The Association of Adult Day Health Services Use and Burden, Self-Rated Health, and Additional Characteristics of Primary, Informal Caregivers of Older Adults

Dissertation

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy in the Graduate School of The Ohio State University

By

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Abstract

The objective of this research was to investigate characteristics, perceptions, and outcomes related to the use of adult day health services (ADS) among primary, informal caregivers of older adults. To accomplish this, a review of the literature about caregivers, adult day health services, and older adults was completed; this information was used to inform further investigation using one group of caregivers newly enrolling a loved one into ADS (ADS caregivers) and a second group of caregivers who were aware of, but not utilizing, this service option (non-ADS caregivers). Comparative baseline analyses, quasi-experimental investigation over time, and review of qualitative data from these caregivers aided with addressing research objectives. The most significant differences noted were: ADS caregivers had poorer self-rated health, felt more anger towards their care recipients, felt as if care recipients were dependent solely upon them (caregivers), and were more frustrated with memory/behavioral issues exhibited by care recipients. The findings may assist care professionals with an enhanced understanding of caregiver characteristics that may align with use of ADS for respite and support. As the population of older adults in the United States grows, the concomitant increase in family caregivers will require additional community-based services such as ADS.

Keywords: caregivers, older adults, adult day health services, caregiver burden
Dedication

This effort is dedicated to the most important people in my life:
to my husband, Jeff -- my best friend and the absolute love of that life,
and to my parents, Harold Morrison (1934-1994) and Dove Morrison.

Ancora imparo (‘Still, I am learning’) ~ Michelangelo

There are four kinds of people in the world:
those who have been caregivers,
those who are currently caregivers,
those who will be caregivers,
and those who will need caregivers.

~Rosalyn Carter
Acknowledgments

Acknowledging countless people who have provided support in some way, shape, or form while you attempted a seemingly unsurmountable task = another challenging task! But clearly, I am not one to pass up a challenge.

My husband Jeff has been so very supportive of me throughout this process (and many others). He is the best butler, chef, and masseur around! Honey, thank you so very much for being such a loving, gentle, funny, smart, encouraging, and beautiful man! Just knowing you were in the house was enough. Love you so very much.

My best friend Heather may not remember what I look or sound like lately (ha), but she continues to be an amazing friend anyway! Heather, thank you for putting up with my absences and for being so supportive after all of these years. Now we can get together more than two or three times a year! Can’t wait.

My family – the Morrisons as well as the Stokes – are wonderful anchors for me. Thanks for never asking too many questions (allowing me to escape school and work) and for being wonderful people in my life. Love to you all.

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Holly Dabelko-Schoeny has my endless admiration. Holly, you are a natural, wonderful teacher with time for all. I truly cannot thank you enough for being my content expert, mentor, and friend. The ADS industry is blessed to have you as an advocate and supporter.

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My work “family” is an amazing group of individuals who are dedicated, as am I, to enhancing the lives of caregivers and older adults as much as possible, even in the face of hardships. Thanks to all of you for all of your dedication to this mission – and to me!
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“We don't stop playing because we grow old; we grow old because we stop playing.” ~ George Bernard Shaw
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List of Abbreviations

AD    Alzheimer’s Disease
ADS   Adult Day Health Services
ADL   activities of daily living
AOA   Association on Aging
BI    Barthel Index
CDC   Centers for Disease Control
CVA   cerebrovascular accident
df    degrees of freedom
EDR   Elderly Dependency Ratio
EEOC  Equal Employment Opportunity Commission
IADL  independent activities of daily living
IGT   impaired glucose tolerance
MCI   mild cognitive impairment
MI    myocardial infarction
n     number
NADSA National Adult Day Services Association
NIA   National Institutes on Aging
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1.1 Population Characteristics

The growth in the elderly population in the United States and concomitant increases in longevity have spurred extensive concern about adequate community-based care options and number of available care providers. In the 20th and 21st centuries, the population of older adults – those aged 65 and older – grew disproportionately as compared to other age groups (Humes, 2005). This uneven growth is attributable to various factors, including prolonged low birth rates seen in the latter part of the 20th century and thus far into the 21st century (Humes); fewer individuals are being born at the same time more individuals are aging. Additionally, advances in medical care, along with improved self-care and prevention, have contributed to increased longevity. Life expectancy is projected to increase from 76 years of age as seen in 1993 to 82.6 years of age by 2050 (Day, 2011).

The overall population of the United States is increasing at about 1% per year while the proportion of those aged 65 and older is expected to increase by 2.8% annually over the next two decades (U.S. Census Bureau, 2010). The proportion of elderly individuals in the United States was 4.1% in 1900 and grew to 12.6% in 2000; this proportion is projected to increase further to reach 20% or higher by the year 2030.
(Gavrilov & Heuveline, 2003). The number of older adults is then expected to rise to 71 million by 2030 (Centers for Disease Control (CDC), 2007) and to 88.5 million in 2050, accounting for one in five Americans during these decades as compared to one in eight in 1994 (CDC; U.S. Census, 2009). The subset known as the oldest-old (individuals aged 85 and older) is the fastest growing segment of our population (U.S. Census).

Currently, another significant dynamic in this population trend is that those in the large group of “Baby Boomers” are becoming senior citizens. Baby Boomers are Americans born post-World War II between 1946 and 1964, a wide span of years during which birth rates soared (U.S. Census Bureau, 2006). The oldest among those in this group began turning 65 in the year 2011. The size of this cohort relative to preceding and subsequent ones is quite large (Kinsella & Velkoff, 2001); 70% more individuals were born during the Baby Boom years than during the two prior decades (Hobbs & Damon, 1996). Currently, Baby Boomers are taking care of the elderly parents while heading into older adulthood themselves.

The elderly dependence ratio (EDR) is a population measure that reflects the number of individuals 65 and older in comparison with every 100 of those within traditional working ages (Gavrilov & Heuveline; U.S. Census Bureau, 2010). The number of births, deaths, and net immigration considerations are used when determining the EDR. With the rise in numbers of older adults, the EDR is projected to rise significantly from 22 in 2010 to 35 in 2030 (Census 2010). The higher this old-age dependency ratio, the greater the potential “burden” to society.
Given all the aforementioned factors, it is no surprise that the almost two decades during which the “Boomers” will be elderly is of particular concern to healthcare providers and policy makers. The need for adequate services, products, and care is great.

Figure 1.1  Population 65 Years of Age and Over: United States, 1950-2030.

1.2 Health of Older Adults: Factors Contributing to the Need for Care Assistance

Although aging is accompanied by a very wide range of heterogeneity –everyone ages differently -- the incidence and prevalence of disease does increase with advancing age. Even normal, “healthy” aging affects one’s reserve capacity to deflect illness or
injury and can negatively impact recovery. Physical and cognitive changes can effect daily functioning through associated reductions in strength, endurance, reflexes, and general self-care abilities. The burden of chronic illness generally leads to pain, functional loss, and decreased independence (or even dependence) before eventually resulting in death (CDC). Various chronic diseases are particularly common in older age and heighten this need for caregiving support.

The prevalence of chronic conditions and disease among care recipients using adult day services is noteworthy. The most recent national study of adult day health services (Metlife Mature Market Institute (MMI), 2010) reported that, among other diagnoses, these individuals exhibit hypertension (46%), physical disability (42%), cardiovascular disease (34%), diabetes (31%), mental illness (25%), and developmental disability (20%). Additionally, approximately half of program participants have dementia (MMI).

In general, health problems common among older adults include bone changes such as osteopenia (a condition of weakened bones) and osteoporosis (significantly lowered bone density). Low bone density elevates the risk of fractures and concomitant changes in functional abilities, increasing the risk for dependence on others (Rachner, Khosla, Hofbauer, 2011). Arthritis, fractures, and sarcopenia (age-related decline in muscle mass and strength) are also common. These conditions increase the risk for falls among older adults.
With one out of every three adults in the 65-plus age group falling annually (Hausdorff, Rios, and Edelber, 2001; Hornbrook, Stevens, Wingfield, Hollis, Greenlick, & Ory, 1994) and 2.2 million non-fatal fall injuries reported by U.S. emergency departments in 2009 (CDC, 2010), the association between elder falls, arthritis, osteoporosis, and increased need for care assistance at home is not difficult to see. Unfortunately, many of those who fall – whether injured or not – develop a fear of falling that then leads to activity restriction, reduced mobility, lowered physical fitness, and a concomitant increase in risk for falling again (Vellas, Wayne, Romero, Baumgartner, & Garry, 1997). Decreased overall health and increased risk for dependence soon follow in many cases.

An estimated 20% of those who are 65 years of age or older have diabetes, although it is also estimated that approximately half of older adults who are diabetic have not yet been diagnosed (Arshag, McLaughlin, Boyer & Winter, 1999). If those with impaired glucose tolerance (IGT) are also taken into account, about 40% of older individuals have some level of carbohydrate intolerance (Harris et al, 1998). Diabetes is associated with circulatory changes, cerebrovascular accidents (CVAs) or strokes, transient ischemic attacks (TIAs) or mini-strokes, decreased visual acuity due to retinopathy, and myocardial infarctions (MI) or heart attacks (American Diabetes Association, 2011) all of which correlate with increased frailty and dependence. A variety of cardiovascular diseases also occur at higher rates among the older population, whether as the result of preventable disease or insidious disease processes. Cancers,
neurological problems, pulmonary problems, renal disease, and sensory changes are also common. Alone, or in combination, these diseases can increase one’s need for caregiving support.

Dementia, a diagnosis primarily facing older adults, is the general term used for changes in the brain that lead to memory loss and functional deficits affecting daily life. Alzheimer’s Disease (AD) is the most common form of dementia, affecting 5.2 million Americans aged 65 and over (one in eight) (Alzheimer’s Association (AA), 2011). This number is expected to rise to 16 million individuals by 2050 (AA). The risk of developing AD increases with advancing age, with about 10% of those 65 to 84 and half of those 85 years of age and older having this affliction (AA). AD is just one of many types of dementia; variation in symptoms and treatment occurs accordingly. Commonalities include memory loss, behavioral, mood, and personality changes that can be highly variable and challenging, loss of ability to perform self-care activities, and declining physical abilities. With rare exception, dementia requires escalating need for care and oversight.

1.2.1 Need for Care

Logically, the proportion of those needing assistance with everyday activities because of disease and disability—whether lifelong or newly acquired—rises with age (Lightfoot, 2007). In 2009, approximately 20% of the almost 21 million individuals between the ages of 65 and 74, and 30% of the approximately 17.2 million aged 75 and over, were in fair or poor health (Adams, Martinez & Vickerie, 2010). Of these,
approximately 25% in the 65 to 74 age range and 43% of those over 75 years of age reported at least one limitation in usual activities (Adams, Martinez & Vickerie).

According to Section 902 of the U.S. Equal Employment Opportunity Commission (EEOC) (written to explain the EEOC’s interpretation of the Americans with Disability Act definition of disability), the statutory definition of disability is defined as “(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or(C) being regarded as having such an impairment” (2011). As reported online by the Ohio State University Medical Center (2011), nearly 42% of individuals aged 65 or older have some level of disability; the Administration on Aging (AOA) reported in the publication *Profile of Older Americans* (2009) that in 2008, 38% of older Americans reported having one or more disabilities.

1.3 Caregivers

Currently, in the United States, an estimated 29% of the population provides care for a loved one with a disability (National Alliance for Caregiving and AARP (NAC w/AARP), 2010). Those who provide care can be classified as either formal or informal caregivers. Formal caregivers are those who are paid for care provided and are generally not related to, or friends of, the care recipient (Timonen, 2009). These professional caregivers may provide care to a patient in the home setting, in a daytime care setting, or in a residential care facility such as a nursing home or assisted living.
1.3.1 Informal, Primary Caregivers

Informal caregivers do not receive monetary compensation for care given. They provide a relative or friend with care assistance with one or more Instrumental Activities of Daily Living (IADLs) and/or Activities of Daily Living (ADLs) (Bertrand, Fredman & Saczynski, 2006). IADLs consist of using the telephone, managing money, driving, grocery shopping, doing laundry, preparing meals, taking medications, and doing housework (Lawton & Brody, 1969), while ADLs include bathing, dressing, transferring from bed or chair, walking, eating, using the toilet, and grooming (Katz, Ford, Moskowitz, Jackson & Jaffe, 1969). Generally, informal caregivers do not have any formal healthcare training, including instruction on how to provide hands-on care or education about disease processes and treatments. The primary caregiver is most commonly referred to as “the family member who spends the most time” caring for another family member (Stephens, Townshed, & Martire, 2001, p. 26).

Over 65 million people in the United States (29% of the population) provide care an average of 20 hours weekly for a chronically ill, disabled and/or elderly family member or friend, with 13% of elder caregivers providing 40 or more hours of care weekly (NAC w/AARP). In 1999, almost 53% of primary informal caregivers provided all care without assistance from other family members (Wolff & Kasper). Greater than three-fourths of community-dwelling adults in need of care depend solely on friends and family for help (Thompson, 2004).
Primary caregivers of older adults are adult children (41.3%), spouses (38.4%) or other family and friends (20.4%), demonstrating that family members provide at least 80% of long term care (Wolff & Kasper). Approximately 66% of family caregivers are female, approximately 37% of whom also have children or grandchildren under 18 years of age living with them (NAC w/AARP). The most “typical” primary caregiver is a 49-year old working, married daughter who is caring for her 69-year-old, widowed mother; they do not live in the same home (NAC w/AARP). Recent data show that 29% of caregivers and care recipients live in the same home (NAC w/AARP).

1.3.2 Cost of Care

The annual cost of this elder care, if it were reimbursed to the caregivers, is estimated to range between $302 billion dollars (or the equivalent of 6% of the national cost of health care expenditures) (Arno, 2006) and $375 billion dollars – which is double the annual amount spent on nursing home and home care services combined (Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving, 2009). In 2010 alone, approximately 14.9 million family and friends provided 17 billion hours of unpaid care to loved ones with dementia (Alzheimer’s Association). The estimated value of this dementia care, if it were to be reimbursed, is estimated at $202.6 billion dollars (Alzheimer’s Association), demonstrating the degree of care needed by those with a dementia diagnosis.

Costs to caregivers are variable but can be great. Informal, primary caregivers for an older loved one may serve as such for as many as 15 years (Vitaliano, Zhang,
Financial burden and the effect of caregiving on a caregiver’s work and social life vary by circumstance and can be very stressful. The physical and/or psychological effects of the provision of long term care to a loved one is of significant concern to social service agencies and for public policy more than ever given the expected continued growth of the number assuming this role.

1.3.3 Caregiver Burden

International research over the course of several decades has demonstrated empirically that caregiving can lead to various negative psychological and physiological effects. Caring for an ill or disabled adult is stressful (Fredman & Daly, 1997; Bugge, Alexander, & Hagen, 1999; Ory et al, 1998; Zarit, Todd, & Zarit, 1986; Kiecolt-Glaser, Glaser, Shuttleworth, Dyer, Ogrocki, & Speicher, 1987), and can lead to caregiver burden (Zarit et al; Zarit & Zarit, 1982) which, in turn, can detrimentally affect health (Connell, Janovic, & Gallant, 2001; Thommessen, Aarsland, Brackhus, & Aksengaard, 2002; Markowitz, Gutterman, Sadik, & Papadopoulos, 2003) and further increase health care spending. The effects of giving care have been characterized and labeled as many generally interchangeable things, including distress, strain, burden, and stress.

Caregiver burden is the degree to which a caregiver’s emotional or physical health, social life, or financial status has suffered as a result of caring for a relative (Zarit, Stephens, Townsend & Greene, 1998).

Caregiver burden is multidimensional and highly variable; responses to the caregiving experience vary from caregiver to caregiver in degree and intensity of
negative and positive outcomes. These differential impacts can be puzzling as some caregivers appear to cope well and report limited negative impact (Montgomery, Rowe, & Kosloski, 2007) while others report serious negative consequences, even in seemingly similar situations. The variability of care recipient needs, relationship history, personal coping styles, and available resources likely interact with other factors to affect burden. Burden can be divided into two main categories: objective burden is the physiological stress associated with the provision of hands-on, physical care while subjective burden reflects the psychological consequences of giving care (Zarit & Zarit, 1987).

1.3.4 Physiological Responses to Caregiving

Studies of the physiological (objective) effects of stressors on humans have shown that certain biochemical markers in the body are altered with stress and can affect the human immune response (Mommersteeg, Heijnen, Kavalaars, van Doornen, 2006; Glaser & Kiecolt-Glaser, 2005). These alterations result in an increased susceptibility to infectious diseases and other increased health risks (Glaser & Kiecolt-Glaser, 2005). Immune function reduction has been shown to result in lengthier illnesses in caregivers as compared to controls (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991) and a decreased effectiveness of certain vaccines, including the influenza vaccine (Holland, 1996; Tseng, Padgett, Dhabhar, Engler & Sheridan, 2005).

In one longitudinal, prospective cohort study, older spousal caregivers with caregiving strain exhibited a relative risk for all-cause mortality that was 63% higher than non-caregiving controls (n=427; RR=1.63; 95% CI 1-2.65) (Schulz & Beach, 1999).
Overall, when compared to control subjects, caregivers report more chronic illnesses, (Pruchno & Potashnik, 1989), are at increased risk for mild hypertension (Shaw, Patterson, Ziegler, Dimsdale, Semple, & Grant, 1999), and exhibit slower rates of wound healing (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995). Caregivers also report physical strain and fatigue (Jo, Brazil, Lohfeld & Willison, 2007) and poorer perceived physical health (Schulz, O’Brien, Bookwala, & Fleissner, 1995). Self-rated health (SRH) has been shown to predict health care costs (Bierman, Bubolz, Fisher & Wasson, 1999) and to correlate with health risk factors such as high cholesterol, obesity, hypertension, mobility limitations, and biological stress measures (Goldman, Glei, & Chang, 2004).

Approximately one in six caregivers rates personal health as fair or poor (National Alliance for Caregiving with the American Association for Retired Persons [NAC w/AARP], 2004 & 2009). Caregivers’ self-rated health (SRH) ratings lower as age of the caregiver increases (NAC). Subjective ratings of caregiver health have been shown as good predictors of objective health outcomes such as long-term illness, diminished ability to participate in social activities or work, and even increased mortality (Burstrom & Fredlund, 2001; Grant, Piotrowski & Chappell, 1995; Idler & Benyamini, 1997; and Ren, Skinner, Lee, & Kazis, 1999). In fact, a five year, prospective cohort study of 392 in-home spousal caregivers and 427 non-caregivers aged 66 to 96 years old found that strained caregivers had mortality risks 63% higher than controls (Schulz & Beach, 1999).

For those who are caring for someone at home, the use of assistance (in the form of a
family member or friend or through community resources) has been associated with improved caregiver health (Danhauer et al, Evans, 2004).

