping with delays or waiting for planned activities? | <input type="checkbox"/> | 4. Very frequently- essentially continuously present. |
| <input type="checkbox"/> | 5. Is (S) cranky and irritable? | | |
| <input type="checkbox"/> | 6. Is (S) argumentative and difficult to get along with? | | |
| <input type="checkbox"/> | 7. Does (S) show any other signs of irritability? | | |
-

**B. AGITATION/AGGRESSION: Does (S) have periods when he/she refuses to cooperate or won't let people help him/her?
Is he/she hard to handle?**

- ☐ N/A, unable to assess, e.g. too impaired.
- ☐ NO, Not since illness began. **GO DIRECTLY TO NEXT BEHAVIOR- ITEM C**
- ☐ YES, since illness began but not in the last month.

YES, HAS OCCURRED IN THE LAST MONTH: If any of these behaviors have occurred, please indicate as a group how often (frequency) and how severe these behaviors have been.

Behavior	Frequency	Severity
<input type="checkbox"/> 1. Does (S) get upset with those trying to care for him/her to resist activities such as bathing or changing clothes?	<input type="checkbox"/> 1. Occasionally- less than once per week	<input type="checkbox"/> 1. Mild- behavior is disruptive but can be managed with redirection or reassurance.
<input type="checkbox"/> 2. Is (S) stubborn, having to have things his/her way?	<input type="checkbox"/> 2. Often- about once per week	<input type="checkbox"/> 2. Moderate- behavior disruptive and difficult to redirect or control.
<input type="checkbox"/> 3. Is (S) uncooperative, resistive to help from others?	<input type="checkbox"/> 3. Frequently- several times per week but less than every day.	<input type="checkbox"/> 3. Marked- agitation is very disruptive and a major source of difficulty; there may be a threat of personal harm. Medications are often required.
<input type="checkbox"/> 4. Does (S) have any other behaviors that make him/her hard to handle?	<input type="checkbox"/> 4. Very frequently- essentially continuously present.	
<input type="checkbox"/> 5. Does (S) shout or curse angrily?		
<input type="checkbox"/> 6. Does (S) slam doors, kick furniture, throw things?		
<input type="checkbox"/> 7. Does (S) attempt to hurt or hit others?		
<input type="checkbox"/> 8. Does (S) have any other aggressive or agitated behaviors?		

C. ANXIETY: Is (S) very nervous, worried, or frightened for no apparent reason? Does he/she seem very tense or fidgety?
Is the patient afraid to be apart from you?

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | N/A, unable to assess, e.g. too impaired. | |
| <input type="checkbox"/> | NO, Not since illness began. | GO DIRECTLY TO NEXT BEHAVIOR- ITEM D |
| <input type="checkbox"/> | YES, since illness began but not in the last month. | |

YES, HAS OCCURRED IN THE LAST MONTH: If any of these behaviors have occurred, please indicate as a group how often (frequency) and how severe these behaviors have been.

Behaviors	Frequency	Severity
<input type="checkbox"/> 1. Does (S) say that he/she is worried about planned events?	<input type="checkbox"/> 1. Occasionally- less than once per week	<input type="checkbox"/> 1. Mild- anxiety is distressing but usually responds to redirection or reassurance.
<input type="checkbox"/> 2. Does (S) have feelings of feeling shaky, unable to relax, or feeling excessively tense?	<input type="checkbox"/> 2. Often- about once per week	<input type="checkbox"/> 2. Moderate- anxiety is distressing; anxiety symptoms are spontaneously voiced by the patient and difficult to alleviate.
<input type="checkbox"/> 3. Does (S) have periods of [or complain of] shortness of breath, gasping, or sighing for no apparent reason other than nervous?	<input type="checkbox"/> 3. Frequently- several times per week but less than every day.	<input type="checkbox"/> 3. Marked- anxiety is very distressing and a major source of suffering for (S).
<input type="checkbox"/> 4. Does (S) complain of butterflies in his/her stomach, or of racing or pounding of the heart in association with nervousness? [Symptoms not explained by ill health]	<input type="checkbox"/> 4. Very frequently- essentially continuously present.	
<input type="checkbox"/> 5. Does (S) avoid certain places or situations that make him/her more nervous such as riding in the car, meeting with friends, or being in crowds?		
<input type="checkbox"/> 6. Does (S) become nervous and upset when separated from you [or his/her caregiver]? [Does he/she cling to you to keep you from being separated?]		
<input type="checkbox"/> 7. Does (S) show any other signs of anxiety?		

