

DEMENTIA CAREGIVERS' PERSPECTIVES REGARDING THE EFFECTIVENESS
OF SUPPORT GROUP INVOLVEMENT

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LIST OF ABBREVIATIONS

AD.....	Alzheimer's Dementia
ADL.....	Activities of Daily Living
BDI.....	Becks Depression Inventory
CCI.....	Cost of Care Index
CDR.....	Clinical Dementia Rating Scale
DAT.....	Dementia of the Alzheimer's type
DSM-IV-TR...	Diagnostic and Statistical Manuel of Mental Disorders, 4 th ed, Text Revision
DSRS.....	Dementia Severity Rating Scale
MMSE.....	Mini Mental State Exam
NIA.....	National Institute on Aging
NINDS	National Institute of Neurological Disorders and Stroke
REACH.....	Resources for Enhancing Alzheimer's Caregivers Health

ABSTRACT

DEMENTIA CAREGIVERS' PERSPECTIVES REGARDING THE EFFECTIVENESS OF SUPPORT GROUP INVOLVEMENT

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Caregiver burden can be defined as the stress experienced by someone caring for another individual with an illness or disorder, and it is influenced by time-dependence, degenerative stage, physical obstacles, social isolation, and emotional strain (Chu et al., 2010). Additional influences include emotional-behavioral problems, required levels of assistance for activities of daily living, level of mobility, and medical assistance (Leggett, Zarit, Taylor, & Galvin, 2010). Data regarding the efficacy of caregiver support groups to improve the health and well-being of caregivers are beginning to emerge. Song and colleagues (2010) suggested that persons involved in a caregiver support group reported greater feelings of support on social network and social support scales than those in the control group that had not been involved in social support. Similarly, Chu et al. (2010) explored the effectiveness of a support group for caregivers of persons with dementia in relieving symptoms of depression and reducing caregiver burden. The data suggested that the caregiver support group reduced depression, attributing this to the realization that feelings experienced are shared by others. However, reductions in caregiver burden as a result of being involved in a support group were not observed.

The purpose of this study is to better understand why support group involvement has a lesser impact on caregiver burden compared to caregiver depression. Utilizing an online survey, the researcher identified trends related to group dynamics and information provided that may shed light on this discrepancy with the ultimate goal of improving support group design and implementation. The survey, delivered electronically to support group facilitators and distributed to group members, elicited information regarding demographics, support group features, caregiver experience, dementia severity, caregiver burden, and caregiver depression.

Due to the small response rate, the data obtained were discussed in terms of frequency counts and percentages for categorical data and median and range scores for scale data. Data suggested that as the frequency of meetings increased, the degree of caregiver burden decreased. Similarly, as the frequency of caregiver attendance at meetings increased, the degree of caregiver depression decreased. It was determined that depression was most influenced by education of caregivers during meetings. Burden was most influenced by provision of financial and physical/health information. The data suggest that providing caregivers with practical information to target specific challenges they face may have the greatest influence on reducing caregiver burden. Training facilitators to provide group members with such information is imperative to making the support group effective. Learning more about how to utilize the caregiver support group for this purpose of reducing caregiver depression and burden is essential. Research should continue and knowledge of best practice shared so that support group implementation can become evidence-based.

CHAPTER ONE: INTRODUCTION

With an increase in Americans over the age of 65, a rise from 34 million in 2000 (United States Census Bureau, 2000) to approximately 41 million in 2011 (United States Census Bureau, 2011); there has been a rise in the prevalence of dementia. Startling, 6.8 million people in the United States, including nearly half of persons over the age of 85, have a diagnosis of dementia (National Institute of Neurological Disorders and Stroke [NINDS], 2012). The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) (2000) defines dementia as cognitive deficits characterized by impairments of memory that coincide with one or more of the following: aphasia, apraxia, agnosia, or executive functioning. These cognitive impairments naturally make a significant impact on daily living to result in a diagnosis of dementia (American Psychiatric Association, 2000).

Alzheimer's Disease

Out of the 6.8 million people with dementia (NINDS, 2012), 5.2 million people over the age of 65 and 200,000 people under the age of 65 (Alzheimer's Association, 2012a) have Alzheimer's disease (AD). AD is the most common cause of dementia followed by vascular and Lewy body dementias (Alzheimer's Association, 2012a; Dalvi, 2012), and dementia resulting from AD is often referred to as dementia of the Alzheimer's type (DAT).

The brain is partly composed of billions of neurons communicating via electrochemical signals. Without this normal structure-function relationship, cognitive, physical, visual, behavioral, and other consequences are observed. In the case of AD, neurons are dying at a rate faster than that observed in healthy aging adults. The reasons

for this neural death include three major signs; one, an increase in protein deposits in the space between the nerve cells which cause amyloid plaques; two, neurofibrillary tangles which are caused by proteins twisted inside nerve cells; and three, a loss of neural connections at the synapse (National Institute on Aging [NIA], 2011). Plaques and tangles usually start off forming in the hippocampus, which is responsible for forming memories (NIA, 2011). The cortex, which is responsible for thinking, planning and remembering, shrinks, and the ventricles grow larger (Alzheimer's Association, 2011b). The plaques and tangles also spread to the areas which are involved in speaking, understanding, and orientation (Alzheimer's Association, 2011a). In the later stages of AD, as the plaques and tangles grow to all areas of the brain, more and more neurons die and as a result the brain shows severe atrophy (NIA, 2011).

A terminal disease, AD is associated with neural death in the brain that leads to a decline in cognitive abilities such as memory, judgment, behavior, movement, and language. There are three predominant stages of AD (i.e., mild, moderate and severe) that have been described in the literature for decades (Reisberg, Ferris, de Leon, & Crook, 1982). In the mild stage of DAT, the individual will demonstrate minor, but noticeable memory losses for recent events, names of objects or people, completion of familiar tasks, or location of frequently used objects. He or she may become completely lost in new places. Denial is often prevalent as the individual is increasingly aware of the challenges he or she now faces completing complex, yet familiar tasks. This may lead to an increase in anxiety, depression, and irritability (Alzheimer's Association, n.d.; Dalvi, 2012).

As the disease progresses into the moderate stage, memory for recent events, personal and otherwise, will continue to decline, and will be obvious to others. The

individual may start having difficulty with managing personal finances, and all complex tasks will become too overwhelming for him or her to complete independently. Orientation to time and place become increasingly difficult and prevalent; however, orientation to person tends to remain relatively intact. Denial is considered a hallmark at this stage as it seems the only defense mechanism available to the individual. Emotional expression may be reduced, and anxiety and depression may be apparent. At this stage, the individual often begins to withdraw from previously enjoyed activities and social settings as they become increasingly overwhelming (Alzheimer's Association, n.d.; Dalvi, 2012).

In the severe stage of DAT, the individual will require assistance for all activities of daily living, including eating, bathing, and toileting. He or she will need constant supervision due to likely behavioral and personality changes which may include delusional behavior, obsessive symptoms, anxiety, agitation, and violence. At this stage, communication abilities severely decline, and will eventually become nonexistent other than perhaps grunting. The individual may become increasingly disoriented to person, and oriented to place and time has long since extinguished. Neurogenic dysphagia, an impairment of swallowing due to neurogenic dysfunction, is often impaired at this stage due to motor dysfunction common at the later stage (Alzheimer's Association, n.d.; Dalvi, 2012).

Caregivers of Persons with DAT

Given the description of the various stages of DAT, it is clear that the need for assistance is significant, albeit in different ways, in all stages. A diagnosis of dementia not only affects the person with the diagnosis, but also the people that care for that individual, commonly referred to as a caregiver. A caregiver is any individual, related or unrelated,

who provides emotional support, supervision, assistance with daily living activities, social support and/or financial aid to another individual (McConaghy & Caltabiano, 2005; World Health Organization Kobe Centre for Health Department, n.d.). According to the Alzheimer's Association (2012a), more than 15 million Americans currently provide care to someone with DAT.

Caring for someone with a progressive disorder, such as DAT, inevitably brings with it the expectation of significant change in the level of care required as the signs and symptoms exhibited are constantly changing. A caregiver may have to deal with varying behaviors from the person with DAT such as personality changes, stealing and hiding items, hallucinations, and paranoia. The caregiver may also be responsible for supporting the care recipient with activities of daily living (ADLs), which can include bathing, shaving, toileting, grooming, dressing, eating, managing medicine, cooking, chores, physical activities, and social activities. There are concerns with safety, such as the person with DAT driving, responding in an emergency, falling, or wandering. The caregiver must deal with all of these issues, and must do so with a demeanor demonstrating the dignity of the care recipient (Alzheimer's Association, 2012b; NIA, n.d.).

As presented by the Alzheimer's Association (2012a), the average unpaid caregiver of a person with DAT is between the ages of 45 and 64 (56%), female (70.3%), and married (72.8%). Half of the people with DAT are cared for in the home, and 30% of these home-caregivers also provide care for someone under the age of 18. Further, 23% of caregivers have only been caring for someone with DAT for less than 1 year, 43% have been caring between 1 and 4 years, and 32% have been caring for more than 5 years. These 15 million unpaid caregivers in the United States have provided a total of about 17.4

billion hours of unpaid care, which equates to 1,139 hours per year or 22 hours per week.

Nearly half of caregivers of people with DAT work full or part-time and are considered the primary financial provider for the family (Alzheimer's Association, 2012a).

Consequences of Caregiving

Given these startling statistics, it is far from surprising that caregivers can and very often do experience personal consequences to caregiving such as depression and burden. Although commonly used interchangeably, a difference exists between them. The DSM-IV-TR (2000) states that an individual with clinical depression must demonstrate five of the following ten symptoms within a two week period: depressed mood; marked diminished interest or pleasure in almost all activities; significant weight loss, weight gain or change in appetite; insomnia or hypersomnia; psychomotor agitation or psychomotor retardation; fatigue or loss of energy; feelings of worthlessness or inappropriate guilt; impaired ability to concentrate or indecisiveness; or recurrent thoughts of death (American Psychiatric Association, 2000). It has been suggested that approximately 43% of those providing care for a person with dementia in the home present with signs consistent with clinical depression (Epstein-Lubow et al., 2012). Another study suggests upwards of 65% of caregivers presented with depressive symptoms (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007).

Caregivers also commonly experience a feeling of burden associated with their role of providing care. Caregiver burden can be defined as negative feelings or consequences resulting from the physical, emotional, social and/or financial demands placed on any individual involved in the care of another (Acton & Kang, 2001; Gaugler, Roth, Haley, & Mittelman, 2008; Black et al., 2010; World Health Organization Kobe Centre for Health

Department, n.d.). Lin and colleagues (2012) listed three variables influencing caregiver burden, including factors related to the patient, caregiver, and support system. Specific to DAT, it is suggested that caring for someone who demonstrates more extensive impairment of cognition and those with psychiatric disorders lead to more severe caregiver burden (Machnicki, Allegri, Dillon, Serrano, & Tarragano, 2009; Mohamed, Rosenbeck, Lyketsos, & Schneider, 2010). Caregivers identified as having poor selection and utilization of coping strategies to manage demands of caregiving also present with greater levels of burden (Papastavrou et al., 2007). Studies of demographics suggest that higher levels of burden have been identified in persons of greater age (Serrano-Aguilar, Lopez-Bastida, & Yanes-Lopez, 2006) and those who were female (Papastavrou et al., 2007). It has been suggested that caregivers living with the care recipient demonstrate higher levels of burden than those living apart, and those caring for a spouse are also at greater risk (Conde-Sala, Garre-Olmo, Turro-Garriga, Vilata-Franch, & Lopez-Pousa, 2010). It has also been suggested that caregivers benefit from the support of extended family (Fung & Chien, 2002). Further, Rodakowski and colleagues (2012) found that social integration, received social support, and social interactions maintained through the caregiving experience were consistent with lower rates of burden (Rodakowski, Skidmore, Rogers, & Schulz, 2012). The financial burden on the caregivers also leads to incredible burden due to the extensive cost of medications for the care recipient, regular medical appointments, changing personal needs, and placement in residential facilities (Brodaty & Green, 2002). There is also the risk of losing employment opportunities as the level of care needed increases (Max, 1998).

Managing Caregiver Depression and Burden: The Caregiver Support Group

Given the need for the unpaid caregiver and the well-documented risk of depression and burden in this population, research has identified several trends that may reduce these risks to improve the caregiving experience. One example of this management is the use of pharmacological intervention to treat clinical depression if it is identified. Research suggests that significantly more caregivers of persons with dementia, compared with caregivers of older adults without dementia, take psychotropic drugs, such as benzodiazepines or antidepressants (Camargos et al., 2012). Further, Rodakowski and colleagues (2012) identified the value of a strong social network in the reduction and prevention of the negative consequences of caregiving. Perhaps in an effort to find this social outlet, some caregivers of persons with dementia have participated in support groups for this population.

In a study conducted by the Alzheimer's Association in 2010, there were estimated to be about 6,663 support groups in the United States with about 39,551 participants (as cited in Steffen & Jackson, 2012). Generally speaking, support groups provide information, skills training, emotional support, counseling, problem-solving strategies, stress management, and coping strategies (Acton & Kang, 2001; Chu et al., 2010; Morrow-Odom & Robbins, 2012).

There is evidence to support the use of support groups, or some form of support system, in managing caregiver burden and depression. Elliott, Burgio, and DeCoster (2010) examined caregivers of Alzheimer's patients in terms of health, burden, and bother. With a sample size of 495 caregivers, the intervention group received intervention through an area program referred to as Resources for Enhancing Alzheimer's Caregiver Health, or REACH. Intervention lasted for 6 months and included an approach involving nine in-home and

three telephone sessions compared to another approach involving two check-in phone calls (control group). After the 6-month intervention, caregivers who were receiving the more intensive intervention reported better overall well-being, which included sleep, mood and physical health, which in turn corresponded to reducing burden and bother.

