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THE EFFICACY OF A 6-WEEK EVIDENCE-BASED SUPPORT GROUP FOR CAREGIVERS OF DEMENTIA IN A PRIMARY CARE SETTING

by

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A dissertation submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
in the Department of Psychology
in the College of Sciences
at the University of Central Florida
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ABSTRACT

More than 16 million Americans provide unpaid care for those with Alzheimer's disease and other dementias. Extant literature has well documented the increased risk for physical, emotional, social and financial burden associated with caregiving. While intensive support groups may be well-suited to caregiver needs, they are often difficult to implement given financial, personnel and resource constraints. Thus, the purpose of this study is to examine the efficacy of a theoretically-based, 6-week caregiver support group in a community primary care setting. The group focuses on self-care, behavior management techniques and interdisciplinary caregiver resources. A total of 22 participants completed the active caregiver support group and they were compared to 19 control participants who participated in community caregiver support groups. Participants on average were in their mid-60s, mostly female and Caucasian, and identified as either the care recipient's child or spouse. All participants completed self-report measures related to demographic information, caregiver preparedness (Caregiver Preparedness Scale), caregiver strain (Caregiver Strain Index), caregiver depressive symptoms (CESD-10), and care recipient's neuropsychiatric symptoms (NPI-Q), at baseline and at 6-weeks. Participants in the active caregiver support group also completed a satisfaction survey. Results from two-way mixed ANCOVA analyses revealed a time by group interaction effect for caregiver preparedness, such that caregivers in the active group demonstrated a significant increase in mean caregiver preparedness scores while scores remained invariant for the control group. No significant main effects nor group by time interaction effects were found for caregiver strain, caregiver depressive symptoms and caregiver distress related to neuropsychiatric symptoms. Participants in the active caregiver support group rated being largely satisfied with the group.

Results suggest that this 6-week caregiver support group may be a promising caregiver intervention that can be readily implemented and accessible in primary care clinics. Further research with larger sample sizes is recommended.

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number one cheerleader, always celebrating my successes and continually reminding me of my strengths to conquer life’s challenges.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

CHAPTER 1: INTRODUCTION

The provision of care for older adults with dementia, a life-limiting condition, is a growing public health concern. Caregiving is often a time-consuming, resource-intensive, physically taxing and an emotionally exhausting activity for family members of older adults with dementia. The economic value of informal caregiving has been estimated at 232.1 billion dollars in 2017 (Alzheimer's Association, 2018), and this figure largely reflects cost offset associated with use of skilled long-term residential care, including nursing homes. Approximately 5.7 million Americans were estimated to have Alzheimer’s disease in 2018, with approximately 96 percent of them being over the age of 65 (Alzheimer's Association, 2018; L. E. Hebert, Weuve, Scherr, & Evans, 2013). More specifically, 16 percent of those with Alzheimer’s disease are between the ages of 65-74 years, 44 percent are between the ages of 75-84 years, and 37 percent are 85 years or older (numbers do not add to 100 due to rounding; Alzheimer's Association, 2018). With the demographic group of older adults projected to double by 2050 and comprise 20 percent of the U.S. population (Shrestha & Heisler, 2011), the number of Americans with Alzheimer’s disease and other dementias is also expected to rise correspondingly, barring the development of a cure for the disease (L. E. Hebert et al., 2013; Plassman et al., 2007; Prince et al., 2013). Availability of beds in long-term care facilities is limited (Harrington, Preston, Grant, & Swan, 1992; Harris-Kohetin et al., 2016) and thus, availability of professional care options for those with memory disorders is largely dependent upon for-profit enterprises that are often unaffordable. Further, long-term facility placement is often not preferred by the caregiver nor the care recipient (Alzheimer's Association, 2018). Facilitation of informal dementia caregiving has been identified as a key strategy to provide care of our aging population (Alzheimer's

Association, 2018). While numerous psychotherapeutic interventions for caregivers have been developed (Brodaty, Green, & Koschera, 2003; Chien et al., 2011; Pinquart & Sorensen, 2006; Schulz, 2000), few have been successfully translated to accessible settings such as primary care clinics.

Dementia is a progressive clinical syndrome caused by varying neurodegenerative diseases and presents with a cluster of cognitive symptoms, most notably memory impairment. As a result, persons with dementia begin to experience gradual cognitive decline and ultimately lose the capacity to live independently (Budson & Kowall, 2011). There are numerous types of dementia including frontotemporal dementia, dementia with Lewy Bodies and vascular dementia; Alzheimer's disease is the most prevalent type (Barker et al., 2002; Reitz, Brayne, & Mayeux, 2011), and thus the most researched.

Alzheimer's disease and other dementias are heterogeneous in their presentations and progressions among individuals. The most commonly cited symptom is the inability to remember and develop new memories, which often leads to confusion and the inability to complete tasks (Alzheimer's Association, 2018; Lichtenberg, Murman, & Mellow, 2003; Sandilyan & Dening, 2015). Other cognitive symptoms include impaired executive functioning and problems with language (Alzheimer's Association, 2018; Budson & Kowall, 2011; Lichtenberg et al., 2003; Sandilyan & Dening, 2015). Impaired executive functioning often leads to disorientation, disinhibition, inability to regulate emotions appropriately and compromised judgment. As a result of memory and executive impairment, persons with dementia gradually lose the ability to care for themselves (e.g., inability to adhere to medication and personal hygiene regimes, pay bills and maintain housecleaning). In an effort to prevent dangerous accidents including traffic accidents, falls, kitchen fires, financial fraud or other preventable loss from occurring, caregivers of persons with dementia often take over responsibilities such as transportation and cooking. Dementia also impairs one's language by creating word-finding problems, object-naming difficulties and comprehension failures (Kemper & Lyons, 1994). Together, these symptoms lead to the inability to start and sustain conversations, feelings of frustration and social isolation.

People with dementia also experience a variety of behavioral and psychiatric symptoms that lead to functional decline (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; Finkel, Costa e Silva., Cohen, Miller, & Sartorius, 1996; Kales, Gitlin, & Lyketsos, 2015; Pinidbunjerdkool, Saengwanitch, & Sithinamsuwan, 2014). These symptoms include delusions and hallucinations (visual hallucinations are a salient feature of Lewy body dementia; Burns & Iliffe, 2009), depression, agitation, mood lability, eating disturbances and wandering (Cerejeira et al., 2012; Finkel et al., 1996; Kales et al., 2015; Pinidbunjerdkool et al., 2014). Further, people with dementia often experience sundown syndrome, or sundowning. Sundowning is a term used to describe the worsening of psychiatric and behavioral symptoms during the late afternoon and evening hours (Khachiyants, Trinkle, Son, & Kim, 2011; Little, Satlin, Sunderland, & Volicer, 1995). The etiology of sundowning has not been identified, and while several theories have been proposed, more recent research suggests that it may be related to a disruption in circadian rhythms (Khachiyants et al., 2011; Volicer, Harper, Manning, Goldstein, & Satlin, 2001).

Cumulatively, these symptoms affect older adults' physical and mental health, and a variety of life domains including social and occupational functioning. These symptoms also make caregiving an arduous task (Donaldson, Tarrier, & Burns, 1997). Caregivers are heavily depended on as persons with dementia have difficulty communicating, display behavioral problems and mood lability, and become disabled in a multitude of ways. Dementia symptomatology progresses over time in both quantity and severity prior to death, leaving caregivers to provide care for years. Research estimates a median survival time of 4.5 years after the onset of dementia (Xie, Brayne, Matthews, Medical Research Council Cognitive Function, & Ageing Study collaborators, 2008); however, the survival time varies significantly based on numerous factors include age of onset (younger age of onset associated with longer median survival times), dementia subtype, comorbidities and severity (Brodaty, Seeher, & Gibson, 2012; Xie et al., 2008). Thus, some with Alzheimer’s disease may live as long as 20 years with the disease (Alzheimer's Association, 2018).

Informal Caregiving

Approximately 75 percent of caregivers of dementia patients are family and friends – informal caregivers (Schulz & Martire, 2004). According to research, family and friends of older adults with dementia choose to provide care most often because: (1) they wish to keep the care recipient at home; (2) their physical proximity to the care recipient facilitates the provision of informal care; and (3) they feel a sense of obligation to personally see to the care of their loved one (Alzheimer's Association, 2018; Brodaty, 2009). The majority of caregivers are spouses and adult children, and over two thirds of these caregivers are female (Alzheimer's Association, 2018; Bouldin & Andersen, 2014; Brodaty et al., 2012; Friedman, Shih, Langa, & Hurd, 2015). Most caregivers (66%) live with their care recipient in the community (Alzheimer's Association, 2018). Over 40 percent of caregivers have some college education or beyond, and over 66 percent identify as non-Hispanic White (Alzheimer's Association, 2018; Bouldin & Andersen, 2014). While some studies indicate that older African-American adults are approximately two times more likely and older Hispanic adults are 1.5 times more likely to have Alzheimer’s and other dementias compared to older White adults, the majority of persons with Alzheimer’s and/or other dementia living in the United States identify as non-Hispanic White (Alzheimer's

Association, 2018). In the 2014 Alzheimer’s Association Women and Alzheimer’s Poll, 25 percent of caregivers reported living with children under the age of 18 making them “sandwich generation caregivers” – caring for both children and aging parents (Alzheimer's Association, 2018). Many sandwich generation caregivers face increased, and often conflicting, caregiving demands and stressors; subsequently, many have reported engaging in less healthy behaviors, such little to no exercise and reduced quality of life (Chassin, Macy, Seo, Presson, & Sherman, 2010; Rubin & White-Means, 2009).

Caregivers of patients with Alzheimer’s and other dementias spend more hours caregiving than caregivers of patients with other later-life disorders (Alzheimer's Association, 2018; Ory, Hoffman III, Yee, Tennstedt, & Schulz, 1999). Specifically, caregivers of patients with Alzheimer’s disease report spending an average of 27 more hours per month providing care than non-dementia caregivers (Alzheimer's Association, 2018). While a little over 33 percent of caregivers report spending 0-8 hours weekly providing care, approximately 28 percent report providing 40 or more hours of care weekly (Ory et al., 1999). Caregivers of dementia assist with a variety of tasks, including management of psychiatric and behavioral symptoms and hiring and supervising formal support services. Dementia caregivers also provide greater assistance in activities of daily living (bathing, toileting, dressing and feeding) and instrumental activities of daily living (medication management, financial management, transportation and meal preparation) than non-dementia caregivers (Alzheimer's Association, 2018; Bouldin & Andersen, 2014; Ory et al., 1999; Schulz, 2000).

The financial burden associated with Alzheimer’s disease and other dementias impacts care recipients, caregivers and our economy as a whole. Using the Health and Retirement Study, a nationally representative longitudinal study of older adults, Hurd and colleagues (2013) estimated that each case of dementia costs between 41,000 and 56,000 dollars; institutionalized and home-based long-term care were the greatest cost contributors. They further estimated that the total cost of dementia nationwide in 2010 ranged from 157 to 215 billion dollars, of which Medicaid covered 11 billion dollars (Hurd et al., 2013). Newer reports suggest that the total cost of care for all patients with Alzheimer’s and other dementias in 2018 is estimated to be $277 billion, of which 67% will be covered by Medicare and Medicaid (Alzheimer's Association, 2018). Research estimates that the total direct costs of managing Alzheimer’s disease is reduced by 21 percent if the patient is living at home (Jankowiak & Knopman, 2006); however, this often leads to an increase costs for caregivers. Approximately 57 percent of caregivers reported that they have to take time off work, leave early from work and/or arrive late to work due to caregiving responsibilities; 16 percent reported taking a leave of absence; 18 percent reported reducing work hours to part-time; and 9 percent reported leaving their job altogether (Alzheimer's Association, 2018). In a study examining male Veterans with probable dementia, researchers found that the largest costs to providing informal care was attributable to caregiving time and caregiver lost earnings (Moore, Zhu, & Clipp, 2001). Further, 11.4 billion dollars in healthcare costs in the United States in 2017 is estimated to result from the physical and emotional impact of dementia caregiving (Alzheimer's Association, 2018). The present literature collectively reveals that Alzheimer’s and dementia management leads to substantial indirect costs, including caregiver lost earnings.

Caregiver Strain and Depression

Copious findings suggest that dementia caregivers are at increased risk for burden, stress, depression and other health problems (Alzheimer's Association, 2018; Brodaty, 2009; Burns & Iliffe, 2009; Cuijpers, 2005; Etters, Goodall, & Harrison, 2008; Schulz, 2000). Caregiver burden has been defined as the subjective experience of physical, psychological, social and financial problems experienced due to caregiving (Chou, 2000; Hoffman & Mitchell, 1998). Dementia caregivers report experiencing high levels of burden and strain (Schulz, O'Brien, Bookwala, & Fleissner, 1995), and higher levels of emotional, physical and financial strain compared to non-dementia caregivers (Ory et al., 1999; Schulz, 2000). Specifically, dementia caregivers report experiencing caregiving-related family conflict, decreased socialization and personal leisure time, employment complications and increased feelings of being overwhelmed (Ory et al., 1999). Strong correlates of caregiver burden include behavioral disturbances displayed by the care recipient and levels of dependence on the caregiver (Etters et al., 2008; Garre-Olmo et al., 2016; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). Studies also suggest that caregiver burden predicts caregiver depression (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; D'Aoust, Brewster, & Rowe, 2015).

Approximately 59 percent of dementia caregivers rated the emotional stress of caregiving as high or very high, and approximately 30 to 40 percent suffer from depression (Alzheimer's Association, 2018). The prevalence and incident rates of depression among dementia caregivers is higher than rates found among comparable community dwelling adults (Cuijpers, 2005; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991). Behavioral and psychological symptoms of dementia, including depression, aggression and sleep disturbances, are common predictors of caregiver depression (Covinsky et al., 2003; Danhauer et al., 2004; Ornstein & Gaugler, 2012). In a cross-sectional study among Taiwanese dementia caregivers, a positive correlation was found between depression, measured using the Center for Epidemiologic Studies Depression Scale (CES-D), and care recipient's behavioral and psychological symptoms, measured using the Neuropsychiatric Inventory (Huang, Liao, & Wang, 2015). A recent meta-analysis revealed that the odds of having depression were 1.53 times higher in female caregivers, 1.83 times higher in caregivers of male care recipients and 2.51 times higher in caregivers who have a spousal relationship with their care recipient (Sallim, Sayampanathan, Cuttilan, & Ho, 2015). Other identified correlates of caregiver depression include perceived patient suffering (Schulz et al., 2008), care recipient irritability (R. Mahoney, Regan, Katona, & Livingston, 2005), and age of dementia patient, dementia severity, caregiver income and caregiver ethnicity (Covinsky et al., 2003). Subsequently, caregiver depression and distress can increase caregivers' risk for cardiovascular disease (Mausbach, Patterson, Rabinowitz, Grant, & Schulz, 2007). In a longitudinal study of a sample of Japanese caregivers, Arai and colleagues (2001) found that caregivers who relinquished caregiving for disabled elderly at home reported greater depressive symptomatology than those who continued caregiving at home, suggesting depression as a predictor of transition to long-term care. Similar results were found in a study of over 400 spouse caregivers of community-dwelling patients such that greater depressive symptomatology was a significant predictor of higher nursing home placement rates (Mittelman, Haley, Clay, & Roth, 2006).

Caregiver Preparedness

Caregiver preparedness is defined as how ready and able a person feels to assume the various duties of caregiving (Archbold, Stewart, Greenlick, & Harvath, 1990). Increased caregiver preparedness has been associated with decreased levels of caregiver strain and burden (Archbold et al., 1990; Scherbring, 2002). Among family caregivers of cancer patients, caregiver preparedness was more strongly associated with caregiver mood than caregiver strain (Schumacher et al., 2008). Among family caregivers in palliative care, increased preparedness was significantly associated with increased hope, increased reward and decreased anxiety;

however, preparedness was not associated with caregiver depression and health (Henriksson & Arestedt, 2013). A cross-sectional study on dementia caregivers in Taiwan found that greater caregiver preparedness correlated with better mental health and greater caregiving rewards (Shyu et al., 2010). Similarly, Wang and colleagues (2013) found that more preparedness in Taiwanese dementia caregivers correlated with less strain and protected against adverse mental health effects when caregiving demands were high.

Filial Obligation

Filial obligation is the duty one feels to care for their aging parents (Rossi & Rossi, 1990), and more broadly can be applied to how family members are expected to care for one another. Filial obligation develops from early socialization to cultural standards that promote social responsibility for aging parents (Cicirelli, 1993) and typically peaks in mid-life (Gans & Silverstein, 2006). Past research, though limited, on filial obligation and ethnicity supports culture as one determinant of caregiving responsibility (Burr & Mutchler, 1999; Chappell & Funk, 2011; Scharlach et al., 2006). Specifically, ethnic minorities including Blacks and Hispanics report a greater sense of filial responsibility than non-Hispanic Whites (Burr & Mutchler, 1999; Connell & Gibson, 1997; Pinquart & Sorensen, 2005). Women also tend to report stronger feelings of filial obligation than men (Stein et al., 1998), which may relate to the fact that women historically have been assigned caregiving responsibilities. Filial obligation has been found to predict helping behaviors (Silverstein, Parrott, & Bengtson, 1995). While filial obligation is related to caregiver burden, the nature of the relationship remains unclear. In a study examining attachment and obligation in daughters caring for elderly mothers, daughters with stronger filial obligations felt a greater sense of burden (Cicirelli, 1993). In contrast, another study revealed relatives who felt a stronger sense of filial obligation experienced an overall reduction in caregiver-related burden (Chou, LaMontagne, & Hepworth, 1999).

Caregiver Interventions

Numerous caregiver interventions and support groups are available for Alzheimer's and dementia caregivers (Mittelman, 2013). Gitlin and colleagues (2015) note that over 200 interventions were reviewed in 24 meta-analyses and systematic reviews conducted between 1966 and 2013. These interventions vary in number of participants, duration, structure, leadership type (community members versus trained health professionals) and setting (Hornillos & Crespo, 2011), and are typically comprised of one or more of the following components: social support, psychoeducation, skills training, and emotional support (Chu, 2011). Overall, interventions target improving caregivers' understanding of dementia and their ability to cope with their care recipient's dementia, resulting in improved quality of life for both the caregiver and care recipient (Alzheimer's Association, 2015). Improvement in quality of life and reduction in distress by facilitating better coping contributes to the delay in need for residential care (Liddle et al., 2012).

Given the numerous types of interventions, many reviews and meta-analyses have been published to help delineate which interventions and intervention components are effective. While there is an overwhelming consensus that caregiver support groups are beneficial, most reporting small to moderate effect sizes (Gitlin et al., 2015; Schulz et al., 2002), the degree and type of benefits received appear to vary among interventions (Acton & Kang, 2001; Alzheimer's Association, 2015; Brodaty et al., 2003; Chien et al., 2011; Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Mittelman, 2013; Parker, Mills, & Abbey, 2008; Peacock & Forbes, 2003; Pinquart & Sorensen, 2006; Pusey & Richards, 2001; Schulz et al., 2002; Sorensen, Pinquart, &

Duberstein, 2002). Meta-analytic reviews conclude that support groups reduce caregiver depression, with effect sizes ranging from small (Cohen's *d* = 0.24; Pinquart & Sorensen, 2006) to medium (Cohen's *d* = 0.68; Brodaty et al., 2003). Reviews also demonstrate that support groups increase caregiver's knowledge about dementia, with moderate effect sizes (Cohen's *d* = 0.46-0.51; Brodaty et al., 2003; Pinquart & Sorensen, 2006). The findings on support groups reducing caregiver burden, however, remains equivocal (Schulz et al., 2002). Some studies report that caregiver support groups provide a small but significant reduction in caregiver burden (Chien et al., 2011; Pinquart & Sorensen, 2006), while others find no reduction in caregiver burden (Acton & Kang, 2001; Brodaty et al., 2003; Chu et al., 2011; Parker et al., 2008).

Both intervention and participant characteristics have been found to impact the effectiveness of the support group. General support groups that offer self-help and peer support or short educational programs, often found in community settings, are not as effective in improving caregiver outcomes (Brodaty et al., 2003; Parker et al., 2008). In contrast, psychoeducational and psychotherapeutic groups demonstrate a significantly higher effect in reducing caregiver depression and improving psychological well-being (Chien et al., 2011; Mittelman, 2013). Multi-component interventions have the broadest range of positive effects (Alzheimer's Association, 2015; Parker et al., 2008), including a small yet significant reduction in caregiver burden (Acton & Kang, 2001). Multi-component interventions also were the only type found to delay transition of care recipient to a long-term placement facility (Pinquart & Sorensen, 2006). Interventions with social, behavioral and problem-solving components are more efficacious (Cooke et al., 2001; Pusey & Richards, 2001). Meta-analytic reviews have consistently reported a dose-effect whereby intervention length is positively associated with improvements in caregiver depression and subjective well-being, as it allows time for effective implementation of skills and problem-solving (Brodaty et al., 2003; Chien et al., 2011; Pinquart & Sorensen, 2006; Sorensen et al., 2002). In addition, group sizes between 6-10 have demonstrated greater caregiver benefits compared to larger group sizes (Chien et al., 2011). One possible reason for this is that caregivers in small groups have more opportunities to share as opposed to those in larger group sizes. Caregiver support groups that require active participation from group members, such as role-playing, yield better caregiver outcomes, including reduced depression and burden (Alzheimer's Association, 2018; Parker et al., 2008; Pinquart & Sorensen, 2006). Findings also suggest that caregiver support groups with the same group leader who can provide as much information as needed and seek help from experts for each group demonstrate greater efficacy (Chien et al., 2011). In sum, findings suggest interventions that are comprehensive, intensive and individually-tailored are more likely to be effective (Schulz, 2000); however, these interventions also tend to require considerable money, resources and time.

