DISSERTATION

A LONGITUDINAL EXAMINATION OF A PSYCHOEDUCATIONAL INTERVENTION AND A RESPITE GRANT FOR FAMILY CAREGIVERS OF PERSONS WITH ALZHEIMER'S OR OTHER DEMENTIAS

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WE HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER OUR SUPERVISION BY SARA ANNE SMITH ENTITLED A LONGITUDINAL EXAMINATION OF A PSYCHOEDUCATIONAL INTERVENTION AND A RESPITE GRANT FOR FAMILY CAREGIVERS OF PERSONS WITH ALZHEIMER'S OR OTHER DEMENTIAS BE ACCEPTED AS FULFILLING IN PART REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY.

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ABSTRACT OF DISSERTATION

A LONGITUDINAL EXAMINATION OF A PSYCHOEDUCATIONAL INTERVENTION AND A RESPITE GRANT FOR FAMILY CAREGIVERS OF PERSONS WITH ALZHEIMER'S OR OTHER DEMENTIAS

Alzheimer's disease can be particularly devastating to those who are caring for their loved one with the condition. Interventions such as support groups, caregiver training, and respite services can be effective in improving quality of life for those with dementia and their family caregivers, but there are few longitudinal studies that last more than 6 months to a year that have examined the longer-term implications of such interventions. The Colorado Alzheimer's Disease Demonstration Grants to States Project initiated in 2002 provided a valuable opportunity to compare psychoeducational, respite grant, and the combination of these two interventions in rural and urban communities across an 18-month period. A total of 82 caregivers participated in the study with 22 in the Savvy Caregiver Program (Savvy), 41 receiving a voucher-type respite grant for up to $1,000, and 19 receiving both. Participants completed multiple surveys and questionnaires both before the training and at 6-, 12-, and 18-month follow-up phone interviews. Positive outcomes of the training, grant, and multicomponent intervention were found at the follow-ups in spite of natural declines in the loved one's ability to perform Activities of Daily Living (ADL's) and increases in problem behaviors. Specifically, no group increases in depression were found at 18-month follow-up, although there was individual variation and the grant intervention appeared to be best at maintaining the improvement in depression initially observed at 6 months. In addition, the Savvy intervention showed significant decreases in depression across the 18 months. Varieties of service usage increased especially in the combination group and for urban participants receiving a grant since these participants were given funds to purchase services. There were no changes in service usage from 12 months to 18 months. All three interventions seemed to get about 30 percent of participants to start attending support groups, and there were no substantial differences in attendance attributable to the interventions at 18-month follow-up. The fact that caregiver depression did not increase on average over time even though problem behavior did, further implies a benefit of the interventions.

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CHAPTER I

INTRODUCTION

Alzheimer's Background and Significance

Alzheimer's disease (AD) is a devastating condition as it gradually destroys a person's memory and ability to learn, reason, make judgments, communicate, and carry out daily activities. As Alzheimer's progresses, individuals may also experience changes in personality and behavior, such as anxiety, suspiciousness or agitation, as well as delusions or hallucinations. The defining pathologies of AD are large numbers of neurofibrillary tangles and amyloid plaques in the brain (Banich, 2004). These tangles and plaques are thought to disrupt the normal neuron's structural matrix and cause vascular damage and neuronal cell loss. The length of the disease varies from 3 to 30 years, with the average life expectancy once the symptoms of the disease arrive ranging from 8 to 12 years (U.S. Congress Office of Technology Assessment, 1987).

Individuals afflicted with this degenerative brain disease seem to progress through a series of stages ranging from minimal cognitive decline to very severe cognitive decline (Reisberg, Ferris, deLeon, & Cook, 1982), with increasing loss of normative social behavior and progressive dependence on others for care. The clinical characteristics that accompany each stage have significant implications for both the person afflicted with AD and the family caregiver. Examples of clinical characteristics associated with the seven stages as delineated by Reisberg et al. (1982) include: stage 1 – no memory deficit; stage 2 – forgetting names or where objects have been placed; stage 3 – word and name finding deficit, concentration deficit, denial; stage 4 – decreased knowledge of current events, inability to perform complex tasks; stage 5 – unable to recall major aspects of their current life (e.g., phone number), disorientation to time; stage 6 – forgetting the name of the spouse, require assistance with activities of daily living (ADLs; e.g., incontinence); stage 7 – all verbal abilities are lost, loss of basic psychomotor skills (e.g., ability to walk). As the disease progresses loss of independence occurs and the person must now heavily depend on those around him/her for everyday functions. These drastic changes in physical and mental abilities have significant implications not only for the loved one afflicted with the disease but for their caregivers as well.