1.3.5 Psychological Responses to Caregiving

Because of the complex nature of understanding the psychological needs of caregivers, multiple factors have been examined in relation to burden. Caregivers of those with dementia have reported higher levels of stress, burden and depression than non-dementia caregivers or non-caregivers (Bertrand, Fredman & Saczynski, 2006; Schulz, O’Brien, Bookwala & Fleissner, 1995; Vitaliano, 1997). Other studies have shown that caregivers who provide more assistance with ADLs or IADLs (Pinquart & Sorenson, 2003) and who provide care for longer periods (Ory, Hoffman, Yee, Tennstedt, Schulz, 1999; Yates, Tennstedt, & Chang, 1999) and for more hours per day (Desbiens, Mueller-Rizner, Viring & Lunn, 2001) also report high levels of stress.

Care recipients with behavioral problems also affect the level of stress reported by caregivers (Hooker, Bowman, Coehlo, Lim, Kaye, Guariglia, et al, 2002; Hooker, Bowman, Coehlo, Lim, Kaye, Guariglia, et al. 2002; Schulz, O’Brien, Bookwala, & Fleissner, 1995; Shanks-McElroy & Stobino, 2001). In fact, a meta-analysis of 228 caregiver studies noted that behavioral problems exhibited by care recipients were more strongly related to caregiver burden than any other analyzed variable (Pinquart & Sorenson, 2003). This meta-analysis also demonstrated significant and positive correlations between caregiver burden with the number of hours of care provided weekly and the number of caregiver tasks required (Pinquart & Sorenson, 2003).
A study of informal caregivers of stroke survivors found that 37% of caregivers fell in the “considerable strain” category (the highest level of strain) of the Caregiver Strain Index six months after the stroke occurred (Bugge, Alexander, & Hagen, 1999). Results from a survey of caregivers (n=1,509) indicated that as compared to non-dementia caregivers, caregivers of loved ones with dementia were more likely to give up personal activities they enjoyed, and reported higher levels of emotional and physical strain (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999).

Those who live in the same home as the one they are providing care for report higher burden scores than those who do not live with their care recipient (Kuzuya et al., 2011). In general, wives who are caregivers to their husbands have exhibited higher burden levels than husbands who are caregivers, and daughters living with a parent of either gender for whom they are providing care report the highest burden of all informal caregivers.

Although some caregivers may adapt to stressors and reach a plateau of distress, caregiver burden should be addressed at any known point in order to maximize caregiver health while minimizing overall costs (Danhauser, McCann, Gilley, Beckett, Beinias, & Evans, 2004). As costs for those requiring care soar, it is likely that costs for the care of caregivers will also rise. Supportive services can help improve quality of life and decrease expenditures for both.

These examples of caregiver research provide just an overview of a small portion of findings about the negative physiological and psychological effects from caregiving.
With few contradictions, the negative consequences of caregiving have been previously established. The goal of this current research is to better understand a service that may serve to alleviate caregiver burden.

1.4 Adult Day Health Services (ADS)

Best practice standards support that those with disabilities should have input into their own care decisions and live in community-based settings rather than institutions (Lightfoot, 2007). For those caring for someone at home, the use of assistance, whether in the form of a family member, friend, or through community resources, has been associated with improved caregiver health related to decreased stress and burden (Danhauer, McCann, Gilley, Beckett, Beinias & Evans, 2004; Pinquart & Sorenson, 2006). Various options for assistance with care provision do exist outside of residential placement and include home health services, home-delivered meals, non-medical companion services, and adult day services. Population growth trends indicate the need for expanded availability of community-based services such as these (Lightfoot).

Over time, adult day services have been provided via three models: the social model (providing oversight and socialization/activity opportunities but no healthcare services); the medical model (providing healthcare oversight and services such as medication administration, assessment of vital signs, and wound care); and mixed-models, providing both social and health services. Models have blended over time and this terminology is not currently used as often as in past years. According to the
National Adult Day Services Association (NADSA), adult day services provide a community-based, congregate alternative to residential placement, offering care and oversight to adults in a group setting (2011). Centers provide a program of social and therapeutic activities, health oversight and services, and hands-on assistance if needed with activities of daily living (Metlife Mature Market Institute, 2010).

1.4.1 2010 National Study of Adult Day Services

In 2010, the MetLife Mature Market Institute and the National Adult Day Services Association (NADSA) partnered collaboratively with researchers from The Ohio State University College of Social Work to perform a national study of adult day services. Those study findings are used here to describe adult day services nationally. In the United States, program attendees (or “participants”) live in the community and attend the day center on a scheduled basis during the daytime. Depending upon individual center hours, participants may attend up to 11.5 hours in a single day, allowing for considerable respite or work time for caregivers. Centers generally operate during normal business hours at least five days a week. Some programs offer services in the evenings and on weekends, and daily operating hours vary widely. Direct staff positions vary by model but include social workers, nurses, nursing assistants, activities staff, and/or transportation providers. While individual state or program guidelines also may differ, the typical staff to participant ratio is at least one direct care staff member for every six program participants.
Also according to the study, over 260,000 program participants and their caregivers are served each day in approximately 4,600 adult day programs in the United States. This reflects an increase of 1,100 centers and 110,000 participants/caregivers since the previous national study conducted by Wake Forest in 2002 (Robert Woods Johnson, 2002). Nationally, ADS centers currently provide approximately 37.5 million days of service annually. The majority (71%) of centers operate on a private non-profit (56%) or public/government basis (16%), with 27% operating as private for-profit businesses. The average length of operation for an ADS center nationally is 17 years, with a range of one to 100 years; 86% of centers are state-certified or licensed (a 10% increase from the 2002 survey, which researchers speculate is a result of changing state funding and quality requirements). Most centers (98%) are open on a Monday through Friday basis, with 15% of centers also being open on Saturday, and approximately 4% being open on both Saturday and Sunday.

Historically, ADS care has been reimbursed to centers by a combination of private and/or public funding. The 2010 national study results indicated this trend continues, with 55% of reimbursement to adult day service centers for care provided coming from public dollars and 26% from private payments out-of-pocket from the program participants/caregivers. The proportion of private payments in 2002 was 35%, demonstrating a change in users’ available personal financial resources, increases in available public funding sources, or both have changed in the time between the two national surveys. The remainder of the reported 2010 revenue sources includes small
percentages of funding from grants (8%), donations and fundraising (5%), internal funding from parent organizations (4%), and private insurance payments (2%).

The average 2010 charge for a full day of ADS was $61.71; the average fee for flat daily fees (rates charged despite total number of hours attended) was $57.96. The range for daily charges was $15 to $177. However, the actual average daily cost for providing care was $68.89 (with a range from $9 to $219 per day), higher than the average reimbursement.

The 2010 survey results established that daily capacity has increased in ADS centers since the previous national survey, growing from 38 participants a day to 51 participants per day. Total enrollment grew from 42 participants enrolled in 2002 to 57 participants enrolled in 2010. (Because participants can attend a range of days weekly, the total number of participants enrolled commonly exceeds the daily enrollment). In 2002, 22% of centers reported having a wait list; this proportion had increased to 29% in 2010, perhaps due to increased awareness and also acceptance of this community-based service. On average, participants were enrolled for 32 months (an increase of 8 months from the previous study). The majority of participants attended at least five hours per scheduled visit (five or more hours is considered a full day). Almost half of participants (46%) attended five days per week, with 29% attending three days per week, and 19% attending two days per week.

Program participants were predominantly female (58%), and 69% were 65 years of age or older. Approximately 61% of attendees were white (as compared with 75% of
the general U.S. population), 16% were black (as compared with 12% of the U.S. population, and 9% each were Hispanic and Asian (as compared with 16% and 4% respectively of the U.S. population).

Data about living arrangements demonstrated that 27% lived with an adult child (a decrease from 35% since 2002), 21% lived with a spouse, 20% lived alone (an increase from 11% in 2002), and 18% lived in a communal setting. However, living arrangement does not necessarily indicate who is considered the primary caregiver. Adult children were the primary caregiver 36% of the time, as compared with spouses (23%) and formal (paid) caregivers (19%).

Almost half of program participants (45%) needed assistance with toileting and also with management of medications (44%), with 30% requiring assistance with bathing. One fifth (20%) needed assistance with eating, and one quarter (25%) needed help with transferring. The most common health diagnoses for participants were dementia (47%), hypertension (46%), and all-cause physical disability (42%), the latter of which is a 19% increase since the 2002 survey. One quarter (25%) displayed chronic mental health conditions (an 11% increase since 2002), and over one third were diagnosed with cardiovascular disease (34%) and diabetes (31%).

The 2010 study assessed reasons for enrollment into an ADS program and found that the most common reason for enrollment was the increase in participants’ functional needs, followed by caregivers’ need for respite. Tied for third were declines in the caregivers’ abilities and an increase in the behavioral problems exhibited by
participants. Conversely, researchers gathered information about reasons for
disenrollment. The most common reason for ending use of ADS was due to participants’
placement into a nursing home, followed by the death of the participant, and a decline
in participants’ health leading to a mismatch between health condition and services.

The majority of centers offered care planning (96%), assistance with some
Activities of Daily Living (ADLs) such as walking (95%), toileting (93%), transferring (93%),
and assistance with meals (91%) for no additional costs. Nursing services can also
include medication management, blood pressure monitoring, diabetes monitoring,
wound care, and catheter and colostomy care. Some but not all adult day programs
offer multiple, on-site supportive services to the participant and caregiver such as
podiatry, rehabilitative services (physical therapy, occupational therapy, speech
therapy), dentistry, nail care, hearing services, laboratory services, bathing, vision
services, psychological services, cosmetology services, and/or accessible transportation
as needed/accepted by the participant and caregiver, often at an additional cost. The
majority of centers provided therapeutic activities designed to entertain and stimulate
program participants while assisting with the maintenance of abilities. Services are
provided for the program participant while in attendance at the adult day setting,
enhancing participant benefits but also preventing the caregiver from providing for or
transporting to such services at another time. Some centers offer minimal basic
services and caregivers need to provide or arrange for other needed services outside of
the day services location, theoretically adding to the caregiver’s personal load.
1.4.2 Adult Day Health Services Research

Adult day services research has been growing, but the field remains understudied. Various studies have focused on positive outcomes related to caregiver use of adult day services. Assessment of three months’ worth of existing data from the Adult Day Care Collaborative Study (n= 400) (Gaugler et al., 2003) demonstrated that “adult day services, if used over time, are effective in restructuring caregiving time and may offer potential benefits not only to family caregivers but to community-residing older adults” (p.37). In a quasi-experimental design (n=129), caregivers who were provided with education, counseling, and referral services for 12 months while using adult day services exhibited statistically significant improvements in depression and confidence in managing care recipient behaviors, and also used services more than controls who were using ADS but did not receive the additional supportive services (Gitlin, Reever, Dennis, Mathieu, & Hauck, 2006).

Jarrott, Zarit and Parris-Stephens (1999) have determined that caregivers of loved ones with dementia reported decreased time spent dealing with care needs when using adult day services. A recent study of ADS use by those with dementia has found that, after a day of mental stimulation and structured activity such as that provided at an ADS center, sleep of the care recipient improves (Zarit et al., in press). Several small studies have indicated that the service is effective in reducing caregivers’ negative self-assessments of psychosocial distress such as depression and overload (Cox, 1997; Kosloski & Montgomery, 1995; Quayhagen et al, 2000; Zarit, Stephens, Townshend, &
Greene, 1998). These studies did not address decreased primary caregiver burden as it relates to service intensity and services received within the program.

One randomized, controlled study comparing the effects of adult day service users (n=180) to those on a waiting list (n=104) found no effect from use of adult day services on caregiver burden or other client outcome measures (Baumgarten, Lebel, Leprise, Leclerc, & Quinn, 2002). The authors suggested objective measurement was difficult based on subjectivity of data from the clients and caregivers and suggested higher levels of attendance for optimum outcomes, thinking perhaps the intensity of use by caregivers may not have been sufficient enough to produce a significant reduction in burden.

Other smaller studies have demonstrated a positive effect of adult day services use on burden (Cox, 1997; Gottlieb & Johnson, 1995) but the concept requires more study for effective recommendations. This inconsistency may be explained by the fact that all adult day programs are not alike, and the range of services provided may have an association with burden. For example, programs providing more service options may decrease burden more than those that provide respite alone.

In one retrospective review of adult day service administrative data sets (n=280), disenrollment from services was less likely for those participants who were married and had psychological diagnoses (Dabelko, 2004). In another retrospective review (n=143), day service disenrollment before four weeks of use was more likely for those participants whose caregivers provided transportation, rather than transportation of the
participant to and from the ADS center being provided by another source (Dabelko, 2005).

In a qualitative article (n=32), Canadian researchers noted that caregivers emphasized their caregiver stress during focus group discussions (Ritchie, 2003). A theme of “the need for respite” emerged. The helpfulness of the provision of personal care and bathing assistance, as well as meaningful activities for care recipients to engage in while at ADS, were noted by some caregivers as positive ADS elements.

Comparative longitudinal research on the effectiveness of adult day services facilities in supporting family caregivers resulted in evidence that ADS is significantly effective in alleviating caregiver stress. The use of adult day care was shown to significantly reduce the conflict resulting from caregivers trying to balance care demands with work responsibilities, other family needs, and social connections; however, the sample size was very small (Schacke & Zank, 2006). Overall, research has shown that the service has high satisfaction ratings from both caregivers and participants (Anetzberger, 2002).

Research of almost a decade ago determined that the minimum intensity and duration of adult day services use needed to show positive impact on care-related stress and depression for caregivers was two days per week for at least eight total hours for a minimum of twelve weeks (Zarit, Stephens, Townsend, & Greene, 1998); this conclusion was drawn from data from caregivers of patients with dementia. No published research has noted the associations of higher intensity of adult day services use (for example,
three or more days per week for at least four hours each visit) with change in caregiver burden for caregivers of patients with varied diagnoses (approximately 50% of attendees were diagnosed with cognitive impairment) (Gaugler et al., 2003). Additionally, no published research has examined the relationship of supportive services offered and accepted in adult day programs with caregiver burden.

1.5 Theoretical Model: Conceptual Stress Process Model for Caregiver Burden

Pearlin and colleagues’ Stress Process Model (SPM) (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Pearlin, Mullen, Semple, & Skaff, 1990) provides a useful structure for examination of the relationship of adult day service use and caregiver burden. The SPM was originally based on family caregiver stress resulting from care provided to a community-based adult with Alzheimer’s Disease. The SPM has been adapted over time, however, to consider the stress of caring for someone with AIDS (Pearlin, Aneshensel & LeBlanc, 1997; Turner, Pearlin, & Mullan, 1998) and for an older adult who has been institutionalized (Gaugler, Zarit, & Pearlin, 2003). The SPM is composed of six elements: a) background and context (socioeconomic characteristics and home relationships); b) primary stressors (difficult behaviors and needs of the care recipient, perhaps causing caregiver role overload); c) secondary role strains (non-caregiving roles that are compromised because of caregiving, such as work); d) secondary intrapsychic strains (the caregiver’s self-concept and personality); e) outcomes (results from stressors, perhaps physical and emotional in nature), and f) mediators (that serve to “mediate” the effect of the stressors) (Pearlin et al., 1997).
A primary assertion of the SPM for caregivers is that one stress can lead to another. In the conceptual model proposed via the current research, (Figure 1.2), background and context continue to represent demographic characteristics as well as home relationships (such as the relationship with care recipient). Primary stressors represent the care given by the caregiver. Secondary role strains are captured through assessing work and other responsibilities as well as caregiver self-rated health. Outcomes are represented by overall caregiver burden as measured by the Zarit Burden Interview (ZBI), and mediators include the use of adult day services and use of supportive services.

Figure 1.2 Conceptual Stress Process Model for Caregiver Burden
1.6 Caregiver Assessment Instruments

The Zarit Burden Inventory (ZBI) is the oldest and most widely-used instrument for measuring caregiver burden. Developed by Steven Zarit in 1980, the ZBI has been translated and studied internationally with consistent results for validity and reliability. Psychometric properties of the ZBI include acceptable inter-item reliability and convergent validity and good test-retest reliability (Hebert et al, 1993; Lai, 2007).

The ZBI is a 22-item assessment tool that can be administered to a caregiver or completed by a caregiver independently. The items assess potential stressors for caregivers in physical, economic, psychological, and relational areas. Items are scored on a zero to four point Likert scale, with 0= never to 4= always. Higher caregiver burden scores on the ZBI have been shown to relate significantly to decreases in physical and emotional health as well as to decreased vitality and social functioning (Schreiner et al, 2006; Lai). Little to no burden scores range from 0 to 20; mid- to moderate burden scores range from 21-40; moderate to severe burden scores range from 41 to 60; and severe burden is detected in scores ranging between 61 and 88 points. Higher caregiver burden scores on the ZBI have been shown to relate significantly to decreases in physical and emotional health as well as to decreased vitality and social functioning (Lai; Schreiner, Morimoto, Arai, & Zarit, 2006).

Additional caregiver health questions from the Short-Form 36 (SF-36) were used to compare the two groups with regard to subjective mental and physical health. The SF-36 was designed for use in general population surveys, clinical practice, healthcare
research, and health policy evaluations; it can be self-administered by those 14 years of age and older or can be administered by a trained investigator by telephone or in person (Ware & Sherbourne, 1992). It has high reliability and validity with various populations (Eshaghi, Ramezani, Shahsanaee, & Pooya, 2006; Jenkinson, Wright, & Coulter, 1994; Taft, Karlsson, & Sullivan, 2001) when used in its entirety.

The ZBI and SF-36 are just two of many commonly used, trusted instruments for capturing useful data related to caregiver needs. As the number of caregivers grows to match the demand of an aging society, such tools and related interventions will be needed in order to provide adequate support.
Family members often provide assistance when loved ones can no longer live independently. In fact, family caregivers provide at least 80% of long term care, with an estimated 53% providing all care without assistance from other family members (Wolff & Kasper, 2006). The growth in the number of older adults, coupled with increases in the incidence and prevalence of disease and disability that comes with advancing age, logically will lead to a concomitant rise in the number of informal (unpaid) family caregivers in the coming years.

Decades of research have established that family caregivers experience negative physical, financial, and/or mental health effects from the provision of care to a loved one (Argimona, Limonb, Vilac, & Cabezasb, 2004; Clark & Chia, 2002; Glaser & Kiecold- Glaser, 2005; Jo, Brazil, Lohfeld, & Willison, 2007; Pinquart & Sorenson, 2003; Pruchno & Potashnik, 1989; Schulz & Beach, 1999; Sleath, Tulsy, Peck, & Thorpe, 2007; Vialiano, Zhang, & Scanlan, 2003). For those caring for someone at home, the use of assistance, whether in the form of a family member, friend, or through community resources, has
been associated with improved caregiver health and decreases in stress and burden (Danhauer et al., 2004; Pinquart & Sorenson, 2006).

One of the community-based care options available for use by caregivers is adult day health services (ADS). ADS offers support to caregivers of adults nationwide through the provision of daytime care, oversight, and socialization for the care recipient, giving respite or work time to the caregiver for multiple days/hours weekly (Dabelko & Zimmerman, 2008). The relative affordability of ADS when compared with other community-based services, particularly in consideration of day-long care and funding assistance in many communities, makes ADS an appealing option with regard to public policy. The U.S Department of Health and Human Services (2006) has identified adult day services as a key community-based service for the support of older individuals and their family caregivers.