Individual participant characteristics also correlate with intervention outcomes. Research demonstrates that female participants corresponded to better effects on depression and psychological well-being (Chien et al., 2011), however, this may be attributed to findings that female caregivers report experiencing greater depression (Mittelman, 2013). Care recipient’s disease progression is positively associated with the caregiver intervention response (Chien et al., 2011). One proposed explanation for this result is that caregivers of patients with more progressive dementia are more motivated to attend group sessions, and thus procure greater benefits (Chien et al., 2011). Caregiver support groups have also been found to be of greater benefit for caregivers who are either dissatisfied with their role as a caregiver or are unemployed during the time of care provision (Cuijpers, Hosman, & Munnichs, 1996). Other individual characteristics affecting treatment outcomes include religiosity (R. S. Hebert, Dang, & Schulz, 2007), caregiver vigilance (D. Mahoney et al., 2003) and ethnicity (Coon et al., 2004; Haley et al., 2004). While these findings reflect the significant need for future work examining the effect of individual differences on caregiving intervention outcomes, these particular variables are outside the immediate scope of the proposed research.

i. Resources for Enhancing Alzheimer's Caregiver Health (REACH) Program

One of the most cited effective interventions for dementia caregivers is the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program (Alzheimer's Association, 2015; Mittelman, 2013). The REACH program, developed in 1995 and funded by the National Institute of Aging and National Institute on Nursing Research, aimed to carry out social and behavioral interventions to improve family caregiving of patients with Alzheimer's disease and related disorders (Schulz et al., 2003). The REACH trial and subsequent work are the most well-funded and heavily published-on manualized caregiver interventions. This multi-site randomized control trial attempted to evaluate the efficacy of various theory-driven interventions that are all consistent with the stress-health model – change the nature of the stressor, the appraisal and/or the response (Schulz et al., 2003). Interventions lasted approximately six months and included individual information and support strategies, group support and family systems therapy, psychoeducational and skill-based training approaches, home-based environmental interventions or enhanced technology support systems (Schulz et al., 2003). A total of 9 active intervention groups were implemented across six sites, with a control condition at each site (Wisniewski et al., 2003). All sites used similar inclusion and exclusion criteria and a common measurement protocol (Wisniewski et al., 2003). A total of 1,222 caregiving dyads participated among the six sites collectively (Wisniewski et al., 2003).

Overall, results demonstrated that active group interventions were more successful at reducing caregiver burden than control groups (Gitlin et al., 2003; Schulz et al., 2003). In addition, interventions that promoted active caregiver engagement (e.g., role play) had the greatest impact in reducing caregiver depression (Wisniewski et al., 2003). Women and participants with a high school education or less in the active intervention groups reported reduced caregiver burden compared to women and participants with a high school education in the control groups. Similarly, Hispanics, non-spouse caregivers and participants with a high school education in the active intervention groups reported less depressive symptomatology relative to participants with the same characteristics in the control group (Wisniewski et al., 2003).

REACH informed the subsequent REACH II trials, which aimed to test a single intervention at multiple sites with ethnically diverse populations (Schulz et al., 2003). Based on results from REACH, the REACH II intervention was designed to target specific problem areas (depression, burden, self-care and healthy behaviors, social support and problem behaviors), respond to the individual needs of caregivers and elicit active engagement from caregivers. The intervention, offered in Spanish and English, lasted 6 months with 12 in-home sessions, 3 telephone session, and 5 structured telephone support group sessions. Over 600 participants (1/3 White or Caucasian, 1/3 Black, 1/3 Hispanic or Latino) engaged in the intervention across all five sites combined. Results demonstrated that intervention-group participants had lower prevalence of clinical depression (defined by CES-D score greater than 14) than did control group respondents (Belle et al., 2006). Intervention-group participants who were White or Caucasian and Hispanic or Latino had significantly greater improvements in quality of life (measured by indicators of depression, burden, social support, self-care and patient problem behaviors) compared to control group participants (Belle et al., 2006). Data analyses comparing pre- and post-intervention measures revealed that the intervention-group caregivers endorsed significantly improved general health, sleep, mood and physical health after the intervention (Elliott, Burgio, & Decoster, 2010). No significant difference was found, however, in the number of care recipients placed in a long-term care facility between the intervention group and control group (Belle et al., 2006).

The REACH II intervention was then modified as the REACH: Offering Useful Treatments (REACH OUT) program to be adapted for use by Area Agencies on Aging (AAAs). The REACH OUT intervention was implemented across four AAAs and consisted of 4 home visits and 3 phone calls over a 4-month period (Burgio et al., 2009). Results demonstrated that caregivers reported less subjective burden, frustration, depression and increased social support (Burgio et al., 2009). More recently, the REACH program has been adapted within the Veterans Affairs system (REACH VA; Nichols, Martindale-Adams, Burns, Zuber, & Graney, 2016). Modifications included reducing the intervention to four sessions, with optional additional sessions available and broadening the modality of treatment to in-person and/or telephone options. Preliminary results demonstrated that after the intervention, caregivers endorsed less burden, anxiety, depression and stress symptomatology, with effect sizes ranging from small (Cohen’s $d = 0.24$) to moderate (Cohen's $d = 0.46$; Nichols et al., 2016).

ii. New York University (NYU) Caregiver Intervention

Another well-funded and empirically supported caregiver intervention is the New York University (NYU) Caregiver Intervention (Mittelman et al., 1993). This comprehensive intervention includes two individual sessions and four family sessions targeted at providing education and resources, and teaching skills to manage problem behaviors over a 4-month period. Caregivers then join a formalized weekly caregiver support group with no session limit, and are provided with ad hoc in-person or telephone counseling as needed (Mittelman et al., 1993). Results demonstrated that compared to control group interventions, the NYU intervention reduced caregiver depression (Mittelman et al., 1995) and reduced caregiver distress associated with problem behaviors displayed by the care recipient (Mittelman, Roth, Haley, & Zarit, 2004). Unlike the REACH trials, the NYU Caregiver Intervention has been found to delay care recipient's time to admission to a nursing home by an average of 228.36 days (Gaugler, Reese, & Mittelman, 2013). Further research suggests improvement in caregiver well-being (increased social support, reduced depression, and improved management of behavior problems) as a mechanism by which nursing home placement delay occurs (Mittelman et al., 2006).

iii.Limitations of the REACH Program and NYU Caregiver Intervention

While both the REACH trials and NYU Caregiver Intervention have demonstrated success in reducing adverse caregiver outcomes, there are several limitations to these interventions. First, and most notably, the REACH II and NYU Caregiver Intervention require substantial financial and resource capital, including trained professionals. They also necessitate a 4-to-6 month time commitment from caregivers who have may have many demands and limited respite care options. While briefer adaptions in the REACH OUT and REACH VA protocols have demonstrated encouraging results, they continue to necessitate resource capital . Thus, several brief interventions have been developed in an effort to address these limitations.

iv. Brief Interventions

The Savvy Caregiver Program is an evidenced-based, 6-week intervention for dementia caregivers aimed at strengthening caregivers' knowledge, skill and outlook for caregiving (Hepburn, Lewis, Sherman, & Tornatore, 2003). While initial program evaluations have demonstrated some efficacy in reducing caregiver distress and burden and increasing caregiver mastery (Hepburn et al., 2003; Hepburn, Lewis, Tornatore, Sherman, & Bremer, 2007), the program is psychoeducational with limited active caregiver engagement.

In contrast, Project CARE is a behavioral intervention aimed at reducing caregiver distress related to care recipient's neuropsychiatric symptoms, care recipient's neuropsychiatric symptoms overall and caregiver burden (Gonyea, O'Connor, & Boyle, 2006). Project CARE involves five, 90-minute weekly sessions that are designed to increase caregivers' engagement in pleasant events and to teach caregivers behavior management techniques for managing care recipient's neuropsychiatric symptoms in the home environment. In a randomized control trial, 80 caregivers, mostly spouses and adult children, were assigned to either the behavioral intervention group or a psychoeducational control group. Compared to participants in the control group, participants in the intervention group reported significantly lower caregiver distress related to neuropsychiatric symptoms (Gonyea et al., 2006). No significant differences, however, were found in reduction of caregiver burden and number of neuropsychiatric symptoms displayed by the care recipient between the two groups. These findings, among others, provide support for the efficacy of brief interventions and the use of targeted interventions based on principles of behavioral therapy (Gonyea et al., 2006).

The proposed caregiver support group is designed according to Gonyea and colleagues' (2006) caregiver intervention given the promising results of both efficacy and effectiveness. Similar to Project CARE, the intervention to be employed in the proposed research is brief, based on principles of behavior therapy, includes social, behavioral, and problem-solving components, and elicits active caregiver involvement. The one notable modification is the addition of a 90-minute session, led by a local Alzheimer and Dementia resource group, to provide caregivers with valuable resources related to caregiving. Resources include and are not limited to information about elder law attorneys, geriatric health professionals, transportation services, nursing home placements and respite care options. This modification was made in an effort to increase group members' knowledge of community resources, navigate the formal resource system, provide respite care options and strengthen their support network. This increased access to resources may increase caregiver preparedness and decrease caregiver burden. The proposed intervention also aligns with what caregivers have reported as beneficial in caregiver interventions: (1) problem-solving for the future; (2) help navigating the formal resource system and strengthening the informal support system; (3) help managing care recipient's troubling behaviors; and (4) facilitating engagement in self-care (Samia, Hepburn, & Nichols, 2012). Further, to increase caregiver self-efficacy, clinical recommendations suggest to provide skill building and psychoeducation, case management, and emotion management in 6 90-120-minute sessions (Tang & Chan, 2016).

Proposed Research

The overall purpose of this study is to examine the efficacy of a theoretically-based caregiver support group in a community primary care setting. The primary objective is to improve caregiver-related outcomes of participants in the active caregiver support group above and beyond those found in participants in community caregiver support groups (i.e., control/treatment as usual group). Specifically, we hypothesize that:

> *Hypothesis 1:* Participants in the active caregiver support group will report feeling more prepared to fulfill the role of dementia caregiver as measured by higher mean scores on the Caregiver Preparedness Scale (CPS) at the end of the six-week period compared to participants in the community caregiver support groups.

Hypothesis 2: Participants in the active caregiver support group will report experiencing less caregiver strain as measured by lower scores on the Caregiver Strain Index (CSI) at the end of the six-week period compared to participants in the community caregiver support groups.

Hypothesis 3: Participants in the active caregiver support group will report experiencing less depressive symptomatology as measured by lower scores on the Center Epidemiologic Studies Short Depression Scale (CESD-10) at the end of the six-week period compared to participants in the community caregiver support groups.

Hypothesis 4: Participants in the active caregiver support group will report experiencing less distress associated with care recipients' neuropsychiatric symptoms as measured by lower scores on the Distress scale of the Neuropsychiatric Inventory – Questionnaire (NPI-Q) at the end of the six-week period compared to participants in the community caregiver support groups.

Hypothesis 5: Participants in the active caregiver support group will indicate being satisfied overall with the group as measured by high ratings on the Satisfaction Survey at the end of the six-week group. Satisfaction with the support group will be indicated by a mean score of 3.5 or higher (scale is described below) in response to questions assessing whether (A) provided information was informative; (B) language used in group was easy to understand; (C) information discussed in group is useful; (D) length of program was appropriate; and (E) willingness to recommend the group to other caregivers.

Auxiliary Aim: To examine the possible moderating role of filial obligation on the relationship between caregiver symptoms, as measured by summing ADL, IADL, and

NPI-Q symptom severity scores, and caregiver burden, as measured by the CSI, and caregiver depressive symptoms, as measured by the CESD-10.

CHAPTER 2: METHODS

Participants

A total of 63 participants enrolled in the study, of which 41 participants completed the study. Participant inclusion criteria included being 18 years or older, English-speaking and caring for an adult suffering from cognitive impairment related to dementia. The nature of the dementia may vary and be related to a wider degree of geriatric diseases (e.g., stroke, Parkinson's disease and traumatic brain injury). For the active caregiver support group, participant inclusion criteria also included attending at least four of the six sessions. Returning participants in the active caregiver support group who attended the group prior were excluded.

Of the 63 participants enrolled in the study, 36 enrolled in the active caregiver support group and 27 enrolled in the control group. In the active caregiver support group, 1 participant did not endorse that their care recipient suffered from cognitive impairment, 4 participants had participated in the group prior and 1 participant did not attend at least 4 sessions; thus, these participants were excluded. Of the remaining 30 participants in the active group, 8 participants did not complete the group (i.e., 6-week follow up measures) leaving 22 participants in the active group. Of the 22 participants in the active caregiver support group, 59.1% attended all six sessions, 31.8% attended five sessions and 9.1% attended four sessions. In the control group, 1 participant did not endorse that their care recipient suffered from cognitive impairment and 7 participants did not complete the 6-week follow-up measures; thus, they were excluded from the study and 19 participants remained in the control group.

An a priori power analysis was conducted to determine the sample size needed to achieve a moderate effect (Cohen's $d = 0.5$) given previous reports of moderate effect sizes across the various outcomes. Based on these anticipated effect size estimates, results of a power analysis suggest an 80 percent probability of identifying statistically significant effects of treatment with a sample size of 32 participants.

Method

The present study collected participants for the active caregiver support group via multiple email listserves of local organizations involved with the care of older adults, University of Central Florida-affiliated email listserves and brochures placed in various facilities related to older adults throughout the Orlando community. Participants in the treatment as usual (control) caregiver support group were recruited by contacting various community run support group leaders, including those run by local churches and nursing homes, in both the Orlando and Chicago areas.

Participants in the active caregiver support group attended a six-week caregiver support group located in a primary care clinic. Sessions were 90 minutes each, and held weekly for six consecutive weeks. The groups were co-facilitated by two doctoral-level graduate students who have had prior clinical experience, and at least one of whom has obtained their Master's degree. Groups consisted of 3-7 participants, with the exception of one group, which had two. All group sessions were audio recorded on a double password protected iPad for treatment fidelity purposes and deleted within two weeks of the recording. The six-week caregiver support group was designed according to Gonyea and colleagues' (2006) targeted behavioral intervention for caregivers of individuals with Alzheimer's disease. The core content of the group included: (1) improving caregiver self-care by promoting caregiver behavioral activation; (2) teaching effective management of psychiatric and behavioral symptoms (e.g., refusing meals, arguing and wandering) posed by care recipients using contingency management and effective communication; and (3) increasing awareness and education of available professional services related to caregiving (e.g., legal services, transportation options and evaluation of residential care facilities). Here is a brief outline of the six sessions (the full treatment manual can be found in the Appendix C):

> Session 1: Provide overview of the group intervention, review Alzheimer's disease and dementia and facilitate introductions. Introduce concept of self-care through engagement in pleasant activities. Administer intake assessment packet (see Appendix D).
>
> Session 2: Review self-care as a method to reduce caregiver distress and burden. Have Alzheimer's and Dementia Resource Center (ADRC) representative provide valuable resources related to caregiving.
>
> Session 3: Provide psycho-education on fundamentals of behavior management through ABC's (antecedent, behavior and consequence).
>
> Session 4: Discuss goal setting regarding behavior change and strategies to improve relationship between caregiver and care recipient, including effective communication.
>
> Session 5: Review the ABC behavioral chain and continue teaching behavior modification techniques. Problem-solve implementation difficulties.
>
> Session 6: Review importance of self-care and fundamentals of behavior change, and discuss plans for future. Administer exit assessment packet (see Appendix E).

If a participant missed a session, they were provided with handouts and content from the missed session at the next group and given an opportunity to discuss any questions with the group leaders; no formal make-up session was provided. Treatment fidelity was assessed by recording each session and rating which treatment components were present in each session (see Appendix H for Treatment Fidelity Coding Sheet). Two graduate student raters coded each session and participated in weekly group supervision for training.

Participants in the control group attended their community support groups as usual. These long-standing community support groups were held monthly with open enrollment. They were relatively unstructured and included components of limited psycho-education and social support. While facilitated with group leaders (e.g., church employees or social work employees at older adult living facilitites), the content of the group was provided and driven by group members. The intake assessment (see Appendix F) data was collected onsite at their group meeting location. The exit assessment (see Appendix G) data was collected six weeks after their intake assessment data either onsite at their group meeting, or individually at their preferred location if no group was held during week six. Note, the community control support groups utilized in this study met monthly. Participants in both the active and control groups received a monetary compensation of 10 dollars upon completing the intake assessment pack and again upon completing the exit assessment packet.

Measures

Demographic Variables. Participants provided information on the following demographic variables for themselves and their care recipients via self-report during the intake survey assessment: (1) age (in years); (2) sex (male or female); (3) ethnicity (African-American/Black; American Indian/Native Alaskan; Asian/Southeast Asian/Asian-American; Caucasian/European/White; Native Hawaiian/Other Pacific Islander; or Latino(a)/Hispanic.); (4) highest level of education completed (less than 8th grade; 8th to 11th grade; 12th grade; Some college; Associate's degree; Bachelor's degree; or Graduate degree); and (5) income (less than $20,000; $20,000 to $39,999; $40,000 to $64,999; $65,000 to $104,999; or $105,000 or more)

Functional Independence of Care Recipient. Participants indicated the functional independence of their care recipient by noting how much difficulty their care recipient has while completing Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs were measured using five criteria: walking across a room, getting in and out of bed, dressing, bathing and eating. IADLs were measured using three criteria: using the telephone, taking medication and handling money. Participants indicated the amount of difficulty their care recipient experiences with each of these activities on a 6-point rating scale, with 0 indicating no difficulty and 5 indicating extreme difficulty. Hence, higher ADL and IADL scores indicate that care recipients are experiencing more difficulty, and thus, more disability.

Obligation Scale. The Obligation Scale (Cicirelli, 1991) is a 7-item scale that measures participants' global sense of obligation to care for and assist family members. Participants rated their level of agreement or disagreement with statements assessing obligation on a 5-point Likert scale with 1 indicating strong disagreement and 5 indicating strong agreement. Items in this scale include "I feel a sense of obligation to help," "I feel that I should do my part in helping," and "I would feel guilty if I didn't help." Higher scores suggest greater global feelings of obligation. The internal consistency (alpha) of this measure is 0.83 (Cicirelli, 1993).

Outcome Variables

Caregiving Preparedness. The Preparedness for Caregiving Scale (Archbold et al., 1990) is an 8-item scale that measures the level of preparedness the participant feels he or she is to perform various aspects of caregiving. Items include questions such as "How well prepared do you think you are to take care of his or her emotional needs?" and "How well prepared do you think you are to respond to and handle emergencies that involve him or her?" Participants answered these questions on a 5-point Likert scale with 0 indicating the participants felt "not at all prepared" and 5 indicating the participant felt "very well prepared." Higher mean scores suggest feeling more prepared to take on the caregiving role. The internal consistency (alpha) of this measure ranges from 0.88-0.93 (Schumacher, Stewart, & Archbold, 2007) .

Depressive Symptomatology. Depressive symptomatology was assessed using the 10-item Center for Epidemiologic Studies Short Depression Scale (CESD-10; E. M. Andresen, Malmgren, Carter, & Patrick, 1994), a shortened version of the 20-item CES-D measure (Radloff, 1997). Eight of the ten items are worded negatively (e.g., “I felt depressed”) and two of the items are worded positively (e.g., “I was happy”), and thus reverse scored. Participants recorded how often they experienced these symptoms of depression during the past week by choosing one of four options: rarely or none of the time (less than 1 day); some or a little of the time (1-2 days); occasionally or a moderate amount of time (3-4 days); and all of the time (5-7 days). Higher scores suggest that the participant is experiencing greater depressive symptomatology, and scores greater than 10 suggest that the participant is experiencing clinically significant levels of depression (E. M. Andresen et al., 1994). The internal consistency of this measure in caregiver research is high (Cronbach's alpha = 0.86-0.88; E.M. Andresen, Byers, Friary, Kosloski, & Montgomery, 2013). The CESD-10 is an internationally used scale to assess depressive symptomatology (Cheng, Chan, & Fung, 2006; Gonzalez et al., 2017), has been validated widely across clinical and community populations (Bjorgvinsson, Kertz, Bigda-Peyton, McCoy, & Aderka, 2013; Mohebbi et al., 2018), and is used commonly in caregiver research (Gallagher et al., 2011; Mausbach et al., 2012).

Caregiver Strain. The Caregiver Strain Index (CSI; Robinson, 1983) is a 13-item measure that assesses for burden associated with caregiving. Participants responded either “yes” or “no” to statements conveying the varying aspects of caregiving that may be burdensome, such as “Sleep is disturbed (e.g., because ___ is in and out of bed or wandering around at night)” and

"It is a financial strain." The internal consistency is high (Chronbach's alpha = 0.86; Robinson, 1983). The CSI is a measure of caregiver strain that is concise and has been used previously in research among caregivers of individuals with dementia (Diwan, Hougham, & Sachs, 2004; Mahdavi, Fallahi-Khoshknab, Mohammadi, Hosseini, & Haghi, 2017).

Neuropsychiatric Inventory-Questionnaire. The Neuropsychiatric Inventory-Questionnaire (NPI-Q), adapted from the standard Neuropsychiatric Inventory (NPI), is an informant-based (typically caregivers) assessment of care recipient's neuropsychiatric symptoms over the past month (Kaufer et al., 2000). The NPI-Q assesses 12 symptom domains (delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, motor disturbance, nighttime behaviors and appetite/eating behaviors). Participants first respond "yes" or "no" to the presence of the symptom; if "yes," participants rated: (1) the severity of the symptom (i.e., how it affects the patient) on a 1 (noticeable, but not a significant change) to 3 (very marked or prominent, a dramatic change) Likert scale; and (2) the caregiver distress experienced by the symptom (i.e., how it affects the informant) on a 0 (not distressing at all) to 5 (extreme or very severe; extremely distressing, unable to cope) Likert scale. The NPI-Q produces a total symptom severity scale score and a total distress scale score. Test-retest correlations range from 0.80-0.94, and the correlation between the NPI-Q and NPI ranges from 0.90-0.95 (Kaufer et al., 2000).