D. DEPRESSION/DYSPHORIA: Does (S) seem sad or depressed? Does he/she say that he/she feels sad or depressed?

- ☐ **N/A, unable to assess, e.g. too impaired.**
- ☐ **NO, Not since illness began. GO DIRECTLY TO NEXT BEHAVIOR- ITEM E**
- ☐ **YES, since illness began but not in the last month.**
- ☐ **YES, HAS OCCURRED IN THE LAST MONTH: If any of these behaviors have occurred, please indicate as a group how often (frequency) and how severe these behaviors have been.**

Behavior	Frequency	Severity
<input type="checkbox"/> 1. Does (S) have periods of tearfulness or sobbing that seem to indicate sadness?	<input type="checkbox"/> 1. Occasionally- less than once per week	<input type="checkbox"/> 1. Mild- depression is distressing but usually responds to redirection or reassurance.
<input type="checkbox"/> 2. Does (S) say or act as if he/she is sad or in low spirits?	<input type="checkbox"/> 2. Often- about once per week	<input type="checkbox"/> 2. Moderate- depression is distressing, depressive symptoms are spontaneously voiced by (S) and difficult to alleviate.
<input type="checkbox"/> 3. Does (S) put him/herself down or say that he/she feels like a failure?	<input type="checkbox"/> 3. Frequently- several times per week but less than every day.	<input type="checkbox"/> 3. Marked- depression is very distressing and a major source of suffering for (S).
<input type="checkbox"/> 4. Does (S) say that he/she is a bad person or deserves to be punished?	<input type="checkbox"/> 4. Very frequently- essentially continuously present.	
<input type="checkbox"/> 5. Does (S) seem very discouraged or say that he/she has no future?		
<input type="checkbox"/> 6. Does (S) say he/she is a burden to the family that the family would be better off without him/her?		
<input type="checkbox"/> 7. Does (S) express a wish for death or talk about killing him/herself?		
<input type="checkbox"/> 8. Does (S) show any other signs of depression or sadness?		

E. ELATION/EUPHORIA: Does (S) seem too cheerful or too happy for o reason? I don't mean the normal happiness that comes from seeing friends, receiving presents, or spending time with family members. I am asking if (S) has a persistent and abnormally good mood or finds humor where others do not.

- ☐ N/A, unable to assess, e.g. too impaired.
- ☐ NO, Not since illness began. **GO DIRECTLY TO NEXT BEHAVIOR- ITEM F**
- ☐ YES, since illness began but not in the last month.

☐ YES, HAS OCCURRED IN THE LAST MONTH: If any of these behaviors have occurred, please indicate as a group how often (frequency) and how severe these behaviors have been.

Behaviors	Frequency	Severity
<input type="checkbox"/> 1. Does (S) appear to feel too good or to be too happy, different from his/her usual self?	<input type="checkbox"/> 1. Occasionally- less than once per week	<input type="checkbox"/> 1. Mild- elation is notable to friends and family but is not disruptive.
<input type="checkbox"/> 2. Does (S) find humor and laugh at things that others do not find funny?	<input type="checkbox"/> 2. Often- about once per week	<input type="checkbox"/> 2. Moderate- elation is notably abnormal.
<input type="checkbox"/> 3. Does (S) seem to have a childish sense of humor with a tendency to giggle or laugh inappropriately (such as when something unfortunate happens to others)?	<input type="checkbox"/> 3. Frequently- several times per week but less than every day.	<input type="checkbox"/> 3. Marked- elation is very pronounced; (S) is euphoric and finds nearly everything to be humorous.
<input type="checkbox"/> 4. Does (S) tell jokes or make remarks that have little humor for others but seem funny to him/her?	<input type="checkbox"/> 4. Very frequently- essentially continuously present.	
<input type="checkbox"/> 5. Does (S) play childish pranks such as pinching or playing "keep away" for the fun of it?		
<input type="checkbox"/> 6. Does (S) "talk big" or claim to have more abilities or wealth than is true?		
<input type="checkbox"/> 7. Does (S) show any other signs of feeling too good or being too happy?		

F. DISINHIBITION: Does (S) seem to act impulsively without thinking? Does he/she do or say things that are not usually done or said in public? Does he/she do things that are embarrassing to you or others?

<input type="checkbox"/>	N/A, unable to assess, e.g. too impaired.	
<input type="checkbox"/>	NO, Not since illness began.	GO DIRECTLY TO NEXT BEHAVIOR- ITEM G
<input type="checkbox"/>	YES, since illness began but not in the last month.	