Chu et al. (2010) examined the impact of a 12 week support group program for caregivers of persons with dementia on the reduction of caregiver burden and depression. The sessions included personal testimonies; discussions of emotional responses to caregiver; obstacles and challenges faced through the caregiving experiences; the need for personal care in addition to caring for others; the availability of community resources; financial challenges; strategies to facilitate communication with the care recipient and others involved; and finally future care-planning. Interestingly, the researchers found that caregivers involved in these support groups demonstrated reduced symptoms of depression; however, there was no decrease in burden. Although still a positive effect as depression decreased, the lack of change of burden raises questions regarding the support group design to facilitate positive change. The findings of Chu and colleagues are not unique findings; a review of the literature found that only 2 out of 27 studies reviewed revealed a positive effect on caregiver burden (Acton & Kang, 2001). This led Acton and Kang to the conclusions that caregiver burden may be too complex of a concept to identify a specific intervention approach to reduce it.

Statement of Purpose

Depression and burden are experienced by many caregivers. Given the value of the caregiver, it is necessary to understand not only what factors predict caregiver depression and burden, but to identify those things that lessen caregiver depression and burden.

Participation in support groups may provide some relief; however, little is understood about what support groups are actually providing to tackle these issues of depression and burden. Research abroad suggests that support groups are only impacting depression, leading to a decrease in symptoms, but not caregiver burden (Chu et al. 2010). The purpose of this exploratory study was to pilot research methods to best explore these issues related to caregiver depression and burden reduction as it relates to support group involvement. It was also hoped that the investigator will gain insight to refine survey questions for clarity and specificity. Finally, and importantly, the current research was designed to present some preliminary descriptive data regarding support group involvement as it relates to caregiver burden and depression. For this latter objective, it is hoped that the data will shed some light on characteristics of the support group, leading to less burden or depression experienced by the caregiver. Questions and hypotheses were as follows:

Question 1: Does support group involvement have an equal effect on reducing caregiver depression and burden?

Hypotheses

H₀: Support group involvement has an equal effect on reducing caregiver depression and burden.

H₁: Support group involvement leads to unequal effects on reducing caregiver depression and burden.

Question 2: Do support groups providing caregivers with information (i.e., education, counseling, social, financial, and/or physical) to manage myriad consequences of dementia

have a greater effect on reducing burden compared to those that do not provide caregivers with such strategies?

Hypotheses

H₀: Providing information does not have a greater effect on reducing caregiver burden.

H₁: Providing information does have a greater effect on reducing caregiver burden.

CHAPTER TWO: METHODS

Participants

A total of 29 people initiated to complete the research survey. Of those, five did not meet the basic eligibility requirements for participation. Each participant was presented with three eligibility questions. Participants were required to be at least 18 years of age, caring for a person with dementia, and a member of a support group within the last year. If a participant indicated that he or she did not meet eligibility requirements for one of these three reasons, he or she was not able to continue to the remainder of the survey. Of the remaining 24 participants, only 14 completed the entire survey, and only those 14 will be discussed for the purpose of this research.

Participants were recruited through their support groups. The primary investigator contacted support group facilitators directly; this information is publicly available on the Alzheimer's Association website. When contact information for facilitators was not available, the primary investigator contacted state chapters of the Alzheimer's Association, specifically those individuals responsible for coordinating support groups (e.g., program managers, executive directors), by phone and email to discuss the possibility of sharing recruitment information with individual support group facilitators. This recruitment information included a brief explanation of the research objectives and information regarding how to access the survey. A request to simply share the information with group members was made. As a result, the research investigators had no direct contact with participants, unless contacted by the participant to answer questions stemming from the informed consent form. An estimate of who responded out of how many people received

the information cannot be made at present because it is not known how many caregivers actually received the flyer. The researcher wanted to stay distant as not to increase the stress placed on caregivers, deemed a valid concern given that some facilitators refused to share the flyer to avoid increasing burden on group members. Initially, recruitment only took place in the state of North Carolina, but was later expanded to include all of the United States. More specific detail regarding recruitment of participants is provided later.

Data Construction

The 85-question, electronic survey used in the present investigation can be seen in Appendix A. It was constructed to obtain information regarding eligibility (3 questions previously discussed), the caregiving experience (11 questions), dementia severity of the care recipient (12 questions), caregiver burden (21 questions), support group dynamics (8 questions), caregiver depression (21 questions), and personal demographics (9 questions).

After confirming eligibility, participants completed the survey anonymously. First, they were asked questions regarding their person caregiving experience. Questions included those related to the relationship between the caregiver and care recipient, hours per week spent providing care, previous experience caring for someone with dementia. If they had cared for another individual with dementia prior to the current experience, they were asked to share about that experience, including their relationship to that care recipient and length of time providing care. The caregivers were asked for their impressions regarding the severity of dementia in the care recipient, the approximate diagnosis date, and the current place of residence of the care recipient. Final questions pertained to financial support.

Given that a diagnosis of dementia requires a compromise in functional independence, such as completion of activities of daily living, a functional measure of dementia severity was selected for the present investigation. The Dementia Severity Rating Scale (DSRS) (Clark & Ewbank, 1996) consists of 12 questions to assess: memory; communication; recognition of family members; orientation to time; orientation to place; ability to make decisions; social and community activity; home activities and responsibilities; personal care; eating; control of urination and bowels; and ability to get from one place to another. The caregiver participants, assumed to be familiar with the functional abilities of the person with dementia, were asked to respond to each question of the DSRS using a likert scale describing behaviors ranging from normal to very severe. After completing the survey, scores are added together to calculate the DSRS score, which can range from 0 (no impairment) to 54 (severe impairment) (Clark et al., 2004). Although the DSRS does not provide specific severity ratings, such as mild or severe, there has been some research to achieve this objective. For example, Xie et al. (2009) indicated that DSRS scores of 40 or more were correlated with persons very likely to be a resident in a long-term care facility. In addition, the authors suggested that these individuals presented with scores on the Mini Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975) score of zero. Further, Clark and Ewbank (1996) compared the DSRS to the Clinical Dementia Rating scale (CDR) (Morris, 1993) to better estimate severity levels of normal, questionable, and mild versus more advance moderate and severe. It was suggested that a score of 21 or less represented persons with mild to normal cognitive function, whereas those with a score of 22 or higher represented those with moderate to severe impairment. Using their mean data, the present investigation categorized participants as having

dementia of a specific severity level (i.e., mild, moderate, severe) given that scores were 21 or less for mild, 22 to 31 for moderate, and 32 or greater for severe.

Caregivers also completed the Cost of Care Index (CCI) (Kosberg & Cairl, 1986) to assess the level of burden experienced as a provider, as well as an open-ended question regarding the caregiver's understanding of burden (i.e., personal definition of burden). The CCI is a 20-question measure allowing caregivers to respond to their physical, emotional, social and financial status, which are all believed to influence caregiver burden levels. Responses from the caregiver completing the survey range from 1 (strongly disagree) to 4 (strongly agree). This would suggest a possible score ranging from 20 to 80 points (Robinson, Adkisson, & Weinrich, 2001). Scores nearer to 20 are indicative of low impact, or low cost, to the caregiver. In other words, less burden is experienced by the caregiver. Conversely, scores approaching 80 are suggestive of high impact, or high cost, to the caregiver. That is, greater burden is experienced. For the purpose of this research, raw scores of the CCI were categorized as little or no burden (scores of 20-40), moderate burden (scores of 41-60), and significant burden (scores of 61-80).

To understand the dynamics of the support group, participants were asked to share information regarding group membership (i.e., who may attend), estimated time of attendance, meeting schedules, frequency of attendance in the past year, and the professional background or training of the support group facilitator. Additional open-ended questions included the participant's expectations for the support group, the types of information or benefits received from the group, and what would they like to learn more about in their group.

The Beck Depression Inventory (BDI) (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) was administered as a measure of depression felt by the caregiver. Questions related to issues of: sadness, the future, feelings of being a failure, satisfaction, guilt, suicidal thoughts, decision making, social interests, attractiveness, sleeping habits, eating habits, weight loss, physical health, and interest in sex. Each answer corresponds to a number valued 0 – 3, where 0 is that the person does not experience or feel the issue related to depression, 1 – 3 relate to varying degrees of the issue, where 3 is the highest. Each answer corresponds to a number value, which, when summed together, provided an overall score representative of normal or mild mood disturbances through several severity levels of depression, including borderline clinical depression to extreme depression. Scores could range from 0 to 63; a score ranging from 0-13 represented no to minimal depression, 14-19 represented a mild depression, 20 - 28 represented moderate depression, and 29-63 represented severe depression (Segal, Coolidge, Cahill, & O’Riley, 2008).

Demographic information was gathered at the end of the survey. Information obtained included: age, gender, marital status, racial or ethnic background, residential community, occupation status, education completed, number of people in the household, and approximate household income.

Procedures

The current research was approved by the Institutional Review Board at Western Carolina University. Following approval, the investigator sought to identify caregiver support group facilitators in the North Carolina region that may serve as a referral source for participation recruitment. Using the Alzheimer’s Association support group locator, 61 North Carolina facilitators were contacted first by phone, and then follow-up contact was

made with those interested in learning more about the research by e-mail and mail. Study information, contact information for researchers, and recruitment flyers were provided in electronic and hard copies (see Appendices B and C). To increase response rates, 158 individuals who were responsible for coordinating support groups, such as program and executive directors, were contacted in the remainder of the United States by e-mail, and those interested were then followed-up by phone, e-mail, and mail. The same information provided to North Carolina facilitators at the time of the follow-up was provided to program and executive directors who forwarded the information to their support group facilitators. Presently, the researcher does not know how many caregivers received the information due to the research not wanting to increase stress of caregivers. It was deemed important for the caregivers to receive the information from a familiar and trusted person, a concern experienced by facilitators as well given that some refused to share information of this research with group members to avoid increasing burden.

The participants interested in completing the survey were instructed to visit a website to access the survey. The electronic survey was administered through the online survey software provided by Qualtrics (Qualtrics, 2013). Immediately upon visiting the web link, participants were instructed to read the informed consent (see Appendix A), ask questions of the researchers as needed, and then provide consent to participate in the research. The informed consent page provided information about the survey including the purpose of the research, survey expectations, approximate length in minutes, anonymity of responses, risk and benefits of participating, and investigators' contact information. Once the participants agreed to participate in the research, they were provided instructions to

navigate the survey. The survey was estimated to take approximately 15 minutes to complete.

Data Analysis

Given that this research was intended to be an exploratory study to pilot methods, refine survey questions, and present some preliminary data, the data obtained in this study were discussed in terms of categorical data, frequency counts and percentages; scaled data, median and range; and descriptive data, open-ended questions. Categorical data included the following demographic variables: gender, ethnicity, residential region, marital status, employment, education, income, and number of persons in the household. Extensive categorical data were obtained regarding the support group experience, including description of group leader and the various types of support received (i.e., education, counseling, financial, social, physical, or other). Categorical data obtained elsewhere in the survey included the caregiver's relationship to the care recipient, previous caregiving experiences, residential location of the care recipient, and presence of financial support. Severity rankings discussed included scores on the DSRS, BDI, and the CCI, which were discussed in terms of categorical data, as well as scale data. Additional scale data included age of the caregiver, average contact hours per day, average contact hours per week, number of years provided care, number of years since the care recipient received a diagnosis of dementia, months attending a support group, and number of times the support group was attended in the last year.

Also collected in the survey were open-ended responses related to issues of defining caregiver burden, expectations of a caregiver support group, and topics of interest the caregiver would like to receive additional information on during a support group.

These open-ended questions were examined to identify trends in participant responses and discussed in terms of descriptive data. Regarding caregiver burden, the researcher examined responses for words and phrases representative of one of the four variables contributing to burden (i.e., emotional, social, physical, financial) as well as other comments not obviously fitting into one of these four variables. Regarding support group expectations and needs, the researcher examined responses for words or phrases consistent with what others have suggested the support group should provide (Acton & Kang, 2001; Chu et al., 2010; Morrow-Odom & Robbins, 2012).

To address the previously stated research questions, trends were examined by exploring the relationship between availability/frequency of support group meetings and frequency of attending support group meetings with caregiver depression (as measured by raw scores and severity rankings of the BDI) and caregiver burden (as measured by raw scores of the CCI). In addition, comparisons between severity rankings of caregiver depression (as measured by categorical data of BDI) and burden (as measured by categorical data of CCI) were made with each of the various types of support received from the support group (i.e., education, counseling, financial, social, physical/health).

CHAPTER THREE: RESULTS

Caregiver Demographics

Fourteen caregivers throughout the United States completed the survey in full. Demographic data of the 14 participants are provided in Table 3.1. Of the caregivers surveyed, 11 were female (78.6%), and 3 were male (21.4%). Caregiver age ranged from 51 to 81 years, with a median of 70.5. Thirteen of the participants were married (92.9%). Thirteen people indicated they were white/Caucasian (92.9%), and one was African American (7.1%). When asked about what type of community the caregiver resides in, three indicated they lived in a rural community (7.1%), seven in a suburban community (21.4%), and four in an urban community (28.6%). One person (7.1%) reported being employed full-time, two part-time (14.3%), two unemployed (14.3%), and nine retired (63.3%). When asked about household size (which included the caregiver), three people indicated living alone (21.4%), eight lived with one other person (57.1%), two people live with two other people (14.3%), and one person lived with more than two other people (7.1%). When asked about annual family income, four participants reported making \$35,001 - \$50,000 per year (28.6%), two \$50,001 - \$75,000 per year (14.3%), one \$75,001 - \$100,000 per year (7.1%), three people reported making \$100,001 or more per year (21.4%), and four people preferred not to answer (28.6%).

Table 3.1

Caregiver Demographic Data Presented as Frequency and Percent of Total Responding.