Participant Satisfaction. A Caregiver Support Group Satisfaction Survey was developed to assess participant's satisfaction with the active caregiver support group. The survey consists of 7 statements assessing varying domains of the group (e.g., "The information provided was informative; "The language used was easy to understand;" and "The length of the program was appropriate"). Participants in the active caregiver support group rated their agreement with these

7 statements on a 4-point Likert scale from 1 (Disagree) to 4 (Agree). For purposes of this study, the two statements measuring caregiver burden and caregiver preparedness will not be utilized as they are better captured independently with the measures stated above. Further, the survey asks three open-ended questions allowing participants to identify strengths and weaknesses the group, and further topics of discussion they would like to be included in the group.

Statistical Methods

In an effort to retain statistical power, missing item-level data for participants were imputed using person mean imputation method if the variable was continuous and person modal imputation if the variable was dichotomous. A total of 12 item-level data points were imputed of the possible 3,553 item-level data points (i.e., 0.003% of the data). These imputations allowed for total scale scores to be calculated and retained participants in subsequent analyses. Missing item-level data was not imputed if the participant did not respond to any items on a particular measure, and that participant was deleted for related analyses using pairwise deletion methods. No imputations were performed for missing demographic information. Thus, the *n* for baseline comparison analyses (results in *Tables 1-3*) may differ by 1-3 participants from the listed *n*.

Group comparisons between the active intervention and control groups were made using Chi-square statistics for categorical variables and either *t*-tests for continuous variables with normal distributions or Mann-Whitney *U* tests for continuous variables with skewed distributions. Due to the low statistical power, it is methodically defensible to evaluate the outcomes independently. Thus, hypotheses 1-4 were examined using a series of two-way mixed design Analysis of Covariance (ANCOVA). The within-subjects factor was time (pre- and post-intervention); the between-subjects factor was condition (two levels: active intervention group and control group); and the dependent variable was the outcome variable of interest (scores on the Caregiver Preparedness Scale, CESD-10, Caregiver Strain Index and NPI-Q Distress scale). Covariates were identified by determining which variables differed significantly at baseline between the active and control groups. Hypothesis 5 examining participants' satisfaction with the active caregiver support group was addressed using descriptive statistics. The auxiliary aim examining the moderating role of filial obligation on caregiver burden and caregiver depressive symptomatology outcomes was analyzed using linear regression analyses. All data were analyzed using *IBM SPSS Statistics 23*.

CHAPTER 3: RESULTS

A total of 41 participants completed the study, with 22 in the active caregivers support group and 19 in the control group. There were no significant differences on any of the demographic variables and baseline measures between those participants who completed the study (n = 41) and those who did not (n = 22; see *Table 1*). For the active group alone, however, participants who completed the study (n = 22; M = 62.59, SD = 11.04) were significantly older than participants who did not complete the study (n = 8; M = 47.13, SD = 19.77; $t(28) = -2.72$, $p = .01$; see *Table 2*).

For participants who completed the study, those in the active caregiver support group were on average 62.59-years-old, mostly female (86.4%), Caucasian (63.6%) and identified as either the care recipient's child (47.6%) or spouse (38.1%). The majority had a Bachelor's degree or greater (63.6%) and a little over half of them reported not working (54.5%). The majority of care recipients being cared for by active group caregivers either resided in their caregiver's home (36.4%) or their own home (31.8%). Participants in the control group were on average 67-years-old, mostly female (73.7%), Caucasian (84.2%) and identified as either the care recipient's child (38.9%) or spouse (55.6%). A little over half reported not working (55.6%) and a little under half reported having a Bachelor's degree or greater (47.4%). Over half of the care recipients in the control group resided in their caregiver's home (57.9%). Participants in the active caregiver support group reported feeling significantly less prepared as a caregiver on the Caregiver Preparedness Scale (M = 1.69, SD = 0.54) than participants in the control group (M = 2.45, SD = 0.67; $t(39) = -4.00$, $p < .001$). Additionally, more participants in the control group (94.7%) reported living with their spouse/long-term partner than did participants in the active group (68.2%; $\chi^2(1) = 4.58$, $p = .05$). Participants in the control group (Modal Income = \$65,000 to \$104,999) also reported a significantly greater annual income than participants in the active group (Modal Income = \$20,000 to \$39,999; $U = 119.50$, $p = .04$). Complete results comparing active and control group participants at baseline are displayed in *Table 3*.

Treatment fidelity was measured by assessing treatment adherence and inter-rater reliability between rater coding for treatment adherence. Results analyzing three different caregiver support groups (i.e., a total of 18 sessions) suggest that there was strong adherence to the caregiver support group treatment protocol ($\kappa = 0.83$-0.88, 95% CI = 0.75 to 0.95, $p<.001$). Inter-rater reliability results reveal that there was substantial agreement between raters for treatment adherence ($\kappa = 0.76$, 95% CI = 0.66 to 0.85, $p<.001$) .

Four separate two-way mixed ANCOVA analyses were run to determine if participants' scores on the four outcome measures – caregiver preparedness, caregiver depression, caregiver strain and caregiver distress related to neuropsychiatric symptoms – changed over time and differed between groups significantly. Violations of normality were assessed utilizing the Shapiro-Wilk statistic and skewedness scores. Results revealed that caregiver depressive symptom (CESD-10) scores at baseline for the active group and at 6-week follow-up for the control group, caregiver distress scores related to neuropsychiatric symptoms (NP1-Q Distress) at 6-week follow-up for the active group and caregiver strain (CSI) scores at 6-week follow-up for the control group all violated normality. Thus, square root transformations were performed on CESD-10 and NPI-Q Distress scores at baseline and follow-up for the active and control groups in an effort to normalize the data (Tabachnick & Fidell, 2007). This transformation eliminated the violation of normality for CESD-10 scores and significantly reduced the violation of normality for NPI-Q Distress scores. Other transformations, including log-based and inverse transformations, were attempted for NPI-Q Distress scores; however, theses transformations did not result in compliance with assumptions of normality for the active and control groups. CSI scores were not transformed as the histogram demonstrated a slightly bi-modal distribution for which transformations do not correct. After the transformations, outliers were detected utilizing boxplots and the following outliers were found for each outcome variable: 1 for caregiver preparedness; 4 for caregiver depression; 1 for caregiver strain; and 4 for caregiver distress related to neuropsychiatric symptoms. Analyses run with and without the outliers did not significantly differ, and thus the outliers were kept in the sample in an effort to retain statistical power. Lastly, homogeneity of variance was assessed using Levene's test of homogeneity of variances and this assumption was met for all four two-way mixed ANCOVA analyses ($p > .05$).

Given that caregiver preparedness, caregiver income and living with a spouse/long-term partner significantly differed at baseline between the active and control groups, these three variables were chosen to be covariates (see *Table 3*) with the exception that baseline caregiver preparedness was not included as covariate when running the analyses for caregiver preparedness as the outcome variable. Caregiver preparedness was the most proximal outcome variable in this study. Results from the two-way mixed ANCOVA revealed a significant interaction effect between time and group ($F(1, 35) = 13.01$, $p = .001$, $\eta_p^2 = 0.27$). The effect of time on caregiver preparedness was dependent on which group the participant was in. Specifically, while mean caregiver preparedness score significantly increased over time for the active group, changing from 1.72 (SD = 0.54) to 2.49 (SD = 0.67), it remained invariant for the control group, shifting from 2.44 (SD = 0.69) to 2.43 (SD = 0.66; see *Table 4*). No significant main effects were found for time ($F(1, 35) = 1.93$, $p = .17$, $\eta_p^2 = 0.05$) and group ($F(1, 35) = 2.79$, $p = .10$, $\eta_p^2 = 0.07$), nor for any of the covariates.

The second two-way mixed ANCOVA examined the therapeutic effect on caregiver depressive symptoms. No significant main effects of time ($F(1, 34) = 0.92$, $p = .35$, $\eta_p^2 = 0.03$) and group ($F(1, 34) = 1.72$, $p = .20$, $\eta_p^2 = 0.05$) were found, and the interaction between time and group also was non-significant ($F(1, 34) = 1.87$, $p = .18$, $\eta_p^2 = 0.05$). However, mean caregiver preparedness score at baseline was a significant predictor ($F(1, 34) = 4.43$, $p = .04$, $\eta_p^2 = 0.12$) of depressive symptoms with correlation results revealing that caregiver preparedness was inversely related to depressive symptoms.

The third two-way mixed ANCOVA examined outcomes with respect to caregiver strain. Again, neither significant main effects of time ($F(1, 33) = 0.28$, $p = .60$, $\eta_p^2 = 0.01$) and group ($F(1, 33) = 0.42$, $p = .52$, $\eta_p^2 = 0.01$) nor interaction effect of time and group ($F(1, 33) = 0.01$, $p = .91$, $\eta_p^2 < 0.001$) were found. The covariates did not significantly relate to caregiver strain.

The fourth and final two-way mixed ANCOVA examined outcomes with respect to caregiver distress due to neuropsychiatric symptoms. Again, no significant main effects for time ($F(1, 29) = 0.04$, $p = .84$, $\eta_p^2 < 0.001$) or group ($F(1, 29) = 0.82$, $p = .37$, $\eta_p^2 = 0.03$), nor interaction effect of time and group ($F(1, 29) = 0.06$, $p = .80$, $\eta_p^2 < 0.001$) were found. The covariates also were non-significant. Please see *Table 5* for complete ANCOVA results.

The covariates were non-significant predictors of outcome variables, except for mean caregiver preparedness score at baseline predicting caregiver depression, and these analyses were arguably underpowered. To address the possibility that therapeutic effects were undetected as a result of power limitations, a second series of four two-way mixed ANOVA analyses without covariates were completed for each dependent variable and results remained very similar. For caregiver preparedness, results revealed a significant main effect for time and interaction effect for time and group; the main effect for group was approaching significance with $p = .06$.

Analogous to prior results, no significant main nor interaction effects of time and group were found for caregiver depressive symptoms, caregiver strain and caregiver distress related to neuropsychiatric symptoms.

Satisfaction survey results revealed that participants in the active group rated being in overall agreement with the following statements about the active caregiver support group: (A) the information provided was informative (M = 3.91, SD = 0.09); (B) the language used in group was easy to understand (M = 4.00, SD = 0.00); (C) the information discussed in group was useful (M = 3.91, SD = 0.09); (D) length of program was appropriate, (M = 3.82, SD = 0.08); and (E) willingness to recommend the group to other caregivers (M = 3.91, SD = 0.09). Please refer to *Figure 3* for depiction of results.

Linear regression analyses were run to determine if filial obligation moderated the relationship between care recipient symptoms and caregiver strain and caregiver depressive symptoms. Care recipient symptom scores were calculated by standardizing and then summing the following variables: ADL total score, IADL total score and NPI Symptom Severity scale score. Scores on filial obligation reflected a ceiling effect and thus, filial obligation was dichotomized using a median split (DeCoster, Gallucci, & Iselin, 2011; Iacobucci, Posavac, Kardes, Schneider, & Popovich, 2015). While more variability in filial obligation was anticipated, most participants attending a caregiver support group for their care recipient would feel personally responsible for the care of their aging loved one, and thus have high scores on filial obligation. No outliers were identified for either caregiver strain or caregiver depressive symptoms, and residuals were adequately independent, as assessed by Durbin-Watson statistics of 1.83 and 2.07, respectively. The assumption of homoscedasticity was met as assessed by visual inspection of a plot of standardized residuals versus standardized predicted values.

Multicollinearity was not present, as assessed by Variance Inflation Factor (VIF) scores that ranged between 1.03 and 1.98 and are well below the cut-off score of 10 (O'brien, 2007). Residuals were normally distributed as assessed by visual inspection of a normal probability plot. Stepwise linear regression models were then run, first entering care recipient symptom score and the median split obligation total score into the model (Model 1) and then entering the interaction term into the model (Model 2). For caregiver strain, care recipient symptom total and caregiver filial obligation only accounted for 1.4% of the variance (Adjusted $R^2 = 0.014$). Filial obligation did not moderate the effect of care recipient symptom total on caregiver strain, as evidenced by an increase in total variation explained of 3.5% with the addition of the interaction term, which was not statistically significant ($F(1, 34) = 1.31$, $p = .26$). Neither Model 1 nor Model 2 were significant, $F(2, 35) = 1.27$, $p = .29$ and $F(3, 34) = 1.29$, $p = .29$, respectively.

The second multiple regression examined whether filial obligation moderated the effect of care recipient impairment on caregiver depressive symptoms. Care recipient symptom total and caregiver filial obligation accounted for 12% of the variance in caregiver depressive symptoms. Filial obligation did not moderate the effect of care recipient symptom total on caregiver strain, as evidenced by an increase in total variation explained of 0.6% with the addition of the interaction term, which was not statistically significant ($F(1, 35) = 0.25$, $p = .62$). Model 1 was statistically significant ($F(2, 36) = 3.59$, $p = .04$), and filial obligation was a significant predictor of caregiver depressive symptoms ($\beta = 4.19$, SE = 1.86, $p = 0.03$). Care recipient total symptom score did not significantly predict caregiver depressive symptoms ($\beta = 0.77$, SE = 0.43, $p = 0.08$). Model 2 was not significant ($F(2, 35) = 2.43$, $p = .08$); however, filial obligation remained a significant predictor of caregiver depressive symptoms ($\beta = 4.25$, SE = 1.88, $p = 0.03$). See *Tables 6-8* for complete linear regression results.

CHAPTER 4: DISCUSSION

Overall, results partially support hypothesis 1 with mean caregiver preparedness scores significantly increasing over time for the active group and remaining essentially invariant for the control group. No significant effects were found for caregiver depressive symptoms, caregiver strain and caregiver distress related to neuropsychiatric symptoms and thus, hypotheses 2, 3 and 4 are not supported. Satisfaction survey results revealed that participants in the active caregiver support group were largely satisfied with the group and this supports hypothesis 5. Active group participants rated the language used in the group to be appropriate, the group to be informative, useful, and suitable in length, and stated that they would recommend the group to others. The auxiliary aim was not supported such that filial obligation was not found to moderate the relationships between care recipient symptom severity and caregiver depression and caregiver strain; however, filial obligation did significantly predict caregiver depression.

Significant increases in the mean caregiver preparedness score for the active caregiver support group suggests that the active caregiver support group facilitated development of caregiver preparedness. These results are to be expected and are consistent with past results of caregiver support groups that include a psychoeducational component (Hepburn et al., 2003; Hepburn et al., 2007). Session 2 in the active group, which increases the provision of information by discussing caregiver resources, may also have contributed to caregivers feeling more prepared. The control group's mean caregiver preparedness score did not change over the 6-week time period and this may reflect that the control caregiver support groups did not target caregiver preparedness. It is important to note that the control group's baseline mean caregiver preparedness score was similar to that of the active group's 6-week follow-up mean caregiver preparedness score. One hypothesis as to why the caregivers in the control group reported feeling more prepared at baseline is that they may have been attending the caregiver support group for a relatively longer period of time. Compared to the time-limited, 6-week active caregiver support group, community support groups tend to be ongoing for years with monthly meetings. As such, changes in caregiver preparedness and how long they took to come about for the community control participants remain unknown. The active caregiver support group, however, was able to increase its participants' perception of caregiver preparedness and further research in which new caregivers are randomized into the active and control groups may assist is determining if the active caregiver support group accelerates caregiver preparedness relative to a similar control group.

The literature on caregiver support interventions is mixed with respect to effects on caregiver burden (Schulz et al., 2002), and thus it is not surprising that results demonstrated that neither the active nor the control group significantly reduced caregiver strain. These results are also similar to findings from Gonyea and colleagues (2006), whose caregiver support group served as the foundation of the active caregiver support group. Given the inevitable progression of dementia disease processes, behavioral disturbances and level of dependence tend to increase over time, and these factors correlate with caregiver burden (Etters et al., 2008; Garre-Olmo et al., 2016; Papastavrou et al., 2007). Thus, it makes sense that caregiver burden tends to increase over time. Additionally, literature reviews of caregiver burden reveal variety in the definition of caregiver burden both operationally and conceptually (Stommel, Given, & Given, 2016), and this may contribute to the mixed findings in the literature. With respect to caregiver depressive symptomatolgy, our results were not consistent with caregiver support group meta-analytic results demonstrating small to moderate effect sizes for the reduction in caregiver depression

(Brodaty et al., 2003; Pinquart & Sorensen, 2006). It may be that 6-weeks is not enough time to produce measurable change in caregiver depression, which may be a more distal effect (Mittelman, 2008). It is also important to note that both the active and control group as a whole indicated that they were not experiencing clinically significant levels of depression at baseline (i.e., CESD-10 mean scores for both groups were less than the suggestive cut-off score of 10; E. M. Andresen et al., 1994), and thus, interfering with the ability to capture significant reductions in depressive symptomatology. Another possible explanation why depressive symptoms were not significantly improved is that the reported depressive symptoms experienced by caregivers consist of factors above and beyond caregiving that were not addressed by the intervention.

This study's null findings with respect to caregiver distress related to neuropsychiatric symptoms was incongruent with findings reported by Gonyea et al. (2006). One possible reason for non-significant results may be due to the smaller sample size and larger variability in distress scores (i.e., greater SD) in this sample relative to Gonyea's sample, which reduces the power to detect a difference. Additionally, a 6-week follow-up time period may not have been sufficient amount of time for the caregivers in the active caregiver support group to fully implement behavioral management strategies learned and observe changes. Contrary to findings by Gonyea and colleagues (2006), in a meta-analysis of non-pharmacological interventions for neuropsychiatric symptoms of dementia, Brodaty and Arasaratnam (2012) reported that interventions implemented by family caregivers are effective at reducing the neuropsychiatric symptoms when the interventions are tailored, include 9-12 sessions, delivered in the home and include 3-6 month follow-up contacts.

The null findings of filial obligation as a moderator between symptom severity and caregiver outcomes may reflect a ceiling effect secondary to selection bias. Specifically, the sample was highly skewed with respect to filial obligation such that most participants scored high on the measure of filial obligation. Given that these participants self-selected to engage in the caregiver support groups, it is not surprising that they scored highly on the filial obligation measure. It is suggested that future studies capture a wider range of filial obligation scores to better assess its role on the relationship between symptom severity and caregiver outcomes.

Results from the present study inform the caregiver support group literature about the efficacy of a brief, structured, targeted caregiver support group intervention. While the proposed 6-week active caregiver support group did not fully correspond with the hypothesized results, the group demonstrated increased caregiver preparedness with potentially other promising results that may be detected with larger sample sizes. Additionally, it is important to consider that the caregivers in the active support group rated the group to be informative and useful, and indicated that they would recommend this group to others. As mentioned by Mittleman (2008), a highly effective intervention that only attracts a small portion of caregivers may not be as worthwhile as an intervention that appeals to the majority of caregivers though may not be as effective. Further, the active caregiver support group is comprised of of qualities that have been associated with positive outcomes, including being multi-component, requiring active group member participation, maintaining the same group leader, and most notably, consisting of evidenced-base components (Alzheimer's Association, 2018; Chien et al., 2011; Cooke et al., 2001; Parker et al., 2008; Pusey & Richards, 2001). In their 2018 report, the Alzheimer’s Association cites that over half (52%) of Area Agencies on Aging did not offer evidenced-base family caregiver interventions.

Another notable quality of the active caregiver support group is that it requires limited resources and is able to be conducted in a primary care clinic, which can increase patients’ and their caregivers' access to care. As stated above, relative to the community control group caregivers, the active group caregivers reported less income, feeling less prepared at baseline and not living a significant other/long-term spouse. This systematic difference in caregivers may possibly suggest that the active caregiver support group held in a primary care clinic captured a subset of caregivers that do not attend community caregiver support groups. Further research examining self-selection of caregivers into particular types of groups may resolve this question.

It also has been suggested that the broad translation of caregiver interventions has been limited by the lack of an economic model for the delivery of these services (Gitlin et al., 2015). In this study, one limitation to participant recruitment for the active caregiver support group was a lack of integration with the primary care clinic's electronic medical record (EMR) system. Subsequently, medical providers did not have a streamlined method to refer potential participants and were continually reminded of the available behavioral health services. Thus, to overcome the nation-wide challenge of translating caregiver interventions in a sustainable manner, it is recommended that these behavioral medicine services be fully integrated on a systematic level and physician education occurs to facilitate appropriate referrals.

Current research supports collaborative care for patients with Alzheimer's in primary care. For example, Callahan et al. (2006) demonstrated that integrated teams, including psychologists who provide caregiver support, help reduce the psychiatric and behavioral symptoms of dementia and related caregiver distress without the use of medications. This is not only beneficial to the caregiver, but also may prevent care recipients from being prescribed medications that have adverse side effects (Brodaty & Arasaratnam, 2012). Recommendations to primary care physicians also have been made to include dementia caregiver evaluations and provide subsequent recommendations, resources and referrals (Dang, Badiye, & Kelkar, 2008;

Levine, 2003). Thus, having caregiver support groups in primary care clinics can provide primary care physicians with an accessible referral source and more effectively address caregiver distress.

Results of the active caregiver support group also revealed an attrition bias such that participants who did not complete the study were significantly younger than those who completed the study. Reasons for dropout per participants' verbal reports included lack of alternate caregiver for their care recipient, caring for young children and work-related responsibilities. This attrition bias reflects a large challenge faced in caregiver research – the underrepresentation of younger adult caregivers. National reports examining caregivers in the United States report that nearly half (48%) of the caregivers of adults with needs are between the ages of 18 and 49 (National Alliance for Caregiving & AARP, 2015), and yet mean ages of caregivers reported in the literature are between 43 and 72 (Chien et al., 2011). One explanation for this underrepresentation is that younger caregivers may have more competing demands, including work/education and romantic relationships. Some also may be sandwich generation caregivers – caring for an aging parent and children – and thus face conflicting caregiving demands (Alzheimer's Association, 2018). Given that younger caregivers report experiencing similar distress and desires for similar support resources (Levine et al., 2005), future research may want to explore options, including targeted outreach and technology-based interventions, to include them.