The literature on elder caregiving is vast, while the contribution ADS makes to the well-being of caregivers of older adults remains limited. One benchmark study revealed that family caregivers using ADS for at least eight hours a week reported fewer depressive symptoms and less care-related stress when compared to non-users (Zarit, Townsend & Greene, 1998). Family caregivers have also been shown to experience 66% less care-related stress on ADS-use days than on days of no ADS use (Zarit, Femia, Kim, and Savla, 2009). Several studies have described characteristics of cross-sections of caregivers using this service; however, research comparing those who seek use of ADS with caregivers who choose not to use ADS has not been located. Additionally, even
though caregivers have reported high satisfaction with ADS (Jarrott, Zarit, Stephens, Townsend & Greene, 1999), several studies have demonstrated that participation rates are low even when ADS is accessible to caregivers (Baumgarten, Lebel, Laprise, Leclerc, & Quinn, 2002; Douglass & Visconti, 1998; Lawton, Brody, & Saperstein, 1989; Montgomery & Borgott, 1989). Comparison of specific measures may provide helpful insight into caregivers’ decisions to use—or not to use--this service.

One response to the caregiver role is perceived burden (Zarit & Zarit, 1982). Caregiver burden is multidimensional and variable, and can lead to considerable negative psychological and physiological outcomes (Aranda & Hayman-White, 2001; Fisher, Ross, MacLean, 2000; Hauser & Kramer, 2004; Waldrop, Kramer, Skretny, J., Milch, R., & Finn, W., 2005; Wennman-Larsen & Tishelman, 2002) and associated costs. Several studies of the effects of regular ADS use on caregiver burden have reported positive outcomes (Baumgarten et al; Cox, 1997; Gottlieb & Johnson, 1995; Sussman & Regehr, 2009; Zarit, Stephens, Townsend, & Greene, 1998); however, baseline differences in burden between those seeking enrollment of a loved one into ADS and those not seeking enrollment have not been reported.

Caregivers of elderly individuals can feel angry or exhibit angry actions toward care recipients (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Williamson, Shaffer, & Schulz, 1998; Zarit, et al, 1998), sometimes reporting that they sought formal services because of concern about these feelings and/or actions of anger. Kramer, Gibson, and Teri (1992) found that anger was prevalent among caregivers of those with behavioral
problems. The relationship of caregivers’ anger—as well as caregivers’ perception that care recipients seem to view them as the only ones to provide their care-- with their decision to use ADS is not known. Finally, a small study demonstrated that the use of ADS significantly reduced the conflict resulting from caregivers trying to balance care demands with work responsibilities, other family needs, and social connections (Schacke & Zank, 2006). These three areas (anger, frustration with competing demands, and feelings of being depended upon) are assessed within the Zarit Burden Interview as contributing to overall caregiver burden and may contribute significantly to caregivers’ reasons for seeking additional assistance.

Memory impairment is common among elderly care recipients and is often accompanied by behavioral changes such as agitation, delusions, hallucinations, sleep disturbances, and wandering, among others (Auer, Monteiro, & Reisberg, 1996; Cohen-Mansfield & Libin, 2005; Femia, Zarit, Stephens, & Greene, 2007; Yaffe, Fox, Newcomer, Sands, Lindquist, Dane & Covinsky, 2002). Caregivers of those with dementia report increased levels of burden and depression when compared to caregivers of individuals without dementia (Bertrand, Fredman, & Saczynski, 2006; Ory, Hoffman, Yee, Tennstedt, & Schulz; 1999; Pinquart & Sorenson, 2003). Baseline comparisons of caregivers seeking and not seeking use of ADS in relation to the degree to which care recipient memory and any associated behavioral problems bother the caregiver have not been located in the literature.

Of final interest for this study is that caregivers often report poorer perceived
health than non-caregiving counterparts; caregivers’ self-rated health (SRH) has been established historically to be an excellent marker of current and future health and mortality (Banks, Marmot, Oldfield & Smith, 2006; Benyamini, Yael, Leventhal, & Leventhal, 2000; Burstrom & Fredland, 2001; Franks, Gold & Fiscella, 2003; Idler & Benyamini, 1997; Long, Stewart, Ritter, Gonzalez, Laurent, & Lynch, 1996; Schoenfeld, Malmrose, Blazer, Gold, & Seeman, 1994; Schulz, O’Brien, Bookwala, & Fleissner, 1995; Wolinsky & Johnson, 1992). In a recent national study, primary caregivers were more likely to report fair or poor health and those co-residing with the care recipient reported poorer health still (Administration on Aging, 2010). Additionally, poorer SRH was found with longer time spent caregiving. Comparison of caregivers’ estimations of SRH may give insight into their decisions to use ADS or to not use this service. This knowledge may also be helpful in guiding caregivers if, at some future point, ADS use is correlated with improvement in SRH.

Understanding caregivers’ reasons for using adult day health service or not is not fully understood. Information in these specific areas may be useful for guiding caregivers to a service – or a combination of services – best suited to their needs. The purpose of this paper is to compare characteristics and care situations of primary informal caregivers of older adults who are seeking initial use of ADS with caregivers who are not seeking use of ADS. Specific research questions were: 1. Do the two groups differ in reports of a. overall subjective burden, and b. self-rated health (SRH) and c. how bothered they feel by memory and behavior problems exhibited by their
care recipients? and 2. Do they differ in their self-ratings related to: a. stress from caring for relative while trying to meet other responsibilities for family or work; b. anger felt when around the care recipient, and c. feeling as if the care recipient expects the caregiver to be the only one to provide care?

2.1 Methods

This cross-sectional, descriptive, two-group comparison study used a convenience sample of primary, informal caregivers of older adults to compare caregivers who chose to utilize ADS with those who did not. Approval was granted by The Ohio State University Office of Responsible Research Practices, Human Subjects Institutional Review Board.

2.1.1 Subjects

Inclusion criteria for participation in this study included: care recipients were 65 years of age or older; caregivers were 30 years of age or older, self-identified as the primary, informal (unpaid) caregiver of the older adult, and could speak and write in English; caregivers had not used adult day health services previously; and caregivers and care recipients lived in the same home. Caregivers could be utilizing other sources of care assistance.

Administrators of one agency providing adult day health services in five adult day centers identified potential subjects for the ADS group. With over twenty years of experience in providing day services in a combination medical and social model approach, this agency was the source for all ADS caregivers.
Caregivers newly enrolling a loved one at a participating adult day health service center were provided with information related to the study by program enrollment social workers. Caregivers who gave permission for these program staff to share their contact information were contacted by phone by the first author for enrollment into the study. Initial calls were made within 48 hours of receipt of contact information; in some cases, multiple contact attempts were necessary to reach the caregiver.

Caregivers who were not seeking use of adult day health services were informed of the study in a variety of ways. Caregivers not interested in utilizing ADS were recruited via flyers provided to community support service locations including churches, counseling centers, the Alzheimer’s Association, and senior centers; and also through word-of-mouth. Two recruitment appeals were also made at Alzheimer’s Association education and support groups. Interested individuals were instructed to call about study participation and were enrolled if they met the study criteria.

2.1.2 Procedures

After phone recruitment, caregivers who were eligible and who agreed to participate were mailed packets that included survey materials, consent forms, and a stamped, addressed return envelope. Materials were expected to take approximately thirty minutes to complete. Caregivers were asked to return documents by a specified date ten days from projected receipt of the packet. Reminder calls were made when the return date passed, and in some cases, another survey packet was mailed to encourage participation. Attempts to determine reason for non-response were made
in all cases. Caregivers who returned completed study consent forms and survey
documents were mailed a ten dollar gift card of their choice. Some questions (about
caregiver mental health diagnoses, care recipients’ memory and/or behavioral problems
and the degree of bother noted by caregivers with regard to these) were added and
sent for response after some caregivers had completed the survey. Those who
responded to this addendum also received a ten dollar gift card.

2.1.3 Measures

Caregiver surveys requested a variety of information in order to make general
comparisons between the ADS and non-ADS caregivers, including data about the
caregiver and the care recipient. Caregiver data collected included caregiver age,
gender, race, marital status, relationship to care recipient, and work status (including
number of hours worked weekly, if applicable). Caregivers provided self-rated health
information by choosing of one of five descriptions: excellent, very good, good, fair, or
poor. Caregivers reported the length of time they had been providing care (in years and
months). Caregivers were also asked about diagnosis of and treatment for personal
current mental health issues (such as depression and anxiety) with dichotomous
answers.

The Short Form 36v2 is a multi-purpose health survey which provides profiles of
functional health and well-being. It has been shown to provide acceptably reliable and
valid measures in various populations (Eshaghi, Ramezani, Shahsanaee, & Pooya, 2006;
Li, Wang, & Shen, 2003; Taft, Karlsson, & Sullivan, 2001; Walters, Munro, & Brazier,
2001) when used in its entirety. Six questions from the Short-Form 36 (SF-36) were used to aid in comparison of subjective mental and physical health between the two caregivers groups.

Caregivers were asked about support received for caregiving duties over the previous three months (prior to new use of adult day health services, where applicable). Response choices included: family or friends, hospice care, home care services, facility respite stay, companion services, and other (with room to elaborate in that choice category if applicable). Caregivers were also asked to indicate how much time they received assistance with caregiving duties weekly in the previous three months (prior to new use of adult day services, where applicable) by selecting the range of hours (0-5 hours, 6-10 hours, 11-15 hours, 16-20 hours, 21-25 hours, 26-30, or 31-plus hours/week).

The Zarit Burden Interview (ZBI) was used to measure self-reported primary caregiver burden at baseline. The ZBI is the most widely-utilized instrument for measuring caregiver burden. This tool has been translated and studied internationally with consistent results for validity and reliability. The ZBI has shown to have high internal consistency as measured by Cronbach's Alpha (.92) (Vitaliano, Young, & Russo, 1991). Psychometric properties of the ZBI include acceptable inter-item reliability and good test-retest reliability (Hebert et al, 1993; Lai, 2007).

The ZBI is a 22-item assessment tool that can be administered to a caregiver or completed by a caregiver independently. The items assess potential stressors for
caregivers in physical, economic, psychological, and relational areas. Items are scored on a zero to four point Likert scale, with 0= never to 4= always. Higher caregiver burden scores on the ZBI have been shown to relate significantly to decreases in physical and emotional health as well as to decreased vitality and social functioning (Lai; Schreiner, Morimoto, Arai, & Zarit, 2006).

Information gathered about the care recipient included age, gender, and relationship to the informal caregiver. To gain insight into the care needs of the individual receiving care, caregivers were asked to complete the Barthel Index (BI). The Barthel Index assesses an individual’s need for assistance with activities of daily living (ADL) in ten areas: eating, bathing, grooming, dressing, bowels, bladder, using the toilet, transfers, mobility, and using stairs. Each category offers two to four descriptions for caregivers to choose from in best describing the care recipient’s needs for assistance, with scoring of 0, 5, 10, or 15 points. The summative score on the Barthel Index ranges from 0 to 100 points. Lower scores indicate need for more hands-on assistance; higher scores indicate the need for less hands-on assistance. The Barthel Index has been shown to meet recommended criteria for internal consistency reliability, intra-rater reproducibility, and validity (Hobart et al, 2001). Information about who provided baths, if applicable, was gathered.

Information about the presence and effect of care recipient memory impairment and behavioral problems was also gathered for comparison. Using yes/no to determine the presence of memory and behavioral problems, categorical choices
were then provided to gather caregivers’ perceptions of how bothersome memory and behavior problems were (not at all, a little, quite a bit, very much).

2.1.4 Analysis

All data were analyzed using PASW (SPSS) v. 18. Means, ranges, and percentages of general caregiver and care recipient data were computed for descriptive statistics. Chi-square analyses and t-tests were also performed on much of the caregiver data gathered in order to be aware of baseline differences that might affect the outcomes of the analyses for the research questions.

For the specific research questions, t-tests for independent samples were performed on caregiver self-rated health, and for the three specific questions from the Zarit Burden Interview (anger related to caregiving role, feeling stressed due to competing demands, and feeling that care a recipient was dependent on caregiver). A t-test for independent samples was also computed for between-group comparison of subjective caregiver burden as measured by the Zarit Burden Inventory. Chi-square tests were run on data gathered related to the presence of care recipient memory impairment and behavioral problems exhibited, and for the degree to which caregivers felt bothered by these. In instances for which the Levine’s Test for Equality of Variance was significant, the unequal variance version of the t-test was applied. In instances of fewer than 5 cases in cells, Fisher’s Exact Tests were run to determine the significance of associations of categorical variables. Level of significance was set at the .05 level for all analyses.
2.2 Results

Fifty-two (52) caregivers completed survey information within two groups. The treatment group comprised 33 caregivers of older adults seeking enrollment of their loved one in adult day services (ADS caregivers); 27 of these participants were females, and 6 were males. The comparison group comprised 19 caregivers of older adults not seeking enrollment of a loved one in adult day services (non-ADS caregivers); no males participated. For addendum questions, 24 ADS caregivers and 18 non-ADS caregivers completed and returned survey information. All caregivers in the comparison group indicated awareness of adult day services as a care option.

2.2.1 General Caregiver Information

Various descriptive data collected to compare the two caregiver groups can be viewed in Table 2.1. No significant differences were found in length of time spent providing care (months), caregiver age, or average number of hours of caregiving assistance received weekly/average number of caregiver hours worked weekly in the previous three months. Ranges were generally wide for these variables. No significant differences were noted with regard to marital status.

Non-ADS caregivers reported receiving more hours of assistance with caregiving at home, and Black, non-Hispanic caregivers comprised a higher proportion of the ADS caregivers than non-ADS caregivers, but these differences were not statistically significant. A larger proportion of ADS caregivers reported caring for spouses while a larger proportion of non-ADS caregivers reported caring for parents or in-laws; again, no
statistically significant differences were noted with analyses. Analyses of caregivers’ subjective responses to SF-36 questions regarding any physical and mental health effects on personal functioning provided similar results. No statistically significant differences were noted between the two groups of caregivers with regard to self-reported mental health diagnoses (such as depression or anxiety). Overall, the two caregiver groups were similar at baseline with regard to these descriptive measures.
<table>
<thead>
<tr>
<th></th>
<th>ADS Group</th>
<th>non-ADS Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=33</td>
<td>n=19</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>35-79</td>
<td>31-87</td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>61.03 ± 12.15</td>
<td>56.74 ± 14.01</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female (n, %)</td>
<td>27(81.8)</td>
<td>19(100)</td>
</tr>
<tr>
<td>Male (n, %)</td>
<td>6(18.2)</td>
<td>0(0)</td>
</tr>
<tr>
<td><strong>Ethnicity (n, %)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>10(30.3)</td>
<td>3 (15.8)</td>
</tr>
<tr>
<td>White</td>
<td>21(63.6)</td>
<td>16 (84.2)</td>
</tr>
<tr>
<td>Other</td>
<td>2(6.0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Marital Status (n, %)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>22(66.7)</td>
<td>10(57.9)</td>
</tr>
<tr>
<td>Single</td>
<td>4(12.1)</td>
<td>5(26.3)</td>
</tr>
<tr>
<td>Widowed/Separated/Divorced</td>
<td>6(18.2)</td>
<td>2(10.5)</td>
</tr>
<tr>
<td>Other</td>
<td>0 (0)</td>
<td>1(3)</td>
</tr>
<tr>
<td><strong>Work Status (n, %)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Part-time</td>
<td>4(12.2)</td>
<td>2(10.5)</td>
</tr>
<tr>
<td>Full-time</td>
<td>13(39.4)</td>
<td>6(31.6)</td>
</tr>
<tr>
<td>Not employed</td>
<td>16(48.5)</td>
<td>11(57.9)</td>
</tr>
<tr>
<td><strong>Other Care Source(s) Used (n, %)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family/Friends</td>
<td>21(63.3)</td>
<td>16(84.2)</td>
</tr>
<tr>
<td>Home Care</td>
<td>13(42.4)</td>
<td>9(47.4)</td>
</tr>
<tr>
<td>Facility Respite</td>
<td>3(9.1)</td>
<td>1(5.3)</td>
</tr>
<tr>
<td>Companion Services</td>
<td>1(3.0)</td>
<td>2(10.5)</td>
</tr>
<tr>
<td>Hospice</td>
<td>1(3.0)</td>
<td>0(0)</td>
</tr>
<tr>
<td>Other</td>
<td>4(12.1)</td>
<td>1(5.3)</td>
</tr>
<tr>
<td>None</td>
<td>1(3.0)</td>
<td>2(10.5)</td>
</tr>
<tr>
<td><strong>Hours/Week Caregiving Assistance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5 hours</td>
<td>20(60.6)</td>
<td>11(57.9)</td>
</tr>
<tr>
<td>6-10 hours</td>
<td>6(18.2)</td>
<td>6(31.6)</td>
</tr>
<tr>
<td>11-15 hours</td>
<td>4(12.1)</td>
<td>1(5.3)</td>
</tr>
<tr>
<td>16-20 hours</td>
<td>1(3.0)</td>
<td>0(0)</td>
</tr>
<tr>
<td>21-25 hours</td>
<td>1(3.0)</td>
<td>0(0)</td>
</tr>
<tr>
<td>26-30 hours</td>
<td>1(3.0)</td>
<td>2(10.5)</td>
</tr>
</tbody>
</table>

Table 2.1 Sample Description/Caregivers

*Caregivers may have used multiple care sources
2.2.2 General Care Recipient Information

Gender breakdown of care recipients and rates of reported memory problems among them were similar between the two caregiver groups (Table 2.2). Every participating ADS caregiver and most of non-ADS caregivers reported that their care recipient exhibited memory loss. Although 23% more ADS caregivers (n=19) reported concurrent behavioral problems than non-ADS caregivers (n=10), this was not a statistically significant difference using chi-square analysis (Table 2.3). Measurement of Activities of Daily Living (ADL) needs of the care recipients (as measured by the Barthel Index) resulted in similar means (with wide standard deviations) and no statistically significant differences. A t-test for independent samples, however, indicated that the average age of care recipients was statistically different at the .05 level between the two groups; the care recipients in the non-ADS group were 4.78 years older on average (t(35)=6.12, p<.010).
### Table 2.2 Sample Description/Care Recipients

<table>
<thead>
<tr>
<th></th>
<th>ADS Group</th>
<th>non-ADS Group</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>61-93</td>
<td>75-93</td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>80.64±8.13</td>
<td>85.42±4.74  <em>p=.010</em></td>
</tr>
</tbody>
</table>

| **Gender (n, %)**       |           |               |
| Female                 | 17(15.1%) | 11(57.9)      |
| Male                   | 16(48.5)  | 8(42.1)       |

| **Functional Status (Barthel Index)** |           |               |
| Range                               | 25-90     | 10-90         |
| Mean ± SD                           | 57.73±18.96| 55.26±23.54  |

### Table 2.3 Sample Description/Additional Information Requested

<table>
<thead>
<tr>
<th></th>
<th>ADS Group</th>
<th>non-ADS Group</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Care Recipient w/Memory Loss n(%)</strong></td>
<td>24(100)</td>
<td>18(94.4)</td>
</tr>
<tr>
<td><strong>Care Recipient w/Behavioral Issues n(%)</strong></td>
<td>19(79)</td>
<td>10(53)</td>
</tr>
<tr>
<td><strong>Caregiver w/Mental Health Diagnosis n(%)</strong> (self-report)</td>
<td>4(17)</td>
<td>(36.89)</td>
</tr>
</tbody>
</table>

### 2.2.3 Findings

ADS caregivers reported poorer self-rated health \((t(50)=2.379, p=.021)\) than non-ADS caregivers. The mean Zarit Burden Interview score for ADS caregivers was higher than the non-ADS mean, but ranges were wide and the difference was not statistically significant.
ADS caregivers reported feeling more angry when around their care recipients 
($t(50)=2.254, p=.030$) and also perceived that their care recipients expected the 
caregiver to provide care as if no one else could do so (dependence) ($t(50)=2.643, 
p=.011$). However, no statistically significant differences were found between the two 
groups with regard to caregivers’ reported stress about providing care while also trying 
to meet other responsibilities for family or work.