☐ **YES, HAS OCCURRED IN THE LAST MONTH: If any of these behaviors have occurred, please indicate as a group how often (frequency) and how severe these behaviors have been.**

Behaviors	Frequency	Severity
<input type="checkbox"/> 1. Does (S) act impulsively without appearing to consider the consequences?	<input type="checkbox"/> 1. Occasionally- less than once per week	<input type="checkbox"/> 1. Mild- disinhibition is notable but usually responds to redirection and guidance.
<input type="checkbox"/> 2. Does (S) talk to total stranger as if he/she knew them?	<input type="checkbox"/> 2. Often- about once per week	<input type="checkbox"/> 2. Moderate- disinhibition is very evident and difficult to overcome by the caregiver.
<input type="checkbox"/> 3. Does (S) say things to people that are insensitive or hurt their feelings?	<input type="checkbox"/> 3. Frequently- several times per week but less than every day.	<input type="checkbox"/> 3. Marked- disinhibition usually fails to respond to any intervention by the caregiver, and is a source of embarrassment or social distress.
<input type="checkbox"/> 4. Does (S) say crude things or make sexual remarks that they would not usually have said?	<input type="checkbox"/> 4. Very frequently- essentially continuously present.	
<input type="checkbox"/> 5. Does (S) talk openly about very personal or private matters not usually discussed in public?		
<input type="checkbox"/> 6. Does (S) take liberties or touch or hug others in a way that is out of character?		
<input type="checkbox"/> 7. Does (S) show any other signs of loss of control of his/her impulses?		

G. APATHY/ INDIFFERENCE: Has (S) lost interest in the world around him/her? Has he/she lost interest in doing things or lack motivation for starting new activities? Is he/she more difficult to engage in conversation or in doing chores? Is the patient apathetic or indifferent?

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | N/A, unable to assess, e.g. too impaired. | |
| <input type="checkbox"/> | NO, Not since illness began. | GO DIRECTLY TO NEXT BEHAVIOR- ITEM H |
| <input type="checkbox"/> | YES, since illness began but not in the last month. | |

☐ **YES, HAS OCCURRED IN THE LAST MONTH:** If any of these behaviors have occurred, please indicate as a group how often (frequency) and how severe these behaviors have been.

Behavior	Frequency	Severity
<input type="checkbox"/> 1. Does (S) seem less spontaneous and less active than usual?	<input type="checkbox"/> 1. Occasionally- less than once per week	<input type="checkbox"/> 1. Mild- apathy is notable but produces little interference with daily routines; only mildly different from (S)'s usual behavior; (S) responds to suggestions to engage in activities.
<input type="checkbox"/> 2. Is (S) less likely to initiate conversation?	<input type="checkbox"/> 2. Often- about once per week	<input type="checkbox"/> 2. Moderate- apathy is very evident; may be overcome by the caregiver with coaxing and encouragement; responds spontaneously only to powerful events such as visits from close relatives or family members.
<input type="checkbox"/> 3. Is (S) less affectionate or lacking in emotions when compared to his/her usual self?	<input type="checkbox"/> 3. Frequently- several times per week but less than every day.	<input type="checkbox"/> 3. Marked- apathy is very evident and usually fails to respond to any encouragement or external events.
<input type="checkbox"/> 4. Does (S) contribute less to household chores?	<input type="checkbox"/> 4. Very frequently- essentially continuously present.	
<input type="checkbox"/> 5. Does (S) seem less interested in the activities and plans of others?		
<input type="checkbox"/> 6. Has (S) lost interest in friends and family members?		
<input type="checkbox"/> 7. Is (S) less enthusiastic about his/her usual interests?		
<input type="checkbox"/> 8. Does (S) show any other signs that he/she doesn't care about doing new things.		

H. ABERRANT MOTOR BEHAVIOR: Does the patient pace, do things over and over such as opening closets or drawers, or repeatedly pick at things or wind string or threads?

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | N/A, unable to assess, e.g. too impaired. | |
| <input type="checkbox"/> | NO, Not since illness began. | GO DIRECTLY TO NEXT BEHAVIOR- ITEM I |
| <input type="checkbox"/> | YES, since illness began but not in the last month. | |

☐ **YES, HAS OCCURRED IN THE LAST MONTH:** If any of these behaviors have occurred, please indicate as a group how often (frequency) and how severe these behaviors have been.