Survey Question	Survey Answer	Frequency	Percent
Gender	Female	11	78.6
	Male	3	21.4
Marital Status	Married	13	92.9
	Not Married	1	7.1
Racial/ethnic background	Caucasian	13	92.9
	African American	1	7.1
Residential Community	Rural	3	21.4
	Suburban	7	50
	Urban	4	28.6
Employment	Full-time	1	7.1
	Part-time	2	14.3
	Unemployed	2	14.3
	Retired	9	63.3
Household size (including caregiver)	1	3	21.4
	2	8	57.1
	3	2	14.3
	4	1	7.1
Annual Household Income	\$35,001 - \$50,000	4	28.6
	\$50,001 - \$75,000	2	14.3
	\$75,001 - \$100,000	1	7.1
	\$100,001 or more	3	21.4
	Prefer not to answer	4	28.6

The Caregiver Experience

The caregiver experience section of the survey was designed to explore factors specific to the caregiving relationship dynamics and time/financial demands on the caregiver. Of the 14 caregivers, seven reported caring for a spouse (50%), three caring for a parent (21.4%), one a sibling (7.1%), one a child (7.1%), one an aunt (7.1%), and one a mother-in-law (7.1%). Thirteen of the participants reported that care recipients were

diagnosed with dementia between 1 and 12 years prior to completion of the survey (median of 7 years). It was also determined that 50% of the care recipients lived in the home with the caregiver, whereas others reported the care recipient living in his/her own home (7.1%), in an assisted living facility (28.6%), in a long-term care facility (7.1%), and in a memory care facility (7.1%).

It was determined that caregivers were spending a median of 21.5 hours with the care recipient each day, with a range of 1 hour to 24 hours (two participants did not answer this question). When considering this topic in terms of contact hours per week, responses ranged from 3 to 100 hours per week with a median of 100 (100 hours per week was the maximum response allowed; one person chose not to answer this question). When asked about the length of their caregiver experience, responses ranged from 1 to 12 years with a median of 5.5 years.

Caregivers were also asked to share about their previous experiences providing care to another individual with dementia. Eleven people indicated no prior experience (78.6%), and three people indicated having prior experience (21.4%). The two of the three participants with previous experience elaborated briefly on that experience. It was reported that one person cared for his/her mother for 5 years, and one person cared for his/her mother-in-law for 15 years.

Finally, participants were asked if they received financial support specifically for provided for the care of the individual with dementia. Eleven people indicated they do not receive financial support (78%), but three people indicated they do receive financial support (21.4%) including savings, long-term care insurance, and Medicare.

Caregiver Definition of Burden

Participants were also invited to attempt their own definitions of burden in an open-ended question in order to better understand whether or not caregivers realize the myriad factors that can influence caregiver burden. All fourteen participants answered this question. Twelve responders indicated some form of emotional burden, describing it as stressful, depressing, emotionally draining, guilty, and consuming. Five people indicated some form of social burden discussing the lack of love, lonely, having no life of their own, not being able to travel anywhere, and no conversations. Four people indicated a physical burden; three people indicated financial burden and one person defined burden as omnipresent.

Support Group

The support group questions of the survey were designed to elicit information regarding support group dynamics, degree of involvement in the support group, and wants/needs of the support group. Of those completing the survey, it was found that the majority of support groups, 10 in this case, were meeting once per month (71.4%). One support group met less than once per month (14.3%), one met at least once a week (7.1%), and one met two to three times per week (7.1%). It was also found that most of the support groups (64.3%) were facilitated by persons other than a counselor (14.3%); others involved in facilitating support groups were reported to include a caregiver, general volunteer, gerontologist, nurse, or senior services employee. In addition, a number of the support groups had multiple facilitators that varied from meeting to meeting (21.4%).

The caregivers responding to this survey indicated that they had been attending a caregiver support group for a median of 40.5 months (approximately 3 years), with a range of 2 to 132 months. This number was calculated using a survey completion date of

December 2012; participants responding with a specific year, rather than a number of months or years, were assumed to have begun attending in the support group in January of the indicated year. Caregivers indicated when they started attending a support group. Caregivers indicated attending between 2 and 30 meetings in the previous 12 months, with a median of nine times last year.

Finally, information regarding what was provided through the support group to the caregivers was requested; these data are summarized in Table 3.2. Topics specifically stated in the survey included education, counseling, financial guidance, social support, physical/health information, and an “other” category for open-ended responses. Twelve participants indicated receiving educational information about dementia and the disease process (85.7%), and nine indicated receiving social support through the group (63.3%). Seven people indicated receiving counseling (50%), three people indicated receiving financial guidance (21.4%), and one person received physical/health information (7.1%). Other verbatim responses included, “Alzheimer’s hotline,” “everyone just talks about what is happens in their situation,” and “the leader sends info by email about Alzheimer’s.”

Table 3.2
Quantitative Data (Frequency and Percent) for Type of Support/Information Received from Support Group.

Survey Question	Survey Answer	Frequency	Percent
Education	Yes	12	85.7%
	No	2	14.3%
Counseling	Yes	7	50%
	No	7	50%
Financial	Yes	3	21.4%
	No	11	78.6%
Social	Yes	9	63.3%
	No	5	35.7%
Physical	Yes	1	7.1%
	No	13	92.9%
Other	Yes	4	28.6%
	No	10	71.4%

Using an open-ended question, participants were encouraged to expand on their perceptions regarding what should be provided to the members by the support group. Fourteen participants were asked this open-ended question and thirteen people responded. A review of the responses revealed two primary themes: education and support. Within education (11/13 responders), there were three topics focused upon more than others, and they included education about the disease and disease progression; education about strategies to manage challenging behaviors and situations; and education about legal, financial, and medical matters. The second primary theme was support (9/13 responders), which was highlighted by responses including, “non-threatening environment,” “empathy, a safe place to share,” “share feelings both good and bad,” “[s]upporting each other in our times of need,” “provide community,” and “to help others through my personal

experiences.” Other topics identified included information about local resources to support them through the caregiving journey (2/13 responders).

Participants were also invited to expand on their support group wants and needs via an open-ended question asking the caregiver to list or explain specific topics he or she wished to learn more about during a meeting. Fourteen participants were asked this open-ended question; thirteen responded. In line with the purpose of the support group, responses revealed that many group members were seeking education. Topics specifically stated included education about different types of dementia; the disease and disease progression; strategies to manage behaviors; coping strategies, and resources available. Three responders indicated that their support groups were already providing them with everything they needed, whereas two responded that their opinion of support group value had diminished over time.

Dementia Severity Rating Scale (DSRS)

Fourteen caregivers completed the DSRS to measure the care recipient’s severity of dementia. Data specific to the DSRS are provided in Table 3.3. Severity raw scores ranged from 18 to 49 with a median of 36. These raw scores are each associated with a level of severity ranging from mild to moderate to severe using the scoring guidelines discussed previously. One care recipient presented with mild dementia (7.1%), two care recipients presented with moderate dementia (21.4%), and ten care recipients presented with severe dementia (71.4%).

Table 3.3

Quantitative Data (Frequency and Percent) for all Participants on the Dementia Severity Rating Scale (DSRS).

Severity Range	Frequency	Percent
Mild (21 or less)	1	7.1%
Moderate (22 - 31)	3	21.4%
Severe (32 - 54)	10	71.4%

Beck Depression Inventory (BDI)

Fourteen caregivers completed the BDI to measure presence and severity of depression as a consequence caregiving. Data specific to the level of depression are provided in Table 3.4. Severity raw scores ranged from 0 to 31 with a median score of 9. Eleven participants fell in the range of minimal (78.6%) suggesting a minimal or an absence of symptoms consistent with depression. However, two participants were found to present with a mild depression (14.3%), and one with severe depression (7.1%).

Table 3.4

Summary of Data (Frequency and Percent) for all Participants on the Beck Depression Inventory (BDI).

Severity Range	Frequency	Percent
Minimal Depression (0 -13)	11	78.6%
Mild Depression (14 - 19)	2	14.3%
Moderate Depression (20 - 28)	0	0%
Severe Depression (29 - 63)	1	7.1%

Cost of Care Index (CCI)

Fourteen participants completed the CCI to measure level of burden experienced by the caregiver. Data specific to the level of burden are provided in Table 3.5. Severity raw scores ranged from 27 to 63 with a median score of 48.5. One participant fell in the range of little or no burden (7.1%) suggesting an absence of symptoms consistent with burden. However, twelve participants were found to present with a moderate burden (85.7%), and one with significant burden (7.1%).

Table 3.5

Summary of Data (Frequency and Percent) for all Participants on the Cost of Care Index (CCI).

Severity Rating	Frequency	Percent
Little or no burden (20 - 40)	1	7.1%
Moderate burden (41 - 60)	12	85.7%
Significant burden (61 - 80)	1	7.1%

Effects of Support Group Meeting Frequency on Caregiver Depression and Burden

To explore the relationship between the frequency with which a support group meets on a monthly basis and its influence on caregiver depression and burden, scatterplots of data were created and fit lines added. Given that these are just intended to be exploratory in nature and given the small sample size, no statistical analyses were conducted on these data. As can be seen in Figure 3.1, there is clearly no trend observed correlating the number of support group meetings offered and caregiver depression (raw scores of the BDI); however, there appears to be a slight decreasing trend of caregiver

burden (raw scores of the CCI) as the number of support group meetings offered is decreased (Figure 3.2).

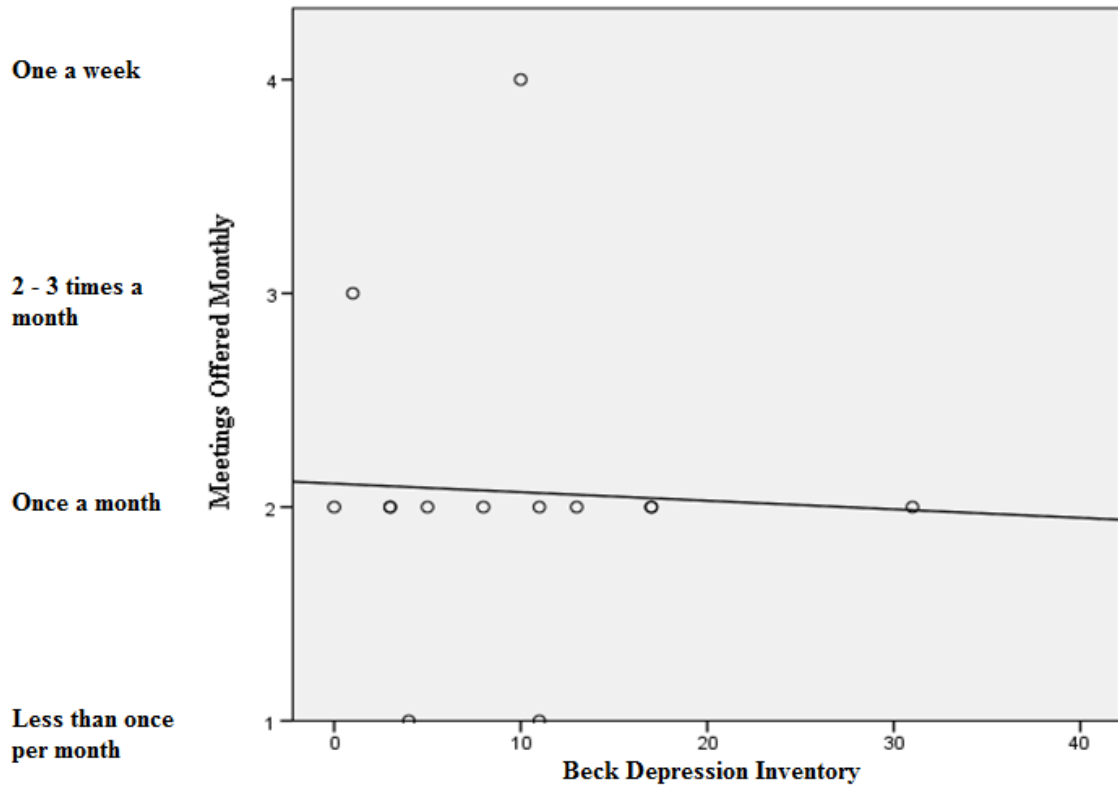


Figure 3.1. Scatterplot with best fit line illustrating the relationship between frequency of support group meetings (in months) and its influence on caregiver depression as measured by the Beck Depression Scale (BDI).

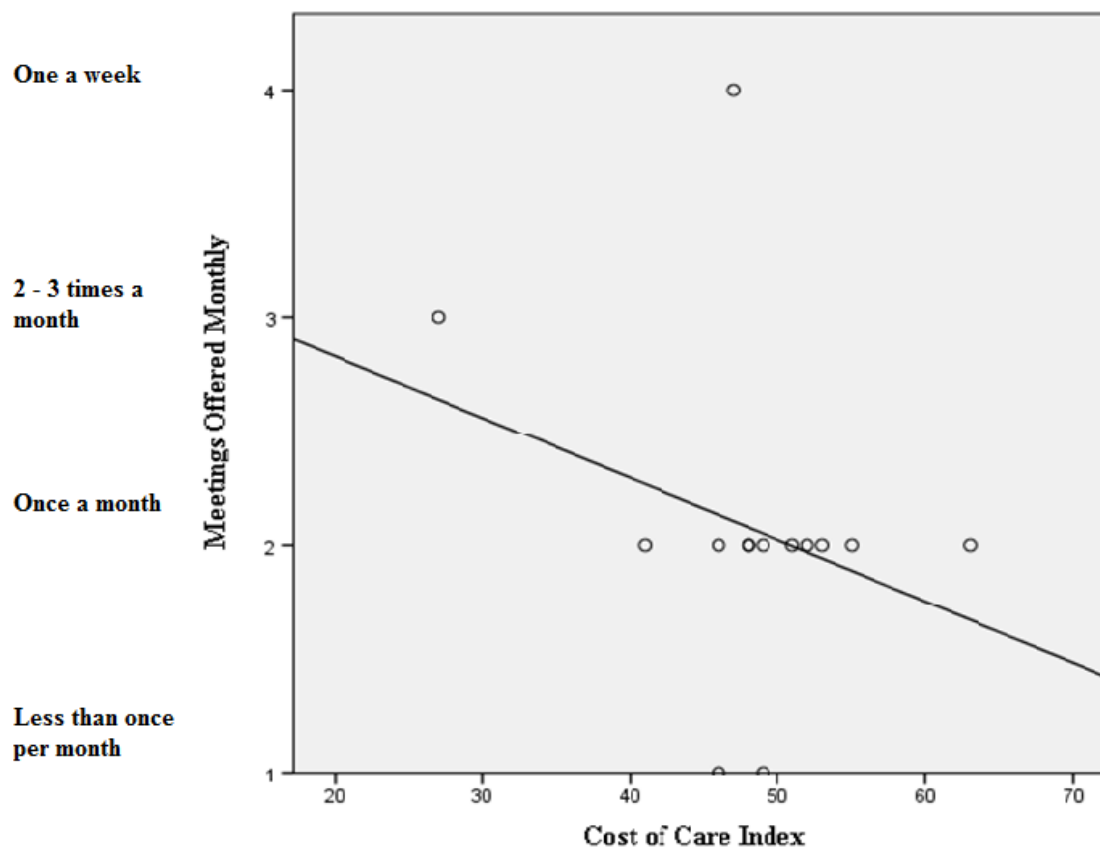


Figure 3.2. Scatterplot with best fit line illustrating the relationship between frequency of support group meetings (in months) and its influence on caregiver burden as measured by the Cost of Care Index (CCI).