All of the ADS care recipients and nearly all of the non-ADS care recipients had 
memory loss; however, ADS caregivers reported being *more bothered* by the exhibited 
memory issues than non-ADS caregivers to a statistically significant degree ($\chi^2(33) 
=4.008, p=.045$). Although more ADS caregivers reported the presence of behavioral 
problems and 63% of those caregivers reported being bothered by behaviors exhibited 
by care recipients “quite a bit” or “very much” as compared to 34% for non-ADS 
caregivers, these findings were not statistically significant with chi-square analysis.
### Table 2.4 Summary of Findings

<table>
<thead>
<tr>
<th>Measure</th>
<th>ADS Caregivers (n=33)</th>
<th>non-ADS Caregivers (n=19)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-Rated Health</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>1-5</td>
<td>1-3</td>
<td></td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>2.64±1.05</td>
<td>2.0 ± .816</td>
<td>.021</td>
</tr>
<tr>
<td><strong>Subjective Burden (ZBI)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>6-67</td>
<td>10-63</td>
<td></td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>38.52±17.27</td>
<td>32.37 ±16.11</td>
<td></td>
</tr>
<tr>
<td><strong>CG anger when around patient</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>0-3</td>
<td>0-2</td>
<td>.030</td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>1.55±.938</td>
<td>.95±.91</td>
<td></td>
</tr>
<tr>
<td><strong>CG feels patient is dependent only on him/her</strong></td>
<td></td>
<td></td>
<td>.011</td>
</tr>
<tr>
<td>Range</td>
<td>0-4</td>
<td>0-4</td>
<td></td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>2.82±1.424</td>
<td>1.68± 1.6</td>
<td></td>
</tr>
<tr>
<td><strong>CG stressed between caregiving and other work/family demands</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>0-4</td>
<td>0-4</td>
<td></td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>2.39 ± .899</td>
<td>2.11± 1.150</td>
<td></td>
</tr>
<tr>
<td>How much care recipient memory loss bothers CG</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>1-4</td>
<td>1-4</td>
<td>.044</td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>2.88 ± .797</td>
<td>2.29 ± .985</td>
<td></td>
</tr>
<tr>
<td>How much care recipient behaviors bothers CG</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>2-5</td>
<td>2-5</td>
<td></td>
</tr>
<tr>
<td>Mean(SD)</td>
<td>3.58± 1.018</td>
<td>3.72± 1.274</td>
<td></td>
</tr>
</tbody>
</table>

2.3 Discussion

In this sample, all caregivers indicated awareness of adult day services as a community-based care option, but some chose to pursue use of ADS while others did...
not. Insight into these differences might be useful for community support professionals who provide education and referral assistance to caregivers. Additionally, the allocation of ADS as a key community-based service for the support of older adults and their caregivers (U.S Department of Health and Human Services, 2006) and the recent Medical Adult Day Services Demonstration project (Centers for Medicare and Medicaid Services, 2010) reveal an increased national interest in ADS from a public policy standpoint. Understanding of variables affecting the decision to utilize ADS from the perspective of users can provide insight to enhance caregiver support at the point of care and policy levels.

The ADS caregivers in this study had poorer self-rated health, were more bothered by memory problems exhibited by their care recipients, felt more anger when around their care recipients, and felt as if their care recipients relied only on them to provide care. These differences seem logical when considering why some caregivers in this study might have decided to use adult day services and others did not. These four areas with significant results relate to caregivers’ subjective physical and/or emotional perceptions – how they were feeling. Perceived health limitations and feelings such as anger and frustration seem reasonably aligned with a quest for increased caregiving assistance. Day services can provide extensive care assistance for as much as eleven hours a day; therefore, if personal health and frustrations with a care recipient and/or the care situation reach a certain personal threshold, pursuit of extended assistance or respite for multiple days weekly intuitively may become an appealing option.
All but one caregiver in this study reported that their care recipient had memory loss; 23% more of the ADS caregivers reported concomitant behavioral issues as compared to non-ADS caregivers. Nationwide, an estimated 83% of individuals with memory problems from dementia have associated behavioral problems (International Psychogeriatric Association, 2005) – this rate is similar to that of the ADS group, but this national rate is 30% higher than the rate of behavioral problems reported by the non-ADS caregivers in this study. Higher stress levels have been noted in caregivers of individuals with behavioral problems (Bertrand, Fredman & Saczynski, 2006; Hooker, Bowman, Coehlo, Lim, Kaye, Guariglia & Li, 2002; Shanks-McElroy and Strobino, 2001), and those who care for individuals with behavioral problems demonstrate elevated levels of physical and emotional demands that affect physical and emotional well-being (Aneshensel, Pearlin, Mullan, Zarit & Whitlatch, 1995; Femia, Zarit, Stephens & Greene, 2007).

Caregivers’ rate of reported “bother” related to memory loss was significantly different for the ADS group – but surprisingly, no statistically significant differences were noted for the rate of “bother” by care recipient behavioral problems exhibited. In the present study, definitions or examples of “problems with memory loss” and “behaviors that you find challenging or difficult to manage” were not defined for caregivers; therefore, it is possible that interpretation of one or both may have differed among the caregivers. For example, one caregiver may have categorized repetitive comments (which are common among those with memory loss) as a problem with
memory while another may have considered this issue to be a challenging behavior.

The care recipients in the non-ADS group were older than those in the ADS group to a statistically significant degree. Logically, one could theorize that advanced age is likely to result in increased frailty and disability, and therefore might lead to caregivers seeking additional assistance such as that provided by adult day services. In fact, poorer caregiver health at any age can increase the need for additional care support like ADS. On the other hand, increased disability and poorer health could lead to challenges for easily seeking out-of-home care, such as attempting to transport the loved one out of the home. Assisting a physically impaired loved one in and out of a vehicle, particularly if a wheelchair also needs loaded into the vehicle, and/or working with a confused care recipient to get in and out of a vehicle are challenges faced frequently by caregivers of older adults.

In a recent Centers for Medicare and Medicaid (CMS) study (2010), home health patients who were older and in poorer health declined participation in ADS at higher rates than other patients. The current study assessed care recipient health status via their need for hands-on care assistance and the presence or absence of memory loss and behavioral symptoms; however, the presence of health symptoms such as fatigue, nausea, and pain that could affect wellbeing were not assessed. Additionally, a post-hoc correlational analysis of care recipient ADL needs (BI score) with age were not significant and showed no relationship. In other words, both groups needed similar amounts of hands-on assistance that was not directly related to age, but we do not know if an
association existed between age and general health status. Poorer general health may have been present among the non-ADS group, possibly contributing to the decision not to use the service. This is an area for potential additional study.

Some measured variables were different though not significantly so between the two groups, but are worthy of discussion. The racial breakdown demonstrated that a higher percentage of ADS caregivers were Black (30.3% as compared to 15.8% for the non-ADS caregivers). Nationally, approximately 16% of program participants are Black, 9% are Hispanic, and 9% are Asian; the remaining (approximate) 61% are White (Metlife Mature Market Institute, 2010). Previous studies in the Columbus, Ohio metropolitan area, however, have noted a higher proportion of Black program participants than is evident in a nationally distributed sample (Dabelko, Koenig, & Danso, 2008).

Non-ADS caregivers reported receiving more hours of assistance with caregiving at home; fewer hours of home support could contribute to caregivers’ decisions to seek ADS and additional study of this concept is warranted. Almost 15% more of the non-ADS caregivers were caring for a parent or in-law, and conversely, about 13% more of ADS caregivers were caring for spouses. Previous research found that for adult daughters who are the primary care givers, use of ADS was associated with a delay in placement of the parent into a nursing home, whereas wives who were primary caregivers were more likely to pursue nursing home placement sooner (Cho, Zarit & Chiriboga, 2009).

A small number (six) of the caregivers in this study were males, all in the ADS
group. The lower/beginning age of the range for the males was 45 years (10 years older than the female ADS caregivers, whose age range began at 35 years of age. The higher end of the age was 79 years of age for the male and female caregivers using ADS. Mean ages for males and females were not significantly different. Because the sample size in this study was small and the subset of males was even smaller, generalizations cannot be made. However, additional study is recommended to determine if male caregivers seek ADS at later ages consistently, and if so, what variables contribute to this phenomenon.

Finally, more of the non-ADS caregivers reported having a diagnosis of a mental health issue such as depression or anxiety (36.8% vs. 22%), although caregiver answers on SF-36 questions related to the effect of emotional health on the ability to perform some activities were similar between the two groups. One might hypothesize that those dealing with mental health diagnoses such as depression or anxiety would be more likely to need/seek the additional care that adult day services can provide in large doses (e.g. care recipient out of the home for multiple hours per day on multiple days per week). An alternate hypothesis, however, is that those caregivers experiencing mental health problems may be more reticent or nervous to seek outside care—or perhaps cannot cope with the processes necessary to choose and enroll a loved one in adult day services. This area is also suggested for further research.

2.4 Limitations

Various study limitations exist. In addition to being cross-sectional and not
randomized, the overall sample size was small, limiting the statistical power available to detect differences between the two groups. Some cells in the chi-square analyses yielded expected cell sizes of less than 5; this was addressed by use of Fisher’s Exact Test. Single questions were analyzed for comparison; ZBI questions are generally not separated for analyses. Because this sample of caregivers volunteered to participate in the study, self-selection bias is of concern. Additionally, the small number of responding males (six) was entirely contained within the ADS caregiver group. Although the non-ADS caregivers noted awareness of the service during the screening and enrollment process, additional information about the extent of their knowledge about ADS was not gathered.

While many areas of caregivers’ lives were examined (for example, work, health, and burden), it is difficult to gather information on all possible confounders affecting caregivers at any point in time. This study, for example, did not assess additional responsibilities such as also providing care to children in the home, personal coping styles, or relationship difficulties with significant others. An additional challenge in caregiver research is that differences found may be unrelated to the caregiving experience entirely. This intent of this study was not to explain those differences but instead, to begin to understand which differences or combinations of differences might lead certain caregivers to seek ADS but not others.

2.5 Conclusions

Increased knowledge about the contribution of supportive services such as adult
Day services on the primary, informal caregiver experience is needed in order to best maintain older adults in the community while also maximizing caregivers’ physical and emotional health. This type of knowledge can also be used to inform public policy. While limitations within this study and other small, cross-sectional studies certainly exist, enhanced understanding of caregiver needs on even minor levels should not be underestimated. This study highlights additional areas for study.
Chapter 3: Association Between Use of Adult Day Health Services and Additional Supportive Services with Changes in Burden of Primary, Informal Caregivers of Older Adults

Research over the course of many years has established that family caregivers experience negative physical, financial, and mental health effects when providing care to a loved one. Those who live in the same home as the one they are providing care for report higher levels of burden scores than those who do not live with the care recipient (Kuzuya, Enoki, Hasegawa, Izawa, Hirakawa, et al., 2011). Immune function reduction (Glaser & Kiecolt-Glaser, 2005), depression (Sleath, Tulsly, Peck, & Thorpe, 2007), increased chronic illnesses (Pruchno & Potashnik, 1989), physical strain and fatigue (Jo, Brazil, Lohfeld, & Willison, 2007), and a 63% increase in all-cause mortality risk among older caregivers (Schulz & Beach, 1999) are some of the adverse effects of providing care. Without careful management, these by-product costs of care are poised to further strain our already burdened healthcare system. In light of older adults’ growing needs and increasing numbers, it is intuitive that the growing number of family caregivers—who provide at least 80% of long-term care (Wolff & Kasper, 2006) — will require considerable support in the coming decades.
Adult day health services (ADS) offer daytime care and socialization opportunities, allowing care recipients to live at home while giving respite or work time to caregivers (National Adult Day Services Association (NADSA), 2011). The literature on ADS is slowly growing, but the contribution this service makes to the well-being of caregivers of older adults may be understudied.

Research of over a decade ago determined that the minimum intensity and duration of adult day health services use needed to show positive impact on caregiver burden is two days per week for at least eight total hours for twelve weeks (Zarit, Stephens, Townsend, & Greene, 1998). This remote finding has been used as the established benchmark in subsequent studies of ADS with variable results. One randomized, controlled study comparing the effects of adult day service users (n=180) to those on a waiting list (n=104) found no effect from use of adult day services on caregiver burden or other client outcome measures (Baumgarten, Lebel, Leprise, Leclerc, & Quinn, 2002). Other smaller studies, however, have demonstrated a positive effect of adult day services use on burden (Cox, 1997; Gottlieb & Johnson, 1995). This area may require more study for effective recommendations.

Additionally, no published research has examined the relationship of supportive services offered and accepted in adult day centers with change in caregiver burden. Supportive services differ across centers and can include bathing assistance and transportation to and from the center. In the ADS industry, these services are widely seen as supportive for both the caregiver and the care recipient.
Further research may assist in determining the most effective dose of ADS use as well as the additional supportive ADS services that might best reduce caregiver burden while also providing optimal care to those in need of oversight. Increased knowledge of outcomes from ADS use may also provide support for public policy related to funding community-based services such as these. Guided practice and policy that lead to adequate care reimbursement as well as exceptional services might make ADS a cost-effective and beneficial option for communities, care recipients, and caregivers alike.

3.1 Methods

This quasi-experimental study used a convenience sample of primary, informal caregivers of older adults. Approval was granted by the Institutional Review Board of The Ohio State University. The purpose of this research was to increase knowledge about the association, if any, of adult day services use and the acceptance of bathing assistance and/or transportation assistance with caregiver burden.

The specific research questions guiding this study were: 1. Is there a correlation between intensity of use of adult day health services and change in caregiver burden? 2. Will caregiver burden decrease more for those who utilize adult day health services than for those who do not? 3-a. Among those using adult day services (whose care recipient needs assistance with bathing), will caregiver burden decrease more for those caregivers accepting ADS bathing services than for those who refuse these services? and
3-b. Will caregiver burden decrease more for those caregivers utilizing transportation assistance than for those who do not use this service?

3.1.1 Subjects

Inclusion criteria for participation in this study included: care recipients were 60 years of age or older; caregivers were 30 years of age or older, self-identified as the primary, informal (unpaid) caregiver of the older adult, had not previously used ADS, were aware of ADS as caregiver support option for which financial assistance is available, and could speak and write in English; and caregivers and care recipients lived in the same home.

Caregiver subjects were enrolled into the study over a 15-month period in the metropolitan Columbus, Ohio area between July of 2010 and September of 2011. The treatment group comprised informal (unpaid), primary caregivers who were newly enrolling their older adult care recipients into ADS; the control group comprised informal, primary caregivers not using this service.

3.1.2 Procedures

One large adult day health services agency that provides services in five centers in the Columbus, Ohio area was the source for ADS caregivers. This agency has over twenty years of experience in providing ADS in a combination medical/social model approach. Caregivers who were seeking new enrollment of a loved one at an ADS center were provided with study recruitment materials. The ADS caregivers who gave permission for the ADS program staff to share their contact information were contacted
for recruitment into the study. ADS caregivers could also contact the primary researcher by phone or e-mail if interested in participating. Initial calls were made to potential subjects within 48 hours of receipt of caregiver contact information; in some cases, multiple contact attempts were necessary to reach the caregiver. Eligible and interested caregivers were recruited into the study.

Caregivers who were not seeking use of adult day health services were recruited through direct outreach with service organizations in the greater Columbus, Ohio metropolitan area. Outreach included the distribution of recruitment flyers to churches, caregiver groups, the Central Ohio Alzheimer’s Association, and senior centers. Word-of-mouth recruitment was also perpetuated. Interested individuals contacted the primary author to inquire about study participation and were enrolled if they met the study eligibility criteria.

Eligible caregivers were sent a packet that included survey materials, consent forms, and a stamped, addressed return envelope for collection of baseline data. After receipt of completed materials, a copy of consent materials was returned to the caregivers for their records. Duplicate (blank) survey materials were sent again just before twelve weeks later (in order to capture feedback as close to twelve weeks later as possible as based on the 1998 research by Zarit et al). Caregivers were asked to return documents as soon as possible and no later than a specified date ten days from projected receipt of the packet. Reminder calls were made when the return date passed, and in some cases, another survey packet was mailed to encourage timely
participation. Attempts to determine reasons for non-response were made in all cases. Caregivers who returned completed study information received a ten dollar gift card of their choice for each time period.

Several questions about presence of caregiver mental health diagnoses, care recipients’ memory and/or behavioral problems and the degree of bother noted by caregivers with regard to these were added after the study began, and in some cases were sent for response after some caregivers had completed participation. Those who responded to this addendum request received an additional ten dollar gift card.

ADS center administrative records were reviewed for data about actual use patterns. Dates of attendance and associated hours of use on those days were gathered as recorded on daily attendance records for all centers. These records also provided data for baths received at the ADS center and use of one-way or two-way transportation. Imbedded in this data was information related to funding sources used to pay for or subsidize the use of ADS, bathing, and/or transportation.

3.1.3 Measures

Descriptive and analytical data were gathered from enrolled caregivers. Some data were collected in order to describe the ADS and non-ADS caregiver groups at baseline. Caregiver data gathered included age, gender, race, marital status, relationship to care recipient, and work status (including number of hours worked weekly, if applicable). Caregivers provided information about the length of time they had been providing care (in years and months) and about self-rated health by choosing
one of five descriptions: excellent, very good, good, fair, or poor. Caregivers were asked about diagnosis of and treatment for personal mental health issues (such as depression and anxiety) with dichotomous answers and self-reported medications taken (for comparison as needed in cases for which caregivers deny presence of anxiety and/or depression that might contribute to burden, but for which a medication list provides conflicting information).

Caregivers were asked to indicate what assistance, if any, they received with caregiving duties over the previous three months (prior to new use of adult day services, if applicable). Response options included: family or friends, hospice care, home care services, facility respite stay, companion services, and other (with room to elaborate in that choice category if applicable). Caregivers could indicate more than one option, if applicable. Caregivers were asked about the amount of time they received assistance with caregiving duties weekly in the previous three months (prior to new use of adult day services, where applicable) by selecting the applicable range of hours (0-5 hours, 6-10 hours, 11-15 hours, 16-20 hours, 21-25 hours, 26-30, or 31-plus hours/week). Care recipient data gathered included age, gender, and relationship to the informal caregiver.