Demographics. Alzheimer's disease has become an increasingly prevalent and dreaded affliction as the population ages. Since the 1980s the number of people diagnosed with the disease has more than doubled, with approximately 4.5 million cases reported in the U.S. (Hebert, Scherr, Binenias, Bennett, & Evans, 2003). The impact is such that one in ten Americans has a family member with the disease and one out of every three people in the U.S. knows someone with Alzheimer's (Alzheimer's Association, 2004). The growth in cases accompanies the aging population (10% risk over age 65, 50% risk over age 85) across the nation, with some of the highest projected increases falling in the Western region of the U.S. Currently, Colorado has approximately 62,000 residents with the disease, as conveyed by the Alzheimer's Association; this state is expected to see a 124% increase by the year 2025, making it the third highest projected increase in the nation (Hebert, Scherr, Binenias, Bennett, & Evans, 2004).

Rural communities. Alzheimer's and other dementias are particularly problematic in rural communities. As younger family members move to larger population centers, the remaining rural population is increasingly older. Census data collected in Colorado in

2000 indicate that statewide 13% of the population is over 60 and 9.7% over 65, but in some rural counties 20% or more of the population is over 65, and that proportion is growing faster than in urban areas. Research has shown that rural elderly are not only likely to be older, but also to have a lower income and be less educated than those in more urban environments (Clifford & Lilley, 1993; Hobbs & Damon, 1996). Non-farm rural elderly have lower incomes compared to farming elderly, poorer housing, fewer family members to provide assistance, and poorer reported health (Coward et al., 1994). Consistent with Barker's (e.g., 1990) ecological psychology propositions, research on the implications of older individuals in rural settings has found that a critical issue among this specific population is loss of community settings and too few people to participate in these settings, leaving remaining residents struggling to sustain settings that are underpopulated and understaffed (Norris-Baker, 1999). Changes such as these reflect social, environmental, and psychological situations that can have a significant impact on the communities' older residents. Implications of these understaffed settings are significant as they can lead to psychological vulnerability, decreased health, and hopelessness and helplessness (Norris-Baker, 1999).

These hardships can be especially taxing when an elderly individual has Alzheimer's disease. Since children of rural elderly often leave home and settle in more urban areas, the responsibility for taking care of the rural elder falls to the spouse or an individual adult living in the area. Help for the caregiver in the form of respite services such as adult day care and in-home health care is not readily available in rural areas because the population density—1.0 to 2.0 per square mile in some Colorado counties—makes it unlikely that an economically viable respite service would be feasible. Clearly, there is a need to implement and examine the effectiveness of possible interventions for these at-risk caregivers.

Alzheimer's Caregivers

Demographics. Informal AD caregivers are individuals who provide unpaid assistance to elderly loved ones suffering from AD. The majority of AD informal caregivers are female, about 57 years of age, and live in the same household as the care recipient. A national sample found that 72% of all dementia caregivers are women (Stone, Cafferata, & Sangl, 1987). The number of informal caregivers who are employed ranges from 30 to 55 percent, although this can change throughout the caregiving experience. Additionally, approximately one-third of the caregiving population has incomes in the poor or near poor category (American Association of Retired Persons and The Travelers Foundation, 1989; Barber, 2004).

Monetary implications. The U.S. Congress Office of Technology Assessment (1987) found that 7 out of 10 people with Alzheimer's disease live at home, where family and friends provide approximately 75% of their care. As Alzheimer's disease progresses, certain behavioral, affective, and cognitive losses make caring for an elder with AD more difficult than caring for loved ones with other chronic conditions and disabilities (Light, Niederehe, & Lebowitz, 1994). Findings have shown that dementia caregivers provide more hours of care (19 vs. 12.5 hrs), are more likely to help with personal activities of daily living (ADLs), and provide more types of care than non-dementia caregivers (Light et al., 1994; National Alliance on Caregiving and Alzheimer's Association, 1999).

Caregivers are a precious resource to our health care system with the value of this care estimated to be roughly $196 billion in 1997 and climbing (Arno, Levine, &

Memmott, 1999). The experience of being a caregiver can cover as long as 20 or 30 years, but the length, amount, and intensity of care can vary depending on family circumstances. The financial burden associated with this caregiving role can be extreme, with total annual costs of informal care at home being estimated at around $19,000 and significantly rising with stage of progression and number of comorbidities (Leon, Cheng, & Neumann, 1998; Moore, Zhu, & Clipp, 2001). Often, caregivers depend on various support services such as in-home health care or adult day care that can strain financial resources but assist in relieving associated psychological and physiological stressors. Clearly, caregivers are a valuable resource in our society and promoting the health of these individuals is a must.

Mental health effects of caregiving. While caregiving can be a fulfilling and rewarding experience, often times it comes with associated stressors for the caregiver. In general, many AD caregivers experience increased depression and anxiety symptoms, lower perceived control, and higher burden compared to noncaregivers or community samples (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Schulz et al., 1997; Vitaliano, Russo, Scanlan, & Greeno, 1996; Zarit, Anthony, & Boutselis, 1987). Specifically, previous studies examining depression rates in AD caregivers have found the prevalence to be between 14 and 81 percent (Kiecott-Glaser et al., 1991; Schulz, Visintainer, & Williamson, 1990).