A major limitation of this research include small sample size, and thus limited power to detect significant changes over time and differences between groups. Post-hoc power analyses reveals that the observed power ranged from 2.9-10%. Small sample sizes remain to be a challenge for clinical and psychosocial intervention studies (Marszalek, Barber, Kohlhart, &

Holmes, 2011). Difficulties in recruiting and maintaining caregivers as participants include caregivers' occupational duties, lack of social support to assist in respite care, and other responsibilities and commitments (e.g., young children). Future research may benefit from further exploring adaptive technology such that caregiver interventions may be provided in the caregiver's preferred choice of location. Future research may also consider utilizing a randomized control trial and implementing mid-treatment data collection such that intent-to-treat analyses using multiple imputation methods may be computed for participants who do not complete treatment; this would help prevent loss of data due to incompletion.

Another limitation of the study is that the control group may not have been well-suited with respect to past caregiving experience. Also, the community control groups utilized were from a broader geographic location and met on a monthly basis, not weekly. While this comparison does not necessarily control for dosage effects, one benefit of sampling these caregivers in community control groups is that these community groups are representative of the groups most commonly utilized by caregivers (i.e., treatment as usual). Future research would benefit from a randomized control design, assessing how long caregivers have been providing care and caregivers' past experiences with support groups to help identify potential confounding variables. While outside the scope of this study, future research may also want to consider care recipient symptom severity and type of care recipient dementia when examining caregiver outcomes.

In their article about challenges and strategies for family care and dementia research, Zarit and Femia (2008) discuss challenges in finding significant findings and positive outcomes from caregiver intervention studies due to the heterogeneity amongst caregivers. They explain that caregivers not only vary in their presentation of burden and depression, but also that they have varying goals with respect to caregiving, and thus, may not all benefit from the same interventions. To better optimize caregiver intervention research, the authors recommend that investigators clearly identify goals of the intervention, define what successful change would be, and carefully select caregivers' whose identified needs align with the intervention's goals such that relevant changes can be detected (Zarit & Femia, 2008).

With the projected growth of the older adult population and increase in the prevalence of dementia, caregivers will continue to face associated physical, emotional, social and financial burden. While intensive support groups may be well-suited to caregiver needs, they are often difficult to implement given financial, personnel and resource constraints. The 6-week caregiver support group in this study offers a promising intervention that can be readily implemented and accessible in primary care clinics and further research, including replication with larger sample sizes, is recommended.

APPENDIX A: FIGURES

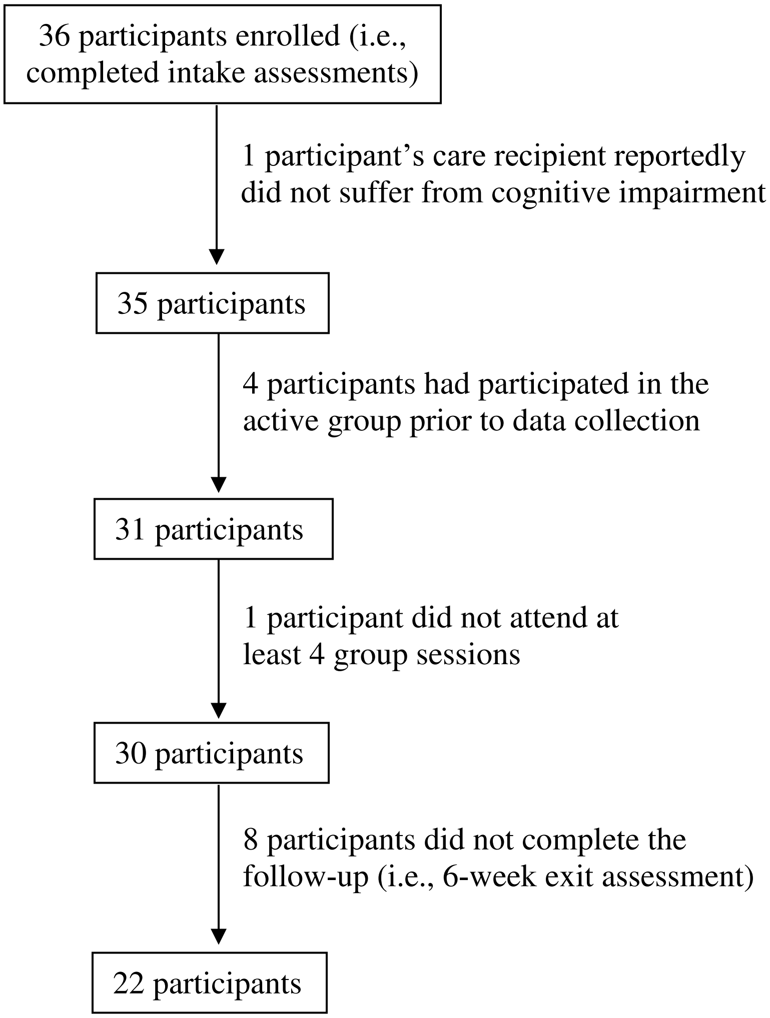


Figure 1: Active Group Sample Selection

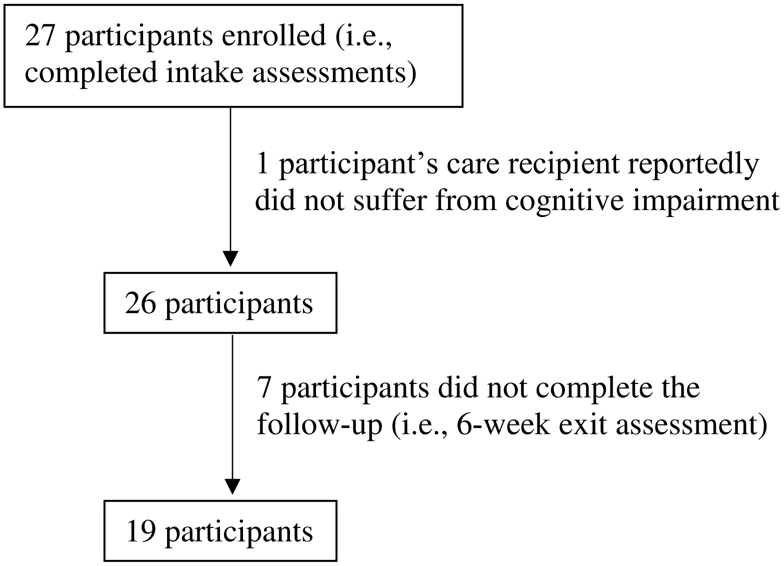


Figure 2: Control Group Sample Selection

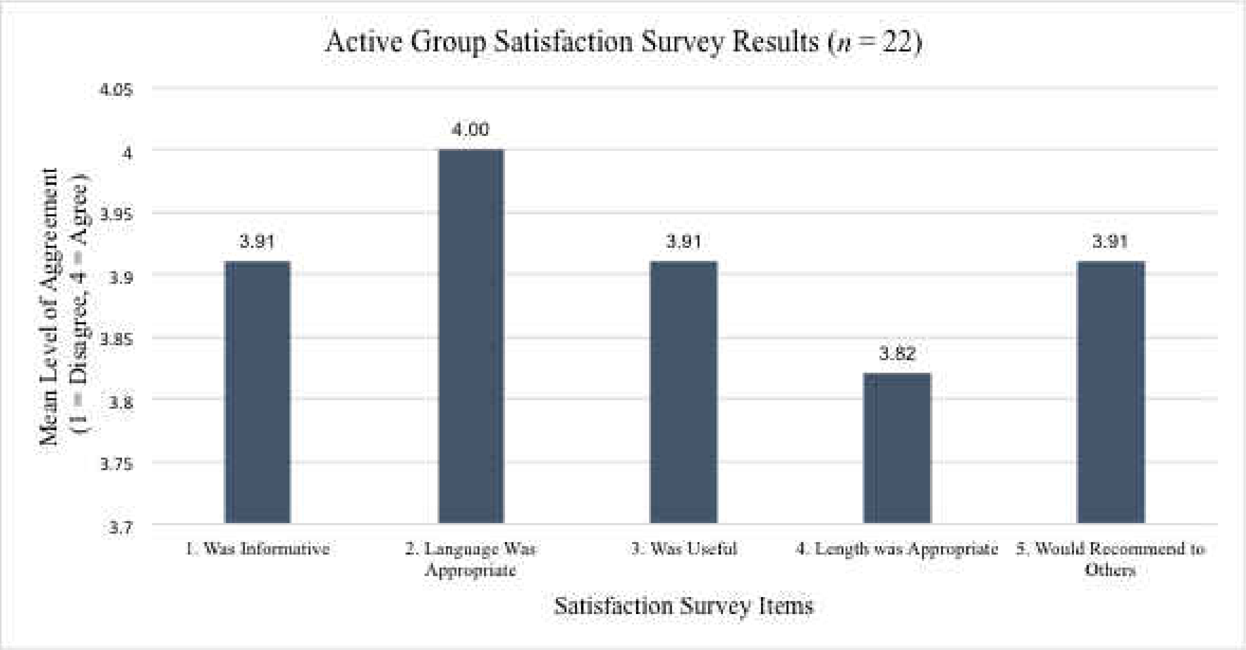
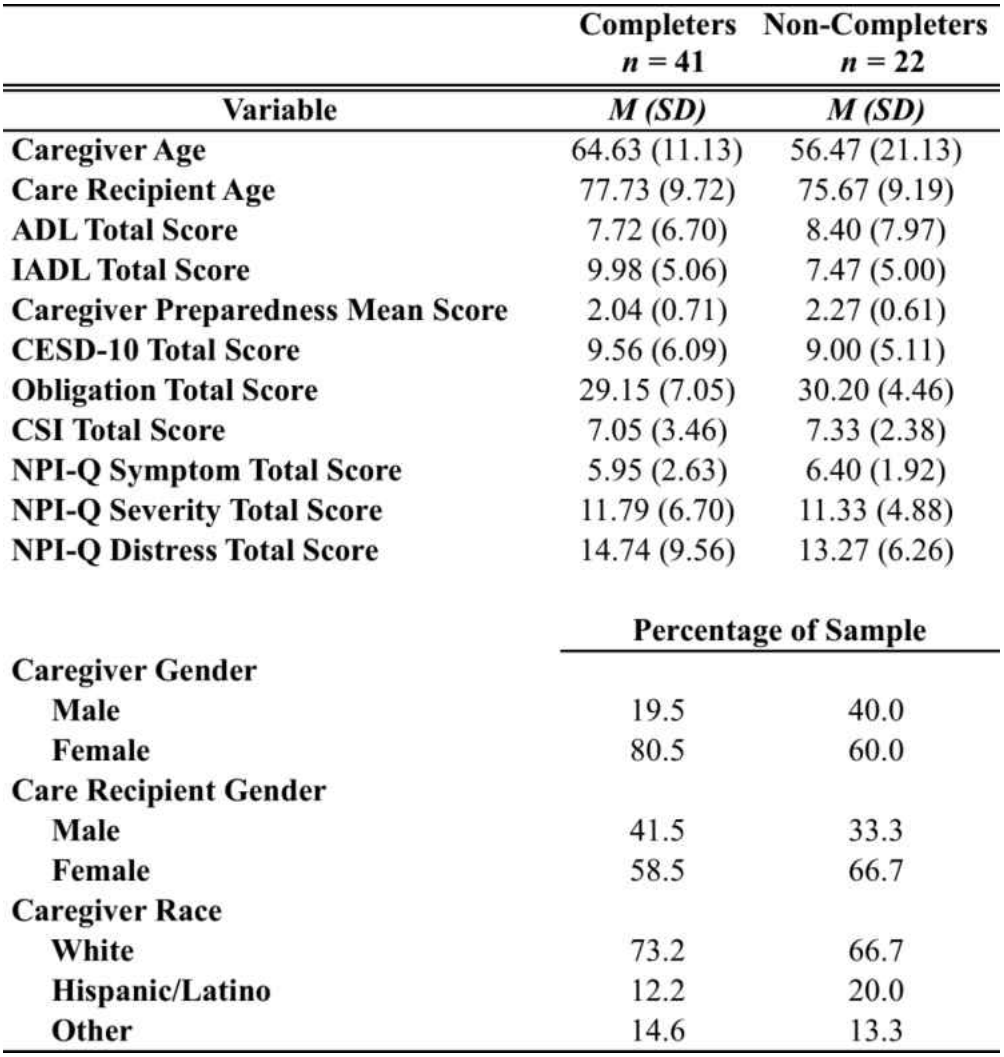


Figure 3: Satisfaction Survey Results for Active Group Participants

APPENDIX B: TABLES

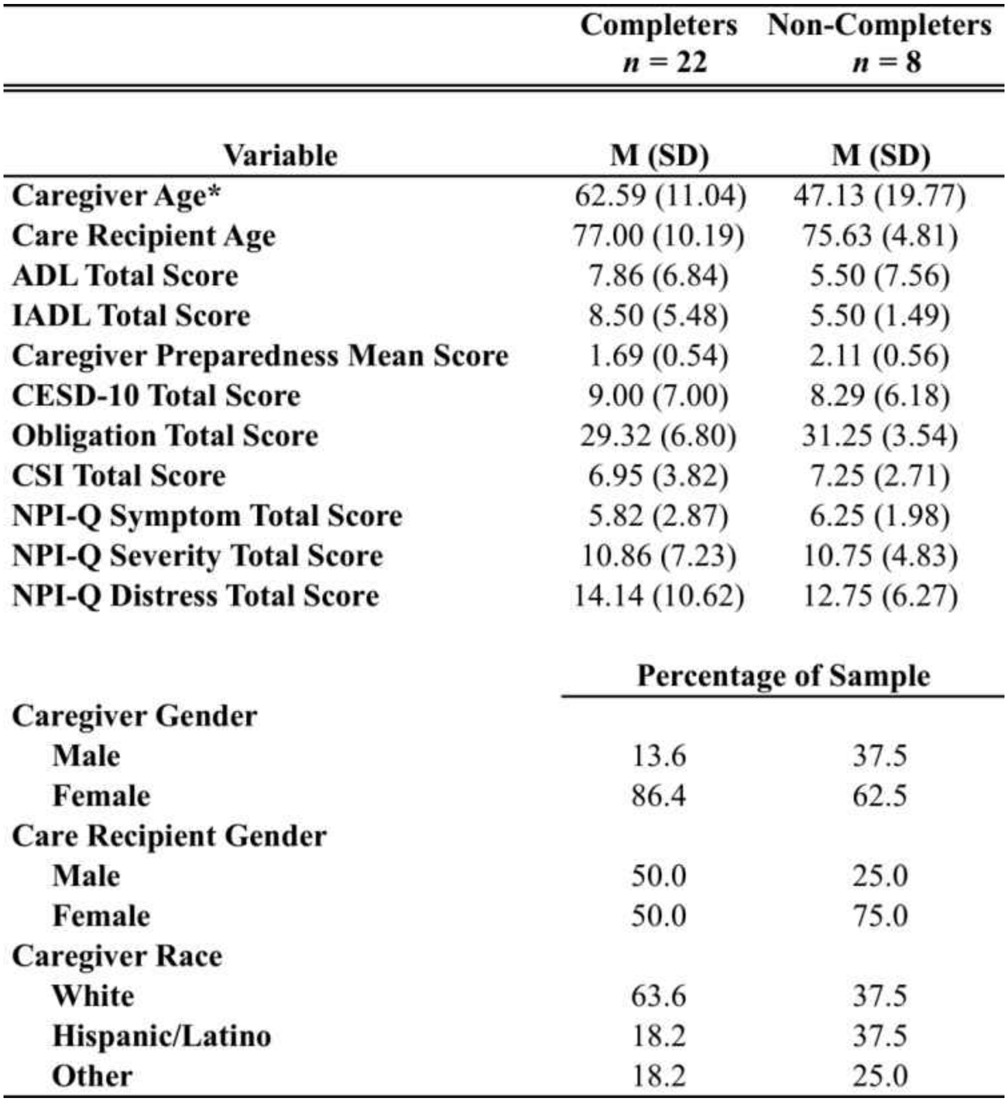
Table 1: Baseline comparisons between participants who met inclusionary criteria and completed the study (n = 41) and participants who met inclusionary criteria and did not complete the study (n = 22).



	Completers ***n* = 41**	**Non-Completers** ***n* = 22**
Variable	***M (SD)***	***M (SD)***
Caregiver Age	64.63 (11.13)	56.47 (21.13)
Care Recipient Age	77.73 (9.72)	75.67 (9.19)
ADL Total Score	7.72 (6.70)	8.40 (7.97)
IADL Total Score	9.98 (5.06)	7.47 (5.00)
Caregiver Preparedness Mean Score	2.04 (0.71)	2.27 (0.61)
CESD-10 Total Score	9.56 (6.09)	9.00 (5.11)
Obligation Total Score	29.15 (7.05)	30.20 (4.46)
CSI Total Score	7.05 (3.46)	7.33 (2.38)
NPI-Q Symptom Total Score	5.95 (2.63)	6.40 (1.92)
NPI-Q Severity Total Score	11.79 (6.70)	11.33 (4.88)
NPI-Q Distress Total Score	14.74 (9.56)	13.27 (6.26)
	Percentage of Sample	
Caregiver Gender		
Male	19.5	40.0
Female	80.5	60.0
Care Recipient Gender		
Male	41.5	33.3
Female	58.5	66.7
Caregiver Race		
White	73.2	66.7
Hispanic/Latino	12.2	20.0
Other	14.6	13.3

	Completers *n* = 41	Non-Completers *n* = 22
Variable	**Percentage of Sample**	
Caregiver Annual Income		
Less than $20,000	2.6	21.4
$20,000-$39,9999	17.9	21.4
$40,000-$64,999	20.5	7.1
$65,000-$104,999	33.3	14.3
$105,000 or more	25.6	35.7
Caregiver Hours/Week Work		
0 hours	55.0	53.3
1-10 hours	2.5	6.7
11-20 hours	7.5	6.7
21-30 hours	7.5	6.7
31-40 hours	10.0	-
more than 40 hours	17.5	26.7
Caregiver's Highest Level of Education		
Less than 12th Grade	2.4	-
High School Degree	4.9	-
Some College	24.4	20.0
Associate's Degree	12.2	6.7
Bachelor's Degree	36.6	46.7
Graduate Degree	19.5	26.7
Caregiver Lives with Spouse/Partner	80.5	66.7
Relationship to Care Recipient		
Child	43.6	33.3
Spouse	46.2	46.7
Sibling	2.6	-
Other Relative	7.7	20.0
Care Recipient Residence		
Caregiver's home	46.3	42.9
Their own home	17.1	42.9
Nursing home	2.4	-
Assisted Living Facility	14.6	14.3
Other Relative's Home	7.3	-
Other	12.2	-

Table 2: Baseline comparisons between active group participants who met inclusionary criteria and completed the study (n = 22) and active group participants who met inclusionary criteria but did not complete the study (n = 8).