Six questions from the Short-Form 36 (SF-36) were used to verify similarity of the two caregiver groups with regard to subjective mental and physical health. The SF-36 was designed for use in general population surveys, clinical practice, healthcare research, and health policy evaluations; it can be self-administered by those 14 years of age and older or can be administered by a trained investigator by telephone or in
person (Ware & Sherbourne, 1992). It has been shown to provide reliable and valid measures to acceptable or better degrees in various populations (Eshaghi, Ramezani, Shahsanaee, & Pooya, 2006; Jenkinson, Wright, & Coulter, 1994; Taft, Karlsson, & Sullivan, 2001) when used in its entirety. Likert-scale choices are provided for SF-36 questions in order to measure caregivers’ perceptions of personal mental and physical health status.

Caregivers completed the Barthel Index (BI) about their respective care recipient at baseline and again approximately twelve weeks later. The BI assesses one’s need for assistance with activities of daily living (ADL) in ten areas: eating, bathing, grooming, dressing, bowel functioning, urinary functioning, toileting use, transferring, getting around (mobility), and using stairs. Each category offers two to four descriptions for describing the care recipient’s needs for assistance, with associated scoring of 0, 5, 10, or 15 points. Aggregate scores range from 0 to 100 points, with lower scores corresponding with the need for more hands-on assistance and conversely, greater scores relating to higher levels of independence. The Barthel Index, first presented in 1965 and modified to its current form over 20 years ago, has been shown to meet recommended criteria for internal consistency reliability, intra-rater reproducibility, and validity (Hobart et al, 2001).

Caregivers were asked if their respective care recipients exhibited memory impairment and/or behavioral problems. They were then asked to indicate how
bothered they personally felt by these self-reported memory and/or behavioral problems (not at all, a little, quite a bit, very much).

3.1.4 Primary Outcome Measure

The Zarit Burden Interview (ZBI) was used to assess subjective caregiver burden at baseline and again approximately twelve weeks later. The ZBI is the most widely-used tool for measuring subjective caregiver burden; this 22-item assessment tool assesses potential caregiver stressors in physical, economic, psychological, and relational areas. Each item (provided in question form) offers choices on a zero to four point Likert scale (0=never to 4= always) with which caregivers can indicate how they feel in relation to their current caregiving situation. This tool can be administered to a subject or can be completed by a subject independently.

Examples of ZBI questions include, “Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?” and “Do you feel your health has suffered because of your involvement with your relative?”

Aggregate scores range from zero to eighty-eight points, with higher scores corresponding with higher levels of caregiver burden. This final score can be interpreted into one of four categories of burden: 0 – 21 points = little or no burden; 21 – 40 points = mild to moderate burden; 41 – 60 points = moderate to severe burden; and 61 – 88 points = severe burden.

The ZBI has been translated and studied internationally and has demonstrated consistently strong validity and reliability. Bachner and O’Rourke (2007) reported that
the average alpha level of studies using the full ZBI is .90. The ZBI has shown to have high internal consistency (Hebert, Bravo, & Girouard, 1993; Vitaliano, Young, & Russo, 1991). Psychometric properties of the ZBI include acceptable inter-item reliability and convergent validity (Lai, 2007) and good test-retest reliability (Hebert et al; Lai).

3.1.5 Analysis

All data were analyzed using PASW (SPSS) v. 18. Means, ranges, and percentages of general caregiver and care recipient data were computed for descriptive statistics and to compare similarity between the groups with regard to potential confounders. Chi squares or t-tests were computed for some comparison variables in order to detect differences between the two groups at baseline.

Change scores for caregiver burden were computed for both caregiver groups. A Pearson’s Product Moment Correlation was performed to determine the correlation between intensity of use of ADS (both in days of use and total hours used weekly) and change in caregiver burden. T-tests for paired samples were performed and then compared to determine whether caregiver burden decreased significantly for those caregivers who used ADS and for those who did not use ADS. Independent samples t-tests were also performed on the ZBI change scores for both caregivers groups to verify any significant differences in burden change between the two groups. Pearson’s Product Moment Correlations were performed to assess for any association of the number of ADS baths used and also number of ADS transportation trips accepted with change in caregiver burden. Post-hoc analyses were also performed to compare ZBI
scores for those in the ADS group who used the service at the recommended minimal dose at the end of three months with those who did not use the services at the recommended dose. The level of significance was set at the .05 level for all analyses.

3.2 Results

Fifty-two (52) caregivers met eligibility criteria and were recruited into this study. The ‘treatment’ group comprised 33 caregivers of older adults seeking enrollment of a loved one into an adult day health services center (ADS caregivers); 27 of these participants were females, and 6 were males. However, three of the caregivers seeking use of ADS (one Caucasian female and two Black females) never used the service due to care recipient refusal; these three caregivers met the criteria for the control group and were analyzed as controls. Therefore, 30 ADS caregivers were analyzed within the treatment group – 6 males and 24 females. A total of 22 females comprised the non-ADS control group.

During recruitment calls, all non-ADS caregivers indicated awareness of adult day services as a care option for which funding assistance might be available (but had opted not to pursue use of ADS). This situation served to provide a unique comparison not previously located in the literature – one caregiver group utilizing ADS, and another aware of the service and the local funding options to subsidize the service but who chose not to pursue use.

All 52 recruited caregivers completed and returned baseline materials. For the second data request, 27 of the 30 ADS caregivers (90%) and 20 of the 22 non-ADS
caregivers (90.9%) completed and returned survey materials. The addendum information requested was returned by 24 of the 30 ADS caregivers (80%) and 18 of the 22 non-ADS caregivers (81.8%).

### 3.2.1 Sample Description

Sample information can be viewed on Tables 3.1 and 3.2. The caregiver groups were not significantly different at baseline with regard to most measures. The breakdown of relationship status of care recipients to care providers was similar for both groups. All caregivers were caring for a parent, spouse, or grandparent except for one male in the ADS group who was providing care for an older female friend. ADS caregivers were slightly older, had been giving care for marginally longer, and took care of individuals who were slightly younger on average than the non-ADS group; however, the data ranges were wide for these measures in both groups and no differences were statistically significant on analyses. Both groups were proportionately similar with regard to race, marital status, and responses to SF-36 questions about physical and emotional functioning. Approximately three quarters of caregivers in each group denied the presence of personal mental health issues (such as depression or anxiety). Review of medications listed supported this. Ninety percent (90%) of the caregivers/care recipients in the ADS group received financial assistance with days of attendance, baths received, and/or transportation.
<table>
<thead>
<tr>
<th></th>
<th>ADS Group n=30</th>
<th>non-ADS Group n=22</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>35-79</td>
<td>31-87</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>61.43 ± 12.66</td>
<td>56.77 ± 12.99</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female (n, %)</td>
<td>24(80.0)</td>
<td>19(100)</td>
</tr>
<tr>
<td>Male (n, %)</td>
<td>6(20.0)</td>
<td>0(0)</td>
</tr>
<tr>
<td><strong>Ethnicity (n, %)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>8(26.67)</td>
<td>5(22.73)</td>
</tr>
<tr>
<td>White</td>
<td>20(66.67)</td>
<td>17(77.27)</td>
</tr>
<tr>
<td>Other</td>
<td>2(6.67)</td>
<td>0(0)</td>
</tr>
<tr>
<td><strong>Marital Status (n, %)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>20(66.67)</td>
<td>14(63.63)</td>
</tr>
<tr>
<td>Single</td>
<td>4(13.33)</td>
<td>5(22.73)</td>
</tr>
<tr>
<td>Widowed/Separated/Divorced</td>
<td>6(20.02)</td>
<td>2(9.09)</td>
</tr>
<tr>
<td>Other</td>
<td>0(0)</td>
<td>1(4.55)</td>
</tr>
</tbody>
</table>

**Table 3.1 Sample Description/Caregivers**

<table>
<thead>
<tr>
<th></th>
<th>ADS Group n=30</th>
<th>non-ADS Group n=22</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>65-93</td>
<td>61-93</td>
</tr>
<tr>
<td>Mean± SD</td>
<td>81.73±6.96</td>
<td>83.272±8.05</td>
</tr>
<tr>
<td><strong>Gender (n, %)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>16(53.33)</td>
<td>11(50.0)</td>
</tr>
<tr>
<td>Male</td>
<td>14(46.67)</td>
<td>11(50.0)</td>
</tr>
<tr>
<td><strong>Relationship to Caregiver (n, %)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>15(50.0)</td>
<td>13(59.09)</td>
</tr>
<tr>
<td>Spouse</td>
<td>11(36.67)</td>
<td>7(31.82)</td>
</tr>
<tr>
<td>Grandparent</td>
<td>3(10.0)</td>
<td>2(9.09)</td>
</tr>
<tr>
<td>Other</td>
<td>1(3.3)</td>
<td>0(0)</td>
</tr>
</tbody>
</table>

**Table 3.2 Sample Description/Care Recipients**
No significant differences existed with regard to gender of care recipients or their relationship to caregivers. Mean scores for the Barthel Index were similar for the two care recipient groups (with wide standard deviations), resulting in no statistically significant differences with regard to the amount of hands-on care they required.

A higher proportion of ADS caregivers worked full time when compared to non-ADS caregivers, and almost 64% of the non-ADS caregivers were not working at all as compared to 43.3% of the ADS caregivers. The rest of all caregivers reported working part time. Of working caregivers, ADS caregivers reported working about seven more hours weekly on average. However, none of these differences were significantly different on analysis. Similar work information was reported at time two.

Self-rated health (SRH) was not significantly different at baseline. About 77% of ADS caregivers and 91% of non-ADS caregivers reported receiving ten or fewer hours of care assistance weekly at baseline (not including ADS hours). Two of the non-ADS caregivers reported receiving 31 or greater hours weekly. The remaining 7 ADS caregivers reported care assistance that ranged from 11 to 30 hours weekly (not including ADS hours). Reported hours of assistance received varied slightly at time two data collection but differences were not statistically significant. Sources of the care assistance at both data collection points varied from friends and family to paid caregivers. Caregivers in both groups commonly reported receiving assistance from multiple sources.
All of the responding ADS caregivers and over 95% of non-ADS caregivers indicated that their care recipients exhibited memory loss. Caregivers in the two groups were similar in proportions for being bothered by this memory loss “quite a bit” and “very much.” However, at baseline, more ADS caregivers (n=19/21; 90.5%) reported concurrent behavioral problems than non-ADS caregivers (n=10/21; 47.6%), a statistically significant difference on chi-square analysis using Fisher’s Exact Test (p=.006). Additionally, ADS caregivers reported being more bothered by these behaviors at baseline than did non-ADS caregivers as evidenced by a statistically significant difference on chi-square analysis using Fisher’s Exact Test (p=.031). At time two, 18 of 20 ADS caregivers (90%) and 9 of 15 non-ADS caregivers (60%) whose care recipient exhibited memory loss reported concomitant behavioral problems. This difference was statistically significant with chi-square analysis using Fisher’s Exact Test (p=.051). ADS caregivers continued to report being more bothered by these behaviors at time two. Chi-square analysis using Fisher’s Exact Test was significant at p=.038.

Caregivers in the ADS group did report higher burden scores at baseline (the mean was 7.40 points higher on the 0-88 point scale). Ranges and therefore standard deviations were wide for both groups, however, so this difference was not statistically significant. When the continuous burden scores were placed into one of the four burden categories for analysis, no statistically significant differences were noted either.
3.2.2 Findings

ADS caregivers used a mean of 25.93 ± 14.26 days during the study period. The caregivers used a mean of 186.65 ± 117.61 hours of ADS over those days. Utilization amounts varied widely, with 19 of the 30 ADS caregivers (63.3%) meeting Zarit et al’s suggested (1998) stress/burden-reducing “dose” of two visits totaling at least eight hours weekly for three or more months (or approximately (at least) 24 visits totaling at least 96 hours). These data can be viewed on Table 3.3. To best answer study questions, all data was analyzed regardless of amount of ADS use, but additional analyses were also run for the 63.3% of caregivers who did meet the suggested dosage use patterns.

<table>
<thead>
<tr>
<th></th>
<th>All ADS Caregivers n=30</th>
<th>Met ADS “dose”* n=19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Days of ADS use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>2-64</td>
<td>24-66</td>
</tr>
<tr>
<td>Mean± SD</td>
<td>25.93±14.26</td>
<td>32.79±13.08</td>
</tr>
<tr>
<td>Hours of ADS use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>10-530</td>
<td>120-530</td>
</tr>
<tr>
<td>Mean± SD</td>
<td>186±117.61</td>
<td>240.24±113.23</td>
</tr>
<tr>
<td>Transportation trips</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>0-142</td>
<td>0-142</td>
</tr>
<tr>
<td>Mean± SD</td>
<td>29.80±39.68</td>
<td>41.79±44.64</td>
</tr>
</tbody>
</table>

Table 3.3  ADS Service Use
*At least 2 days/week X 8 hours/week for 12 weeks
For the entire sample, no statistically significant findings were discovered with regard to relationship between intensity of use of ADS in hours and change in caregiver burden (r= -.059, p=.770), or between intensity of use of ADS in days and change in caregiver burden (r=.082, p<.685). For this population of caregivers, use of ADS was not related to a change in caregiver burden for the study period.

<table>
<thead>
<tr>
<th></th>
<th>ADS Group</th>
<th>non-ADS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=30</td>
<td>n=22</td>
</tr>
<tr>
<td>T1 Burden</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>6-67</td>
<td>10-63</td>
</tr>
<tr>
<td>Mean± SD</td>
<td>39.40±16.55</td>
<td>32±16.95</td>
</tr>
<tr>
<td>T2 Burden</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>8-76</td>
<td>9-67</td>
</tr>
<tr>
<td>Mean± SD</td>
<td>38.67±18.67</td>
<td>33.95±17.49</td>
</tr>
</tbody>
</table>

Table 3.4 Caregiver Burden Scores
T1=Baseline, T2= after 3 months

An independent t-test analysis of the burden change scores for both caregiver groups did not show statistically significant changes in burden between the two groups by time two (t(45)=.508, p=.391). Use of ADS was not associated with a change in burden that was different than non-use of ADS.
Table 3.5  Caregiver Burden Scores by ADS Dose

For the entire ADS caregiver sample, the mean ZBI burden decreased minimally during the study period (-1.30 ± 12.00), while the burden score for non-ADS caregivers increased slightly (+1.60 ± 10.35). These changes did not represent significantly different within-group or between-group changes. The ranges for reported burden remained wide for both groups. Although closer at the time of second data collection, ADS mean burden remained higher than that of non-ADS caregivers by 4.72 points (as compared to 7.4 points difference at baseline). Not surprisingly, t-tests for independent samples analysis also did not result in statistically significant findings with relation to change in burden from baseline to time two.

For those ADS caregivers who used the suggested dose of ADS utilization, t-tests for independent samples did not reveal significant differences in burden change as compared to those ADS caregivers who did not use the suggested dose. Paired samples t-tests did not highlight significant differences for burden among the caregivers using
the suggested dose either. Increased use of days and hours of ADS did not affect burden change more than lower utilization rates did.

ADS caregivers indicated that 20 of the 30 care recipients using ADS needed assistance with bathing; however, only 3 of these individuals opted to utilize bathing at an ADS center. Home bathing assistance was utilized in some cases, but had been used prior to the start of this study. Additionally, the intensity of use for the three who did utilize bathing services at an ADS center was low; therefore, the data were insufficient to determine if burden decreased more for caregivers accepting bathing services than for those who did not accept this service.

Exactly half of caregivers used transportation assistance to and/or from the ADS center (for a total of 890 one-way trips). Caregiver burden did not decrease more for those caregivers who accepted transportation assistance to and/or from the ADS center when compared to those who provided transportation themselves.

Of interest to note is that caregivers’ SRH was not significantly different at baseline, although the ADS caregivers did report slightly lower SRH. Three months later, the ADS caregivers reported a slight worsening of SRH, while the SRH of non-ADS caregivers remained stable. This resulted in a statistically significant difference in SRH between the two groups by the end of the study ($t(45)=2.29$, $p=.027$).

### 3.3 Discussion

The burden of the ADS caregivers in this study was not significantly reduced after three months of ADS. This result is not necessarily surprising as previous studies
exploring the association of ADS with reduction in caregiver burden have resulted in mixed results. The current sample may have been too small to best represent this caregiver population’s experiences. The utilization of days of ADS, bathing, and transportation may also have been too low to reduce burden more significantly. Other ADS studies have been challenged also by low utilization rates as well, a common complaint from researchers in this field. Additionally, the service may need to be utilized for longer periods of time to consistently reduce burden for a wider range of caregivers and their associated situations. Another consideration is that just as all caregivers are not created equally, and neither are ADS centers, even within the same parent organization. In addition to geographical and environmental ADS center differences, staffing and potentially center-specific norms surely differ. Centers cannot be assumed heterogenous with regard to care recipient and caregiver outcomes.

A meta-analysis by Pinquart and Sorenson (2005) found that the mean burden level for caregivers of older adults across 58 studies using the ZBI was 29.9. This result was used as a population mean for comparison with the present burden scores. A one-sample t-test found no significant differences between the comparison mean and non-ADS caregiver ZBI scores at baseline or three months later. However, both the mean baseline ZBI score (t(3.144)=29, p=.004) and the time two ZBI score (t(2.440)=26, p=.022) for the ADS caregivers were significantly different when compared to the comparison mean score. In other words, when compared to the mean ZBI result of these 58 caregiver studies, the ADS caregivers in the present study reported feeling
significantly more burdened at both points in time. A more recent but smaller study (n=85) found a mean ZBI score of 35 (SD = 14.1) (Sussman & Regehr, 2009); a one-sample t-test was performed using this comparison mean, and no significant differences were discovered for these comparison scores and the ZBI scores of the ADS and non-ADS caregivers in the current study. While the summary score from the meta-analysis provides a more useful comparison score because of the larger number of studies represented, this more recent study does assist with demonstrating the variability of burden among caregivers, particularly as noted in individual, cross-sectional studies.

Primary, informal caregivers of older adults do not have heterogeneous circumstances or characteristics. The provision of support for them, therefore, may also be most successful through the availability of multiple support options.

The ADS caregivers did report higher mean burden than the non-ADS caregivers, but the variability of subjective burden reported was wide in both groups. Caregivers of those with dementia have reported higher levels of stress, burden and depression than non-dementia caregivers or non-caregivers (Bertrand, Fredman & Saczynski, 2006; Schulz, O’Brien, Bookwala & Fleissner, 1995; Vitaliano, 1997). In the present study, nearly 100% of participating caregivers in both groups reported caring for someone with memory loss. The ADS caregivers also reported significant bother from dealing with problem behaviors. A meta-analysis of 228 caregiver studies noted that behavioral problems exhibited by care recipients were more strongly related to caregiver burden
than any other analyzed variable (Pinquart & Sorenson, 2003). The ADS caregivers may have been inspired to utilize ADS because of these behaviors.

The self-rated health of the ADS caregivers declined slightly over the course of the study, while the non-ADS caregivers’ SRH remained stable. Additionally, although not statistically significant (perhaps due to very wide ranges), the ADS caregivers worked more hours per week, had been giving care for an average of 7 months longer, and reported lower self-rated health as compared to the non-ADS caregivers. The investigation of the interaction of these variables with burden in a larger population of caregivers might provide useful information for understanding why some caregivers choose to utilize ADS when others do not.