Effects of Frequency of Support Group Attendance on Caregiver Depression and Burden

To explore the relationship between the annual frequency with which a caregiver attends a support group and its influence on caregiver depression and burden, scatterplots of data were created and fit lines added. As in the previous section, these data were intended to be exploratory in nature and the sample size remains small; therefore, no statistical analyses were conducted on these data. As can be seen in Figure 3.3, there is a slight decreasing trend observed suggesting that the more often a caregiver attends a

support group, caregiver depression (raw scores of the BDI) decreases. No apparent trends in the data were observed comparing annual frequency of support group attendance and caregiver burden (raw scores of the CCI) (Figure 3.4).

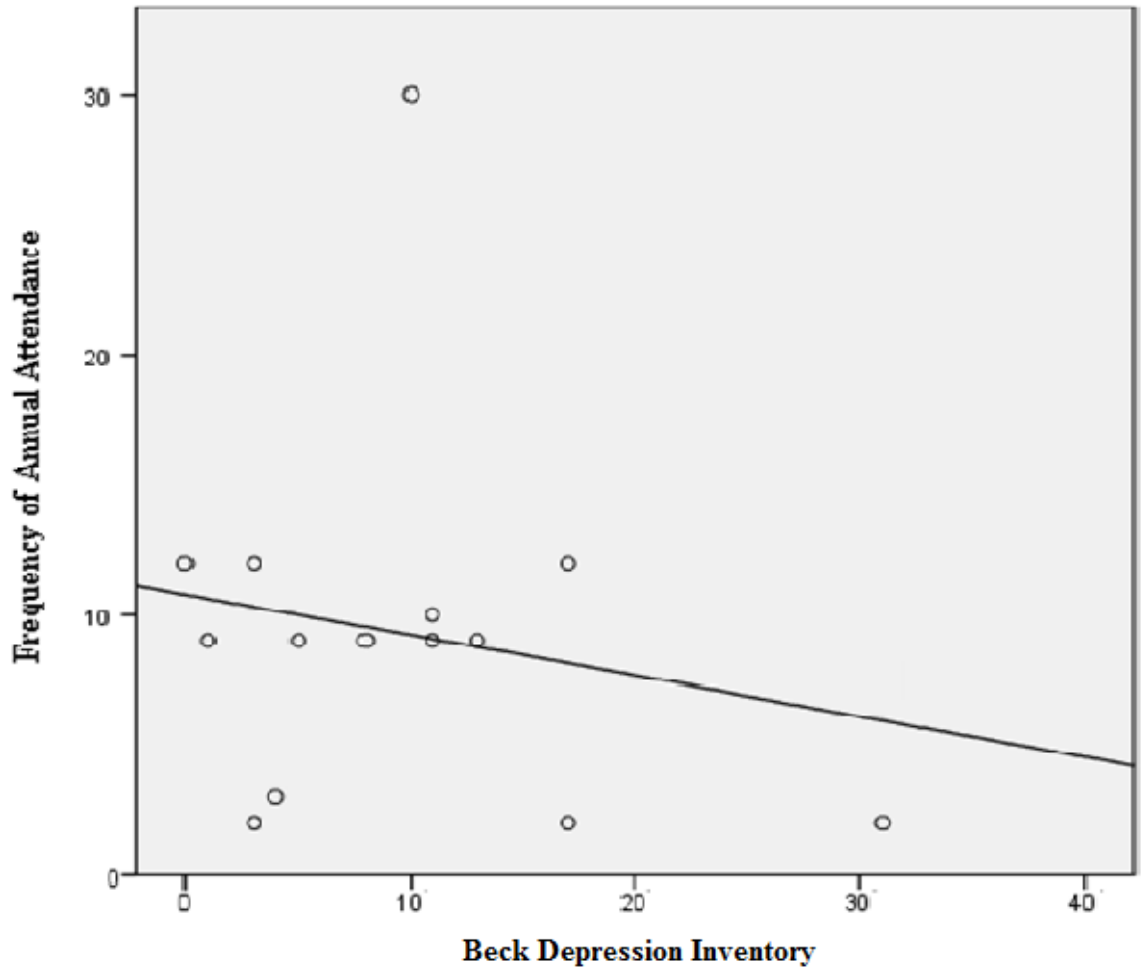


Figure 3.3. Scatterplot with best fit line illustrating the relationship between frequency of support group attendance (annually) and its influence on caregiver depression as measured by the Beck Depression Scale (BDI).

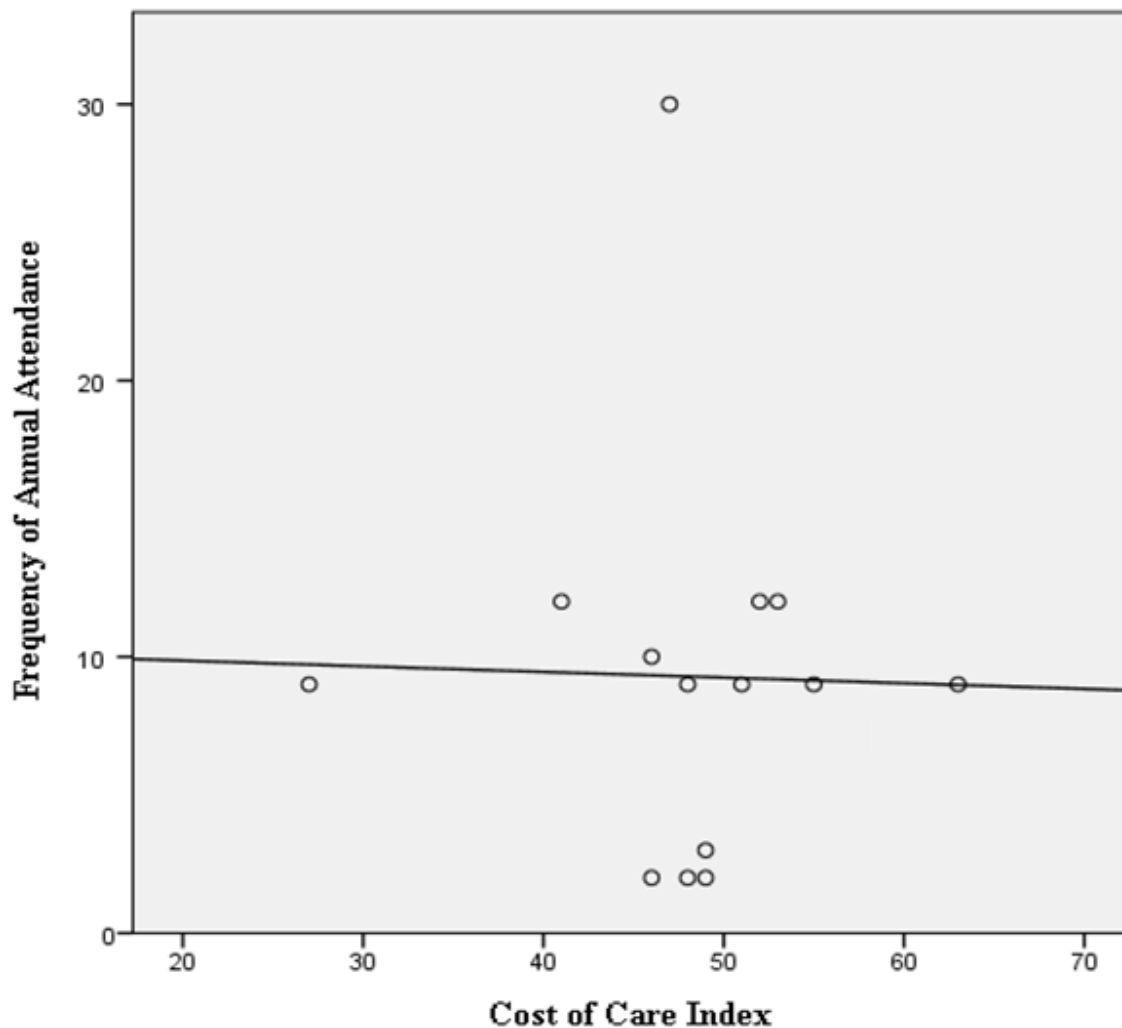


Figure 3.4. Scatterplot with best fit line illustrating the relationship between frequency of support group attendance (annually) and its influence on caregiver burden as measured by the Cost of Care Index (CCI).

Effects of Information Provided at Support Group Meetings on Caregiver Depression and Burden

To explore the relationships between the types of information provided to caregivers at support group meetings and their influences on caregiver depression and burden, the data were examined to identify trends. Figures 3.5 through 3.9 present these

data as they apply to persons presenting with minimal depression, mild depression, or severe depression as measured by the BDI. It can be seen in Figure 3.5 that the majority of participants receiving educational information are experiencing minimal depression. Five participants reported receiving counseling whereas six participants do not receive counseling, yet both groups experience minimal depression suggesting that perhaps counseling has no impact on depression (Figure 3.6). As illustrated in Figure 3.7, nine participants indicated not receiving financial information and experiencing minimal depression, and two participants not receiving financial information experience mild depression. Two participants receiving financial information are experiencing minimal depression and one participant who receives financial information is experiencing severe depression. Of the nine participants indicating receiving social support information, six experience minimal depression, two experience moderate depression, and one experiences severe depression. Five participants indicated they were not receiving social support information and all fell in the range of mild depression (Figure 3.8). It can be seen in Figure 3.9 that thirteen participants do not receive physical/health information and depression levels range; eleven are in the minimal level of depression and two are in the level of mild depression. The one participant indicating receiving physical/health information is in the severe range of depression.

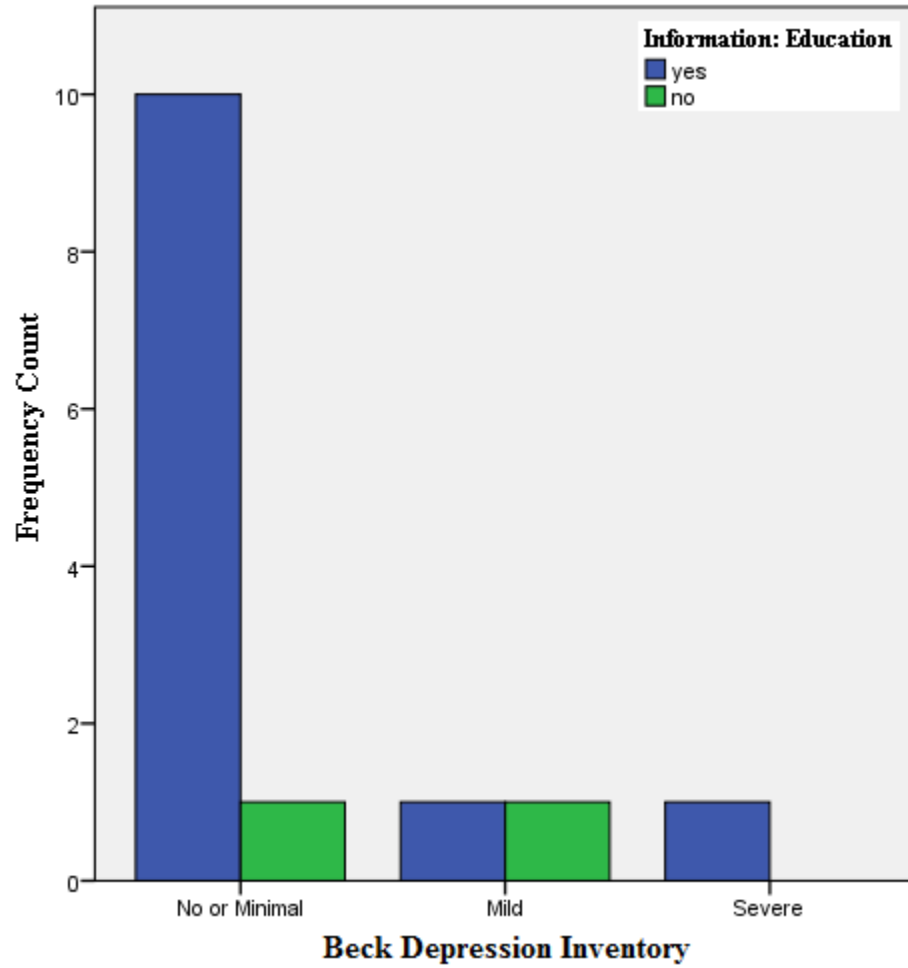


Figure 3.5. Bar graph illustrating the relationship between educational information received and depression as measured by the Beck Depression Inventory (BDI).