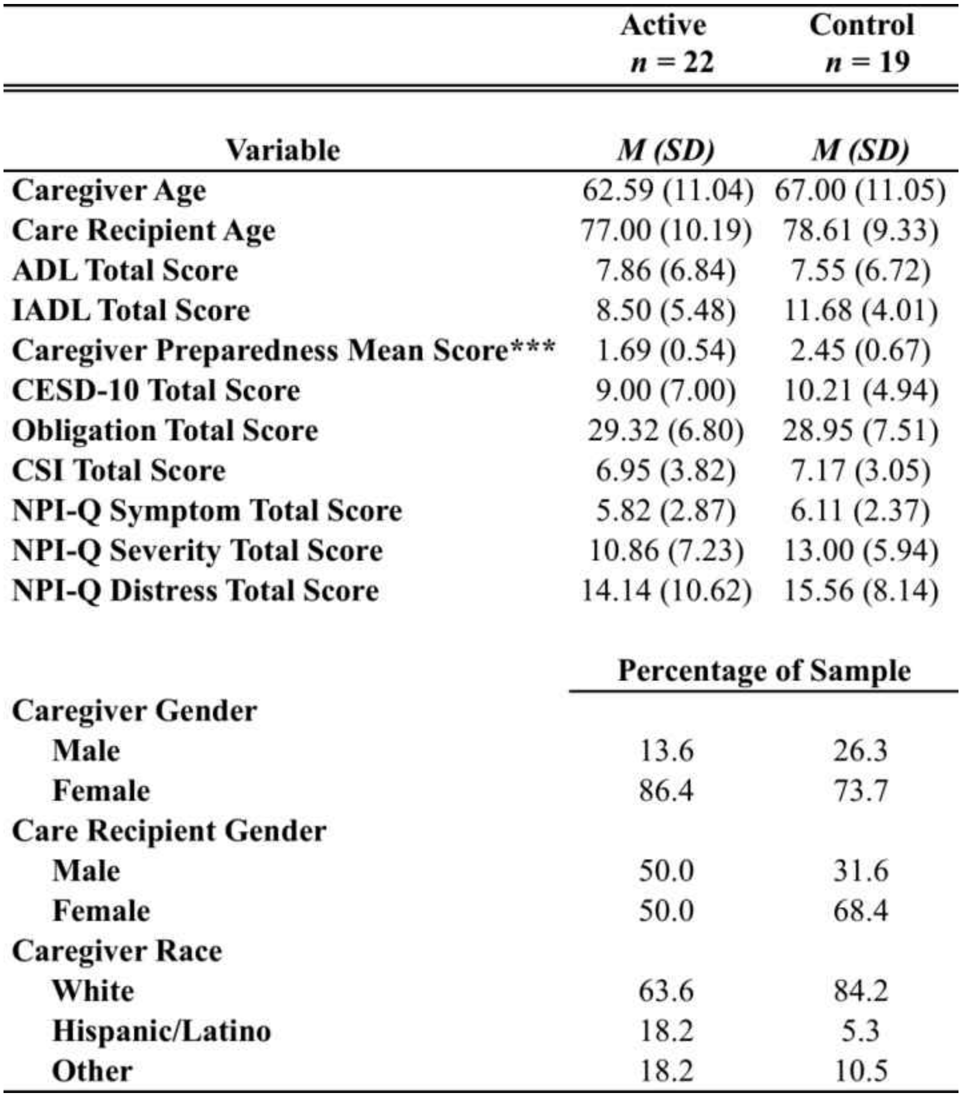


	Completers *n* = 22	**Non-Completers** *n* = 8
Variable	**M (SD)**	**M (SD)**
Caregiver Age*	62.59 (11.04)	47.13 (19.77)
Care Recipient Age	77.00 (10.19)	75.63 (4.81)
ADL Total Score	7.86 (6.84)	5.50 (7.56)
IADL Total Score	8.50 (5.48)	5.50 (1.49)
Caregiver Preparedness Mean Score	1.69 (0.54)	2.11 (0.56)
CESD-10 Total Score	9.00 (7.00)	8.29 (6.18)
Obligation Total Score	29.32 (6.80)	31.25 (3.54)
CSI Total Score	6.95 (3.82)	7.25 (2.71)
NPI-Q Symptom Total Score	5.82 (2.87)	6.25 (1.98)
NPI-Q Severity Total Score	10.86 (7.23)	10.75 (4.83)
NPI-Q Distress Total Score	14.14 (10.62)	12.75 (6.27)
	Percentage of Sample	
Caregiver Gender		
Male	13.6	37.5
Female	86.4	62.5
Care Recipient Gender		
Male	50.0	25.0
Female	50.0	75.0
Caregiver Race		
White	63.6	37.5
Hispanic/Latino	18.2	37.5
Other	18.2	25.0

	Completers	**Non-Completers**
	$n = 22$	**$n = 8$**
Variable	**Percentage of Sample**	
Caregiver Annual Income		
Less than $20,000	-	37.5
$20,000-$39,9999	33.3	12.5
$40,000-$64,999	23.8	12.5
$65,000-$104,999	23.8	12.5
$105,000 or more	19.0	25.0
Caregiver Hours/Week Work		
0 hours	54.5	37.5
1-10 hours	-	12.5
11-20 hours	4.5	12.5
21-30 hours	4.5	12.5
31-40 hours	18.2	-
more than 40 hours	18.2	25.0
Caregiver's Highest Level of Education		
Less than 12th Grade	4.5	-
High School Degree	9.1	-
Some College	22.7	25.0
Associate's Degree		12.5
Bachelor's Degree		37.5
Graduate Degree or greater	63.7	25.0
Caregiver Lives with Spouse/Partner	68.2	62.5
Relationship to Care Recipient		
Child	47.6	37.5
Spouse	38.1	25.0
Sibling	4.8	-
Other Relative	9.5	37.5
Care Recipient Residence		
Caregiver's home	36.4	28.6
Their own home	31.8	71.4
Nursing Home	4.5	-
Assisted Living Facility	13.6	-
Other Relative's Home	4.5	-
Other	9.1	-

*$p < 0.05$

Table 3: Baseline comparisons between particiants in the active group who met inclusionary criteria and completed the study (n = 22) and participants in the control group who met inclusionary criteria and completed the study (n = 19).

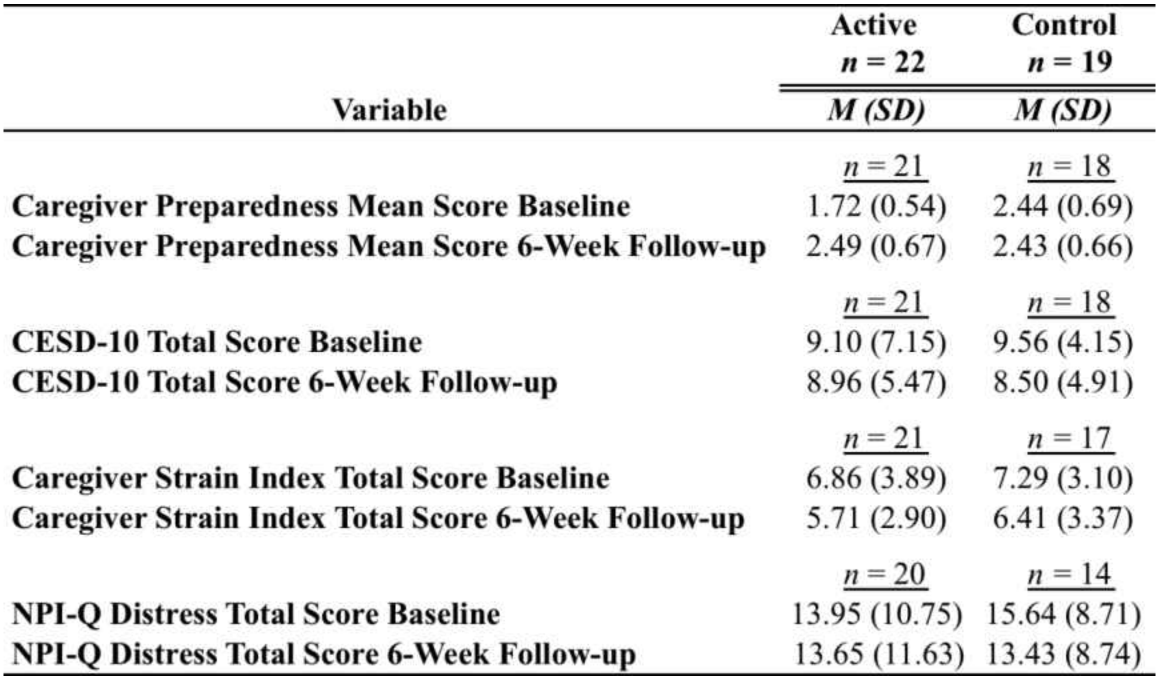


	Active ***n* = 22**	**Control** ***n* = 19**
Variable	***M (SD)***	***M (SD)***
Caregiver Age	62.59 (11.04)	67.00 (11.05)
Care Recipient Age	77.00 (10.19)	78.61 (9.33)
ADL Total Score	7.86 (6.84)	7.55 (6.72)
IADL Total Score	8.50 (5.48)	11.68 (4.01)
Caregiver Preparedness Mean Score* **	1.69 (0.54)	2.45 (0.67)
CESD-10 Total Score	9.00 (7.00)	10.21 (4.94)
Obligation Total Score	29.32 (6.80)	28.95 (7.51)
CSI Total Score	6.95 (3.82)	7.17 (3.05)
NPI-Q Symptom Total Score	5.82 (2.87)	6.11 (2.37)
NPI-Q Severity Total Score	10.86 (7.23)	13.00 (5.94)
NPI-Q Distress Total Score	14.14 (10.62)	15.56 (8.14)
	Percentage of Sample	
Caregiver Gender		
Male	13.6	26.3
Female	86.4	73.7
Care Recipient Gender		
Male	50.0	31.6
Female	50.0	68.4
Caregiver Race		
White	63.6	84.2
Hispanic/Latino	18.2	5.3
Other	18.2	10.5

	Active *n* = 22	Control *n* = 19
Variable	**Percentage of Sample**	
Caregiver Annual Income*		
Less than $20,000	-	5.6
$20,000-$39,9999	33.8	-
$40,000-$64,999	23.8	16.7
$65,000-$104,999	23.8	44.4
$105,000 or more	19.0	33.3
Caregiver Hours/Week Work		
0 hours	54.5	55.6
1-10 hours	-	5.6
11-20 hours	4.5	11.1
21-30 hours	4.5	11.1
31-40 hours	18.2	-
more than 40 hours	18.2	16.7
Caregiver's Highest Level of Education		
8th to 11th Grade	4.5	-
12th Grade	9.1	-
Some College	22.7	26.3
Associate's Degree	-	26.3
Bachelor's Degree	40.9	31.6
Graduate Degree or greater	22.7	15.8
Caregiver Lives with Spouse/Partner*	68.2	94.7
Relationship to Care Recipient		
Child	47.6	38.9
Spouse	38.1	55.6
Sibling	4.8	-
Other Relative	9.5	5.6
Care Recipient Residence		
Caregiver's Home	36.4	57.9
Their Own Home	31.8	-
Nursing Home	4.5	-
Assisted Living Facility	13.6	15.8
Other Relative's Home	4.5	10.5
Other	9.1	15.8

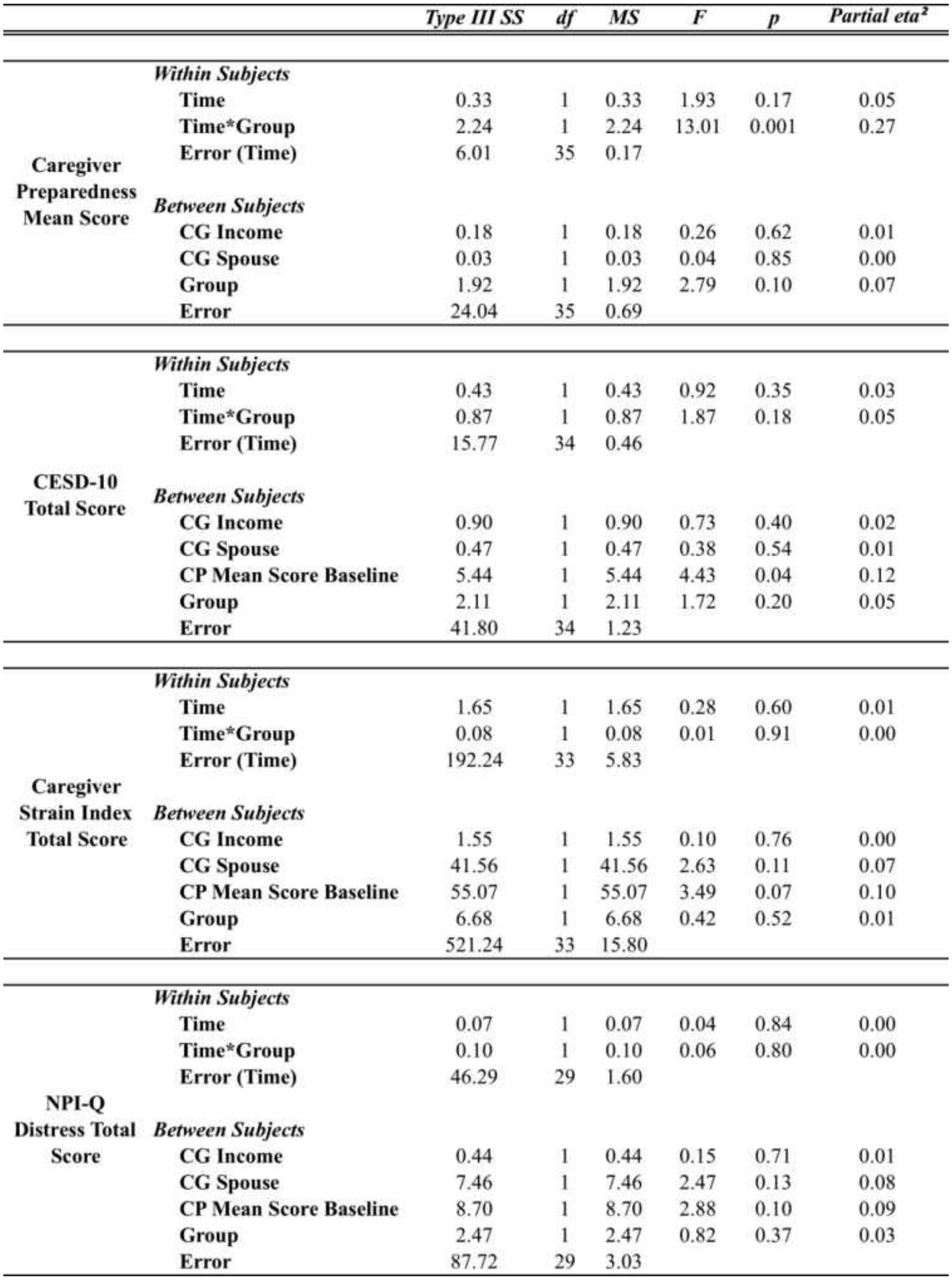
*$p < .05$; **$p < .01$; ***$p < .001$

Table 4: Baseline comparisons on outcome measures between particiants in the active group who met inclusionary criteria and completed the study (n = 22) and participants in the control group who met inclusionary criteria and completed the study (n = 19).



	Active	**Control**
	***n* = 22**	***n* = 19**
Variable	***M (SD)***	***M (SD)***
	n = 21	*n* = 18
Caregiver Preparedness Mean Score Baseline	1.72 (0.54)	2.44 (0.69)
Caregiver Preparedness Mean Score 6-Week Follow-up	2.49 (0.67)	2.43 (0.66)
	n = 21	*n* = 18
CESD-10 Total Score Baseline	9.10 (7.15)	9.56 (4.15)
CESD-10 Total Score 6-Week Follow-up	8.96 (5.47)	8.50 (4.91)
	n = 21	*n* = 17
Caregiver Strain Index Total Score Baseline	6.86 (3.89)	7.29 (3.10)
Caregiver Strain Index Total Score 6-Week Follow-up	5.71 (2.90)	6.41 (3.37)
	n = 20	*n* = 14
NPI-Q Distress Total Score Baseline	13.95 (10.75)	15.64 (8.71)
NPI-Q Distress Total Score 6-Week Follow-up	13.65 (11.63)	13.43 (8.74)

Table 5: Results from the Four Separate Two-way Mixed ANCOVA Analyses. The within factor was time (baseline and 6-weeks), between factor was group (active or control) and covariates were baseline caregiver income (CG Income), baseline caregiver residing with spouse/long-term partner (CG Spouse) and baseline mean caregiver preparedness score (CP Mean Score Baseline). The four outcome measures were Caregiver Preparedness Mean Score, CESD-10 Total Score (caregiver depressive symptoms), Caregiver Strain Index Total Score, and NPI-Q Distress Total score (caregiver distress related to care recipient's neuropsychiatric symptoms).

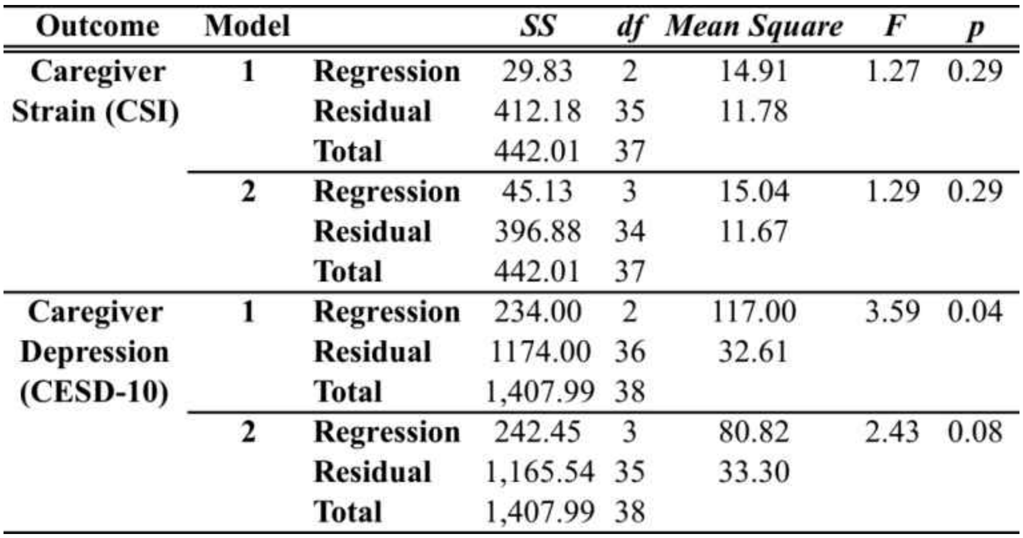


		Type III SS	*df*	*MS*	*F*	*p*	*Partial eta^2*
Caregiver Preparedness Mean Score	***Within Subjects***						
	Time	0.33	1	0.33	1.93	0.17	0.05
	Time*Group	2.24	1	2.24	13.01	0.001	0.27
	Error (Time)	6.01	35	0.17			
	Between Subjects						
	CG Income	0.18	1	0.18	0.26	0.62	0.01
	CG Spouse	0.03	1	0.03	0.04	0.85	0.00
	Group	1.92	1	1.92	2.79	0.10	0.07
	Error	24.04	35	0.69			
CESD-10 Total Score	***Within Subjects***						
	Time	0.43	1	0.43	0.92	0.35	0.03
	Time*Group	0.87	1	0.87	1.87	0.18	0.05
	Error (Time)	15.77	34	0.46			
	Between Subjects						
	CG Income	0.90	1	0.90	0.73	0.40	0.02
	CG Spouse	0.47	1	0.47	0.38	0.54	0.01
	CP Mean Score Baseline	5.44	1	5.44	4.43	0.04	0.12
	Group	2.11	1	2.11	1.72	0.20	0.05
	Error	41.80	34	1.23			
Caregiver Strain Index Total Score	***Within Subjects***						
	Time	1.65	1	1.65	0.28	0.60	0.01
	Time*Group	0.08	1	0.08	0.01	0.91	0.00
	Error (Time)	192.24	33	5.83			
	Between Subjects						
	CG Income	1.55	1	1.55	0.10	0.76	0.00
	CG Spouse	41.56	1	41.56	2.63	0.11	0.07
	CP Mean Score Baseline	55.07	1	55.07	3.49	0.07	0.10
	Group	6.68	1	6.68	0.42	0.52	0.01
	Error	521.24	33	15.80			
NPI-Q Distress Total Score	***Within Subjects***						
	Time	0.07	1	0.07	0.04	0.84	0.00
	Time*Group	0.10	1	0.10	0.06	0.80	0.00
	Error (Time)	46.29	29	1.60			
	Between Subjects						
	CG Income	0.44	1	0.44	0.15	0.71	0.01
	CG Spouse	7.46	1	7.46	2.47	0.13	0.08
	CP Mean Score Baseline	8.70	1	8.70	2.88	0.10	0.09
	Group	2.47	1	2.47	0.82	0.37	0.03
	Error	87.72	29	3.03			

Table 6: Linear Regression Model Results – Variance of outcome variables accounted for by models.

						Change Statitics				
Outcome	**Model**	***R***	***R^2***	**Adjusted *R^2***	***SE***	***R^2* Change**	***F* change**	***df1***	***df2***	***p***
Caregiver Strain	**1**	0.260	0.067	0.014	3.43	0.067	1.27	2	35	0.29
(CSI)	**2**	0.320	0.102	0.023	3.42	0.035	1.31	1	34	0.26
Caregiver Depression	**1**	0.408	0.166	0.120	5.71	0.166	3.59	2	36	0.04
(CESD-10)	**2**	0.415	0.172	0.101	5.77	0.006	0.25	1	35	0.62

Table 7: Linear Regression Model Results – Model significance.



Outcome	Model		*SS*	*df*	*Mean Square*	*F*	*p*
Caregiver Strain (CSI)	**1**	**Regression**	29.83	2	14.91	1.27	0.29
		Residual	412.18	35	11.78		
		Total	442.01	37			
	2	**Regression**	45.13	3	15.04	1.29	0.29
		Residual	396.88	34	11.67		
		Total	442.01	37			
Caregiver Depression (CESD-10)	**1**	**Regression**	234.00	2	117.00	3.59	0.04
		Residual	1174.00	36	32.61		
		Total	1,407.99	38			
	2	**Regression**	242.45	3	80.82	2.43	0.08
		Residual	1,165.54	35	33.30		
		Total	1,407.99	38			

Table 8: Linear Regression Results – Model 1 with main effects of care recipient symptom total (CR Symptom Total) and caregiver obligation (CG Obligation) and Model 2 with the addition of interaction term between care recipient symptom total and caregiver obligation (Interaction CRSymp*CGObl).