Behavior	Frequency	Severity
<input type="checkbox"/> 1. Has (S) paced around the house without apparent purpose?	<input type="checkbox"/> 1. Occasionally- less than once per week	<input type="checkbox"/> 1. Mild- abnormal motor activity is notable but produce little interference with daily routines.
<input type="checkbox"/> 2. Does (S) rummage around opening and unpacking drawers or closets?	<input type="checkbox"/> 2. Often- about once per week	<input type="checkbox"/> 2. Moderate- abnormal motor activity is very evident; can be overcome by the caregiver.
<input type="checkbox"/> 3. Does (S) repeatedly put on and take off clothing?	<input type="checkbox"/> 3. Frequently- several times per week but less than every day.	<input type="checkbox"/> 3. Marked- abnormal motor activity is very evident; it usually fails to respond to any intervention by the caregiver and is a major source of distress.
<input type="checkbox"/> 4. Does (S) have repetitive activities or "habits" that he/she performs over and over?	<input type="checkbox"/> 4. Very frequently- essentially continuously present.	
<input type="checkbox"/> 5. Does (S) engage in repetitive activities such as handling buttons, picking, wrapping string, etc?		
<input type="checkbox"/> 6. Does (S) fidget excessively, seem unable to sit still, or bounce his/her feet, or tap his/her fingers a lot?		
<input type="checkbox"/> 7. Does (S) do any other activities over and over?		

I. DELUSIONS: Does (S) have beliefs that you know are not true? For example, insisting that people are trying to harm him/her or steal from him/her. Has he/she said that family members are not who they say they are or that the house is not their home? I'm not asking about mere suspiciousness; I am interested if (S) is convinced that these things are happening to him/her.

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | N/A, unable to assess, e.g. too impaired. | |
| <input type="checkbox"/> | NO, Not since illness began. | GO DIRECTLY TO NEXT BEHAVIOR- ITEM J |
| <input type="checkbox"/> | YES, since illness began but not in the last month. | |

☐ **YES, HAS OCCURRED IN THE LAST MONTH:** If any of these behaviors have occurred, please indicate as a group how often (frequency) and how severe these behaviors have been.

Behavior	Frequency	Severity
<input type="checkbox"/> 1. Does (S) believe that he/she is in danger- that others are planning to hurt him/her?	<input type="checkbox"/> 1. Occasionally- less than once per week	<input type="checkbox"/> 1. Mild- delusions present but seem harmless and produce little distress in the patient.
<input type="checkbox"/> 2. Does (S) believe that others are stealing from him/her?	<input type="checkbox"/> 2. Often- about once per week	<input type="checkbox"/> 2. Moderate- delusions are distressing and disruptive.
<input type="checkbox"/> 3. Does (S) believe that his/her spouse is having an affair?	<input type="checkbox"/> 3. Frequently- several times per week but less than every day.	<input type="checkbox"/> 3. Marked- delusions are very disruptive and are a major source of behavioral disruption [If PRN medications are prescribed, their use signals that the delusions are of marked severity.]
<input type="checkbox"/> 4. Does (S) believe that unwelcome guests are living in his/her house?	<input type="checkbox"/> 4. Very frequently- essentially continuously present.	
<input type="checkbox"/> 5. Does (S) believe that his/her spouse or others are not who they claim to be?		
<input type="checkbox"/> 6. Does (S) believe that his/her house is not his/her home?		
<input type="checkbox"/> 7. Does (S) believe that family members plan to abandon him/her?		

Behavior	Frequency	Severity
<input type="checkbox"/> 8. Does (S) believe that television or magazine figures are actually present in the home? [Does he/she try to talk to them?]		
<input type="checkbox"/> 9. Does (S) believe any other unusual things that I haven't asked about?		

J. HALLUCINATIONS: Does (S) have hallucinations such as false visions or voices? Does he/she seem to see, hear or experience things that are not present? By this question we do not mean just mistaken beliefs such as stating that someone who has died is still alive; rather we are asking if the patient actually has abnormal experiences of sounds, or visions.

- | | | |
|--------------------------|---|---|
| <input type="checkbox"/> | N/A, unable to assess, e.g. too impaired. | |
| <input type="checkbox"/> | NO, Not since illness began. | GO DIRECTLY TO NEXT BEHAVIOR- ITEM K |
| <input type="checkbox"/> | YES, since illness began but not in the last month. | |

☐ **YES, HAS OCCURRED IN THE LAST MONTH:** If any of these behaviors have occurred, please indicate as a group how often (frequency) and how severe these behaviors have been.