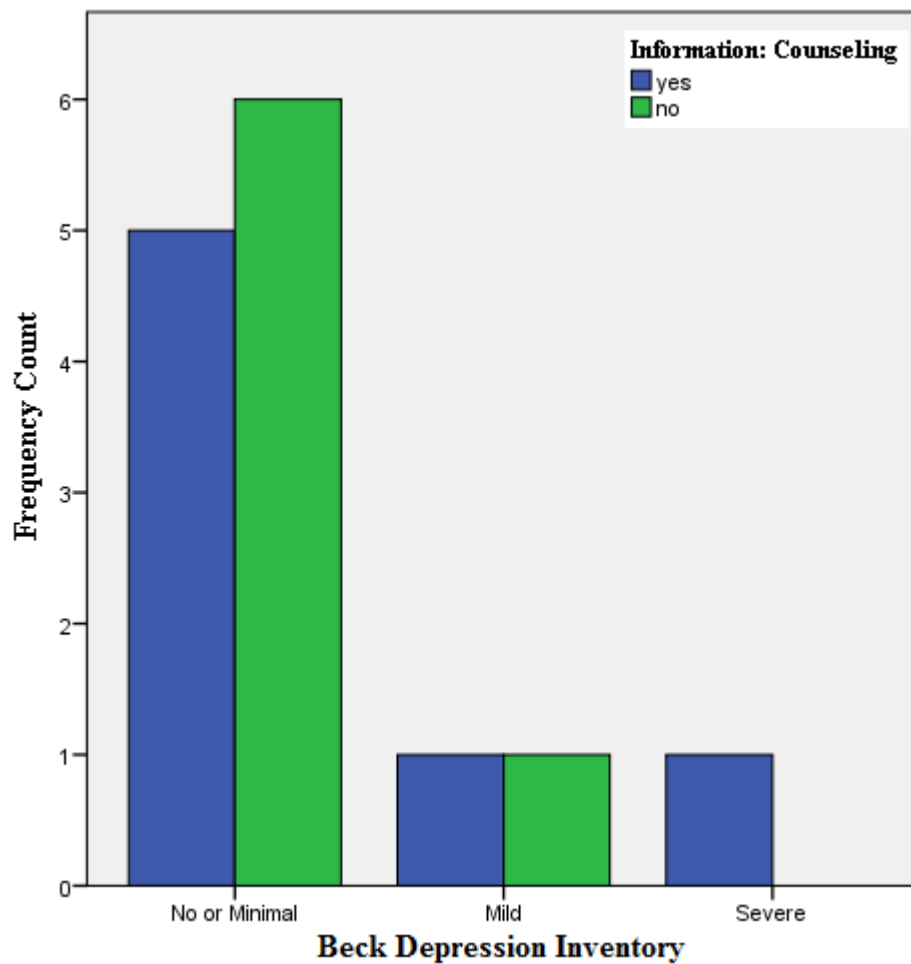


Figure 3.6. Bar graph illustrating the relationship between counseling information received and depression as measured by the Beck Depression Inventory (BDI).

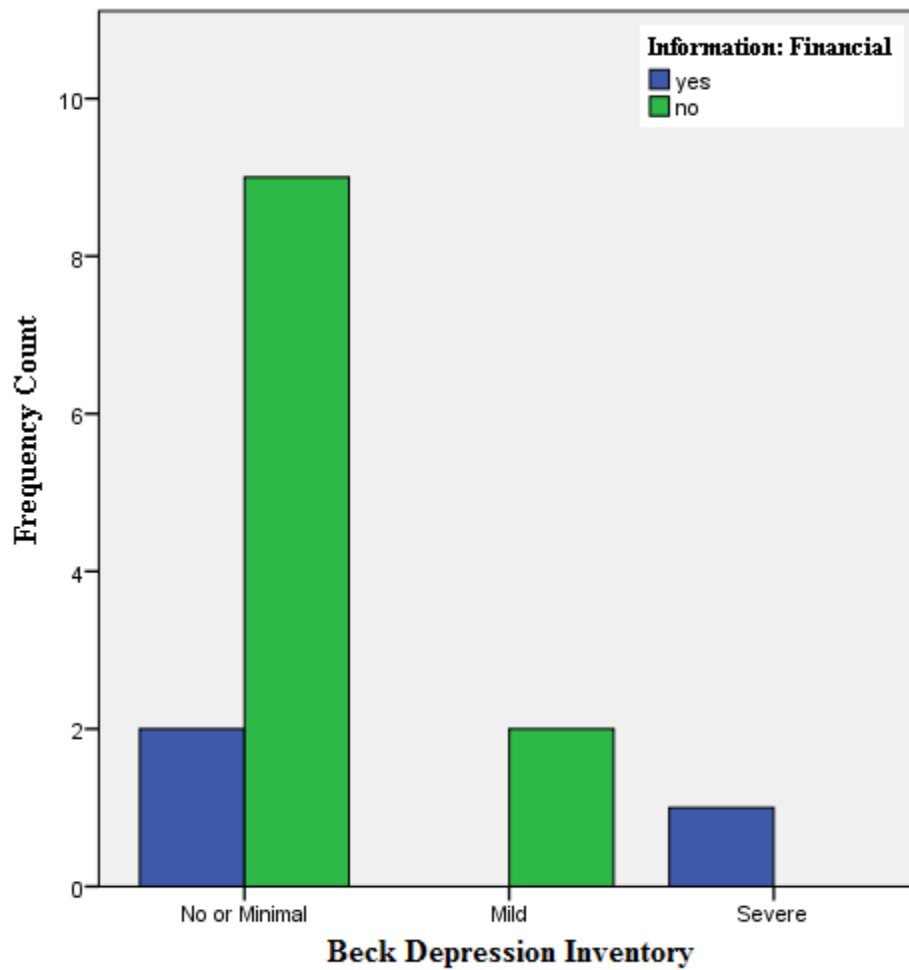


Figure 3.7. Bar graph illustrating the relationship between financial information received and depression as measured by the Beck Depression Inventory (BDI).

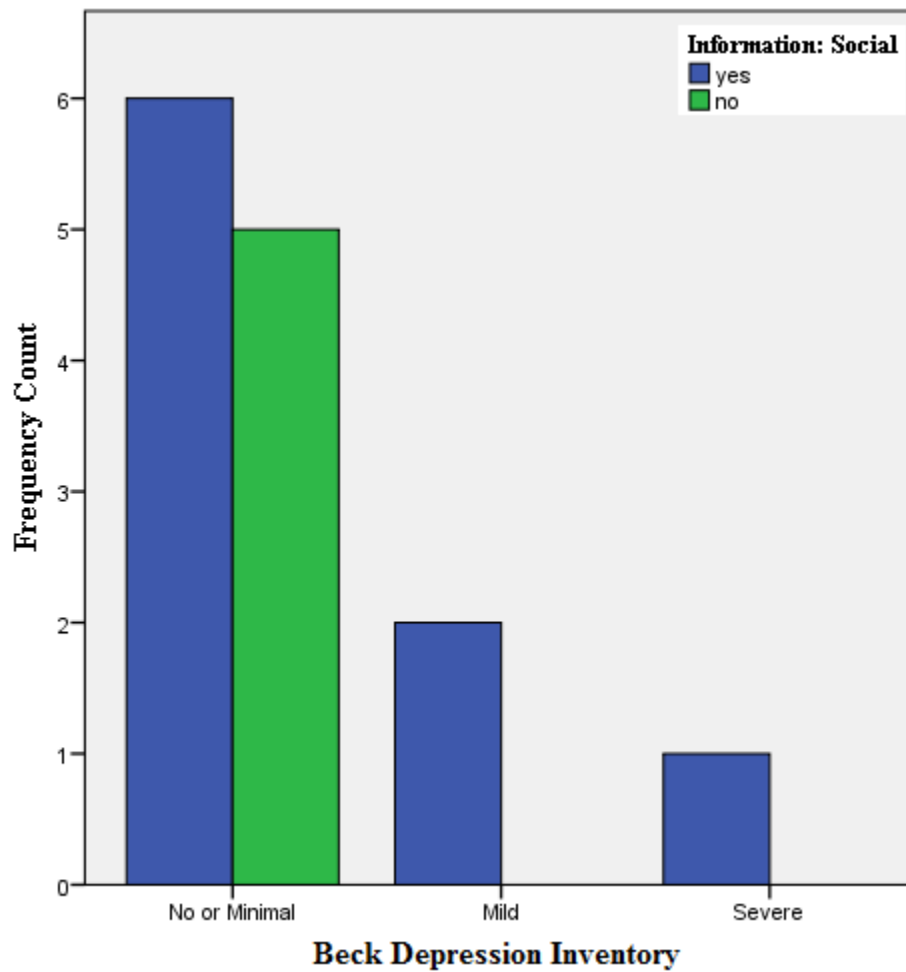


Figure 3.8. Bar graph illustrating the relationship between social support information received and depression as measured by the Beck Depression Inventory (BDI).

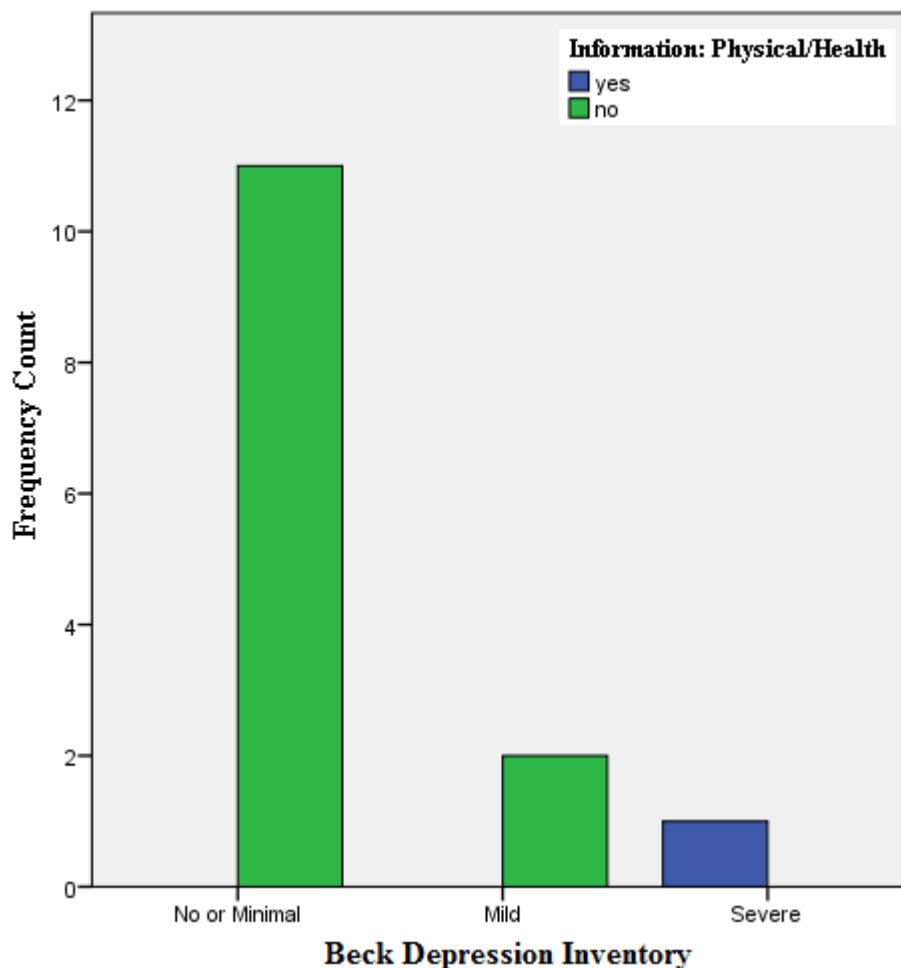


Figure 3.9. Bar graph illustrating the relationship between physical/health information received and depression as measured by the Beck Depression Inventory (BDI).

Similar comparisons were made between the various information topics and caregiver burden. Figures 3.10 through 3.14 present these data as they apply to persons presenting with little to no burden, moderate burden, and significant burden as determined by raw scores of the CCI. It can be seen in Figure 3.10 that the majority of participants received educational information yet burden is still experienced by 12 of the participants, indicating no trend between caregiver burden and educational information received. As illustrated in Figure 3.11, participants indicating that they had not received counseling at

their support groups had significant levels of burden, whereas persons experiencing moderate burden were equal in number of receiving or not receiving counseling. Apparent trends in the data were observed comparing caregiver burden and receiving financial information (Figure 3.12). Ten people experiencing moderate or significant burden did not receive financial information through the support group. It can be seen in Figure 3.13 that seven participants indicated moderate burden and one participant indicated significant burden while still receiving social support information from their support group. Only one participant indicated receiving physical/health information from his/her support group and yet still experienced moderate burden. Eleven participants indicated not receiving any physical/health information while still experiencing moderate burden, and one person indicated not receiving physical/health information while experiencing significant burden (Figure 3.14).