Outcome	Model	Predictor	Unstandardized β	*SE*	Standardized β	*t*	*p*	95% CI
Caregiver Strain (CSI)	**1**	**(Constant)**	6.85	0.80		8.56	0.00	5.22 - 8.47
		CR Symptom Total	0.41	0.26	0.26	1.58	0.12	-0.12 - 0.94
		CG Obligation	0.50	1.13	0.07	0.44	0.66	-1.80 - 2.79
	2	**(Constant)**	6.79	0.80		8.50	0.00	5.16 - 8.41
		CR Symptom Total	0.70	0.36	0.44	1.94	0.06	-0.03 - 1.43
		CG Obligation	0.41	1.13	0.06	0.36	0.72	-1.89 - 2.70
		Interaction CRSym*CGObl	-0.60	0.52	-0.26	-1.15	0.26	-1.65 - 0.46
Caregiver Depression (CESD-10)	**1**	**(Constant)**	7.51	1.31		5.72	0.00	4.85 - 10.12
		CR Symptom Total	0.77	0.43	0.28	1.80	0.08	-0.10 - 1.64
		CG Obligation	4.19	1.86	0.35	2.26	0.03	0.42 - 7.95
	2	**(Constant)**	7.56	1.33		5.68	0.00	4.86 - 10.26
		CR Symptom Total	0.56	0.60	0.20	0.93	0.36	-0.66 - 1.78
		CG Obligation	4.25	1.88	0.35	2.26	0.03	0.44 - 8.07
		Interaction CRSym*CGObl	0.44	0.87	0.11	0.50	0.62	-1.32 - 2.19

APPENDIX C: CAREGIVER SUPPORT GROUP MANUAL

Caregiver Support Group Experimental Intervention: Session Outlines

1. Meeting 1 - Introduction
    a. Intake paperwork
        i. Consent for Services
        ii. Release of Information (if applicable)
        iii. Personal Health Information Notice
        iv. Intake Assessment Survey Packet
    b. Caregivers introduce themselves to begin to foster group rapport
        i. First names
        ii. Who is their care recipient, and what are their main problems
        iii. Hobbies/what they do for fun, and the last time they did something fun
    c. Overview of group goals and guidelines
        i. Individual preferences for aging-in-place and LTC utilization
        ii. Social need for informal caregiving
        iii. Preventing or postponing the transition to long-term care
        iv. Caregiver self-care, burden, depression, neglect, burnout, and caregiving ruptures VS appropriate, compassionate utilization of professional services
        v. Informal Support Groups VS Caregiver Interventions
    d. Therapists give overview of Alzheimer's disease/dementia and caregiver burden. *****This may require modification based on group members' needs**
        i. Cognitive Symptoms
            1. Forgetfulness
            2. Verbal difficulties
        ii. Psychiatric Symptoms
            1. Sleep disturbances
            2. Agitation (physical or verbal outbursts, distress, restlessness, pacing, yelling)
            3. Delusions – firmly held beliefs in things that are not real
            4. Hallucinations – seeing or hearing things that are not there
        iii. Neuropsychiatric symptoms associated with Alzheimer's disease
            1. Explain that they, like memory loss, are symptoms of the disease
    e. The Intervention
        i. Concept #1: Our behaviors affect our feelings about ourselves and those around us.
            1. If we do fun things with a friend, we may feel closer to that person.
            2. Enjoyable hobbies help us to break up difficult or monotonous times of our life. People who don't take breaks from difficult things like work or caregiving feel sad, feel more depressed, feel more anxious, and burn out much faster.
            3. Describe the importance of pleasant activities, behavioral activation, and self-care.
            4. Describe the importance of increasing pleasant activities as one method for improving care recipients' behavior the caregiver–care recipient relationship.

        ii. **Concept #2: We can change other people's behaviors by changing the way we react to them.**
            1. Pick a behavior - any behavior. That behavior can probably be made more frequent or less frequent through reward or punishment, respectively.
            2. Positive rewards can work very effectively to increase the frequency of a positive behavior.
            3. We want to identify undesirable/problem/difficult behaviors (Targets) and interact with our care recipients in ways that increase positive behaviors.
            4. First, we have to pick some behaviors to change. Some examples include:
                a. Arguing
                b. Wandering
                c. Nutritional Rejection
                d. Sundowning
        iii. **Concept #3: Awareness and utilization of resources to assist navigating through this difficult process.**
            1. Briefly mention ADRC coming to next meeting to provide valuable resources.
    f. Therapists present:
        i. Pleasant Events Activity List
        ii. Pleasant Activity Log.
    g. Caregiver Homework:
        i. Record daily pleasant activities
        ii. Generate three ideas for future pleasant events

2. Meeting 2 – ADRC Meeting
    a. Review Homework
        i. Elicit group members to share pleasant activities they engaged in.
        ii. Clarify homework where necessary. Often people simply identify pleasant events they were already planning, or identifying normal day-to-day experiences (making tea in the morning) as a pleasant event.
        iii. Identify the target behaviors. Clarify conceptual misunderstandings.
        iv. Provide a second Pleasant Activity Log and a Target Behavior Log for this week's homework.
    b. Introduce Alzheimer's and Dementia Resource Center (ADRC) Representative
        i. Describe the ADRC
            1. Commitment to promoting informal caregiving
            2. Describe their goals regarding putting caregivers in contact with community resources, such as attorneys specializing in aging issues (guardianship and conservatorship), regional caregiver support care groups, professional and paraprofessionals specializing in facilitating in-home care, etc.
        ii. Present the individual and his/her qualifications

c. ADRC representative will:
    i. Discuss further their niche in facilitating informal caregiving
    ii. Discuss the challenges of working with the caregiving system
    iii. Distribute contact information and other relevant materials describing various resources to the group
    iv. Address questions raised by group members
d. Review Caregiver homework:
    i. Schedule, complete, and log pleasant events
    ii. Track number of target behavior events this week

3. Meeting 3 – Increasing Pleasant Events and Improving Communication
    a. Review homework:
        i. What types of activities did they do? How many activities did they count?
            1. How did they feel about it this time?
            2. Discuss the importance of engaging in pleasant events as a method for improving care recipients' behavior; Behavioral Activation; Accomplishment
        ii. Review selected target behaviors
            1. Discuss frequency of target behaviors
            2. Did they notice anything about what came before or after the target behaviors?
    b. Introduce Fundamentals of Behavior Management
        i. Talk about ABC's
            1. Antecedent: What events happen before the behavior.
            2. Behavior: Describe (which we've done already).
            3. Consequences: What happens after the behavior.
        ii. Illustrate this with an example from the group
            1. What happens before the behavior?
            2. What happens after the behavior?
                a. Now, why is this behavior persisting?
        iii. Introduce behavioral management theory: they teach how to identify and define problem behaviors, and their antecedents, and consequences.
            1. When we know the antecedent (what prompts the behavior), and the consequence (what reinforces the behavior), then we can figure out how to how we interact with our family members to improve relationships and reduce distress.
                a. Antecedents – Raise the following questions:
                    i. How does our family member experience the antecedent?
                    ii. Can the antecedent be prevented altogether?
                    iii. Can we revise how the family member experiences the antecedent?
                b. Behavior – What is the goal of the behavior?
                    i. What are they trying to accomplish?
                c. Consequence – How is our behavior reinforcing the target

behavior?

i. Types of reinforcement:
   1. Attention
   2. Getting something accomplished
   3. Experiencing a feeling of support
   4. Transferring personal responsibilities to others
   5. Feeling of freedom to… eat as they wish, go out, etc.

2. These skills are used by managers, day care workers, and nursing home personnel alike.
3. **ALL PEOPLE RESPOND THE SAME WAY, even you.**

iv. Caregiver Homework:
   1. Engage in one pleasant activity daily
   2. Identify and record care recipient target behaviors, when they occur, why they are upsetting, and how they have to be changed

4. Meeting 4 – Increasing Pleasant Events and Understanding Behavior
   a. Review homework
   b. Pleasant Events
      i. Discuss strategies for increasing pleasant events
      ii. Problem-solve around difficulties that may have occurred as caregivers attempted to engage in pleasant activities.
   c. ABC's:
      i. Provide and review the ABC Form.
      ii. Evaluate understanding of ABC model
      iii. Go from person to person, each providing a recent example
      iv. Answer questions and address misunderstandings of the model
   d. Discuss strategies to improve communication.
   e. Discuss Goal Setting
      i. Could frequency of the target behavior be reduced?
      ii. What behaviors might replace the target behavior?
   f. Basic Strategies for Changing Relationships
      i. Preemptively meet family member's need for food, water, socialization, toileting, sleep
      ii. Engage family member positively at non-distressed times
      iii. Redirect toward pleasurable activities (e.g., listening to music, playing a game, life-review)
      iv. Give complements, especially if target behaviors are replaced by a preferable behavior.

      ➔ The goal of these strategies is to **reduce distress.**
   g. Caregiver Homework:
      i. Engage in one new pleasant activity daily
      ii. Compliment the individual with dementia at least one time every day

5. Meeting 5 – Understanding and Changing Difficult Behaviors
    a. Review:
        i. Homework
        ii. Definition of target behaviors, their antecedents, and consequences
    b. Present the ABC behavioral chain and continue teaching behavior modification techniques.
    c. Help caregivers practice goal setting and employ methods for changing problem behaviors in the home.
    d. Caregiver Homework:
        i. Add one more pleasant event every day
        ii. Choose one target behavior and attempt to modify it on the basis of the presented and practiced strategies

6. Meeting 6 – Final Review: Where Do We Go From Here?
    a. Review:
        i. Homework
        ii. Lessons on understanding behavior
        iii. ABCs of behavior
        iv. Behavior modification techniques
    b. Problem-solve difficulties caregivers had in modifying behaviors at home, and provide guidance on how to continue using these new skills in the future.
    c. Discuss and explore thoughts about and plans for the future.
    d. Recognize group members for the completion of the group, their contributions, personal growth, challenges, and willingness to participate and share.

APPENDIX D: CAREGIVER SUPPORT GROUP INTAKE PACKET

Participant Name: ______________________

Caregiver Support Group Intake Survey

OLDeR Lab

University of Central Florida

What is your birth month? (Bubble only one)

January	February	March	April	May	June	July	August	September	October	November	December
○	○	○	○	○	○	○	○	○	○	○	○

How tall are you? (Bubble only one)

≤4'11"	5'0"	5'1"	5'2"	5'3"	5'4"	5'5"	5'6"	5'7"	5'8"	5'9"	5'10"	5'11"	6'0"	6'1"	6'2"	6'3"	6'4"	≥6'5"
○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○

How many full BIOLOGICAL SIBLINGS do you have? (not step or half)

0 1 2 3 4 5 (or more)

What is the FIRST LETTER of your *MOTHER'S* FIRST Name?

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

What is the FIRST LETTER of your *FATHER'S* FIRST Name?

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

With whom do you live? (Bubble *all that apply*)

Roommate(s)	Alone	Parent(s)	Significant Other	Other
○	○	○	○	○

How many hours do you typically work at a job, PER WEEK?

0	5-10	11-20	21-30	31-40	More than 40
○	○	○	○	○	○

What is your *FATHER'S* highest level of education? (Please bubble ONE)

Less than High School	Some High School	High School Diploma/ GED	Some College	Associate's Degree (A.A. or A.S.)	Bachelor's Degree	Graduate Degree
○	○	○	○	○	○	○

What is your *MOTHER'S* highest level of education? (Please bubble ONE)

Less than High School	Some High School	High School Diploma/ GED	Some College	Associate's Degree (A.A. or A.S.)	Bachelor's Degree	Graduate Degree
○	○	○	○	○	○	○

What is your current relationship status?

Single, Never Married	Long-term Relationship (Unmarried)	Married or Domestic Partnership	Separated	Divorced	Widowed
○	○	○	○	○	○

What is the first letter of the high school you graduated from?

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

Where does your care recipient reside?

o in your home
o in his/her own home
o in other family member's home
o nursing home
o assisted living facility
o hospital
o other (please specify): ______________________

Is your care recipient receiving hospice?

o Yes
o No

Does your care recipient suffer from cognitive impairment?

o Yes
o No

Demographic Survey

CAREGIVERS

1. **Sex** ***(please circle one)*:**
   Male Female
2. **Age** ***(in years)*:** ____________
3. **Ethnicity** ***(please check all that apply)*:**
   a. ______ African-American/ Black
   b. ______ American Indian/Native Alaskan
   c. ______ Asian/Southeast Asian/Asian-American
   d. ______ Caucasian/European/White
   e. ______ Native Hawaiian/Other Pacific Islander
   f. ______ Latino(a)/ Hispanic
4. **Highest Level of Education Completed:**
   a. ______ Less than 8th grade
   b. ______ 8th to 11th grade
   c. ______ 12th grade
   d. ______ Some college
   e. ______ Associates degree
   f. ______ Bachelor's degree
   g. ______ Graduate degree
5. **What was your total household income before taxes during the past 12 months?**
   a. ______ Less than $20,000
   b. ______ $20,000 to $39,999
   c. ______ $40,000 to $64,999
   d. ______ $65,000 to $104,999
   e. ______ $105,000 or more
6. **Do you live with a spouse or other long-time partner?** ***(please circle one)***
   YES NO

CARE RECIPIENTS

1. **Sex** ***(please circle one)*:**
   Male Female
2. **Age** ***(in years)*:** ____________
3. **Ethnicity** ***(please check all that apply)*:**
   a. ______ African-American/ Black
   b. ______ American Indian/Native Alaskan
   c. ______ Asian/Southeast Asian/Asian-American
   d. ______ Caucasian/European/White
   e. ______ Native Hawaiian/Other Pacific Islander
   f. ______ Latino(a)/ Hispanic
4. **Highest Level of Education Completed:**
   a. ______ Less than 8th grade
   b. ______ 8th to 11th grade
   c. ______ 12th grade
   d. ______ Some college
   e. ______ Associates degree
   f. ______ Bachelor's degree
   g. ______ Graduate degree
5. **What was his/her total household income before taxes during the past 12 months?**
   a. ______ Less than $20,000
   b. ______ $20,000 to $39,999
   c. ______ $40,000 to $64,999
   d. ______ $65,000 to $104,999
   e. ______ $105,000 or more
6. **Do he/she live with a spouse or other long-time partner?** ***(please circle one)***
   YES NO

Caregiver's relationship to care recipient: ____________________
Have you ever participated in this support group before? YES NO

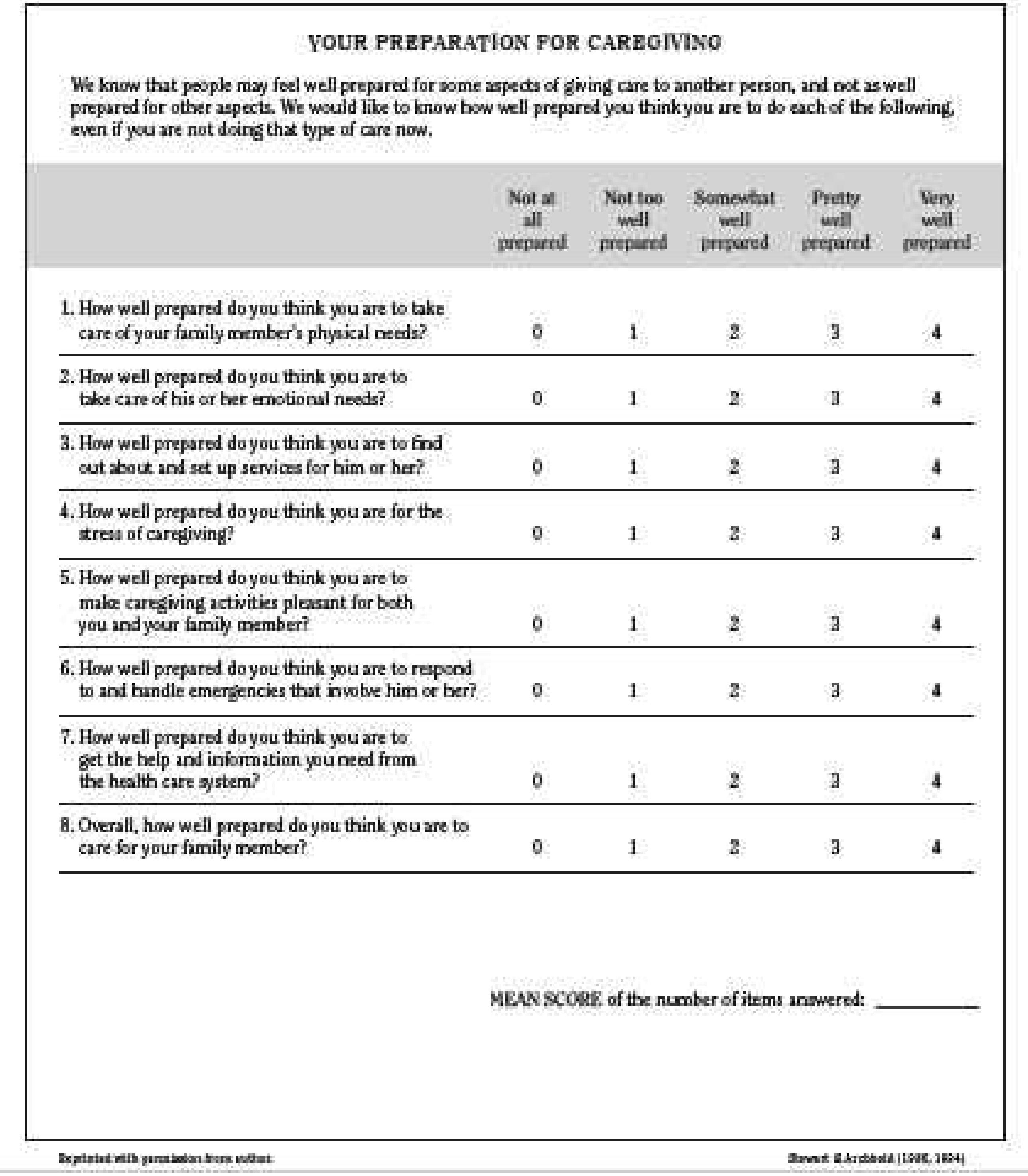
ADL and IADL Survey

For each statement, please indicate only one answer.

How much difficulty does your care recipient experience . . .

	No difficulty					**Extreme Difficulty**
	0	**1**	**2**	**3**	**4**	**5**
Walking across a room?						
Getting in and out of bed?						
Dressing?						
Bathing?						
Eating?						
Using the telephone?						
Taking medication?						
Handling money?						

The Preparedness for Caregiving Scale



YOUR PREPARATION FOR CAREGIVING

We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not doing that type of care now.

	Not at all prepared	Not too well prepared	Somewhat well prepared	Pretty well prepared	Very well prepared
1. How well prepared do you think you are to take care of your family member's physical needs?	0	1	2	3	4
2. How well prepared do you think you are to take care of his or her emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out about and set up services for him or her?	0	1	2	3	4
4. How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your family member?	0	1	2	3	4
6. How well prepared do you think you are to respond to and handle emergencies that involve him or her?	0	1	2	3	4
7. How well prepared do you think you are to get the help and information you need from the health care system?	0	1	2	3	4
8. Overall, how well prepared do you think you are to care for your family member?	0	1	2	3	4

MEAN SCORE of the number of items answered: __________

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Stewart & Archbold (1986, 1994)

Center for Epidemiologic Studies Short Depression Scale (CES-D 10)

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the past week by checking the appropriate box for each question.

Items:	**Rarely or none of the time** (less than 1 day)	**Some or a little of the time** (1-2 days)	**Occasionally or a moderate amount of time** (3-4 days)	**All of the time** (5-7 days)
1. I was bothered by things that usually don't bother me.				
2. I had trouble keeping my mind on what I was doing				
3. I felt depressed.				
4. I felt that everything I did was an effort.				
5. I felt hopeful about the future.				
6. I felt fearful.				
7. My sleep was restless.				
8. I was happy.				
9. I felt lonely.				
10. I could not "get going."				

Obligation Scale

Please indicate how much you agree or disagree with each of the following statements about your relationship with your care recipient. A "1" means that you strongly disagree. A "5" means that you strongly agree. Or you can indicate any number between "1" and "5" to show the extent to which you agree or disagree.

	Strongly disagree----------------------Strongly agree				
1. I feel a sense of obligation to help.	**1**	**2**	**3**	**4**	**5**
2. It's a child's duty to help.	**1**	**2**	**3**	**4**	**5**
3. I feel that I should do my part in helping.	**1**	**2**	**3**	**4**	**5**
4. I'm the one in the family who should help.	**1**	**2**	**3**	**4**	**5**
5. I was raised to believe I should help.	**1**	**2**	**3**	**4**	**5**
6. I would feel guilty if I didn't help.	**1**	**2**	**3**	**4**	**5**
7. I would feel ashamed if I didn't help.	**1**	**2**	**3**	**4**	**5**

Score ____

Caregiver Strain Index

	Yes=1	No=0
Sleep is disturbed (e.g., because _____ is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been other demands on my time (e.g., from other family members)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; _____has trouble remembering things; or _____accuses people of taking things)		
It is upsetting to find_____ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)		
TOTAL SCORE (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

The Neuropsychiatric Inventory Questionnaire (NPI-Q)

Please answer the following questions based on changes that have occurred since the patient first began to experience memory problems.

Circle "Yes" only if the symptom(s) has been present in the last month. Otherwise, circle "No". For each item marked "Yes":

a) Rate the SEVERITY of the symptom (how it affects the patient):
1 = Mild (noticeable, but not a significant change)
2 = Moderate (significant, but not a dramatic change)
3 = Severe (very marked or prominent, a dramatic change)

b) Rate the DISTRESS you experience due to that symptom (how it affects you):
0 = Not distressing at all
1 = Minimal (slightly distressing, not a problem to cope with)
2 = Mild (not very distressing, generally easy to cope with)
3 = Moderate (fairly distressing, not always easy to cope with)
4 = Severe (very distressing, difficult to cope with)
5 = Extreme or Very Severe (extremely distressing, unable to cope with)

Please answer each question carefully. Ask for assistance if you have any questions.

Delusions — Does the patient have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Hallucinations — Does the patient have hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Agitation/Aggression — Is the patient resistive to help from others at times, or hard to handle?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Depression/Dysphoria — Does the patient seem sad or say that he /she is depressed?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Anxiety Does the patient become upset when separated from you? Does he/she have any other signs of nervousness such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Elation/Euphoria Does the patient appear to feel too good or act excessively happy?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Apathy/Indifference Does the patient seem less interested in his/her usual activities or in the activities and plans of others?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Disinhibition Does the patient seem to act impulsively, for example, talking to strangers as if he/she knows them, or saying things that may hurt people's feelings?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Irritability/Lability Is the patient impatient and cranky? Does he/she have difficulty coping with delays or waiting for planned activities?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Motor Disturbance Does the patient engage in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Nighttime Behaviors Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Appetite/Eating Has the patient lost or gained weight, or had a change in the type of food he/she likes?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

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APPENDIX E: CAREGIVER SUPPORT GROUP EXIT PACKET

Participant Name: ______________________

Caregiver Support Group Exit Survey

OLDeR Lab

University of Central Florida

What is your birth month? (Bubble only one)

January	February	March	April	May	June	July	August	September	October	November	December
○	○	○	○	○	○	○	○	○	○	○	○

How tall are you? (Bubble only one)

≤4'11"	5'0"	5'1"	5'2"	5'3"	5'4"	5'5"	5'6"	5'7"	5'8"	5'9"	5'10"	5'11"	6'0"	6'1"	6'2"	6'3"	6'4"	≥6'5"
○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○

How many full BIOLOGICAL SIBLINGS do you have? (not step or half)

0 1 2 3 4 5 (or more)

What is the FIRST LETTER of your *MOTHER'S* FIRST Name?