In post-hoc analyses, it is important to note that burden scores were not influenced by the relationship of caregiver to care recipient. In other words, within this small sample, whether a caregiver was caring for a parent or spouse did not change the outcomes in this study. The overall sample size was low, however. When separated from female ADS caregivers on post-hoc analyses, some minor differences were noted for the male ADS caregivers with regard to age, ADS utilization patterns, burden scores, work patterns, and self-rated health. However, the number of participating males was low, and the study was not intended initially to investigate the differential experiences of male and female caregivers using ADS. Therefore, this line of investigation is suggested for future study. The overall results of this study, however, were not significantly altered if the males were removed from analyses.
3.3.1 Limitations

Various study limitations exist. This study used a non-randomized convenience sample. In addition to being cross-sectional and not randomized, the overall sample size was small, limiting the statistical power available to detect differences between the two groups. The number of participants was unequal for the two groups, as was gender breakdown. Self-selection bias is of concern since all of the participating caregivers volunteered to participate in the study. Some potential confounders were not measured, such as other family stressors that may have affected burden (children in the home), work pressures, personal coping styles, the historical relationship with care recipients, or problems with personal relationships. Utilization rates for the ADS caregivers were lower than optimal. Information about caregiver educational attainment and income levels was not gathered. Some questions on the caregiver survey were developed for this study and so reliability and validity of these measures have not been established over time. The addition of a control group for general comparison provided some useful information for contrasting and comparing; however, the samples were not well-matched despite efforts to the contrary (for example, no males were contained in the comparison group).

3.4 Conclusions

This study contributed some useful information about caregivers and use of ADS. Perhaps for this caregiver population and others, the presence of higher burden and
behavioral problems exhibited by care recipients – as well as the more caregiver frustration with these behaviors -- increased caregiver interest in trying ADS. ADS can provide respite for multiple hours at a time outside of the home setting, offering caregivers more considerable work or personal time for what is widely viewed as a more affordable cost (or subsidized cost) than most other typical care options per hour. Additionally, ADS allows care recipients to remain in a community-based home rather than in an institutional setting, which may be beneficial to both the care recipient and society’s financial burden of care. Therefore, a heightened use of ADS has the potential for a win-win situation, one for suggested further study.
Chapter 4: Caregiver Self-Rated Health and Use of Adult Day Health Services

The current and anticipated growth in the population of older adults in the United States has spurred significant concern about how to provide the most optimal and affordable care for older adults, a certain requirement in the coming decades. An important aspect of senior care is that it is provided in the least-restrictive environment possible, preferably in the community and at home with family caregivers. Informal caregivers require considerable supportive care options and assistance of their own. However, caregiving circumstances and individual characteristics are as variable as the care recipients’ situations are, making situational guidance about supportive care options a challenge for professionals. Increased knowledge about caregiver characteristics in relation to selective agreement to use of community-based service options is increasingly important. Why some caregivers choose ADS while others opt not to utilize this service is not well-understood. This information may be helpful for better understanding caregivers’ acceptance of services as well as aid in making the services themselves more desirable for use by caregivers and care recipients.

Decades of research have shown that caring for an ill or disabled adult is stressful (Bugge, Alexander, & Hagen, 1999; Fredman & Daly, 1997; Kiecolt-Glaser, Glaser et al, 1987; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Zarit, Todd, & Zarit,
1986), and can lead to caregiver burden (Zarit et al; Zarit & Zarit, 1982) which, in turn, can detrimentally affect health (Connell, Janovic, & Gallant, 2001; Markowitz, Gutterman, Sadik, & Papadopoulos, 2003; Thommessen, Aarsland, Brackhus, & Aksengard, 2002;) and further increase health care spending. Resultant stress from the ongoing provision of care can also lead to reductions in self-care behaviors by caregivers (Son, Erno, Shea, Femia, & Zarit, 2007).

Approximately one in six caregivers rates personal health as fair or poor (National Alliance for Caregiving with the American Association for Retired Persons (NAC w/AARP), 2004 & 2009). Caregivers’ self-rated health (SRH) ratings are lower as age of the caregiver increases (NAC w/AARP). Subjective ratings of caregiver health have been shown as good predictors of objective health outcomes such as long-term illness, diminished ability to participate in social activities or work, and even increased mortality (Burstrom & Fredlund, 2001; Grant, Piotrowski & Chappell, 1995; Idler & Benyamini, 1997; and Ren, Skinner, Lee, & Kazis, 1999). In fact, a five year, prospective cohort study of 392 in-home spousal caregivers and 427 non-caregivers aged 66 to 96 years old found that strained caregivers had mortality risks 63% higher than controls (Schulz & Beach, 1999).

For those who are caring for someone at home, the use of assistance (in the form of a family member or friend or through community resources) has been associated with improved caregiver health (Danhauer et al; Evans, 2004). Adult day health services (ADS) are a community-based care option that may buffer negative
caregiver consequences. ADS provides extended hours of daytime care, may offer benefits to both care recipients and caregivers, and is relatively affordable when compared to other services. Funding options exist to assist with payment for ADS, including some subsidy options across the nation for those who are not considered “low-income.” A previous benchmark study of ADS use found that strain and overload decreased for caregivers who used the service for at least 8 hours per week for 3 months (approximately 24 visits totaling 96 hours) (Zarit, Stephens, Townshend & Greene, 1998). Little is known about why some caregivers choose to utilize ADS and others do not, despite knowledge of the service and available funding. Although the contribution ADS makes to the long-term care industry, caregivers, and older adults has been receiving increased attention in recent years, experiential and empirical data remain limited.

4.1 Methods

A two group, quasi-experimental, mixed methods design was used to compare primary, informal (unpaid) caregivers of older adults using ADS (ADS) with primary, informal caregivers not using this service (non-ADS) on self-rated health. Additionally, requested caregiver responses to open-ended statements were analyzed to further describe the caregiving experience. Study approval was granted by the Institutional Review Board of The Ohio State University.

Our purpose was to investigate the relationship of caregiver self-rated health (SRH) with the use of ADS by primary caregivers of older adults. Caregivers’ written
qualitative comments were also analyzed to look for references to personal health in relation to caregiving, perhaps aiding to further explain physical and emotional health. The specific research questions were: 1. Does self-rated health improve when caregivers use ADS? 2. Are changes in self-rated health greater for caregivers using ADS (ADS) than for those not using ADS (non-ADS)?

4.1.1 Subjects

Inclusion criteria for participation in this study included: care recipients were 60 years of age or older; caregivers were 30 years of age or older, self-identified as the primary, informal (unpaid) caregiver of the older adult, had not previously used ADS, were aware of ADS as caregiver support option for which financial assistance is available, and could speak and write in English; and caregivers and care recipients lived in the same home.

Caregiver subjects were enrolled into the study over a 15-month period in the metropolitan Columbus, Ohio area between July of 2010 and September of 2011, with final subjects completing the study in November of 2011. The treatment group comprised informal (unpaid), primary caregivers who were enrolling their older adult care recipients into ADS in Franklin and Delaware Counties; the control group comprised informal, primary caregivers not using this service.

4.1.2 Procedures

One large adult day health services agency operating five centers throughout the metropolitan Columbus, Ohio area was the source for ADS caregivers. This agency has
provided a combination of medical and social ADS for over two decades. Caregivers who were seeking to enroll an older loved one into ADS were provided with study recruitment materials by ADS staff at the five centers. ADS caregivers who gave permission for their contact information to be shared were contacted for recruitment into the study. ADS caregivers could also contact the primary researcher directly if interested in participation. Potential caregiver subjects were called within 48 hours for screening and recruitment into the study in order to capture baseline information prior to the first day of ADS use. In a few cases, multiple contact attempts were necessary to reach the caregiver.

Caregivers who were not seeking use of adult day services were recruited through direct outreach with service organizations in the Columbus, Ohio area. Outreach included the distribution of recruitment flyers to churches, caregiver groups, the Central Ohio Alzheimer’s Association, and senior centers. Word-of-mouth recruitment was also perpetuated. Interested individuals contacted the primary author to inquire about study participation and were enrolled if they met the study eligibility criteria. During recruitment calls, all non-ADS caregivers indicated awareness of adult day services as a care option for which funding assistance might be available (but had opted not to pursue use of ADS).

Eligible caregivers were immediately sent a packet that included survey materials, consent forms, and a stamped, addressed return envelope for collection of baseline data. After receipt of completed materials, a copy of consent materials was
returned to the caregivers for their records. Duplicate (blank) survey materials were sent for return at three months after enrollment. Caregivers were asked to return documents as soon as possible and no later than a specified date ten days from projected receipt of the packet. Reminder calls were made when the return date passed. Attempts to determine reason for non-response were made in all cases. At both data collection points, caregivers who returned completed study information received a ten dollar gift card of their choice. After receipt of all time two data from ADS caregivers, ADS center administrative records were reviewed for collection of attendance data, including dates and hours of service use. Some questions (about caregiver mental health diagnoses, presence of care recipient memory and/or behavioral problems and how much these bothered caregivers) were added a baseline and time two data had been collected for several participants. Those caregivers received a third mailing and those who provided this information received a ten dollar gift card.

4.1.3 Measures

Data gathered at baseline and three months later to describe participating caregivers included: age, gender, race, marital status, relationship to care recipient, work status (part time, full time, or not working) and number of hours worked weekly if applicable, and length of time providing care (in months). Caregivers were also asked to indicate all types of caregiving assistance accepted (home health care, hospice, facility respite, help from friends and/or family, companion services, and other), and number of
associated hours of assistance received weekly, if applicable, over the previous three months.

Information requested about care recipients included age, gender, presence of memory loss and/or behavioral problems, and if their respective care recipients exhibited memory impairment and/or behavioral problems (yes/no). If applicable, caregivers were asked to indicate how bothered they personally felt by these reported memory and/or behavioral problems (not at all, a little, quite a bit, very much). The amount of hands-on assistance care recipients required daily was measured by the Barthel Index (BI). The BI assesses need for assistance with activities of daily living (ADL) in ten areas: eating, bathing, grooming, dressing, bowel functioning, urinary functioning, toileting use, transferring, getting around (mobility), and using stairs. The BI has been widely used for over two decades in its current format, from which aggregate scores range from zero to 100 points, with lower scores correlating with lower functional status. The BI has been shown to consistently meet recommended criteria for intra-rater reproducibility, validity, and internal consistency reliability (Hobart et al., 2001).

Caregivers were asked to complete the Zarit Burden Inventory (ZBI) at baseline and again three months later. The ZBI is the most widely-used instrument for measuring subjective caregiver burden, measuring potential caregiver stressors in physical, economic, psychological, and relational areas through 22 questions resulting in an aggregate score that ranges between zero and 88 points, with higher scores correlating
with higher burden. Answers from one of the ZBI questions, “Do you feel your health has suffered because of your involvement with your relative?” were also used to examine changes in caregivers’ self-rated health. ZBI items are scored on a zero to four point Likert scale of with zero representing ‘never’ and four representing ‘always.’

Caregivers were asked to indicate, “In general, would you say your health is...” by choosing one of five descriptions: excellent, very good, good, fair, or poor. This particular SRH question and rating scale is used by the Stanford Patient Education Research Center (Loring, Ritter, Gonzalez, Laurent & Lynch, 1996) and in the 36-item Short-Form Health Survey (SF-36) (Ware, 1995). In the SF-36, this question has exhibited good test-retest reliability and internal consistency reliability (Andresen, Bowley, Rothenberg, Panzer & Katz, 1996). Variations of this question and similar answers are commonly found in the literature. Caregivers were asked about the presence of personal mental health issues (such as depression and anxiety) with dichotomous yes/no answers and self-reported medications taken (for comparison as needed in cases for which caregivers denied presence of anxiety and/or depression that might contribute to burden, but for which a medication list provided conflicting information).

Selected caregiver health questions from the Short-Form 36 (SF-36) were used to compare the two groups with regard to subjective mental and physical health. The SF-36 was designed for use in general population surveys, clinical practice, healthcare research, and health policy evaluations; it can be self-administered by those 14 years of
age and older or can be administered by a trained investigator by telephone or in person (Ware & Sherbourne, 1992). It has high reliability and validity with various populations (Eshaghi, Ramezani, Shahsanaee, & Pooya, 2006; Jenkinson, Wright, & Coulter, 1994; Taft, Karlsson, & Sullivan, 2001) when used in its entirety.

Two questions from the SF-36 asked caregivers to describe the degree to which they perceived their personal health affected their functioning in daily activities (yes, limited a lot; yes, limited a little; no, not limited at all). Four of the chosen questions asked for caregivers’ perceptions of how much, over the previous two weeks, they had accomplished “less than you would like” and were “limited in the kind of work or other activities” in relation to physical and emotional health. Five Likert-scale choices were provided for each question, with responses ranging from “not at all” to “extremely.” SF-36 aggregate scores have been shown to consistently distinguish between well and sick individuals (Garratt, Ruta, Abdalla, Buckingham, & Russell, 1993).

In order to better understand the experiences of primary caregivers of older adults living in the same home and to complement the quantitative data, qualitative feedback was solicited. Two open-ended statements were developed for this study and asked of both groups of caregivers, “Please share some positive aspects of your overall caregiving experience” and “Please share some frustrating aspects of your overall caregiving experience.” Caregivers were purposely not guided to provide information about any specific area, such as personal health.
4.1.4 Analysis

All quantitative data were analyzed using PASW (SPSS) v. 18. Level of significance for all analyses was set at the .05 level. Descriptive statistics were first computed in order to review sample characteristics of the two caregiver groups and to note potential baseline differences. Chi squares or t-tests for independent samples were computed for selected comparison variables in order to identify significant baseline differences.

To compare caregiver responses for the SRH question at baseline and again three months later, four of the SF-36 questions about physical and emotional health, and the ZBI question about caregiver health, t-tests for independent samples were run. Chi square tests were run for the two SF-36 questions with three response choices to examine within-group changes between baseline and time two.

In order to better understand the experiences of primary caregivers of older adults living in the same home and to complement the quantitative data, the qualitative data were also reviewed. Written caregiver responses requested from open-ended statements were extracted and compiled verbatim by question, separated by caregiver group. Informed by grounded theory, examination of this qualitative data was completed through a multi-step process, starting with thematic analysis. In order to establish a preliminary coding theme, a PhD-trained researcher and a PhD candidate separately reviewed all lines of text, using open-coding to extract emerging concepts (Marshall & Rossman, 1999). This examination of the data was maintained within the
boundaries of each question asked and within each question by caregiver group (ADS or non-ADS caregivers) in order to compare and contrast results. Multiple coding was used by both researchers warranted as themes became evident. Codes were then grouped into similar concepts. The researchers met at length on two occasions to discuss results, reconcile limited differences noted in coding and concepts, and to agree on a final data categories (themes).

4.2 Results

Fifty-two (52) caregivers met eligibility criteria and were recruited into this study. The ADS (treatment) group comprised 33 caregivers of older adults newly enrolling their care recipient into an ADS center; 27 of these participants were females, and 6 were males. Three of these caregivers (one Caucasian female and two Black females) did not actually utilize ADS services because of care recipients’ refusal. Therefore, having never used ADS, these three caregivers met the criteria for the control group, and were analyzed as controls. In total, 30 caregivers were analyzed within the ADS/treatment group – 6 males and 24 females. A total of 22 females comprised the non-ADS control group; no non-ADS males met the eligibility criteria for the study.

All 52 recruited caregivers completed and returned baseline materials. For the time two data request, 27 of the 30 ADS caregivers (90%) and 20 of the 22 non-ADS caregivers (90.9%) completed and returned survey materials. The addendum data added into the study once it was in progress were provided by 24 of the 30 ADS caregivers (80%) and 18 of the 22 non-ADS caregivers (81.8%).
4.2.1 Sample Description

Demographic characteristics and baseline measures for the caregivers and care recipients were similar in the two groups. Sample characteristics were previously presented on Tables 3.1 and 3.2 in Chapter 3 of this document. No statistically significant differences were noted with regard to relationship of caregivers to care recipients; average caregiver age; length of time spent providing care (months); age of care recipients; marital status and race of caregivers; care recipient gender, age, or amount of assistance needed daily as measured by the BI (at both data collection points); or caregiver hours worked weekly (at both data collection points). Although ADS caregivers reported a mean burden score (ZBI) that was about 7 points higher than non-ADS caregivers at baseline, ranges were wide and this difference was not statistically significant. Caregivers in both groups utilized assistance with caregiving from a variety of sources at both data collection points, for a range of hours weekly. Similar proportions of ADS and non-ADS caregivers denied the presence of personal mental health issues such as depression or anxiety (and that was not statistically significant on analysis).

As noted in Chapter 3, all of the responding ADS caregivers and over 95% of non-ADS caregivers indicated that their care recipients exhibited memory loss. Caregivers in the two groups were similar in proportions for being bothered by this memory loss “quite a bit” and “very much.” However, at baseline, more ADS caregivers (n=19/21; 90.5%) reported concurrent behavioral problems than non-ADS caregivers (n=10/21;
47.6%), a statistically significant difference on chi-square analysis using Fisher’s Exact Test (p=.006). Additionally, ADS caregivers reported being more bothered by these behaviors at baseline than did non-ADS caregivers as evidenced by a statistically significant difference on chi-square analysis using Fisher’s Exact Test (p=.031). At time two, 18 of 20 ADS caregivers (90%) and 9 of 15 non-ADS caregivers (60%) whose care recipient exhibited memory loss reported concomitant behavioral problems. This difference was approaching statistical significance on chi-square analysis using Fisher’s Exact Test (p=.051). ADS caregivers continued to report being more bothered by these behaviors at time two. Chi-square analysis using Fisher’s Exact Test was significant at p=.038.

ADS caregivers used a mean of 25.93 ± 14.26 ADS days or 186.65 ± 117.61 ADS hours during the study period, with 19 of the 30 ADS caregivers (63.3%) met the “dose” suggested by Zarit et al (1998). Additional analyses were run for the 63.3% of caregivers who met Zarit et al.’s criteria for sufficient ADS use. See Table XXX in Chapter 3 for this data.

4.2.2 Caregiver Self-Reported Health

Summaries of caregiver responses to subjective, health-related questions are presented in Table 4.1. At baseline response to the SRH question, ADS caregivers reported lower SRH than did non-ADS caregivers; this difference was not statistically significant at the .05 level but was approaching significance. Analysis of time two data revealed that the SRH of ADS caregivers had worsened slightly, while the SRH of non-
ADS caregivers had remained stable. This resulted in a statistically significant difference in SRH between the two groups by the end of the study (p=.027). No significant within-group changes occurred between baseline and time two for either group in relation to the health-related caregiver data gathered from SRH, SF-36, or ZBI questions (Table 4.2).