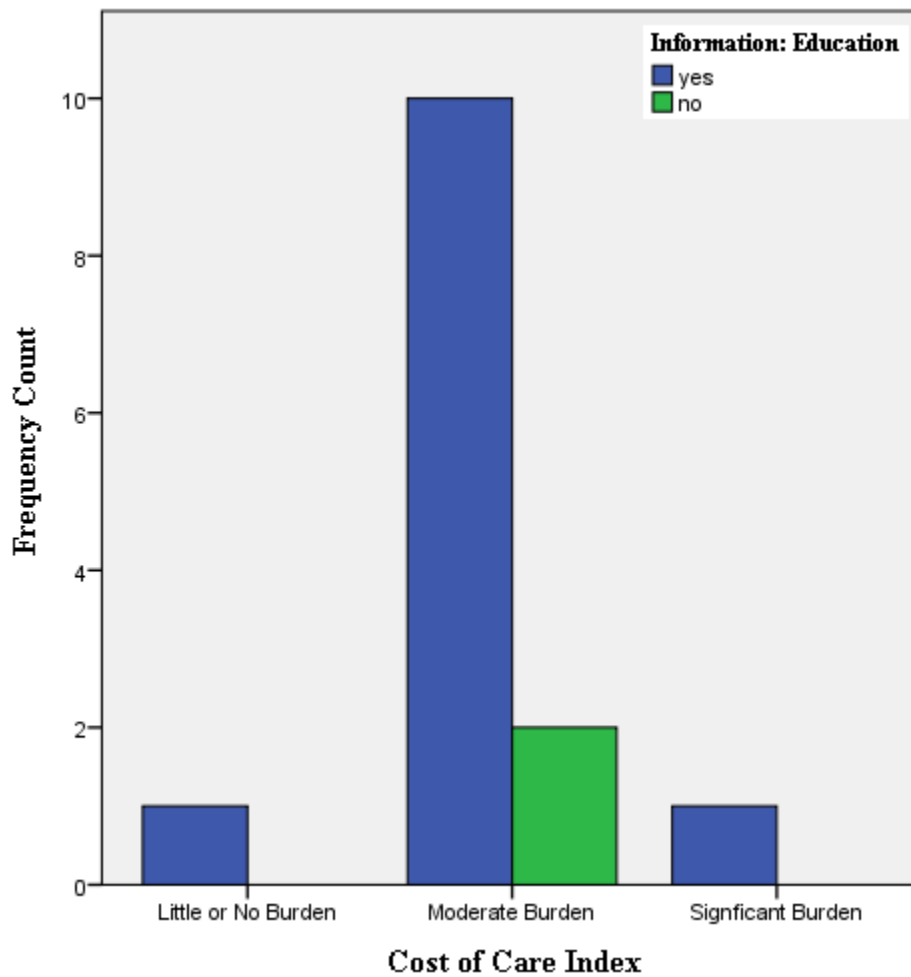


Figure 3.10. Bar graph illustrating the relationship between educational information received and burden as measured by the Cost of Care Index (CCI).

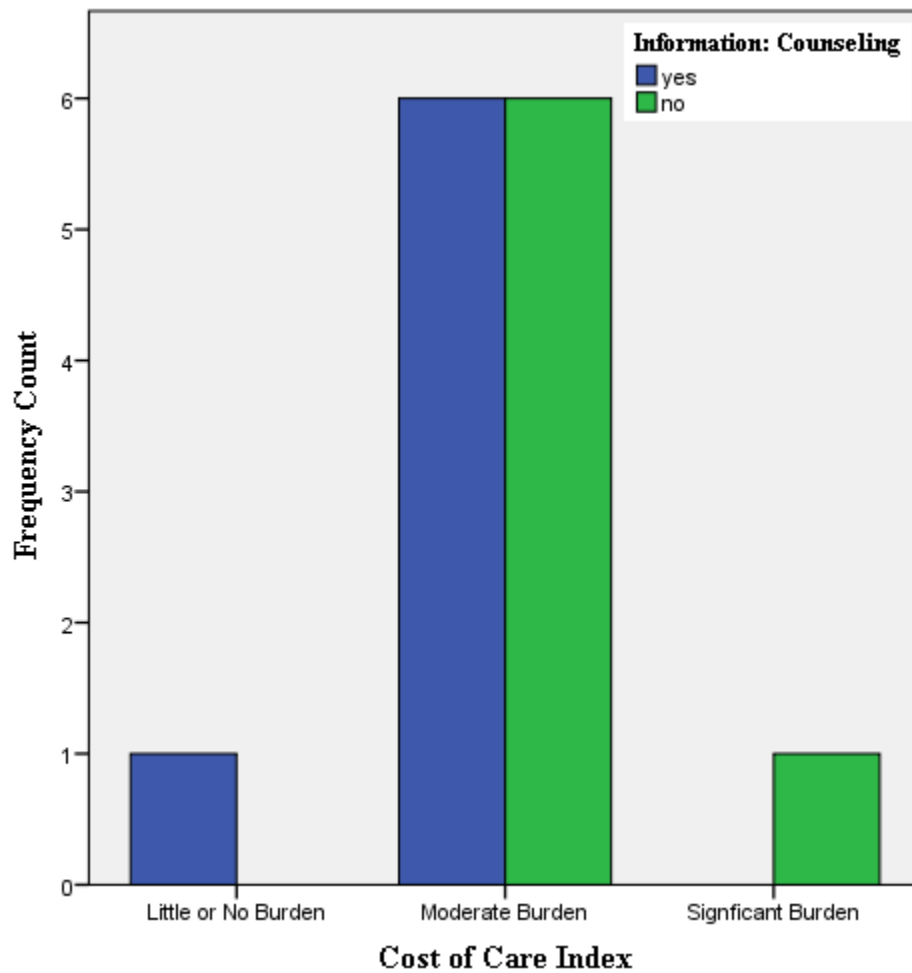


Figure 3.11. Bar graph illustrating the relationship between counseling information received and burden as measured by the Cost of Care Index (CCI).

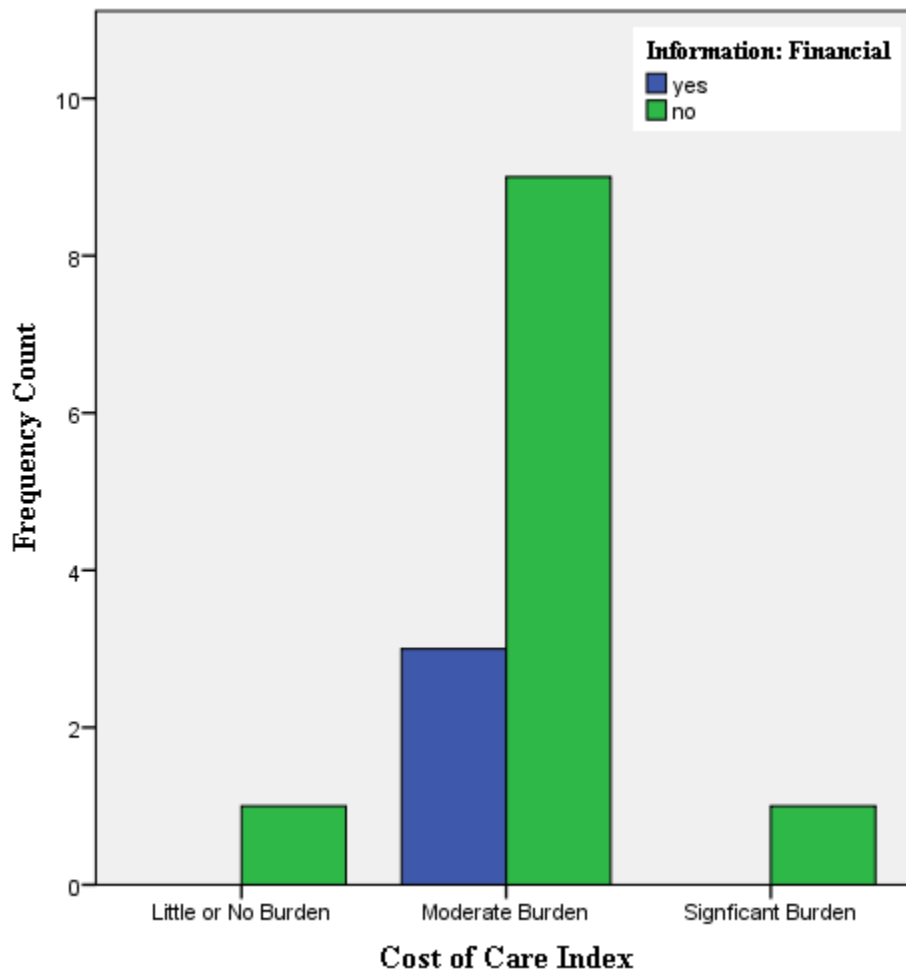


Figure 3.12. Bar graph illustrating the relationship between financial information received and burden as measured by the Cost of Care Index (CCI).

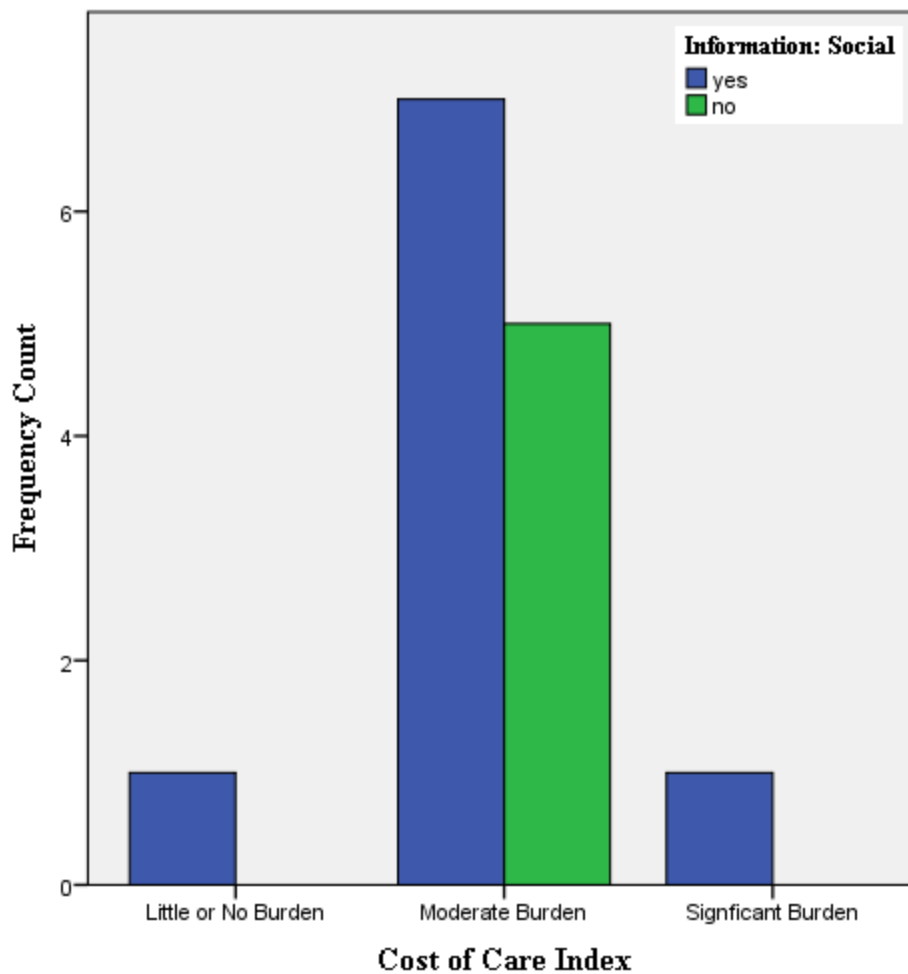


Figure 3.13. Bar graph illustrating the relationship between social support information received and burden as measured by the Cost of Care Index (CCI).

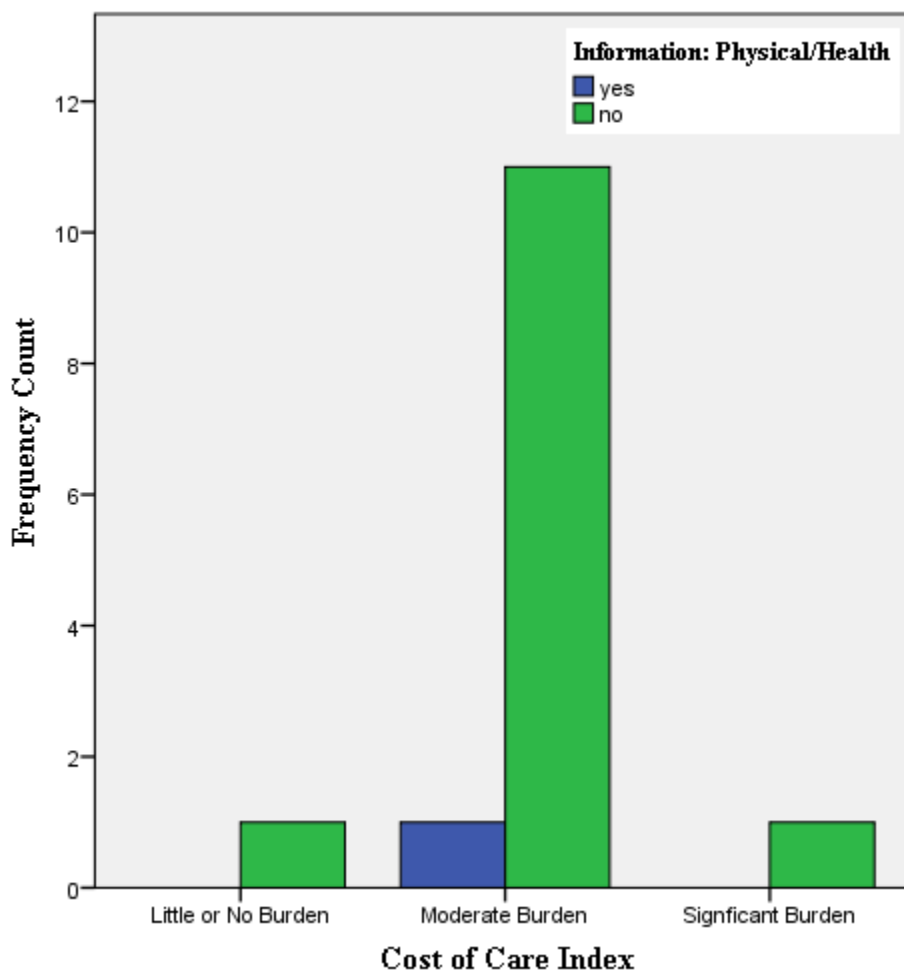


Figure 3.14. Bar graph illustrating the relationship between physical/health information received and burden as measured by the Cost of Care Index (CCI).