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

What is the FIRST LETTER of your *FATHER'S* FIRST Name?

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

With whom do you live? (Bubble *all that apply*)

Roommate(s)	Alone	Parent(s)	Significant Other	Other
○	○	○	○	○

How many hours do you typically work at a job, PER WEEK?

0	5-10	11-20	21-30	31-40	More than 40
○	○	○	○	○	○

What is your *FATHER'S* highest level of education? (Please bubble ONE)

Less than High School	Some High School	High School Diploma/ GED	Some College	Associate's Degree (A.A. or A.S.)	Bachelor's Degree	Graduate Degree
○	○	○	○	○	○	○

What is your *MOTHER'S* highest level of education? (Please bubble ONE)

Less than High School	Some High School	High School Diploma/ GED	Some College	Associate's Degree (A.A. or A.S.)	Bachelor's Degree	Graduate Degree
○	○	○	○	○	○	○

What is your current relationship status?

Single, Never Married	Long-term Relationship (Unmarried)	Married or Domestic Partnership	Separated	Divorced	Widowed
○	○	○	○	○	○

What is the first letter of the high school you graduated from?

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

Since you began the caregiver support group, has your care recipient changed residences?

- ○ Yes
- ○ No

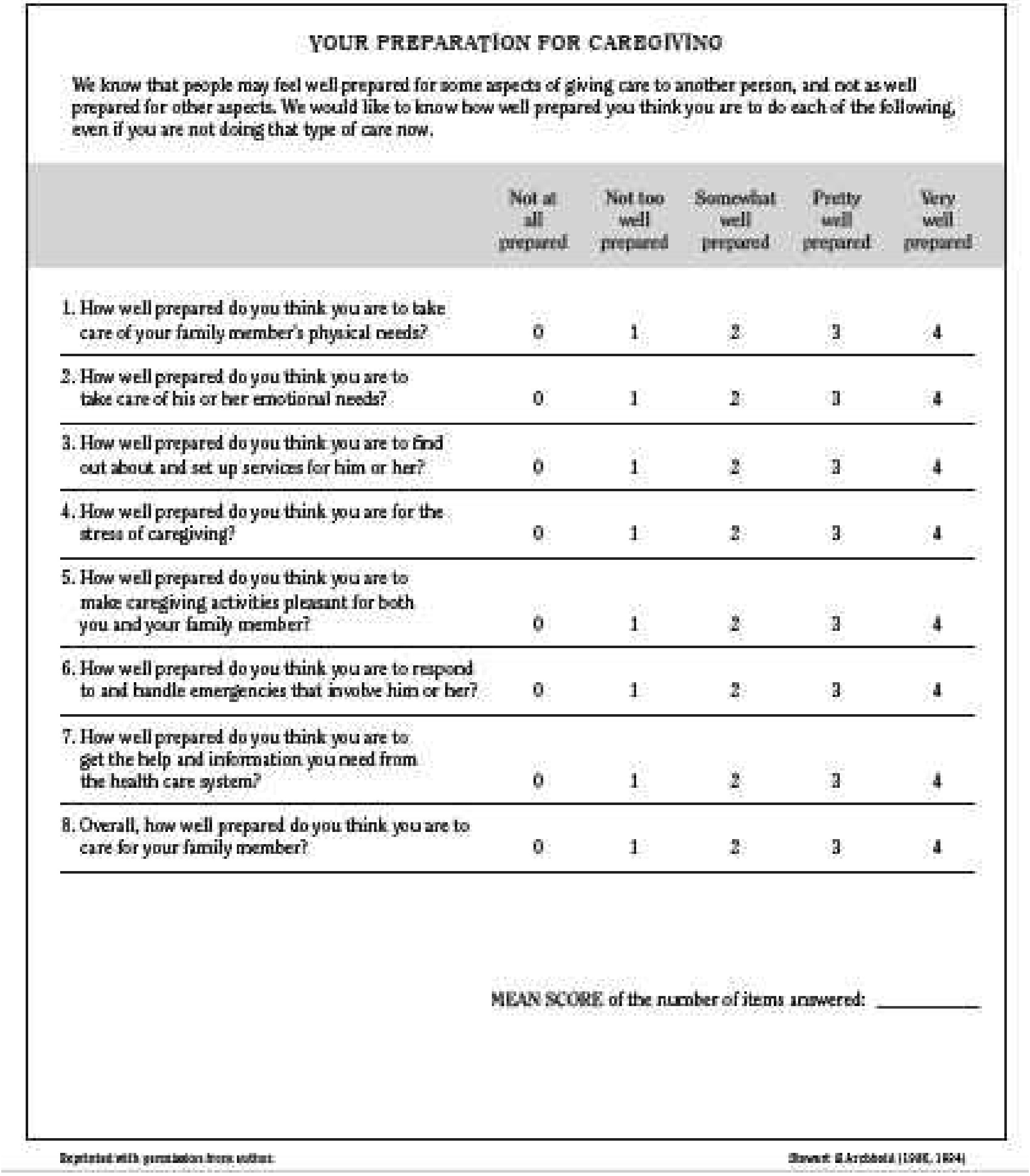
If yes, where does your care recipient currently reside?

- ○ in your home
- ○ in his/her own home
- ○ in other family member's home
- ○ nursing home
- ○ assisted living facility
- ○ hospital
- ○ other (please specify): ______________________

Is your care recipient receiving hospice?

- ○ Yes
- ○ No

The Preparedness for Caregiving Scale



YOUR PREPARATION FOR CAREGIVING

We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not doing that type of care now.

	Not at all prepared	Not too well prepared	Somewhat well prepared	Pretty well prepared	Very well prepared
1. How well prepared do you think you are to take care of your family member's physical needs?	0	1	2	3	4
2. How well prepared do you think you are to take care of his or her emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out about and set up services for him or her?	0	1	2	3	4
4. How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your family member?	0	1	2	3	4
6. How well prepared do you think you are to respond to and handle emergencies that involve him or her?	0	1	2	3	4
7. How well prepared do you think you are to get the help and information you need from the health care system?	0	1	2	3	4
8. Overall, how well prepared do you think you are to care for your family member?	0	1	2	3	4

MEAN SCORE of the number of items answered: ___________

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Stewart & Archbold (1986, 1994)

Center for Epidemiologic Studies Short Depression Scale (CES-D 10)

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the past week by checking the appropriate box for each question.

Items:	**Rarely or none of the time** (less than 1 day)	**Some or a little of the time** (1–2 days)	**Occasionally or a moderate amount of time** (3–4 days)	**All of the time** (5–7 days)
1. I was bothered by things that usually don't bother me.				
2. I had trouble keeping my mind on what I was doing				
3. I felt depressed.				
4. I felt that everything I did was an effort.				
5. I felt hopeful about the future.				
6. I felt fearful.				
7. My sleep was restless.				
8. I was happy.				
9. I felt lonely.				
10. I could not "get going."				

Caregiver Strain Index

	Yes=1	**No=0**
Sleep is disturbed (e.g., because _____ is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been other demands on my time (e.g., from other family members)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; _____has trouble remembering things; or _____accuses people of taking things)		
It is upsetting to find_____ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)		
TOTAL SCORE (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

The Neuropsychiatric Inventory Questionnaire (NPI-Q)

Please answer the following questions based on changes that have occurred since the patient first began to experience memory problems.

Circle "Yes" only if the symptom(s) has been present in the last month. Otherwise, circle "No". For each item marked "Yes":

a) Rate the SEVERITY of the symptom (how it affects the patient):
1 = Mild (noticeable, but not a significant change)
2 = Moderate (significant, but not a dramatic change)
3 = Severe (very marked or prominent, a dramatic change)

b) Rate the DISTRESS you experience due to that symptom (how it affects you):
0 = Not distressing at all
1 = Minimal (slightly distressing, not a problem to cope with)
2 = Mild (not very distressing, generally easy to cope with)
3 = Moderate (fairly distressing, not always easy to cope with)
4 = Severe (very distressing, difficult to cope with)
5 = Extreme or Very Severe (extremely distressing, unable to cope with)

Please answer each question carefully. Ask for assistance if you have any questions.

Delusions Does the patient have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Hallucinations Does the patient have hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Agitation/Aggression Is the patient resistive to help from others at times, or hard to handle?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Depression/Dysphoria Does the patient seem sad or say that he /she is depressed?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Anxiety Does the patient become upset when separated from you? Does he/she have any other signs of nervousness such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Elation/Euphoria Does the patient appear to feel too good or act excessively happy?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Apathy/Indifference Does the patient seem less interested in his/her usual activities or in the activities and plans of others?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Disinhibition Does the patient seem to act impulsively, for example, talking to strangers as if he/she knows them, or saying things that may hurt people's feelings?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Irritability/Lability Is the patient impatient and cranky? Does he/she have difficulty coping with delays or waiting for planned activities?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Motor Disturbance Does the patient engage in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Nighttime Behaviors Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Appetite/Eating Has the patient lost or gained weight, or had a change in the type of food he/she likes?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

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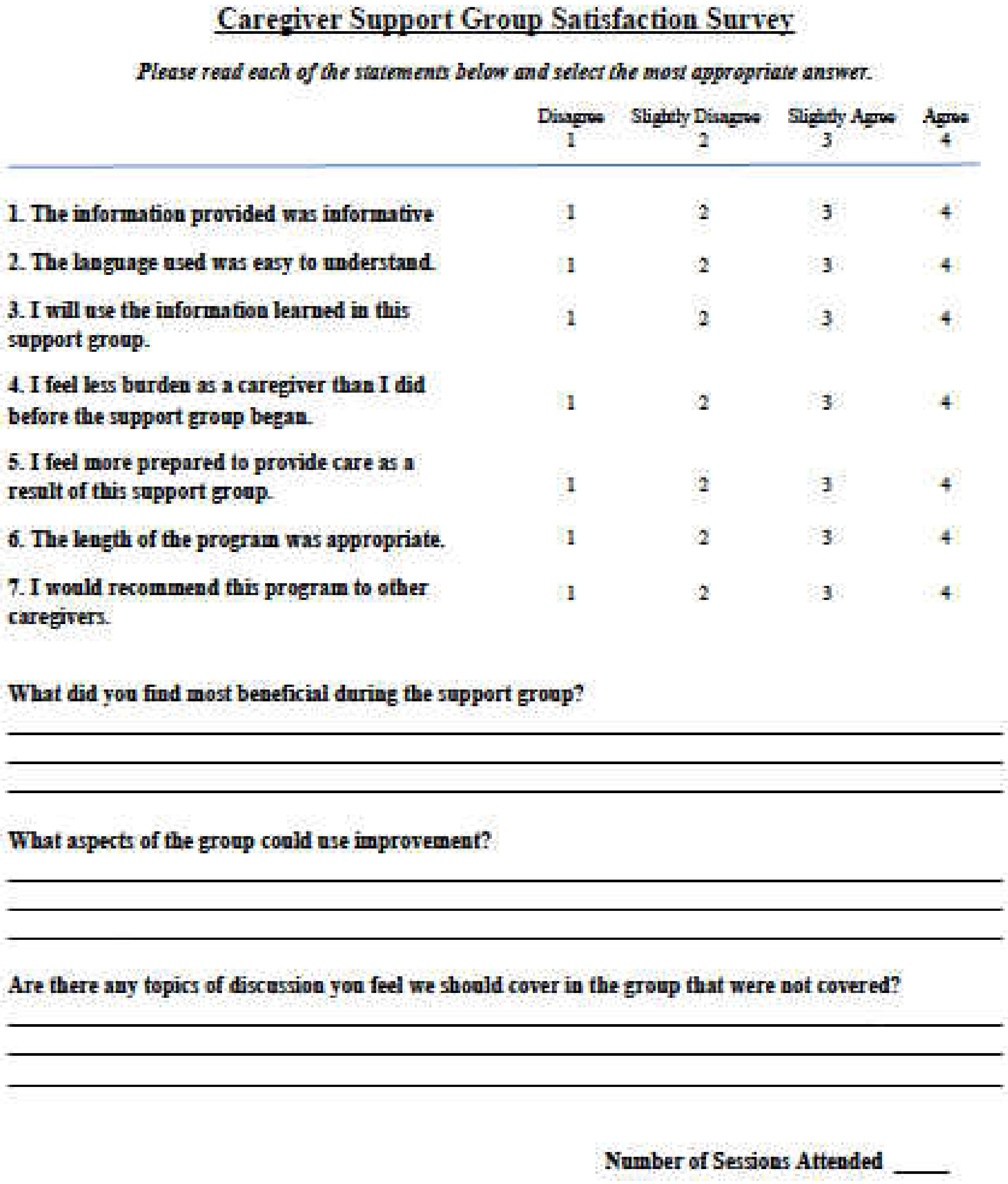


Caregiver Support Group Satisfaction Survey

Please read each of the statements below and select the most appropriate answer.

	Disagree 1	Slightly Disagree 2	Slightly Agree 3	Agree 4
1. The information provided was informative	1	2	3	4
2. The language used was easy to understand.	1	2	3	4
3. I will use the information learned in this support group.	1	2	3	4
4. I feel less burden as a caregiver than I did before the support group began.	1	2	3	4
5. I feel more prepared to provide care as a result of this support group.	1	2	3	4
6. The length of the program was appropriate.	1	2	3	4
7. I would recommend this program to other caregivers.	1	2	3	4

What did you find most beneficial during the support group?

What aspects of the group could use improvement?

Are there any topics of discussion you feel we should cover in the group that were not covered?

Number of Sessions Attended _____

APPENDIX F: CONTROL GROUP INTAKE PACKET

Caregiver Support Group Intake Survey

OLDeR Lab

University of Central Florida

What is your birth month? (Bubble only one)

January	February	March	April	May	June	July	August	September	October	November	December
○	○	○	○	○	○	○	○	○	○	○	○

How tall are you? (Bubble only one)

≤4'11"	5'0"	5'1"	5'2"	5'3"	5'4"	5'5"	5'6"	5'7"	5'8"	5'9"	5'10"	5'11"	6'0"	6'1"	6'2"	6'3"	6'4"	≥6'5"
○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○

How many full BIOLOGICAL SIBLINGS do you have? (not step or half)

0 1 2 3 4 5 (or more)

What is the FIRST LETTER of your *MOTHER'S* FIRST Name?

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

What is the FIRST LETTER of your *FATHER'S* FIRST Name?

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

With whom do you live? (Bubble *all that apply*)

Roommate(s)	Alone	Parent(s)	Significant Other	Other
○	○	○	○	○

How many hours do you typically work at a job, PER WEEK?

0	5-10	11-20	21-30	31-40	More than 40
○	○	○	○	○	○

What is your *FATHER'S* highest level of education? (Please bubble ONE)

Less than High School	Some High School	High School Diploma/ GED	Some College	Associate's Degree (A.A. or A.S.)	Bachelor's Degree	Graduate Degree
○	○	○	○	○	○	○

What is your *MOTHER'S* highest level of education? (Please bubble ONE)

Less than High School	Some High School	High School Diploma/ GED	Some College	Associate's Degree (A.A. or A.S.)	Bachelor's Degree	Graduate Degree
○	○	○	○	○	○	○

What is your current relationship status?

Single, Never Married	Long-term Relationship (Unmarried)	Married or Domestic Partnership	Separated	Divorced	Widowed
○	○	○	○	○	○

What is the first letter of the high school you graduated from?

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

Since you began the caregiver support group, has your care recipient changed residences?

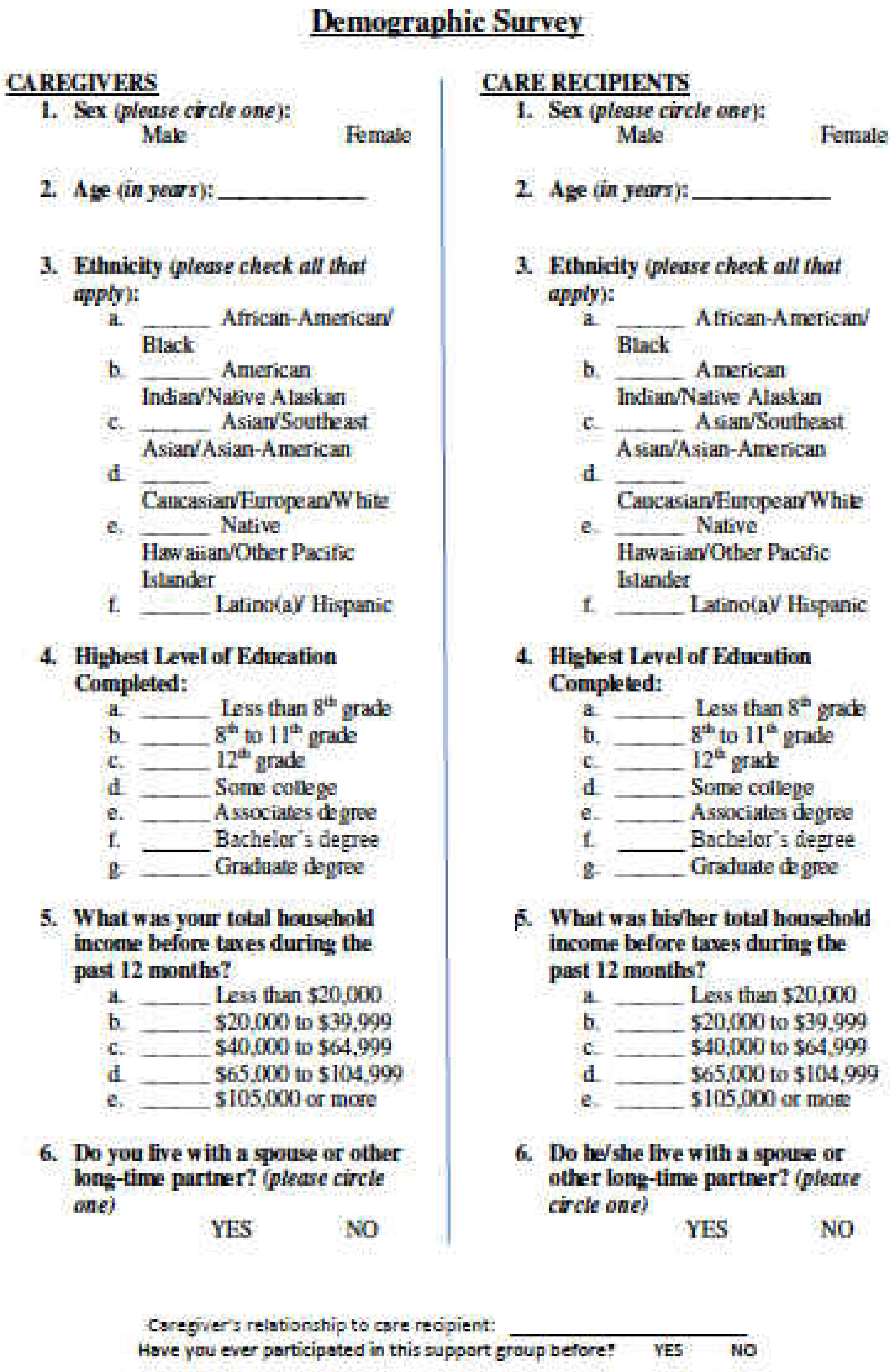
- ○ Yes
- ○ No

If yes, where does your care recipient currently reside?

- ○ in your home
- ○ in his/her own home
- ○ in other family member's home
- ○ nursing home
- ○ assisted living facility
- ○ hospital
- ○ other (please specify): ______________________

Is your care recipient receiving hospice?