<table>
<thead>
<tr>
<th>Do you feel your health has suffered because of your involvement with your relative?</th>
<th>ADS Caregivers T1 (n=30)</th>
<th>ADS Caregivers T2 (n=27)</th>
<th>non-ADS Caregivers T1 (n=22)</th>
<th>non-ADS Caregivers T2(n=19)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>4(13.3)</td>
<td>4(14.8)</td>
<td>7(31.8)</td>
<td>7(36.8)</td>
</tr>
<tr>
<td>Rarely</td>
<td>10(33.3)</td>
<td>7(25.9)</td>
<td>2(9.0)</td>
<td>4(21.1)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>12(40.0)</td>
<td>12(44.4)</td>
<td>10(45.5)</td>
<td>6(31.6)</td>
</tr>
<tr>
<td>Quite frequently</td>
<td>3(10.0)</td>
<td>2(7.4)</td>
<td>2(9.0)</td>
<td>1(5.3)</td>
</tr>
<tr>
<td>Nearly always</td>
<td>1(3.3)</td>
<td>2(7.4)</td>
<td>1(4.5)</td>
<td>1(5.3)</td>
</tr>
</tbody>
</table>

In general, would you say your health is... (n, %)*

<table>
<thead>
<tr>
<th>In general, would you say your health is... (n, %)*</th>
<th>ADS Caregivers T1 (n=30)</th>
<th>ADS Caregivers T2 (n=27)</th>
<th>non-ADS Caregivers T1 (n=22)</th>
<th>non-ADS Caregivers T2(n=19)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>4(13.3)</td>
<td>3(11.1)</td>
<td>6(27.2)</td>
<td>4(21.1)</td>
</tr>
<tr>
<td>Very good</td>
<td>10(33.3)</td>
<td>5(18.5)</td>
<td>8(36.4)</td>
<td>9(47.4)</td>
</tr>
<tr>
<td>Good</td>
<td>11(36.7)</td>
<td>11(40.7)</td>
<td>7(31.8)</td>
<td>1(5.3)</td>
</tr>
<tr>
<td>Fair</td>
<td>3(10.0)</td>
<td>4(14.8)</td>
<td>1(4.5)</td>
<td>2(10.6)</td>
</tr>
<tr>
<td>Poor</td>
<td>2(6.67)</td>
<td>1(3.71)</td>
<td>0(0)</td>
<td>0(0)</td>
</tr>
</tbody>
</table>

Table 4.1  Caregiver Self-Rated Health Comparisons

*T1=baseline, T2=after 3 months
*p=.027 between groups at T2
**Table 4.2 SF-36/ Activity Limitations**

For non-ADS caregivers, a change trending towards significance was noted between baseline and time two responses for the ZBI question, “Do you feel your health has suffered because of your involvement with your relative?” At baseline and again at
time two, just 13.3% of ADS caregivers answered “never” to this question, as compared to 31.82% of non-ADS caregivers (see Table. 4.2).

No significant correlations were found between change scores for ADS caregivers’ subjective health data and intensity of use of ADS (both in days of use and total hours used weekly). This finding is not surprising as 20% of ADS caregivers reported slightly improved health and 10% of ADS caregivers reported decreased self-rated health between baseline and time two data collection, while 70% reported no change at all. Ad hoc correlational analyses between changes in perception of health and caregiver age, needs of care recipients (BI), relationship of caregiver to care recipient, and for differences between male and female caregivers) were not significant.

4.2.3 Qualitative Commentary

We requested and reviewed comments from the ADS and non-ADS caregivers to describe their perceptions of the caregiving experience and to further investigate their perceptions of health. The two researchers who reviewed the written responses reached full agreement on themes based on their iterative review of caregiver written comments (Glaser, 1992).

Positive aspects of caregiving

Caregivers in both groups provided ample and similar feedback in response to “Please share some positive aspects of your overall caregiving experience.” Both groups clearly indicated that a positive result from the provision of care to a loved one was the perceived benefits to the care recipient, both in terms of the quality of care provided
and for the positive impact on the care recipient’s *quality of life*. ADS caregiver comments included, “I feel if I haven’t taken care of them (sic) they wouldn’t be alive this long,” and “I am giving my mom the care she needs and wants in her old age.” Non-ADS caregivers’ comments were similar in portraying the belief that their provision of care (in the home setting) was best for the care recipient’s quality of life and quality of care, including, “I know home care is the best (better environment, food, care, more personal care, more one-on-one quality care, cleaner, home environment, parent/person cleaner, more control on her care (sic). All better!”

A second positive theme for both caregiver groups was that of *self-development* as a result of the caregiving experience. Three trends within this over-arching theme were noted for both groups: *skill development, relationship development, and psychosocial-spiritual development*. Examples of skill development from both groups included narrative about having learned “how to do business and financial matters” and gathering healthcare knowledge, including “I have learned a lot of valuable information on everything from drug interactions to wound care.” Both groups clearly accentuated a theme of *relationship development* – of feeling needed and spending more time with their loved one, making him/her happy, and receiving positive reinforcement. Comments such as, “Wants me to be with her. Sits beside me in the evenings at home. Counts on me to help her. Likes to cuddle” and “I am blessed to spend more time with my mother than I ordinarily would” were equally common in both caregiver narratives.
Finally, comments labeled here as *psychosocial-spiritual development* were evident also as positive aspects of caregiving noted by both groups. Caregivers provided multiple similar remarks such as “I’ve learned to love unconditionally and pray a lot more,” “I’ve learned a whole new dimension of love,” and “I know when my mother leaves this world, I can raise my head up high and know that I did everything I could with God’s help.” Two final examples that help to clarify this sub-category of psychosocial-spiritual development include, “I am learning patience” and “Caregiving enables me to shift from my own concerns and focus on her needs, pray with her, share the Lord’s love with her.” None of the caregivers made any comments about personal health.

**Negative aspects of caregiving**

Narrative about perceived frustrating aspects of the caregiving experience overlapped in two of three themes for both caregiver groups. ADS and non-ADS caregivers alike provided feedback that emerged into two negative themes: *lack of personal balance,* and *losses.* Within *lack of balance,* both groups indicated challenges related to multiple responsibilities such as time to get everything done, lack of family help, feeling like the sole, responsible party. ADS caregiver comments included, “I do it all. Family members do not help,” “I do not have much me time. I have full responsibility of caring for D., our home, finances,” “Always on duty,” “Missing work, sleep, and just worry that I am doing the right thing...” and “... I miss the interaction between friends.” Comments from non-ADS caregivers were comparable, including,
“Lack of control over time. Abandonment of siblings once they figure out (I am) good at caregiving,” and “It is very difficult to be 100% responsible for everything in our own lives. I have no help and often feel overwhelmed trying to keep up.” These frustrations about lack of balance were clearly evidenced in both groups of caregivers.

With regard to losses noted in both caregiver groups, comments ranged from dealing practically with the loss of the loved ones’ physical and/or cognitive abilities, to dealing emotionally with these losses and the subsequent changes in the caregivers’ lives with feelings of guilt, sadness, and loneliness. One of the ADS caregiver’s comments succinctly aids in summing this category up for both groups, “Loss of a good friend. My wife.” No explicit comments related to health were made by any caregivers within this area of ‘losses.’

A third theme from caregiver comments about negative aspects of caregiving emerged strongly among the ADS comments but much less so in the non-ADS narrative. ADS caregivers more strongly emphasized the frustrations associated with behavioral issues exhibited by their loved ones. Examples provided included frustration related to care refusal, care recipient “being mean,” needing to repeat information, and dealing with behaviors perceived as rude by others. While the non-ADS caregivers noted a couple of behavior-related frustrations as well, the saturation of behavior-related comments much stronger for ADS caregivers. Again, comments literal in relation to caregiver health were not made by caregivers in either group.
4.3 Discussion

Caregivers in this study provided a wide range of answers to most questions, perhaps contributing to a lack of significant findings in some cases due to large standard deviations. The caregivers using ADS were somewhat different from non-ADS users. On average, ADS caregivers were five years older, and had been giving care for about seven months longer than the non-ADS caregivers. The ADS caregivers had slightly worse self-rated health at baseline and significantly worse SRH at the end of the study. Finally, to a significant degree, ADS caregivers reported higher levels of behavioral problems among their care recipients, and subsequently reported being more bothered by behavioral problems than the non-ADS caregivers who also reported dealing with this type of challenge. These noted differences “seem” logical when considering why some caregivers might accept use of ADS while others do not.

The literature is largely supportive of this speculation. For example, the effect of caregiving on health seems to increase with time. Of the 1,397 caregivers in 2009 Caregiving in the U.S. report, 23% of those who had provided care for five years or more reported fair or poor health as compared to 15% of those who had not provided care for this long. Authors noted that, among all caregivers in this national study regardless of length of time spent caregiving, using the 5-point SRH scale also used in the current study, 16% described their health as fair or poor on average. In the current study, ADS caregivers had given care for just seven months longer than non-ADS caregivers on average – well under the five years noted in the national study. However, 16.7% of ADS
caregivers reported poor or fair health (a proportion similar to the national study result) compared to less than 5% of the non-ADS caregivers. Additionally in the current study, in response to the ZBI question, “Do you feel your health has suffered because of your involvement with your relative?” 13.3% of the ADS caregivers reported “never” as compared to a larger 31.82% of the non-ADS caregivers.

All but one of the 52 caregivers in this study reported caring for a loved one with memory loss. Caregivers of those with dementia report lower subjective health than non-dementia caregivers (Teel & Press, 1999). According to the 2009 Caregiving in the U.S. report, 23% of caregivers for those with Alzheimer’s Disease/dementia reported their health as worse after becoming a caregiver, as compared to 13% of caregivers for those without dementia. In the current study, 98% of caregivers reported that care recipients exhibited memory loss. With caregivers in both groups providing care to individuals with dementia, we would not expect to note 31.82% of one group and 13.3% of the other to report “never” for how often caregiving has affected health. Even though both groups report caring for those with memory loss, the ADS caregivers reported more effect on health as a result of caregiving.

However, ADS caregivers reported dealing with more behavioral problems and reported being more bothered by the behaviors than were the non-ADS caregivers who were also taking care of loved ones with challenging behaviors. This difference is worthy of speculation with regard to the previously noted differences in SRH. In their written qualitative comments, ADS caregivers focused on behavioral challenges when
discussing frustrating aspects of caregiving. Comments included, “I am constantly making excuses for his rude behavior at home and away” and “I get tired of repeating items to my husband about getting up or coming for meals, getting dressed, or taking charge of eating more because his weight is so low.” Additional comments about behavior included, “Name calling, rude, says nasty things to me” and “When she does not listen to me. She can get like a child, refuse to take meds.”

Previous research has demonstrated that caregivers for loved ones with behavioral problems leads to higher levels of stress (Hooker et al., 2002; Shanks-McElroy & Strobino, 2001). Since years of empirical data has established that caregiving can be stressful and negatively affect health (Connell et al., 2001; Thomessen et al.; Aarsland, Brackhus, & Aksengaard, 2002; Markotwitz et al.), lower ratings of personal health by caregivers managing frustrating behaviors seems logical. One ADS study found that consistent use of ADS over time was associated with a reduction in behavior-related problems (Femia, Zarit, Stephens, & Greene, 2007).

All caregivers were asked to list the problem behaviors observed and a large variety of behaviors were listed without clear themes overall. However, ADS caregivers noted care recipients’ sleep disturbances a handful of times, while non-ADS caregivers did not mention sleep at all. ADS caregiver comments included, “She gets up in the middle of the night insisting she has somewhere to go. Gets angry and talks to people who aren’t there or people who has (sic) passed away,” “angry, irritability (sic), not
sleeping at night” and “Sleeps too much, lacks interests, lost initiative, needs coaxing for many tasks...”

A recent study of ADS use by those with dementia has found that, after a day of mental stimulation and structured activity such as that provided at an ADS center, sleep of the care recipient improves (Zarit et al., 2011). This information may be useful in discussion with caregivers pondering the use of ADS. It is important to note, however, that an adjustment period is likely necessary in most cases before this or other positive outcomes may occur, which again supports the suggestion to carefully craft programs (and the staff within them) to “win over” both caregivers and care recipients. Unfortunately, adjustment challenges often lead to disenrollment rather than eventual adjustment. Disenrollment after short ADS stays has been noted previously in the literature (Cox, 1997; Dabelko, 2004; Zarit et al, 1998; Zarit et al, 1999).Ironically, in relation to the current study, a common reason for disenrollment from ADS is an increase in behavioral problems among participants (Metlife Mature Market Institute, 2010).

Caregivers in both groups did not specifically list personal health concerns or use the word “health” in any of the qualitative commentary. Both groups did provide considerable positive comments about their overall caregiving experiences. The positive effects perceived may serve to mediate some of the negative effects on physical and emotional health and so were included here. Previous research has noted that positive factors associated with caregiving (for example, satisfaction from giving care
and social support) can mediate the stresses of caring (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Pearlin, Mullan, Semple, & Skaff, 1990).

4.4 Limitations

The generalizability of this study is limited. The sample size was small (52), limiting the statistical power available to detect differences between the two groups. The number of subjects in each group was not equal (30 vs. 22). The small number of male subjects who participated (6) were entirely contained in the ADS group. Self-selection bias is of concern since all of the participating caregivers volunteered to participate in the study. For those ADS caregivers who were newly enrolling a care recipient into ADS, some agreed to be contacted about the study and others did not, further adding to selection bias concerns with those for whom data was not captured. As with most studies, it difficult to measure for all potential confounders; for example, we did not ask about other relationship stressors such as caring for children, or about educational level, personal coping styles, or financial concerns. Some questions on the caregiver survey were developed for this study, so reliability and validity of these measures have not been established over time. Over 98% of the caregivers in this study reported caring for someone with memory loss. Although the prevalence and incidence of Alzheimer’s Disease and related dementias is growing as the population ages, this study proportion is far greater than what would be expected as a representative sample. Qualitative data were collected at one point in time and caregivers could not be reached for probing to verify findings. Finally, ADS utilization
rates were lower than optimal; 37% of ADS caregivers did not use the recommended dose as suggested by a landmark study (Zarit et al, 1998).

In the present study, definitions or examples of “problems with memory loss” and “behaviors that you find challenging or difficult to manage” were not defined for caregivers; therefore, it is possible that interpretation of one or both may have differed among the caregivers. For example, one caregiver may have categorized repetitive comments (which are common among those with memory loss) as a problem with memory while another may have considered this issue to be a challenging behavior.

4.5 Conclusions

Self-rated health of ADS caregivers was lower than non-ADS caregivers at baseline (nearing statistical significance). By time two, slight shifts in caregivers SRH resulted in a statistically significant difference in perceived health; even after utilization of ADS, caregivers assessed their SRH as poorer than non-ADS caregivers. Among the caregivers in this sample, caregivers who chose to utilize ADS were also more likely to report caring for someone with behavioral problems, and were more bothered by those behaviors than were non-ADS caregivers who also noted behavioral problems. The association of this trend regarding behavioral challenges with caregiver SRH is suggested for further study. Given the vast literature about the effect of caregiving on health, it was surprising that no caregivers discussed personal health directly in the many written comments provided. However, positive comments about the caregiving experience may have offset negative experiences – including with relation to SRH – in this sample;
more direct investigation into this area qualitatively may provide useful information about caregivers’ SRH.
Chapter 5: Research Findings and Future Directions

The objective of this research was to investigate characteristics, perceptions, and outcomes related to the use of adult day health services (ADS) among primary, informal caregivers of older adults. To accomplish this, a review of the literature about caregivers, adult day health services, and older adults was completed; this information was used to inform further investigation using one group of caregivers newly enrolling a loved one into ADS (ADS caregivers) and a second group of caregivers who were aware of, but not utilizing, this service option (non-ADS caregivers) for three months. That all caregivers were aware of ADS and had made a decision about service use provided a unique comparison not otherwise located in the literature. Comparative baseline analyses, quasi-experimental investigation over time, and review of qualitative data from these caregivers aided with addressing research objectives.

5.1 Summary of Findings

The background and literature review for this research emphasized that, in the coming decades, the population of older adults in the United States will grow significantly, requiring a concomitant rise in the number of available caregivers. Additionally, increases in affordable, effective community-based services will be crucial.
ADS offer caregivers respite or work time for extended hours per daytime visit and multiple days weekly. ADS also allows the care recipient to live at home while receiving care and socialization at ADS. ADS is not as widely-known or understood as are assisted living or nursing home care, and, even when caregivers are aware of ADS, they may be reticent to utilize it. The contribution this service makes to the healthcare community has received increased attention in recent years, but additional study is warranted. Healthcare providers may be able to better guide caregivers to this or other services with a heightened understanding of caregiver characteristics associated with successful ADS outcomes.

In chapter two, comparative analyses revealed several significantly different baseline characteristics between the caregivers who were selecting to newly enroll a loved one into ADS and those who were not. ADS caregivers reported poorer self-rated health, felt considerably more anger when around their care recipients, and perceived that their care recipients expected them to be the only ones to provide care. All but one responding caregiver reported the presence of memory loss in care recipients; however, the ADS caregivers were significantly more bothered by this memory loss than were non-ADS caregivers. A higher number of ADS caregivers reported behavioral problems among their care recipients.

In chapter three, change in caregiver burden was examined after three months of use of ADS (and acceptance of bathing and transportation services, as applicable). For this study, however, it is important to note that three of the caregivers who were
originally seeking use of ADS were now moved into the non-ADS group because their care recipients refused to attend ADS after enrollment, and these caregivers acquiesced. These caregivers never actually utilized the service. The move of these three caregivers -- from intention to utilize ADS to actual use of ADS -- changed the baseline dynamics a bit. Burden changed less than one point for both groups with this shift. However, caregivers’ frustration with memory loss exhibited by care recipients was no longer significantly different between the two groups in the second study; the ADS caregivers as a whole now reported being significantly more bothered by behaviors exhibited by their care recipients. These three caregivers were more bothered by memory loss and less bothered by behaviors, shifting the summary of the situation. Qualitative comments by the ADS caregivers also clearly emphasized frustrations associated with care recipients’ behaviors, while this was not the case with the comparison caregivers.

Other ADS caregivers noted resistance to ADS use by care recipients, but still utilized the service. Whether continued use was a challenge based on additional care recipient resistance is not known (as this data were not collected).

Also noteworthy is that self-rated health (SRH) of the original group of ADS-seeking caregivers was significantly worse than those not seeking use of ADS; the shifting of the three “seekers” who became non-users of ADS altered the SRH differences between the two groups in the second study. SRH was no longer significantly different (although the difference was approaching statistical significance). The three caregivers who were shifted when actual service use was examined had self-
rated health that was worse than the mean of either group at any point (good, fair, good in the first study; fair, fair, fair in the second study). Regardless of this situation, SRH seems to be associated with the decision to use ADS.

At baseline for the second study, the mean caregiver burden of ADS users was higher than the mean burden of non-ADS caregivers; these means decreased minimally over the study period, while mean burden of the non-ADS caregivers rose minimally. No statistically significant difference in burden was found. The variability of scores for reported subjective burden for both groups was great at all study points. Very few ADS caregivers utilized bathing services at the center (many were also receiving home health care assistance at home). The use of ADS and additional supportive services such as bathing and transportation was not associated with reduction in burden over three months, even for those caregivers who utilized the benchmark attendance dose suggested by Zarit and colleagues (1998).