Behavior	Frequency	Severity
<input type="checkbox"/> 1. Does (S) describe hearing voices or act as if he/she hears voices?	<input type="checkbox"/> 1. Occasionally- less than once per week	<input type="checkbox"/> 1. Mild- hallucinations are present but harmless and cause little distress for the patient.
<input type="checkbox"/> 2. Does (S) talk to people who are not there?	<input type="checkbox"/> 2. Often- about once per week	<input type="checkbox"/> 2. Moderate- hallucinations are distressing and are disruptive to the patient.
<input type="checkbox"/> 3. Does (S) describe seeing things not seen by others or behave as if he/she is seeing things not seen by others (people, animals, lights, etc.)?	<input type="checkbox"/> 3. Frequently- several times per week but less than every day.	<input type="checkbox"/> 3. Marked- hallucinations are very disruptive and are a major source of behavioral disturbance. PRN medications may be required to control them.
<input type="checkbox"/> 4. Does (S) report smelling odors not smelled by others?	<input type="checkbox"/> 4. Very frequently- essentially continuously present.	
<input type="checkbox"/> 5. Does (S) describe feeling things on his/her skin or otherwise appear to be feeling things crawling or touching him/her?		
<input type="checkbox"/> 6. Does (S) describe tastes that are without any known cause?		
<input type="checkbox"/> 7. Does (S) describe any other unusual sensory experiences?		

K. SLEEP: Does (S) have difficulty sleeping (do not count as present if (S) simply gets up once or twice per night only to go to the bathroom and falls back asleep immediately)? Is he/she up at night? Does he/she wander at night, get dressed, or disturb your sleep?

<input type="checkbox"/>	N/A, unable to assess, e.g. too impaired.	
<input type="checkbox"/>	NO, Not since illness began.	GO DIRECTLY TO NEXT BEHAVIOR- ITEM L
<input type="checkbox"/>	YES, since illness began but not in the last month.	

☐ **YES, HAS OCCURRED IN THE LAST MONTH:** If any of these behaviors have occurred, please indicate as a group how often (frequency) and how severe these behaviors have been.

Behavior	Frequency	Severity
<input type="checkbox"/> 1. Does (S) have difficulty falling asleep?	<input type="checkbox"/> 1. Occasionally- less than once per week	<input type="checkbox"/> 1. Mild- night-time behaviors occur but they are not particularly disruptive.
<input type="checkbox"/> 2. Does (S) get up during the night (do not count if the patient gets up once or twice per night only to go to the bathroom and falls back asleep immediately)?	<input type="checkbox"/> 2. Often- about once per week	<input type="checkbox"/> 2. Moderate- night-time behaviors occur and disturb the patient and the sleep of the caregiver; more than one type of night-time behavior may be present.
<input type="checkbox"/> 3. Does (S) wander, pace, or get involved in inappropriate activities at night?	<input type="checkbox"/> 3. Frequently- several times per week but less than every day.	<input type="checkbox"/> 3. Marked- night-time behaviors occur several types of night-time behavior may be present; (S) is very distressed during the night and the caregiver's sleep is markedly disturbed.
<input type="checkbox"/> 4. Does (S) awaken you during the night?	<input type="checkbox"/> 4. Very frequently- essentially continuously present.	
<input type="checkbox"/> 5. Does (S) awaken at night, dress, and plan to go out thinking that it is morning and time to start the day?		
<input type="checkbox"/> 6. Does (S) awaken too early in the morning (earlier than what was his/her habit)?		
<input type="checkbox"/> 7. Does (S) sleep excessively during the day?		
<input type="checkbox"/> 8. Does (S) have any other night-time behaviors that bother you that we haven't talked about?		

L. APPETITE AND EATING DISORDERS: Has (S) had any change in appetite, weight, or eating habits (count as N/A if (S) is incapacitated and has to be fed)? Has there been any change in type of food he/she prefers?

- ☐ **N/A, unable to assess, e.g. too impaired.**
- ☐ **NO, Not since illness began. END HERE.**
- ☐ **YES, since illness began but not in the last month.**

☐ **YES, HAS OCCURRED IN THE LAST MONTH: If any of these behaviors have occurred, please indicate as a group how often (frequency) and how severe these behaviors have been.**