To summarize, 14 caregivers answered questions relating to demographics, support group features, caregiver experiences, dementia severity, caregiver burden, and caregiver depression. Data were used to explore the relationship between the frequency of support group meetings and caregiver depression and burden. Data suggest that there is no trend correlating the number of meetings offered and caregiver depression (raw scores of the

BDI); however, there appears to be a slight decreasing trend between number of support group meetings offered and caregiver burden (raw scores of the CCI). Data were also used to explore the relationship between the frequency of support group attendance and caregiver depression and burden. There is a slight decreasing trend in the number of support groups attended and caregiver depression levels (raw scores of the BDI), suggesting the more times a caregiver attends a support group, his/her depression decreases. There were no apparent relationships between frequency of support group attendance and caregiver burden (raw scores of the CCI). Data were collected and analyzed to examine the effects of information provided at support group meetings and its relationship between caregiver depression and burden. Depression does not appear to be associated with any of the information variables. Provision of counseling during a support group meeting may be associated with decreased caregiver burden. Additional findings suggest that participants are not receiving information about financial support and physical health/wellness during meetings

CHAPTER FOUR: DISCUSSION

Conclusions and Implications

The purpose of this study was to acquire preliminary data regarding the features of a caregiver support group that reliably lessen depression and burden commonly experienced by a caregiver of a person with dementia. In addition, the researcher sought to improve the survey questions for clarity and specificity for a larger scale study of the same purpose. Using an online survey, 14 caregivers answered questions pertaining to the following general topics: demographics, support group features, the caregiver experience, dementia severity, caregiver burden, and caregiver depression. Statistical analyses were not completed on the data collected due to the small sample size; therefore, only descriptive data were discussed in terms of data trends.

To answer research questions, the relationships between frequency of support group meetings and caregiver depression and burden were examined. Visual examination of the data would suggest no relationship between the frequency of support group meetings offered and presence of caregiver depression. However, there was a slight decrease in caregiver burden as the frequency of support group meetings offered increased. In open-ended questions, the majority of caregivers expressed a desire for more frequent meetings. Given that the caregivers' needs rapidly change, more frequent meetings may allow for the rapid changes to be addressed, helping the caregiver manage and cope with changes.

In line with this previous question, this research also examined the relationship between annual frequency of attending a support group and its influence on caregiver depression and burden. Visual examination of the data suggested that depression was

lower in persons attending support group meetings with greater frequency; however, this trend was far from impressive. The majority of the participants in this study demonstrated few, if any, symptoms of depression, so there was little room for comparison across depression severity levels. In a similar line of thinking, the majority of support groups in this sample met once per month, again limiting the variability of the sample. Regarding burden, no trend was evident in these data suggesting a relationship between frequency of attendance and varying extents of caregiver burden. In the present sample, most of the participants demonstrated moderate burden. Therefore, the variability in the sample was again lacking. However, it could be argued that these findings do not dispute previous findings of Chu et al. (2010) suggesting that support groups are doing very little to influence caregiver burden. Importantly, they do not reliably support these previous findings either.

Finally, this study aimed to investigate how caregiver depression and burden were influenced by different types of information provided to the members during support group meetings. It has been suggested that support groups should provide its members with information regarding skills training, emotional support, counseling, problem-solving strategies, stress management, and coping strategies to effectively reduce to risk of caregiver depression and burden (Acton & Kang, 2001; Chu et al., 2010; Morrow-Odom & Robbins, 2012). With these elements in mind, and given that the definition of caregiver burden specifically names physical, emotional, social, and financial demands as increasing burden (Acton & Kang, 2001; Gaugler, Roth, Haley, & Mittelman, 2008; Black et al., 2010; World Health Organization Kobe Centre for Health Department, n.d.), this study sought to explore five specific types of information received: education, counseling, financial, social,

physical/health. None of the information variables appeared to have an impact on depression or burden.

Given that this research was focused on better understanding why caregiver burden did not decrease with support group involvement, these trends were combined with responses to open-ended questions to draw tentative conclusions. First, the present data suggest that providing members with practical information, such as information about financial planning and management of personal physical/health needs, could positively impact burden. Responses to open-ended questions also revealed that members are receiving significant amounts of support, but would like to receive more practical strategies and solutions to manage challenging behaviors. Some respondents indicated that their groups were all-encompassing, meaning that they provided this practical information in addition to emotional support, but others specifically stated this practical component was lacking. Therefore, support groups may wish to consider including practical training and education for members during meetings, such as strategies to manage challenging behaviors or completion of applications to receive local funds for respite care.

Second, providing information alone is insufficient to have a full impact on burden. Although information and general education appears to be helpful in managing symptoms of depression, this may be the case because understanding why something is happening may improve coping. However, it does not mean that the caregiver is better prepared to handle specific situations that arise. Therefore, information alone, even if potentially including all topics discussed in this research, appears to solve only a portion of the problem. Therefore, caregiver burden is complex, and attempting to manage it by addressing one of many parts is not doing justice to the big picture.

A third factor to be considered is the facilitator. Considering that the variables previously listed as primary to influencing burden require understanding of the disease process, strategies to manage myriad behaviors, knowledge of area resources, and training in responding to the emotional reactions of the caregiver, the facilitator is integral to the support group. The data gathered here highlight the variability across groups in terms of the effectiveness of the support group to improve the state of the caregiver. Anecdotal responses would suggest that a knowledgeable facilitator is a motivating factor for some caregivers deciding whether or not to attend the meeting. If the facilitator is unable to provide members with the information needed, the group will be ineffective in its mission and members will have negative support group experiences.

Limitations of the Present Study

Several factors need to be considered when analyzing, interpreting and generalizing these data. This research is in need of a larger sample size to run statistical analyses on the data before any conclusions can be drawn and applied to the population at large. The small sample size was most likely a consequence of recruitment strategies. Recruitment took place during a holiday month when the majority of support groups were not meeting. Another consideration effecting sample size was the length of availability of the survey. There was a window of two and a half months in which caregivers were allowed to access the survey. Due to the vulnerability of the population and considering what questions were asked of them, many facilitators did not give their support group members the option of taking the survey as to not add more burden to their lives. It is also a concern that people with depression and/or burden did not complete the survey when given the option. When analyzing the data, the majority of caregivers were not experiencing high levels of

depression and burden. Simplifying the research questions and task requirements may increase participation. In addition, paper copies of surveys could be provided and completed during meetings which may improve response rates and due to the age of this population accessing technology might have been an issue.

A second limitation to the study was the construction of the survey. The survey included a total of 85 questions and might have proved to be too time consuming and complex to complete. Some questions could have been disregarded that were not related to the primary questions being addressed. Upon analysis of data, there were increasing concerns that participants may not have understood the questions. For example, definitions and examples of the various types of information explored in the final research question should be provided to ensure that participants had similar understanding of these important variables. The researcher had hoped that this initial data collection would improve survey design, which it appears to have done by identifying variables such as these allowing for an improved survey before collecting data from a larger sample.

A third limitation of the study included the participation requirements. Specifically, if this study was open to caregivers who have not attended support groups, data could have been gathered regarding caregiver burden and depression in this population. Including data from persons such as this would allow for better understanding of the effects of support groups on caregiver depression and burden by comparing those who attend the groups and those who do not. Relevant data could have also been collected regarding reasons for not attending a support group.

Directions for Future Study

In order to be able to run statistical analysis on the effects of support group involvement in regards to caregiver depression and burden, a larger sample size is needed. Clearly, a larger sample of participants that more directly matches that of other larger-scale studies is needed before any of these conclusions can be generalized to the population at large. To achieve this, other recruitment options should be considered such as utilizing the Alzheimer's Association research center, newsletters, and social media as well as incentives to completing the survey such as money, gift cards, books, or registration for training workshops. Including a broader participant base may also be beneficial to better explore the effectiveness of the caregiver support groups. Including a sample of caregivers not attending support groups and support group facilitators may allow for a more comprehensive view of the issues at hand.

Clearly, there is a need for research such as this. As the population of persons with dementia increases, the cost of caring for this population will also increase making the role of the family caregiver even more important. If caregivers are to be willing to accept this role and be successful in it, professionals need to be working together to educate, train, and support this invaluable group of people. Learning more about how to utilize the caregiver support group for this purpose is essential. Research should continue and knowledge of best practice shared so that support group implementation can become evidence-based.

CHAPTER FIVE: REFERENCES

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APPENDIX A

SURVEY

Informed Consent Form Dementia Caregiver's Perspectives Regarding the Effectiveness of Support Group Involvement

What is the purpose of this research?

The purpose of this study is to better understand changes in caregiver burden and depression as it relates to support group involvement. Specifically, we hope to learn more about the types of support you are receiving in your group, and how those types of support affect caregiver burden and depression.

What will be expected of me?

You will be asked to complete a survey related to your caregiving experiences and your support group involvement.

How long with the research take?

This survey will take approximately 15-minutes.

Will my information be kept anonymous?

No identifying information, such as name, date of birth, address, or social security number, will be collected from you. All materials will be kept in a locked drawer in the primary investigators office for five years at which time it will be destroyed. When presenting this research, only summaries of group data will be discussed.

Can I withdraw from the study if I decide to?

Participation is voluntary. That is, you may stop the survey whenever you choose. However, already answered questions will be saved and used in the data analysis. Your participation or refusal to participate will not result in any consequences to you or your loved-one.

Is there any harm that I might experience from taking part in the study?

You may experience temporary sadness by taking part in this study, but this is not anticipated to be greater than what you may experience in regular discussion with support group members or other medical professionals involved in your loved-one's care. If you happen to experience any distress as a result of participating in the research, we encourage you to contact the leader of your support group.

How will I benefit from taking part in the research?

Participation in this research will contribute to our understanding of caregiver burden as it relates to support group involvement. We will learn strategies to reduce caregiver burden more effectively, thus improving quality of life for future caregivers like you.

Who should I contact if I have questions or concerns about the research?

If you have questions or concerns about this research, please feel free to contact Katherine Scott by phone (828-227-7251) or email (kescott1@catamount.wcu.edu). You may also contact Dr. Leigh Odom, faculty research director, at 828-227-3834 or kmodom@email.wcu.edu. If you have concerns about your treatment as a participant in this study, contact the chair of WCU's Institutional Review Board through the office of Research Administration at WCU (828-227-7212).

If you would like you receive a summary of the results, once the study has been completed, please e-mail Katherine Scott (kescott1@catamount.wcu.edu).

By clicking the link, you acknowledge that you have read this consent document and received sufficient answers to your questions. Clicking the link below indicates that you are consenting to participate in this study.

Thank you for your time and support of this endeavor.

I agree to participate

I do not agree to participate

Instructions:

Your answers will be saved as you go.

After you finish answering a set of questions, please hit the NEXT (>>) button located at the bottom of the page.

Please do not hit the back (or backspace) button on your computer/web browser. If you need to revisit a question, please hit the BACK (<<) button at the bottom of the page.

QUALIFYING INFORMATION

1. Are you at least 18 years of age?
 - Yes
 - No

2. Are you a caregiver of a person with dementia?
 - Yes
 - No

3. In the past 12 months, have you attended a caregiver (or similar) support group?
 - Yes
 - No
 - a. You selected no, you have not attended a caregiver (or similar) support group, please select why (check all that apply).
 - Time Commitment
 - Traveling Distance
 - Unable to find care for your loved one
 - Other _____

CAREGIVER INFORMATION

4. What is your relationship to this person with dementia or Alzheimer's disease that you are caring for right now?
- Spouse
 - Child
 - Sibling
 - Parent
 - Friend
 - Other _____

5. On average, how much contact do you have with this person with dementia or Alzheimer's disease?

	0	10	20	30	40	50	60	70	80	90	100
Time per week (hours)											
Time per day (hours)											

6. How long have you been a caregiver to the person with dementia or Alzheimer's disease?

	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Years																

7. Do you care for anyone else with dementia before this current experience?
- Yes
 - No
- a. You answered yes to having prior caregiver experience please explain. (Ex: Who did you provide care for and how long?)
- _____

8. Considering the person you care for now, how long has he or she been diagnosed with dementia?

	0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Years																

9. In your opinion, how severe is the dementia or Alzheimer's disease?
- Mild

- Moderate
- Severe

10. Where does this person with dementia or Alzheimer's disease live?

- In your home
- In his/her home
- With friends
- In an assisted living facility
- Long term care
- Other _____

11. Do you receive financial support to help care for the person with dementia or Alzheimer's disease?

- Yes
- No

a. What type of financial support do you receive and how do you find this support? (Check all that apply).

- Grants
- Savings
- Support groups
- Long term care insurance
- Other _____

DEMENTIA SEVERITY RATING SCALE

In each section, please choose the description that **most closely applies** to the person with dementia. This is a generated form, so no one description may be exactly right. Please choose the answer that seems to apply most of the time. There are 12 questions in all.

1. MEMORY

- Normal memory.
- Occasionally forgets things that they were told recently. Does not cause many problems.
- Mild consistent forgetfulness. Remembers recent events but often forgets parts.
- Moderate memory loss. Worse for recent events. May not remember something you just told them. Causes problems with everyday activities.
- Substantial memory loss. Quickly forgets recent or newly-learned things. Can only remember things that they have known for a long time.
- Does not remember basic facts like the day of the week, when last meal was eaten or what the next meal will be.
- Does not remember even the most basic things.

2. SPEECH AND LANGUAGE

- Normal ability to talk and to understand others.
- Sometimes cannot find a word, but able to carry on conversations.
- Often forgets words. May use the wrong word in its place. Some trouble expressing thoughts and giving answers.
- Usually answers questions using sentences but rarely starts a conversation.
- Answers questions, but responses are often hard to understand or don't make sense. Usually able to follow simple instructions.
- Speech often does not make sense. Can not answer questions or follow instructions.
- Does not respond most of the time.

3. RECOGNITION OF FAMILY MEMBERS

- Normal - recognizes people and generally knows who they are.
- Usually recognizes grandchildren, cousins or relatives who are **not** seen frequently but may not recall how they are related.
- Usually does not recognize family members who are not seen frequently. Is often confused about how family members such as grandchildren, nieces, or nephews are related to them.
- Sometimes does not recognize close family members or others who they see frequently. May not recognize their children, brothers, or sisters who are not seen on a regular basis.
- Frequently does not recognize spouse or caregiver.
- No recognition or awareness of the presence of others.

4. ORIENTATION TO TIME

- Normal awareness of time of day and day of week.