In chapter four, additional investigation of measures of self-rated health for all caregivers was completed. At baseline, reported SRH of ADS caregivers was lower (worse) than that of non-ADS caregivers, with a statistical difference that was nearing significance. At the end of the study, this difference was significant; the SRH health of the ADS caregivers had declined slightly, and the SRH of the non-ADS caregivers had improved slightly. The large majority of caregivers in both groups actually exhibited no changes in SRH at all over three months. It is suspected that improvements in measures such as SRH and caregiver burden may be more positively affected by higher
doses of cooperative use of ADS by care recipients and caregivers over a longer period of time.

Qualitative comments were solicited with regard to both positive and frustrating perceptions of the overall caregiving experience and of the ADS experience, as applicable. Both sets of home-based primary caregivers provided considerable positive comments that highlighted satisfaction at the quality of life and quality of care they were affording to care recipients, and self-development as a result of the caregiving role (in relation to personal skill development, enhanced relationships, and psychosocial-spiritual development). The positive comments far outweighed comments about frustrations from caregiving, perhaps serving to mediate some of the negative aspects of the caregiving experience. The exception was the significant focus on problem behaviors as emphasized by the ADS caregivers. Dealing with losses and lack of balance in life were also noted consistently by both groups of caregivers.

Both the quantitative and qualitative evidence in this study supports continued investigation for adult day health services as a support service to caregivers of older adults at home. Caregivers and care recipients alike are the “customers” in ADS, necessitating improved understanding of the service in relation to user characteristics and outcomes.

5.2 Limitations

The primary limitations of the studies in this report can be attributed to the small overall sample size of subjects recruited from a convenience sample of caregivers.
The number of caregivers in the treatment (ADS) and control (non-ADS) groups were not equal, which can affect the results of t-tests for independent samples, and cells in some chi-square analyses contained fewer than five cases (for which cases Fisher’s Exact Test scores were examined). The gender distribution was also different between the two groups (six males were entirely contained within the treatment group). Self-selection bias of caregivers to participate in the study or not, even if eligible, may have affected study results. The results are not generalizable to all caregivers of older adults. The need to shift three caregivers from an ADS-seeking status to non-ADS user status may have altered results (or may have served to highlight areas in need of more in-depth study).

All potential confounders were not accounted for, including other relationship stressors (such as childcare responsibilities), personal coping styles, financial concerns, or educational level. Several questions were developed for this study, so reliability and validity of them have not been established over time. The proportion of responding caregivers who reported that care recipients exhibited memory loss was very large and likely not representative of caregiving situations in the general population.

Caregivers provided many comments in response to open-ended statements; however, circumstances did not allow for cross-checking to verify researchers’ interpretation of this data, or for triangulation of the data. This limits the usefulness of the qualitative data. The utilization rates of ADS were lower than optimal, with approximately one third of caregivers not utilizing the suggested optimal dose.
Analyses of single questions from larger instruments – sometimes without other measures of the variable of interest – are also limitations of this study.

5.3 Future Research

Increased knowledge about the contribution of supportive, community-based services such as ADS is needed in order to best maintain older adults in the community and to support caregivers’ physical and emotional health. As the number of older adults and caregivers grows, the availability of affordable, community-based care options with favorable outcomes for caregivers and care recipients alike will concomitantly grow. In fact, the U.S. Department of Health and Human Services (2006) has allocated ADS as a key community-based service for both of these populations.

Despite limitations, these data provided evidence to support further study of ADS use by caregivers of older adults. Data suggest that some differences may exist between caregivers who are open to utilizing ADS and those who are perhaps less interested for unknown reasons. Enhanced understanding of why some caregivers choose to utilize ADS and others do not would be useful for professionals attempting to direct caregivers to supportive services; when caregivers try services that do not “work” for them, they may be more reticent to then attempt use of other services. Better knowledge of the relationship of caregiver characteristics with successful ADS experiences may limit the trial and error of finding appropriate caregiving supports. In these studies, differences noted between users of ADS and non-users of ADS can inform future ADS studies.
5.3.1 Caregiver Anger and Frustrations with Challenging Care Recipient Behaviors

In these studies, caregivers who were initially seeking use of ADS reported feeling more angry when around their care recipients and also perceived that care recipients expected them alone to provide care (even when others were willing and/or available, according to some qualitative caregiver comments). The role of anger and perception of being solely depended upon by care recipients may be key characteristics for healthcare professionals to screen for when attempting to direct caregivers to supportive care options.

Other studies have also noted caregiver feelings of anger toward care recipients (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Williamson, Shaffer, & Schulz, 1998; Zarit et al, 1998). Previous research has also suggested that anger is more prevalent among caregivers of those with behavioral problems (Kramer, Gibson, & Teri, 1992). According to the International Psychogeriatric Association (2005), an estimated 83% of individuals with memory problems from dementia also exhibit behavioral problems, so associated anger may also be a widespread issue. Anger has not been a focus of study with relation to ADS caregivers. The prevalence of dementia will rise in the coming years, and behavioral challenges will follow in many cases. Additional research is suggested in this area.

5.3.2 Caregiver Self-Rated Health

The proportion of ADS caregivers in this study who reported fair or poor health was quite similar to national caregiver data (Caregiving in the U.S., 2009); however, the
caregivers not using ADS reported fair or poor health well below this national benchmark. Additionally, caregiver answers to the ZBI question, “Do you feel your health has suffered because of your involvement with your relative?” revealed that ADS caregivers were far less likely to answer “never” as compared to non-ADS caregivers. Subjective ratings of caregiver health have been shown as good predictors of objective health outcomes – including mortality – (Burstrom & Fredlund, 2001; Grant, Piotrowski & Chappell, 1995; Idler & Benyamini, 1997; Ren, Skinner, Lee, & Kazis, 1999; Schulz & Beach, 1999). Additionally, for those caring for someone at home, the use of assistance (in the form of a family member, friend, or community resources) has been associated with improved caregiver health (Danhauer, McCann, Gilley, Beckett, Beinias, & Evans, 2004). That ADS caregivers report poorer SRH, which is associated with poorer future health (and associated costs), and that use of ADS may serve to improve SRH if used over time suggests that further study in this area is merited.

5.3.3 Qualitative Inquiry

Finally, qualitative studies (or mixed-mode inquiries) that investigate caregiver characteristics and experiences in relation to ADS use may provide additional information with regard to caregiver anger, frustration with dementia-related behaviors, and self-rated health. In the current study, caregiver commentary supported quantitative findings with regard to voiced frustrations about behavioral challenges. Investigation of the interrelationship of this feeling and other reported frustrations (lack
of balance, dealing of losses) with ADS may provide useful information. Examination of these feelings in relation to SRH is also suggested.

Additionally, caregivers provided considerable written commentary about positive perceptions of their caregiving experience. They noted that taking on the role of caregiver certainly led to an improved quality of care and quality of life for their love ones; a sense of pride was either stated or implied widely. Many of them also noted that their relationships with these loved ones, spiritual development, and presence of skills not previously held were enhanced because of the caregiving role. A theoretical model of these findings can be viewed in Figure 5.1. More rigorous inquiry and follow up to assess caregivers’ positive outcomes of the caregiving experience are suggested.

5.3.4 General Suggestions

ADS caregivers in this study worked more than did the comparison group of caregivers. While this difference was not statistically significant and work also was not emphasized by caregivers in qualitative comments, outcomes of ADS use for working caregivers is an area of further suggested study. Demographics of a changing population suggest that more caregivers will be working in future years. Proactive knowledge versus reactive research is necessary.

In the current study, caregiver subjects were recruited from one parent ADS organization, which is an inherently positive situation; basic structure of services offered, staffing arrangements, and mission are similar among all centers. This allows for some assumption of similarities among caregiver and care recipient experiences at
the centers. However, other characteristics of each center – and in centers across the nation – surely varied in terms of staff personalities, strengths, and weaknesses; and other qualitative program elements such as layout of space and activities offered (sometimes based on staff talents – such as piano playing – and preferences—such as arts and crafts). None of the data in the current study was analyzed with regard to caregiver outcomes by center utilized. However, services offered, and the staff providing these services are surely important in retaining and pleasing caregivers and care recipients alike; therefore, further study of outcomes by staff and center characteristics is suggested.

Caregivers did note a few frustrating aspects of ADS in a few cases, related to activity programming for the care recipient at ADS, to care recipients’ perceptions of being less impaired than others at ADS, and about transportation. Examples of comments include, “He so dislikes being with people he thinks are physically and mentally worse than he that I find it difficult to take him to the program,” At this time she is more active than the others. It is hard to keep her busy, doesn’t want to just sit and watch others sleep,” and “Only trouble (is) by (transportation provider), some time can’t be on time (sic).” Centers should maintain a variety of activity programs that meet different functional and interest levels of care recipients; if a care recipient does not like the program and/or does not feel a sense of belonging with others, s/he may refuse to attend, thereby affecting the caregiver’s experience as well. Anecdotally, in the ADS industry both caregivers and care recipients are considered ADS customers. As the
populations of older adults and caregivers continues to grow, community-based care options such as ADS may be in increased demand, and should be made to appeal to as many individuals as possible.

Even when caregivers are aware of ADS and financial assistance is widely available, they may not utilize the service. In this sample, applicable caregivers noted the decision to not use the service after enrollment was largely based on care recipient refusal. This is a common anecdotal report in the ADS industry. Consideration of options for trying to make ADS more attractive to care recipients and caregivers alike is suggested.

Finally, one challenge in ADS research is the ability to recruit large numbers of subjects utilizing the service with optimal frequency and duration. Prospective, longitudinal studies of the service and outcomes for caregivers and care recipients alike are sorely needed. Study of multiple interrelationships of variables in these populations in these populations is challenging but necessary to best inform future care.

Advanced knowledge of positive effects of the service can also provide support for policy changes for increased ADS use in lieu of more expensive long term care placement. Guided practice and policy that lead to adequate care reimbursement as well as exceptional services can make adult day health services a beneficial option for care recipients and caregivers alike.

5.4 Conclusion

Since 2002, the number of individuals using ADS has doubled across the nation
(Metlife Mature Market Institute, 2010). As the need for more community-based services continues to rise in order to keep up with the concomitantly rising number of older adults and their caregivers, ADS use is expected to grow. In order for ADS to best attract and retain consumers while also facilitating positive support outcomes, considerable additional study is needed.

The current study concluded that caregivers who pursue use of ADS may feel more anger towards their care recipients; may be more bothered by care recipients’ memory loss/behaviors; and may have poorer self-rated health. This information may be useful for professionals working in the community to guide caregivers to supportive care services such as ADS.

Although caregiver burden changes and other measures were not significantly improved after use of ADS in this study, ADS remains as an attractive care option as it can allow an older adult to live in the community at home rather than in an institutional setting. Care recipients have widely noted a preference for non-institutionalization. At the same time, national costs for long-term care have risen, making the more affordable, community-based care options such as ADS more desirable from a policy standpoint. That caregivers can be provided with considerable respite or work hours for up to 11 hours at ADS provides additional support for further use and study of ADS. The availability and affordability of this care option serve as positive outcomes aside from other specific caregiver and care recipient outcomes.
Figure 5.1  Theoretical Caregiver Model: Positive perceptions of caring for older family members at home

- Perceived benefits to care recipients
  - Quality of Life
  - Quality of Care

- Relationship development

- Skill development

- Psychosocial-spiritual development
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Appendix A: Recruitment Flyer
Are You a Caregiver
for a loved one who is 60 years old or older?

If so, please consider participating in a study.
You will complete surveys materials
two times & will receive a $10 gift card
for each completed & returned survey packet.

Please contact Michele at (614) 206-1393 or at
stokes.101@osu.edu for more information.

This study is approved by The Ohio State University IRB #2008B0298

Help us help other caregivers!
Appendix B: Caregiver Survey
**CAREGIVER SURVEY**

**Please provide the following information.**

1. Your First Name: __________________  Study ID. Number: __________________
2. Date of birth: ___________  Gender: (circle one) Male  Female
3. Marital status: □ Married  □ Single  □ Widowed  □ Divorced  □ Separated  □ Other
4. Race/ethnicity: (circle one) Black  Asian  White  American Indian  Hispanic  Other __________
5. E-mail address: __________________

7a. Are you currently employed? Yes  No
7b. If yes, are you employed: (circle one)  Part Time  Full Time
7c. If you are employed, how many hours per week do you work, on average? __________
8. In general, would you say your health is: (circle one)
   Excellent  Very Good  Good  Fair  Poor

9. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
   __________

<table>
<thead>
<tr>
<th>Yes, limited a lot</th>
<th>Yes, limited a little</th>
<th>No, not limited at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

b. Climbing several flights of stairs
   □ □ □

10. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?
   All of the time  Most of the time  Some of the time  A little of the time  None of the time

   a. Accomplished less than you would like
      □ □ □ □ □

   b. Were limited in the kind of work or other activities
      □ □ □ □ □

11. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?
   All of the time  Most of the time  Some of the time  A little of the time  None of the time

   a. Accomplished less than you would like
      □ □ □ □ □

   b. Did work or other activities less carefully than usual
      □ □ □ □ □

12. How long have you been providing care? _______ years ______ months
13. What is the first name of the adult (60+ years old) you care for? __________
14. His/her date of birth: __________
15. His/her gender: (circle one) Male  Female
16. How are you related to the person you give care to? (circle correct answer)
   She is my: husband  wife  father  mother  son  daughter other __________
17. Please indicate which of the following supports you have used to assist you with elder caregiving responsibilities in the last three months. Check all that apply.
   □ Family or friends  □ Hospice care  □ Home care services  □ Facility respite stay
   □ Companion services  □ Other: __________
18. Estimate the amount of time you currently receive assistance with caregiving responsibilities
   □ 0-5 hours per week  □ 6-10 hours per week  □ 11-15 hours per week
   □ 16-20 hours per week  □ 21-25 hours per week  □ 26-30 hours per week
   □ more than 30 hours per week __________
   (Choose one answer)
19. Please place an “X” by the selection in each section that best describes the person you give care to. Base your answers on what this person actually does, not what he/she can do.

<table>
<thead>
<tr>
<th>a. Eating</th>
<th>f. Using Toilet (getting on &amp; off, dressing, wiping)</th>
</tr>
</thead>
<tbody>
<tr>
<td>___ Unable to feed self</td>
<td>___ Needs total assistance</td>
</tr>
<tr>
<td>___ Needs help eating &amp;/or cutting food &amp;/or spreading butter, &amp;/or needs special diet, etc.</td>
<td>___ Needs some help, but can do some things for self</td>
</tr>
<tr>
<td>___ Entirely independent</td>
<td>___ Entirely independent</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>b. Bathing</th>
<th>g. Transfers (bed to chair and back)</th>
</tr>
</thead>
<tbody>
<tr>
<td>___ Needs help of some kind</td>
<td>___ Unable, has no sitting balance</td>
</tr>
<tr>
<td>___ Entirely independent</td>
<td>___ Needs major help (1-2 people, can sit up)</td>
</tr>
<tr>
<td></td>
<td>___ Minor help (verbal or physical)</td>
</tr>
<tr>
<td></td>
<td>___ Independent</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>c. Grooming (washing face, brushing hair, brushing teeth, shaving, etc.)</th>
<th>h. Mobility (getting around) on level surfaces</th>
</tr>
</thead>
<tbody>
<tr>
<td>___ Needs help</td>
<td>___ Dependent for getting around, mobile, not able to get around alone even for short distances (i.e., under 50 yards), needs much help</td>
</tr>
<tr>
<td>___ Entirely independent</td>
<td>___ Uses wheelchair independently</td>
</tr>
<tr>
<td></td>
<td>___ Can walk with help of one person (verbal or physical help) for over 50 yards</td>
</tr>
<tr>
<td></td>
<td>___ Goes around independently (may use any aid, cane, walker, etc.)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>d. Dressing</th>
<th>i. Stairs (Unable to do stairs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>___ Independent</td>
<td>___ Needs help (physical, verbal, cane, etc.)</td>
</tr>
<tr>
<td>___ Entirely independent</td>
<td>___ Entirely independent</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>e. Bowels</th>
<th>j. Bladder (Constantly incontinent/has accidents)</th>
</tr>
</thead>
<tbody>
<tr>
<td>___ Consistently incontinent/has accidents</td>
<td>___ Occasional accident</td>
</tr>
<tr>
<td>___ Occasional accident</td>
<td>___ No accidents/incontinence</td>
</tr>
</tbody>
</table>

Office use only: AAD, notes 

20a. Are you currently diagnosed with depression, anxiety, or any other emotional health diagnoses? (circle one) Yes No (if you circled No, please go to question 14)

b. If you circled yes, are you currently taking medication to treat the diagnoses? (circle one) Yes No (if you circled No, please go to question 14)

c. If you circled Yes, Please list the medications/dosages you are taking for your emotional health diagnoses: 

21a. Does the person for whom you provide care display problems with his or her memory? (circle one) Yes No (if you circled no, please go to question 15)

b. If you circled Yes, please circle the phrase that best describes how you feel this memory impairment affects your stress or burden on average. Not at all A little Quite a bit Very much

22a. Does the person for whom you provide care display behaviors that you find challenging or difficult to manage or deal with? Yes No (if you circled no, please skip question 15b).

b. If you circled Yes, please circle the phrase that best describes how you feel these behaviors affect your stress or burden on average. Not at all A little Quite a bit Very much

c. If you circled Yes, please list the behavior(s): 

Please return this with the other study materials in the postage paid envelope provided. Thank you!
Appendix C: Zarat Burden Inventory
**THE ZARIT BURDEN INTERVIEW**

Please circle the response that best describes how you feel.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you feel that your relative asks for more help than he/she needs?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2. Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<td>3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?</td>
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<td>4. Do you feel embarrassed over your relative’s behaviour?</td>
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<td>5. Do you feel angry when you are around your relative?</td>
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<td>6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?</td>
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<td>7. Are you afraid what the future holds for your relative?</td>
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<td>8. Do you feel your relative is dependent on you?</td>
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<td>9. Do you feel strained when you are around your relative?</td>
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<td>10. Do you feel your health has suffered because of your involvement with your relative?</td>
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<td>11. Do you feel that you don’t have as much privacy as you would like because of your relative?</td>
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<tr>
<td>12. Do you feel that your social life has suffered because you are caring for your relative?</td>
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<td>13. Do you feel uncomfortable about having friends over because of your relative?</td>
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<td>14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?</td>
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<td>15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?</td>
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<td>16. Do you feel that you will be unable to take care of your relative much longer?</td>
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<td>17. Do you feel you have lost control of your life since your relative's illness?</td>
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<td>18. Do you wish you could leave the care of your relative to someone else?</td>
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<td>19. Do you feel uncertain about what to do about your relative?</td>
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<td>20. Do you feel you should be doing more for your relative?</td>
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<td>21. Do you feel you could do a better job in caring for your relative?</td>
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<td>22. Overall, how burdened do you feel in caring for your relative?</td>
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</tbody>
</table>

Total Score (out of 88)

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Interpretation of Score:
0 – 21 little or no burden
21 – 40 mild to moderate burden
41 – 60 moderate to severe burden
61 – 88 severe burden