Behavior	Frequency	Severity
<input type="checkbox"/> 1. Has (S) had a loss of appetite?	<input type="checkbox"/> 1. Occasionally- less than once per week	<input type="checkbox"/> 1. Mild- changes in appetite or eating are present but have not led to changes in weight and are not disturbing
<input type="checkbox"/> 2. Has (S) had an increase in appetite?	<input type="checkbox"/> 2. Often- about once per week	<input type="checkbox"/> 2. Moderate- changes in appetite or eating are present and cause minor fluctuations in weight.
<input type="checkbox"/> 3. Has (S) had a loss in weight?	<input type="checkbox"/> 3. Frequently- several times per week but less than every day.	<input type="checkbox"/> 3. Marked- obvious changes in appetite or eating are present and cause fluctuations in weight, are embarrassing, or otherwise disturb (S).
<input type="checkbox"/> 4. Has (S) gained weight?	<input type="checkbox"/> 4. Very frequently- essentially continuously present.	
<input type="checkbox"/> 5. Has (S) had a change in eating behavior such as putting too much food in his/her mouth at once?		
<input type="checkbox"/> 6. Has (S) had a change in the kind of food he/she likes such as eating too many sweets or other specific types of food?		
<input type="checkbox"/> 7. Has (S) has developed eating behaviors such as eating exactly the same types of food each day or eating the food in exactly the same order?		
<input type="checkbox"/> 8. Have there been any other changes in appetite or eating that I haven't asked about?		

Appendix C

Caregiver Measurement Scales:

- **Caregiver Questionnaire**
- **Health Perceptions**
- **Feelings and Thoughts
(ABS and PSS)**
- **Weekly Mood Rating
(CES-D)**
- **Caregiver's Experiences Questionnaire**

Caregiver Questionnaire

Thank-you for taking the time to complete these questionnaires. We are interested in how caregiving has affected your life, so answering all of these questions is important. However, if there are questions you do not want to answer you can skip them. It is not necessary to complete this questionnaire in one sitting. There are no “correct” answers. Your honest evaluations are what are most important.

Demographic Information

1. Age: _____
2. Female/ Male (circle one)
3. Which of the following best describes your ethnic identity? (check one)
 - _____ Caucasian
 - _____ African American
 - _____ Asian American
 - _____ Hispanic American
 - _____ American Indian/ Alaskan Native
 - _____ Other: (please specify) _____
4. Marital status: (check one)
 - _____ Married
 - _____ Divorced or separated
 - _____ Single
 - _____ Other (Please specify, e.g. living with partner) _____
5. What was the last year of school you completed? (check one)
 - _____ Graduate or professional degree
 - _____ College graduate (4 year degree)
 - _____ Partial college
 - _____ High school graduate
 - _____ Completed 8th grade
 - _____ Other: (fill in last grade you completed) _____
6. Employment status: (check one)
 - _____ Retired
 - _____ Homemaker

- ☐ Employed full-time
☐ Employed part-time _____ hours/week
☐ Unemployed

7. What is your current occupation? (be very specific please)-

8. If Retired, what was your previous occupation? (Be very specific please) _____

9. Please tell us about your relationship with the person with dementia for whom you are caring. Is the person your: (check one)

- ☐ Wife
☐ Husband
☐ Mother or mother-in-law
☐ Father or father-in-law
☐ Other (please specify, e.g. sibling)
- _____

10. How many years have you been the primary caregiver?

11. Where does the person whom you are caring reside?

- ☐ With me, in our home
☐ In a long-term care facility (e.g., a nursing home)
☐ Other (please specify):
- _____

12. Do you currently receive help with caregiving tasks? (check all that apply)

- ☐ Yes, paid help for about _____ hours/week
☐ Yes, family members help out on average about _____ hours/week
☐ Yes, friends and neighbors help out on average about _____ hours/week
☐ No, I am currently not receiving any help with caregiving
☐ Other (please specify):
- _____

13. In general, how close is your current emotional relationship with the person for whom you are caring? (check one)

- ☐ Not close

- ☐ Close
☐ Very close

14. Who would you say is your main source of emotional support?
(check one)

- ☐ Spouse
☐ Family member
☐ Friend
☐ Clergy
☐ Other (please specify):

15. While caregiving can be stressful, it can also be a positive experience for some people. Are there aspects of caregiving that are positive for you?

- ☐ No
☐ Yes (list anything you can think of):

HEALTH PERCEPTIONS

Please read each of the following statements, and then circle one of the numbers on each line to indicate whether the statement is true or false for you.

There are no right or wrong answers.

If a statement is definitely true for you, circle 5.

If a statement is mostly true for you, circle 4.

If you don't know whether a statement is true or false, circle 3.

If a statement is mostly false, circle 2.

If a statement is definitely false for you, circle 1.

Some of the statements may look or seem like others. But each statement is different, and *should be rated by itself*.