- Some confusion about what time it is or what day of the week, but not severe enough to interfere with everyday activities.
- Frequently confused about time of day.
- Almost always confused about the time of day.
- Seems completely unaware of time.

5. ORIENTATION TO PLACE

- Normal awareness of where they are even in new places.
- Sometimes disoriented in new places.
- Frequently disoriented in new places.
- Usually disoriented, even in familiar places. May forget that they are already at home.
- Almost always confused about place.

6. ABILITY TO MAKE DECISIONS

- Normal - as able to make decisions as before.
- Only some difficulty making decisions that arise in day-to-day life.
- Moderate difficulty. Gets confused when things get complicated or plans change.
- Rarely makes any important decisions. Gets confused easily.
- Not able to understand what is happening most of the time.

7. SOCIAL AND COMMUNITY ACTIVITY

- Normal - acts the same with people as before
- Only mild problems that are not really important, but clearly acts differently from previous years.
- Can still take part in community activities without help. May appear normal to people who don't know them.
- Often has trouble dealing with people outside the home without help from caregiver. Usually can participate in quiet home activities with friends. The problem is clear to anyone who sees them.
- No longer takes part in any real way in activities at home involving other people. Can only deal with the primary caregiver.
- Little or no response even to primary caregiver.

8. HOME ACTIVITIES AND RESPONSIBILITIES

- Normal. No decline in ability to do things around the house.
- Some problems with home activities. May have more trouble with money management (paying bills) and fixing things. Can still go to a store, cook or clean. Still watches TV or reads a newspaper with interest and understanding.
- Makes mistakes with easy tasks like going to a store, cooking or cleaning. Losing interest in the newspaper, TV or radio. Often can't follow a long conversation on a single topic.
- Not able to shop, cook or clean without a lot of help. Does not understand the newspaper or the TV. Cannot follow a conversation.
- No longer does any home-based activities.

9. PERSONAL CARE - CLEANLINESS

- Normal. Takes care of self as well as they used to.
- Sometimes forgets to wash, shave, comb hair, or may dress in wrong type of clothes. Not as neat as they used to be.
- Requires help with dressing, washing and personal grooming.
- Totally dependent on help for personal care.

10. EATING

- Normal, does not need help in eating food that is served to them.
- May need help cutting food or have trouble with some foods, but basically able to eat by themselves.
- Generally able to feed themselves but may require some help. May lose interest during the meal.
- Needs to be fed. May have trouble swallowing.

11. CONTROL OF URINATION AND BOWELS

- Normal - does not have problems controlling urination or bowels except for physical problems.
- Rarely fails to control urination (generally less than one accident per month).
- Occasional failure to control urination (about once a week or less).
- Frequently fails to control urination (more than once a week).
- Generally fails to control urination and frequently can not control bowels.

12. ABILITY TO GET FROM PLACE TO PLACE

- Normal, able to get around on their own. (May have physical problems that require a cane or walker).
- Sometimes gets confused when driving or taking public transportation, especially in new places. Able to walk places alone.
- Cannot drive or take public transportation alone, even in familiar places. Can walk alone outside for short distances. Might get lost if walking too far from home.
- Cannot be left outside alone. Can get around the house without getting lost or confused.
- Gets confused and needs help finding their way around the house.
- Almost always in a bed or chair. May be able to walk a few steps with help, but lacks sense of direction.
- Always in bed. Unable to sit or stand.

DEFINITION OF CAREGIVER BURDEN

12. In your own words, how would you define caregiver burden?

SUPPORT GROUP INFORMATION

13. Who is your support group for? (Check all that apply)

- Spouses
- Children
- Parents
- Men
- Women
- Anyone who wishes to attend
- Other _____

14. What is the approximate month and year you began attending a support group?

15. How often does your support group meet? Please indicate how many days per month.

- Never
- Less than once a month
- Once a month
- 2 – 3 times a month
- Once a week
- 2 – 3 times a week
- Daily

16. How many times in the last year have you attended this group?

	0	3	6	9	12	15	18	21	24	27	30
Per year											

17. Who is the support group leader? (Check all that apply)

- Speech-Language Pathologist
- Psychologist
- Nurse
- Counselor
- No group leader
- It varies
- I do not know
- Other _____

18. What are your expectations of your support group? What do you think a caregiver support group should provide its members?

19. What types of support/information do you receive? (Check all that apply)

- Education about dementia
- Counseling
- Financial
- Social
- Physical
- Other _____

20. What would you like to learn more about from your support group? Please explain, and, if possible, provide examples.

BECK DEPRESSION SCALE

In each section, please choose the description that most closely applies to you. This is a generated form, so no one description may be exactly right. Please choose the answer that seems to apply most of the time. There are 21 questions in all.

1.

- I do not feel sad.
- I feel sad
- I am sad all the time and I can't snap out of it.
- I am so sad and unhappy that I can't stand it.

2.

- I am not particularly discouraged about the future.
- I feel discouraged about the future.
- I feel I have nothing to look forward to.
- I feel the future is hopeless and that things cannot improve.

3.

- I do not feel like a failure.
- I feel I have failed more than the average person.
- As I look back on my life, all I can see is a lot of failures.
- I feel I am a complete failure as a person.

4.

- I get as much satisfaction out of things as I used to.
- I don't enjoy things the way I used to.
- I don't get real satisfaction out of anything anymore.
- I am dissatisfied or bored with everything.

5.

- I don't feel particularly guilty
- I feel guilty a good part of the time.
- I feel quite guilty most of the time.
- I feel guilty all of the time.

6.

- I don't feel I am being punished.
- I feel I may be punished.
- I expect to be punished.
- I feel I am being punished.

7.

- I don't feel disappointed in myself.
- I am disappointed in myself.
- I am disgusted with myself.

- I hate myself.

8.

- I don't feel I am any worse than anybody else.
- I am critical of myself for my weaknesses or mistakes.
- I blame myself all the time for my faults.
- I blame myself for everything bad that happens.

9.

- I don't have any thoughts of killing myself.
- I have thoughts of killing myself, but I would not carry them out.
- I would like to kill myself.
- I would kill myself if I had the chance.

10.

- I don't cry any more than usual.
- I cry more now than I used to.
- I cry all the time now.
- I used to be able to cry, but now I can't cry even though I want to.

11.

- I am no more irritated by things than I ever was.
- I am slightly more irritated now than usual.
- I am quite annoyed or irritated a good deal of the time.
- I feel irritated all the time.

12.

- I have not lost interest in other people.
- I am less interested in other people than I used to be.
- I have lost most of my interest in other people.
- I have lost all of my interest in other people.

13.

- I make decisions about as well as I ever could.
- I put off making decisions more than I used to.
- I have greater difficulty in making decisions more than I used to.
- I can't make decisions at all anymore.

14.

- I don't feel that I look any worse than I used to.
- I am worried that I am looking old or unattractive.
- I feel there are permanent changes in my appearance that make me look unattractive
- I believe that I look ugly.

15.

- I can work about as well as before.
- It takes an extra effort to get started at doing something.
- I have to push myself very hard to do anything.
- I can't do any work at all.

16.

- I can sleep as well as usual.
- I don't sleep as well as I used to.
- I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
- I wake up several hours earlier than I used to and cannot get back to sleep.

17.

- I don't get more tired than usual.
- I get tired more easily than I used to.
- I get tired from doing almost anything.
- I am too tired to do anything.

18.

- My appetite is no worse than usual.
- My appetite is not as good as it used to be.
- My appetite is much worse now.
- I have no appetite at all anymore.

19.

- I haven't lost much weight, if any, lately.
- I have lost more than five pounds.
- I have lost more than ten pounds.
- I have lost more than fifteen pounds.

20.

- I am no more worried about my health than usual.
- I am worried about physical problems like aches, pains, upset stomach, or constipation.
- I am very worried about physical problems and it's hard to think of much else.
- I am so worried about my physical problems that I cannot think of anything else.

21.

- I have not noticed any recent change in my interest in sex.
- I am less interested in sex than I used to be.
- I have almost no interest in sex.
- I have lost interest in sex completely.

COST OF CARE INDEX

Please answer the following questions truthful and to the best of your ability

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. I feel that my elderly relative is (will be) an overly demanding person to care for.				
2. I feel that caring for my elderly relative puts (will out) a strain on family relationships.				
3. I feel that caring for my elderly relating disrupts (will disrupt) my routine in my home.				
4. I feel that caring for my elderly relative interferes (will interfere) with my friends or friends of my family coming to my home.				
5. I feel that caring for my elderly relative has negatively affected (will negatively affect) my family's or my physical health.				
6. I feel that caring for my elderly relative has negatively affected (will negatively affect) my appetite.				
7. I feel that caring for my elderly relative has caused me (will cause me) to be physically fatigued.				
8. I feel that caring for my elderly relative has caused me (will cause me) to become anxious.				
9. I feel that meeting the psychological needs of my elderly relative for feeling wanted and important is not (will not be) worth the effort.				
10. I feel that meeting the health needs of my elderly relative is not (will not be) worth the effort.				
11. I feel that meeting the daily needs of my elderly relative is not (will not be) worth the effort.				
12. I feel that meeting the social needs of my elderly relative for companionship is not (will not be) worth the effort.				
13. I feel that my elderly relative is (will be) an overly demanding person to care				

for.				
14. I feel that my elderly relative tried (will try) to manipulate me.				
15. I feel that caring for my elderly relative has caused (will cause) my family and me much aggravation.				
16. I feel that my elderly relative makes (will make) unnecessary requests of me for care.				
17. I feel that caring for my elderly relative is causing me (will cause me) to dip into savings meant for other things.				
18. I feel that my family and I must give up (will have to give up) necessities because of the expense to care for my elderly relative.				
19. I feel that my family and I cannot (will not be able to) afford those little extras because of the expense to care for my elderly relative.				
20. I feel that caring for my elderly relative is (will be) too expensive.				

DEMOGRAPHICS

21. What is your age?

22. What is your gender?

- Male
- Female
- Prefer not to answer

23. What is your marital status?

- Single
 - Married
 - Divorced
 - Separated
 - Committed Relationship
 - Prefer not to answer
 - Other _____
-

24. Which of the following best describes your racial or ethnic background?

- Asian
 - Black/African American
 - White/Caucasian
 - Hispanic
 - Native American/American Indian
 - Prefer not to answer
 - Other _____
-

25. Where do you live?

- Rural Community
 - Suburban Community
 - Urban Community
 - Prefer not to answer
 - Other _____
-

26. What is your occupation status? Check all that apply.

- Student
- Full-time (30 hours or more per week)
- Part-time (less than 30 hours per week)
- Unemployed
- Retired
- Prefer not to answer

27. What is the highest level of education you have completed?

- Less than High School
- High School/GED

- Some College
 - 2-year College Degree (Ex: Associates)
 - 4-year College Degree (Ex: BA)
 - Master's Degree
 - Doctorial Degree
 - Professional Degree (Ex: MD)
28. How many people live in your household? (Including you)
- 1 person
 - 2 people
 - 3 people
 - 4 people
 - 5 or more people
29. What is your approximate household income before taxes?
- \$10,000 and under per year
 - \$10,001 - \$20,000 per year
 - \$20,001 - \$35,000 per year
 - \$35,001 - \$50,000 per year
 - \$50,001 - \$75,000 per year
 - \$75,001 - \$100,000 per year
 - \$100,001 or more per year
 - Prefer not to answer

APPENDIX B

FACILITATOR LETTER



November 1, 2012

Dear Colleagues,

At Western Carolina University in Cullowhee, North Carolina, students and faculty are involved in numerous research projects related to improving the care and quality of life of persons with communication and cognitive disorders and their families. In line with this effort, we are conducting a research project related to the involvement of caregivers of persons with dementia in support groups. More specifically, we are hoping to identify variables related to support group demographics, dynamics, education approaches, and collaboration among members that have positive impact on caregiver burden and depression. Ultimately, it is hoped that the data collected in this research will lead to improved support group design and implementation.

The target population for this research is caregivers of persons with dementia involved in a support group. These individuals are asked to complete a 10-15 minute online survey in which they will answer a series of questions related to financial, physical, emotional, and social impacts of caregiving. Additional questions include those related to demographics, support group descriptions, and dementia characteristics of the person receiving care.

Although you are not necessarily a caregiver, you have been identified as someone who facilitates a support group for this population. As a result, we are asking that you share the enclosed information regarding this project with the members of your group, thus giving them an opportunity to share their experiences in a meaningful way if they choose to. No one is obligated to participate in this research; it is voluntary and anonymous. No foreseeable negative consequences will be incurred by participating or refusing to participate in this study.

We hope that you will share this information with your group members. Ultimately, the information gained will only improve our service to this population at present and in the future. If you have any questions regarding this research, please contact us at your earliest convenience.

Sincerest appreciation,

Katherine E. Scott, B.S.
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APPENDIX C

RECRUITMENT FLYER

Dementia Caregiver's Perspectives Regarding the Effectiveness of Support Group
Involvement

Purpose: The purpose of this study is to better understand changes in caregiver burden and depression as it relates to support group involvement. Specifically, we hope to learn more about the types of support you are receiving in your group, and how those types of support affect caregiver burden and depression.

Sponsored by: Western Carolina University, Department of Communication Sciences & Disorders

Criteria to Participate: In order to participate in this survey, you must:

- Be a caregiver of someone with dementia or Alzheimer's disease;
- Have attended a support group within the past 12 months;
- Be over the age of 18 years.

What will you do?

You will be asked to complete a survey related to your caregiving experiences and your support group involvement. The survey will take approximately 15 – 20 minutes.

To learn more about the survey and participation expectations, please visit our department's website (<http://www.wcu.edu/8389.asp>) and look for the link to this research on the right side of the page. If you are unable to find the link, please email Katherine Scott at the address below.

Thank you for your time and help with this effort. With this information, we will better understand how to make caregiving easier and more successful.

Sincerely,

Katherine E. Scott, B.S.
Graduate Candidate

Leigh Odom, Ph.D. CCC-SLP
Assistant Professor, Thesis Director

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Western Carolina University
Cullowhee, NC

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