- ○ Yes
- ○ No



Demographic Survey

CAREGIVERS

1. **Sex** ***(please circle one)*:**
   Male Female

2. **Age** ***(in years)*:** ____________

3. **Ethnicity** ***(please check all that apply)*:**
   a. ______ African-American/ Black
   b. ______ American Indian/Native Alaskan
   c. ______ Asian/Southeast Asian/Asian-American
   d. ______ Caucasian/European/White
   e. ______ Native Hawaiian/Other Pacific Islander
   f. ______ Latino(a)/ Hispanic

4. **Highest Level of Education Completed:**
   a. ______ Less than 8th grade
   b. ______ 8th to 11th grade
   c. ______ 12th grade
   d. ______ Some college
   e. ______ Associates degree
   f. ______ Bachelor's degree
   g. ______ Graduate degree

5. **What was your total household income before taxes during the past 12 months?**
   a. ______ Less than $20,000
   b. ______ $20,000 to $39,999
   c. ______ $40,000 to $64,999
   d. ______ $65,000 to $104,999
   e. ______ $105,000 or more

6. **Do you live with a spouse or other long-time partner?** ***(please circle one)***
   YES NO

CARE RECIPIENTS

1. **Sex** ***(please circle one)*:**
   Male Female

2. **Age** ***(in years)*:** ____________

3. **Ethnicity** ***(please check all that apply)*:**
   a. ______ African-American/ Black
   b. ______ American Indian/Native Alaskan
   c. ______ Asian/Southeast Asian/Asian-American
   d. ______ Caucasian/European/White
   e. ______ Native Hawaiian/Other Pacific Islander
   f. ______ Latino(a)/ Hispanic

4. **Highest Level of Education Completed:**
   a. ______ Less than 8th grade
   b. ______ 8th to 11th grade
   c. ______ 12th grade
   d. ______ Some college
   e. ______ Associates degree
   f. ______ Bachelor's degree
   g. ______ Graduate degree

5. **What was his/her total household income before taxes during the past 12 months?**
   a. ______ Less than $20,000
   b. ______ $20,000 to $39,999
   c. ______ $40,000 to $64,999
   d. ______ $65,000 to $104,999
   e. ______ $105,000 or more

6. **Do he/she live with a spouse or other long-time partner?** ***(please circle one)***
   YES NO

Caregiver's relationship to care recipient: ____________________

Have you ever participated in this support group before? YES NO

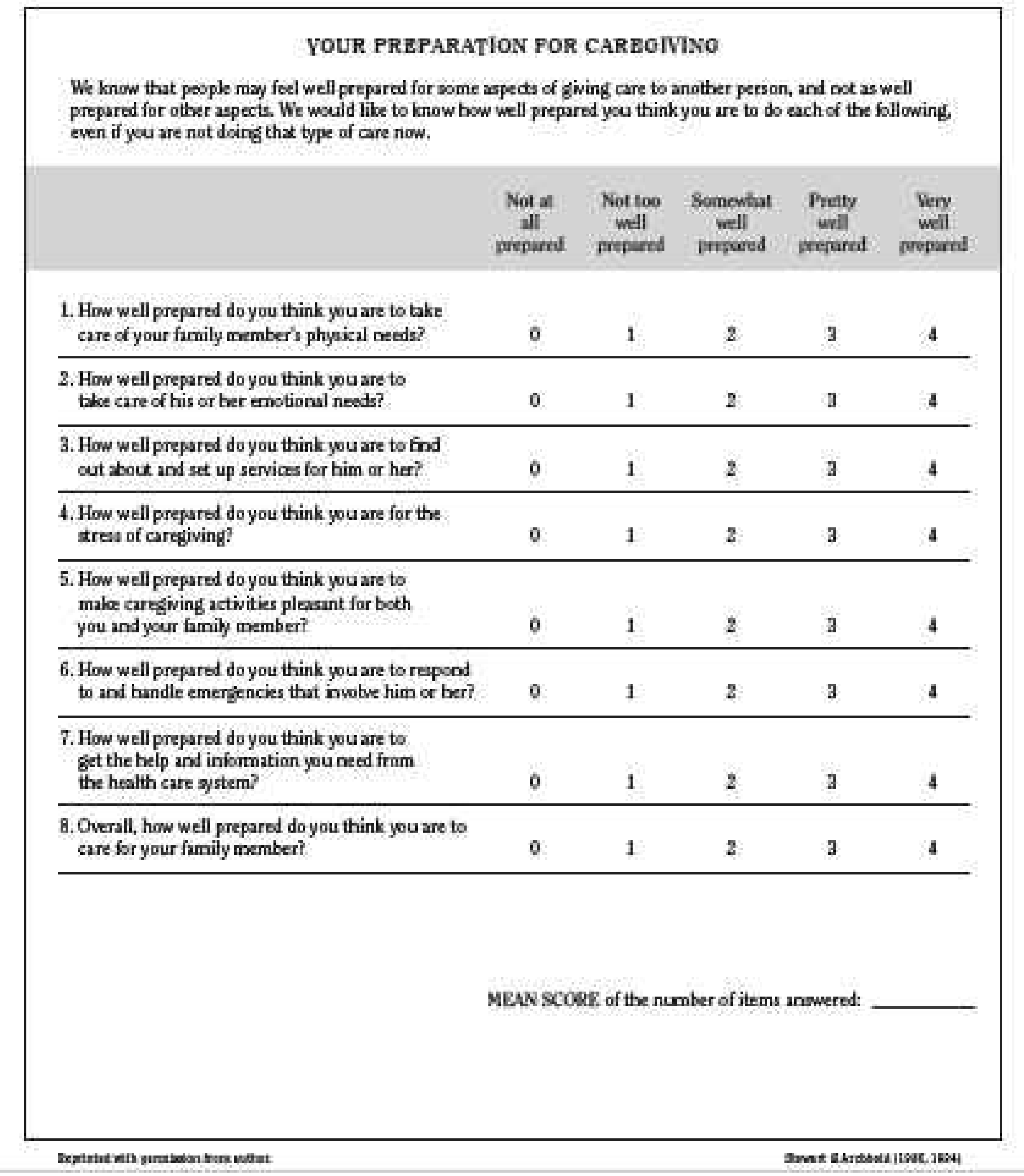
ADL and IADL Survey

For each statement, please indicate only one answer.

How much difficulty does your care recipient experience . . .

	No difficulty					**Extreme Difficulty**
	0	**1**	**2**	**3**	**4**	**5**
Walking across a room?						
Getting in and out of bed?						
Dressing?						
Bathing?						
Eating?						
Using the telephone?						
Taking medication?						
Handling money?						

The Preparedness for Caregiving Scale



YOUR PREPARATION FOR CAREGIVING

We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not doing that type of care now.

	Not at all prepared	Not too well prepared	Somewhat well prepared	Pretty well prepared	Very well prepared
1. How well prepared do you think you are to take care of your family member's physical needs?	0	1	2	3	4
2. How well prepared do you think you are to take care of his or her emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out about and set up services for him or her?	0	1	2	3	4
4. How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your family member?	0	1	2	3	4
6. How well prepared do you think you are to respond to and handle emergencies that involve him or her?	0	1	2	3	4
7. How well prepared do you think you are to get the help and information you need from the health care system?	0	1	2	3	4
8. Overall, how well prepared do you think you are to care for your family member?	0	1	2	3	4

MEAN SCORE of the number of items answered: ____________

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Stewart & Archbold (1986, 1994)

Center for Epidemiologic Studies Short Depression Scale (CES-D 10)

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the past week by checking the appropriate box for each question.

Items:	**Rarely or none of the time** (less than 1 day)	**Some or a little of the time** (1–2 days)	**Occasionally or a moderate amount of time** (3–4 days)	**All of the time** (5–7 days)
1. I was bothered by things that usually don't bother me.				
2. I had trouble keeping my mind on what I was doing				
3. I felt depressed.				
4. I felt that everything I did was an effort.				
5. I felt hopeful about the future.				
6. I felt fearful.				
7. My sleep was restless.				
8. I was happy.				
9. I felt lonely.				
10. I could not "get going."				

Obligation Scale

Please indicate how much you agree or disagree with each of the following statements about your relationship with your care recipient. A "1" means that you strongly disagree. A "5" means that you strongly agree. Or you can indicate any number between "1" and "5" to show the extent to which you agree or disagree.

	Strongly disagree				Strongly agree
1. I feel a sense of obligation to help.	**1**	**2**	**3**	**4**	**5**
2. It's a child's duty to help.	**1**	**2**	**3**	**4**	**5**
3. I feel that I should do my part in helping.	**1**	**2**	**3**	**4**	**5**
4. I'm the one in the family who should help.	**1**	**2**	**3**	**4**	**5**
5. I was raised to believe I should help.	**1**	**2**	**3**	**4**	**5**
6. I would feel guilty if I didn't help.	**1**	**2**	**3**	**4**	**5**
7. I would feel ashamed if I didn't help.	**1**	**2**	**3**	**4**	**5**

Score _____

Caregiver Strain Index

	Yes=1	No=0
Sleep is disturbed (e.g., because _____ is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been other demands on my time (e.g., from other family members)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; _____has trouble remembering things; or _____accuses people of taking things)		
It is upsetting to find_____ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)		
TOTAL SCORE (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

The Neuropsychiatric Inventory Questionnaire (NPI-Q)

Please answer the following questions based on changes that have occurred since the patient first began to experience memory problems.

Circle "Yes" only if the symptom(s) has been present in the last month. Otherwise, circle "No". For each item marked "Yes":

a) Rate the SEVERITY of the symptom (how it affects the patient):
1 = Mild (noticeable, but not a significant change)
2 = Moderate (significant, but not a dramatic change)
3 = Severe (very marked or prominent, a dramatic change)

b) Rate the DISTRESS you experience due to that symptom (how it affects you):
0 = Not distressing at all
1 = Minimal (slightly distressing, not a problem to cope with)
2 = Mild (not very distressing, generally easy to cope with)
3 = Moderate (fairly distressing, not always easy to cope with)
4 = Severe (very distressing, difficult to cope with)
5 = Extreme or Very Severe (extremely distressing, unable to cope with)

Please answer each question carefully. Ask for assistance if you have any questions.

Delusions Does the patient have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Hallucinations Does the patient have hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Agitation/Aggression Is the patient resistive to help from others at times, or hard to handle?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Depression/Dysphoria Does the patient seem sad or say that he /she is depressed?
Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4

Anxiety Does the patient become upset when separated from you? Does he/she have any other signs of nervousness such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Elation/Euphoria Does the patient appear to feel too good or act excessively happy?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Apathy/Indifference Does the patient seem less interested in his/her usual activities or in the activities and plans of others?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Disinhibition Does the patient seem to act impulsively, for example, talking to strangers as if he/she knows them, or saying things that may hurt people's feelings?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Irritability/Lability Is the patient impatient and cranky? Does he/she have difficulty coping with delays or waiting for planned activities?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Motor Disturbance Does the patient engage in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Nighttime Behaviors Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Appetite/Eating Has the patient lost or gained weight, or had a change in the type of food he/she likes?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

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APPENDIX G: CONTROL GROUP EXIT PACKET

Participant Name: ______________________

Caregiver Support Group Exit Survey

OLDeR Lab

University of Central Florida

What is your birth month? (Bubble only one)

January	February	March	April	May	June	July	August	September	October	November	December
○	○	○	○	○	○	○	○	○	○	○	○

How tall are you? (Bubble only one)

≤4'11"	5'0"	5'1"	5'2"	5'3"	5'4"	5'5"	5'6"	5'7"	5'8"	5'9"	5'10"	5'11"	6'0"	6'1"	6'2"	6'3"	6'4"	≥6'5"
○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○

How many full BIOLOGICAL SIBLINGS do you have? (not step or half)

0 1 2 3 4 5 (or more)

What is the FIRST LETTER of your *MOTHER'S* FIRST Name?

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

What is the FIRST LETTER of your *FATHER'S* FIRST Name?

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

With whom do you live? (Bubble *all that apply*)

Roommate(s)	Alone	Parent(s)	Significant Other	Other
○	○	○	○	○

How many hours do you typically work at a job, PER WEEK?

0	5-10	11-20	21-30	31-40	More than 40
○	○	○	○	○	○

What is your *FATHER'S* highest level of education? (Please bubble ONE)

Less than High School	Some High School	High School Diploma/ GED	Some College	Associate's Degree (A.A. or A.S.)	Bachelor's Degree	Graduate Degree
○	○	○	○	○	○	○

What is your *MOTHER'S* highest level of education? (Please bubble ONE)

Less than High School	Some High School	High School Diploma/ GED	Some College	Associate's Degree (A.A. or A.S.)	Bachelor's Degree	Graduate Degree
○	○	○	○	○	○	○

What is your current relationship status?

Single, Never Married	Long-term Relationship (Unmarried)	Married or Domestic Partnership	Separated	Divorced	Widowed
○	○	○	○	○	○

What is the first letter of the high school you graduated from?

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

Since you began the caregiver support group, has your care recipient changed residences?

- ○ Yes
- ○ No

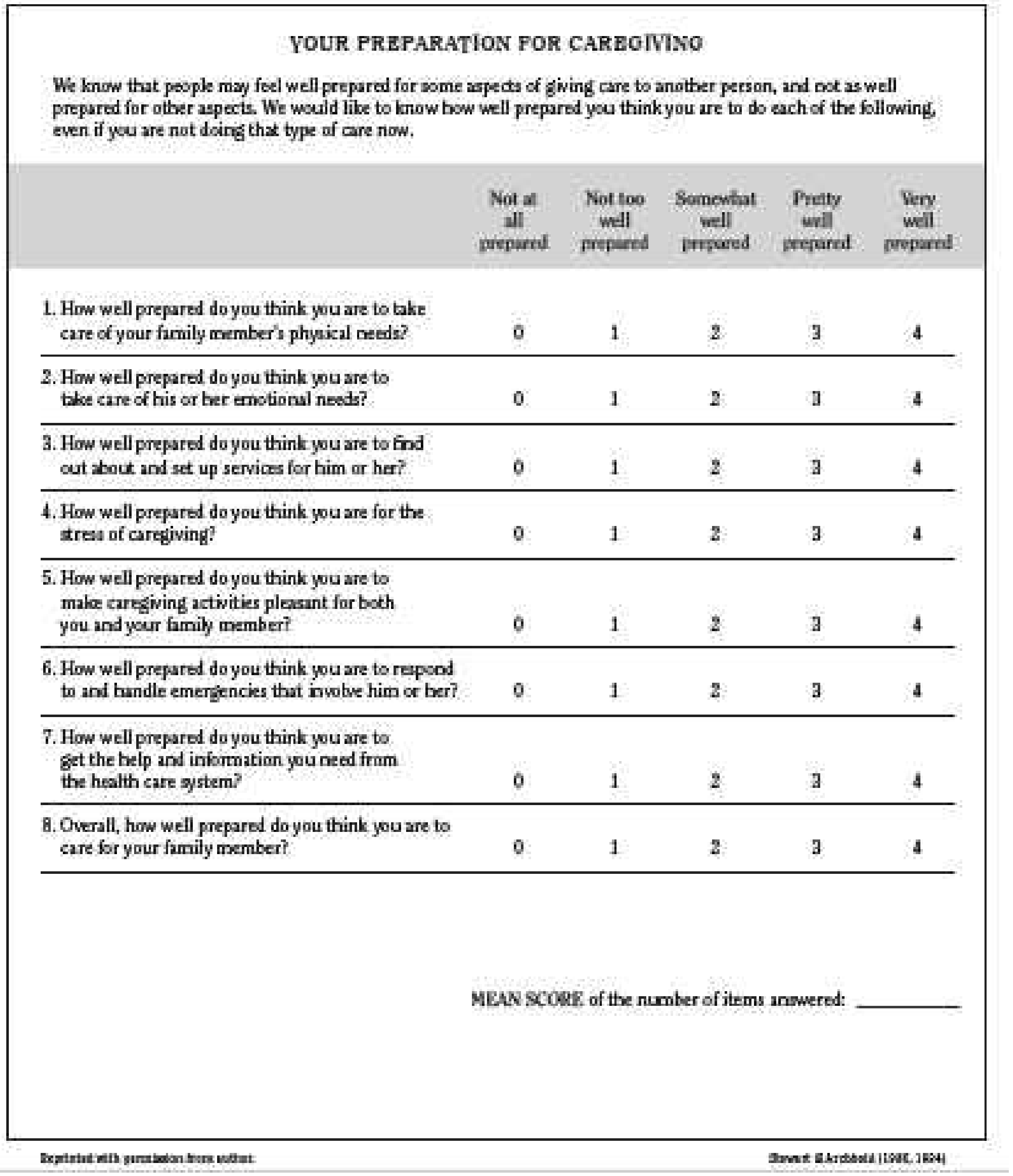
If yes, where does your care recipient currently reside?

- ○ in your home
- ○ in his/her own home
- ○ in other family member's home
- ○ nursing home
- ○ assisted living facility
- ○ hospital
- ○ other (please specify): ______________________

Is your care recipient receiving hospice?

- ○ Yes
- ○ No

The Preparedness for Caregiving Scale



YOUR PREPARATION FOR CAREGIVING

We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not doing that type of care now.

	Not at all prepared	Not too well prepared	Somewhat well prepared	Pretty well prepared	Very well prepared
1. How well prepared do you think you are to take care of your family member's physical needs?	0	1	2	3	4
2. How well prepared do you think you are to take care of his or her emotional needs?	0	1	2	3	4
3. How well prepared do you think you are to find out about and set up services for him or her?	0	1	2	3	4
4. How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your family member?	0	1	2	3	4
6. How well prepared do you think you are to respond to and handle emergencies that involve him or her?	0	1	2	3	4
7. How well prepared do you think you are to get the help and information you need from the health care system?	0	1	2	3	4
8. Overall, how well prepared do you think you are to care for your family member?	0	1	2	3	4

MEAN SCORE of the number of items answered: ___________

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Stewart & Archbold (1986, 1994)

Center for Epidemiologic Studies Short Depression Scale (CES-D 10)

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the past week by checking the appropriate box for each question.

Items:	**Rarely or none of the time** (less than 1 day)	**Some or a little of the time** (1–2 days)	**Occasionally or a moderate amount of time** (3–4 days)	**All of the time** (5–7 days)
1. I was bothered by things that usually don't bother me.				
2. I had trouble keeping my mind on what I was doing				
3. I felt depressed.				
4. I felt that everything I did was an effort.				
5. I felt hopeful about the future.				
6. I felt fearful.				
7. My sleep was restless.				
8. I was happy.				
9. I felt lonely.				
10. I could not "get going."				

Caregiver Strain Index

	Yes=1	No=0
Sleep is disturbed (e.g., because _____ is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been other demands on my time (e.g., from other family members)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; _____has trouble remembering things; or _____accuses people of taking things)		
It is upsetting to find_____ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)		
TOTAL SCORE (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

The Neuropsychiatric Inventory Questionnaire (NPI-Q)

Please answer the following questions based on changes that have occurred since the patient first began to experience memory problems.

Circle "Yes" only if the symptom(s) has been present <u>in the last month</u>. Otherwise, circle "No". For each item marked "Yes":

a) Rate the SEVERITY of the symptom (how it affects <u>the patient</u>):
1 = Mild (noticeable, but not a significant change)
2 = Moderate (significant, but not a dramatic change)
3 = Severe (very marked or prominent, a dramatic change)

b) Rate the DISTRESS you experience due to that symptom (how it affects <u>you</u>):
0 = Not distressing at all
1 = Minimal (slightly distressing, not a problem to cope with)
2 = Mild (not very distressing, generally easy to cope with)
3 = Moderate (fairly distressing, not always easy to cope with)
4 = Severe (very distressing, difficult to cope with)
5 = Extreme or Very Severe (extremely distressing, unable to cope with)

Please answer each question carefully. Ask for assistance if you have any questions.

Delusions Does the patient have false beliefs, such as thinking that others are stealing from him/her or planning to harm him/her in some way?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Hallucinations Does the patient have hallucinations such as false visions or voices? Does he or she seem to hear or see things that are not present?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Agitation/Aggression Is the patient resistive to help from others at times, or hard to handle?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Depression/Dysphoria Does the patient seem sad or say that he /she is depressed?
Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4

Anxiety Does the patient become upset when separated from you? Does he/she have any other signs of nervousness such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Elation/Euphoria Does the patient appear to feel too good or act excessively happy?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Apathy/Indifference Does the patient seem less interested in his/her usual activities or in the activities and plans of others?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Disinhibition Does the patient seem to act impulsively, for example, talking to strangers as if he/she knows them, or saying things that may hurt people's feelings?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Irritability/Lability Is the patient impatient and cranky? Does he/she have difficulty coping with delays or waiting for planned activities?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Motor Disturbance Does the patient engage in repetitive activities such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Nighttime Behaviors Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

Appetite/Eating Has the patient lost or gained weight, or had a change in the type of food he/she likes?

Yes No **SEVERITY**: 1 2 3 **DISTRESS**: 0 1 2 3 4 5

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APPENDIX H: TREATMENT FIDELITY CODING SHEET

UCF Caregiver Support Group
Treatment Fidelity Coding Form

Session Number

Date and time of coding

Coder

Clinical Activity	**Yes**	**No**	**Notes**
Introducing group members			
Empathic listening: Group members describe their challenges and group leaders acknowledge their emotions, express sympathy			
Problem solving: Group members describe practical problems and group members suggest solutions			
Community resource provision: ADRC and group leaders discuss specific community resources (professional services, transportation, etc.)			
Psychoeducation - dementia: Group leader trains group members on sympoms of dementia			
Psychoeducation - behavior management: Group leader trains group members on ABC's of behavior management principles			
Application of behavior management: Group members use behavior management principles to understand and create a modification plan for care recipient behaviors			
Psychoeducation - pleasant events: Group leader describes benefits of pleasant events, burnout, and self-care			
Discussing pleasant events: Problem solving around pleasant events specifically, discussing perceived benefits			
Other			

APPENDIX I: IRB APPROVAL OF HUMAN RESEARCH

University of Central Florida Institutional Review
Board Office of Research & Commercialization 12201
Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Approval of Human Research

From: **UCF Institutional Review Board #1**
FWA00000351, IRB00001138

To: **Daniel Lee Paulson** and Co-PIs **Danielle Herring, David Brush, Ian Dalton, Manuel Herrera Legon, Mona Shah, Nicholas T James, Rachel Bassett, Rosanna Scott**

Date: **May 03, 2017**

Dear Researcher:

On 05/03/2017 the IRB approved the following modifications to human participant research until 10/25/2017 inclusive:

Type of Review: IRB Addendum and Modification Request Form
Modification Type: Added Nicholas James as Co-PI, Removed research assistants not engaged in research, added a treatment fidelity checklist, added new advertisement, updated protocol and consent forms
Project Title: Caregiver burden and depression: Caring for those who care for others.
Investigator: Daniel Lee Paulson
IRB Number: SBE-15-11548
Funding Agency: UCF College of Medicine(UCF COM)
Grant Title: UCF Caregiver Support Group and Stress Study

Research ID: N/A

The scientific merit of the research was considered during the IRB review. The Continuing Review Application must be submitted 30days prior to the expiration date for studies that were previously expedited, and 60 days prior to the expiration date for research that was previously reviewed at a convened meeting. Do not make changes to the study (i.e., protocol, methodology, consent form, personnel, site, etc.) before obtaining IRB approval. A Modification Form **cannot** be used to extend the approval period of a study. All forms may be completed and submitted online at https://iris.research.ucf.edu .

If continuing review approval is not granted before the expiration date of 10/25/2017, approval of this research expires on that date. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

Use of the approved, stamped consent document(s) is required. The new form supersedes all previous versions, which are now invalid for further use. Only approved investigators (or other approved key study personnel) may solicit consent for research participation. Participants or their representatives must receive a copy of the consent form(s).

All data, including signed consent forms if applicable, must be retained and secured per protocol for a minimum of five years (six if HIPAA applies) past the completion of this research. Any links to the identification of participants should be maintained and secured per protocol. Additional requirements may be imposed by your funding agency, your department, or other entities. Access to data is limited to authorized individuals listed as key study personnel.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

Renea Carver

Signature applied by Renea C Carver on 05/03/2017 01:26:02 PM EDT

IRB Coordinator

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