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
According to the doctors I've seen, my health is now excellent.	5	4	3	2	1
I feel better now than I ever have before.	5	4	3	2	1
I am somewhat ill.	5	4	3	2	1
I'm not as healthy now as I used to be.	5	4	3	2	1
I'm as healthy as anybody I know.	5	4	3	2	1
My health is excellent.	5	4	3	2	1
I have been feeling bad lately.	5	4	3	2	1
The doctors say that I am now in	5	4	3	2	1

poor health.					
I feel about as good as I ever have.	5	4	3	2	1

1. In general, would you say your health is excellent, good, fair, or poor?

(circle one)

Excellent 1
 Good 2
 Fair 3
 Poor 4

During the past 12 months about how many:

- a) days have you spent in a hospital? _____
 b) times did you see any type of a doctor? Do not include doctors seen while you were a patient in a hospital. _____
 c) days have you been sick in bed all or most of the day? _____

2. In the past year, did you have (circle one):

	YES	NO
Diabetes or sugar sickness	1	2
High blood pressure or Hypertension	1	2
Heart trouble	1	2
Circulation problems or hardening of the arteries	1	2
Been paralyzed in any way	1	2
Any other effects of stroke	1	2
Arthritis or Rheumatism	1	2
Stomach ulcer	1	2
Emphysema or Asthma	1	2
Glaucoma or pressure behind the eye	1	2
Cataracts	1	2
A tumor or growth or cancer	1	2
Liver trouble or jaundice	1	2
Gall bladder trouble	1	2
Kidney trouble	1	2
Bladder trouble	1	2
Broken hip	1	2
Other broken bones	1	2
Anemia	1	2
Parkinson's disease	1	2
Other (specify)	1	2

Feelings and Thoughts

Please be as honest and accurate as you can throughout. Try not to let your responses to one statement influence your responses to other statements. There are no “correct” or “incorrect” answers. Answer according to your own feelings, rather than how you think “most people” would answer.

A = I Agree a lot

B = I Agree a little

C = I neither Agree or Disagree

D = I Disagree a little

E = I Disagree a lot

Please circle A, B, C, D, or E:

1. In uncertain times, I usually expect the best.
A- agree a lot B- agree a little C- neither agree or disagree
D- disagree a little E- disagree a lot
2. If something can go wrong for me, it will.
A- agree a lot B- agree a little C- neither agree or disagree
D- disagree a little E- disagree a lot
3. I always look on the bright side of things.
A- agree a lot B- agree a little C- neither agree or disagree
D- disagree a little E- disagree a lot
4. I'm always optimistic about my future.
A- agree a lot B- agree a little C- neither agree or disagree
D- disagree a little E- disagree a lot
5. I hardly ever expect things to go my way.
A- agree a lot B- agree a little C- neither agree or disagree
D- disagree a little E- disagree a lot
6. Things never work out the way I want them to.
A- agree a lot B- agree a little C- neither agree or disagree
D- disagree a little E- disagree a lot
7. I'm a believer in the idea that “every cloud has a silver lining.”
A- agree a lot B- agree a little C- neither agree or disagree
D- disagree a little E- disagree a lot
8. I rarely count on good things happening to me.
A- agree a lot B- agree a little C- neither agree or disagree
D- disagree a little E- disagree a lot

Please check the most appropriate answer:

1. In the **last month**, how **often** have you felt that you were unable to control the important things in your life?

- ☐ **never**
- ☐ **almost never**
- ☐ **sometimes**
- ☐ **fairly often**
- ☐ **very often**

2. In the **last month**, how **often** have you felt confident about your ability to handle your personal problems?

- ☐ **never**
- ☐ **almost never**
- ☐ **sometimes**
- ☐ **fairly often**
- ☐ **very often**

3. In the **last month**, how **often** have you felt that things were going your way?

- ☐ **never**
- ☐ **almost never**
- ☐ **sometimes**
- ☐ **fairly often**
- ☐ **very often**

4. In the **last month**, how **often** have you felt difficulties were piling up so high that you could not overcome them?

- ☐ **never**
- ☐ **almost never**
- ☐ **sometimes**
- ☐ **fairly often**
- ☐ **very often**

WEEKLY MOOD RATING

Please indicate how often you have felt this way during the past week. Write the selected number in the space provided for each question.

0	Rarely or none of the time (less than once a week)
1	Some or a little of the time (1-2 days a week)
2	Occasionally or a moderate amount of the time (3-4 days a week)
3	Most or all the time (5-7 days a week)

- _____ 1. I was bothered by things that usually don't bother me.
0- rarely 1- sometimes 2- occasionally 3- most or all of the time
- _____ 2. I felt that everything I did was an effort.
0- rarely 1- sometimes 2- occasionally 3- most or all of the time
- _____ 3. I felt that I was just as good as other people.
0- rarely 1- sometimes 2- occasionally 3- most or all of the time
- _____ 4. I had trouble keeping my mind on what I was doing.
0- rarely 1- sometimes 2- occasionally 3- most or all of the time
- _____ 5. I felt sad.
0- rarely 1- sometimes 2- occasionally 3- most or all of the time
- _____ 6. I felt fearful.
0- rarely 1- sometimes 2- occasionally 3- most or all of the time
- _____ 7. I felt lonely.
0- rarely 1- sometimes 2- occasionally 3- most or all of the time
- _____ 8. I had crying spells.
0- rarely 1- sometimes 2- occasionally 3- most or all of the time
- _____ 9. I talked less than usual.
0- rarely 1- sometimes 2- occasionally 3- most or all of the time

_____ 10. My sleep was restless.

**0- rarely 1- sometimes 2- occasionally 3- most or
all of the time**

_____ 11. I enjoyed life.

**0- rarely 1- sometimes 2- occasionally 3- most or
all of the time**

_____ 12. I felt that I could not shake off the blues even with
the help of my family/friends.

**0- rarely 1- sometimes 2- occasionally 3- most or
all of the time**

_____ 13. I thought my life had been a failure.

**0- rarely 1- sometimes 2- occasionally 3- most or
all of the time**

_____ 14. I was happy.

**0- rarely 1- sometimes 2- occasionally 3- most or
all of the time**

_____ 15. I could not get "going".

**0- rarely 1- sometimes 2- occasionally 3- most or
all of the time**

_____ 16. I felt hopeful about the future.

**0- rarely 1- sometimes 2- occasionally 3- most or
all of the time**

_____ 17. People were unfriendly.

**0- rarely 1- sometimes 2- occasionally 3- most or
all of the time**

_____ 18. I did not feel like eating; my appetite was poor.

**0- rarely 1- sometimes 2- occasionally 3- most or
all of the time**

_____ 19. I felt depressed.

**0- rarely 1- sometimes 2- occasionally 3- most or
all of the time**

_____ 20. I felt that people disliked me.

**0- rarely 1- sometimes 2- occasionally 3- most
or all of the time**

During the past few weeks, did you ever feel: (Check YES or NO)

	YES	NO
...pleased about having accomplished something?		
...on top of the world?		
...bored?		
...particularly excited or interested?		
...proud because someone complimented you on something you had done?		
...depressed or unhappy?		
...that things were going your way?		
...upset because someone criticized you?		
...very lonely or remote from other people?		
...so restless that you couldn't sit long in a chair?		

CAREGIVER EXPERIENCES

During the past month, how much of the time have the following statements been true for you? Please circle the number, based on the scale below, that is most reflective of your thoughts and experiences.

- (1) Never**
(2) Some of the time
(3) Most of the time
(4) All of the time

1. I wish I were free to lead a life of my own.
1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time
2. I wish I could just run away.
1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time
3. I feel trapped by my relative's illness.
1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time
4. I feel confident that I am meeting the needs of my relative.
1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time
5. I feel competent in my ability to care for my relative.
1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time
6. I feel that I am doing a good job as a caregiver.
1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time
7. I can get a lot done during the day.
1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time
8. I am able to relax.
1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time
9. I can count on having a block of time to use as I like.
1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

10. I am exhausted when I go to bed at night.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

11. I feel responsible for my relative.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

12. I have more things to do than I can handle.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

13. I have time just for myself.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

14. I worry about my relative.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

15. I have difficulty concentrating on activities because of thought about my relative.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

16. I think about plans or arrangement for care of my relative.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

17. The physical strain on me is more than I can take.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

18. I feel more and more tense as the day goes on.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

19. I wish I could take more breaks during the day.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

20. I don't know what to expect from one hour to the next.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

21. I feel if things continue like this, I will not be able to care for my relative at home.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

22. I am in control of my emotions.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

23. I am patient with my relative.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

24. My patience is stretched to the limit.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

25. Physically, I am strong enough to do everything I have to do.

1- Never 2- Some of the Time 3- Most of the Time
4- All of the Time

Thank you so much for your assistance with this project. A ten dollar reimbursement will be sent to you after we receive this questionnaire back.