Various hypotheses for this increase in depression have been proposed, including use of negative coping styles (Lazarus & Folkman, 1984; Powers, Gallagher-Thompson, & Kraemer, 2002), a wear-and-tear hypothesis (Alspaugh, Stephens, Tounsend, Zarit, & Greene, 1999; Gaugler, Pearlin, Davey, & Zarit, 2000; Schulz & Williamson, 1991), and lack of social support (Thoits, 1986). Specific identified risk factors for depression in AD caregivers include: inappropriate guilt, fear of inadequacy, social isolation, hopelessness, concerns regarding financial implications, reduced control over their lives, lack of positive reinforcement, use of avoidant coping strategies, and loss of a previously joyous relationship (Baumgarten et al., 1992; Morris, Morris, & Britton, 1988; Powers et al., 2002; Roscoe & Cohen, 1999; Schulz & Williamson, 1991).

A more recent construct that has been examined with AD caregivers is their self-efficacy regarding caregiving, or their perception of confidence in their own ability to handle the demands of caregiving. Social cognitive theory holds that people can effect change in themselves and situations through their efforts. Bandura uses the idea of reciprocal causation, which views personal factors (i.e., cognitive, affective) and environmental events operating as interacting determinants of human action. Self-efficacy beliefs operate as a vital set of proximal determinants of human motivations, action, and affect (Bandura, 1986). Efficacy expectations are the beliefs an individual has regarding his or her ability to execute the necessary behaviors required to produce outcomes. Perceived self-efficacy can influence coping strategies and thus choice of behavioral settings that require use of alternative strategies for successful coping.

Bandura (1977) states that self-efficacy is an important explanatory construct of behavior as it has three significant behavioral consequences. These behavioral consequences are approach versus avoidance behavior, quality of performance of behaviors in the target domain, and persistence in the face of obstacles or disconfirming experiences. One exploratory study found that caregivers' perceived self-efficacy had a direct positive influence on the Personal Accomplishment component of burnout as measured by the Maslach Burnout Inventory (MBI; Maslach, Jackson, & Leiter, 1996). Additionally, high self-efficacy has been linked to a decrease in depression for caregivers. It was found that higher self-efficacy scores were associated with fewer depressive symptoms and fewer physical health symptoms in AD caregivers (Fortinsky, Kercher, & Burant, 2002). Recent caregiver interventions have begun to utilize this construct in order to have a better understanding of the dynamics of the caregiving role and also as a possible tool in looking at intervention outcomes (Bourgeois, Schulz, Burgio, & Beach, 2002).

In addition to perceived confidence in the caregiving role, how a caregiver copes with stressors that result from that role has been examined. An example of such a model is the cognitive-phenomenological model of stress by Lazarus and Folkman (1984). This model suggests that distress is a function of a stressor (event/experience), the person's appraisal of that stressor, coping responses to appraisal, and reciprocal relationships among appraisal, coping, and distress. Differences in coping and appraisal of stressors in the caregiving role can result in vast variation regarding reactions to that role. Stress coping models that have been examined for AD caregivers find that a complex interaction between behaviors of the AD loved one, consequences of those behaviors, reactions by the caregiver and various moderators such as the particular environment can lead to both physical and psychiatric implications for the caregiver (Cohen, Kessler, & Gordon, 1995; Elliot & Eisdorfer, 1982).

Stress-coping models suggest that dealing with particular stressors is a complex process where responses at one stage may feed back to earlier stages. Initially, primary stressors being placed on the caregiver include the functional limitations and behavioral problems of the care recipient and related social and environmental stressors (Cohen et al., 1995). These demands are then evaluated by the caregiver to assess whether potential threats exist and whether the caregiver has coping resources for these threats. If these stress appraisals are negative this can create harmful emotional, physiological, and behavioral reactions that can place the caregiver at risk for physical and mental complications. For example, if a caregiver becomes flustered in response to the disruptive behavior of a care recipient, this may cause the recipient to become more disruptive, thus leading to increased stressors for the caregiver (Schulz et al., 2000).

Also important in the stress coping framework is the use of appropriate coping styles, or the use of coping styles that best match the appraisal of the situation. A study examining the fit of a stressor, coping, and depression with a sample that included spousal AD caregivers found support for the idea that different appraisals match different coping styles. For example, the researchers found that when the stressor was appraised as changeable, correlations of depression with problem-focused coping were negative. As opposed to when the caregivers appraised the stressors as changeable and used emotion-focused coping, here the correlations of emotion-focused coping and depression were positive (Vitaliano, DeWolfe, Maiuro, Russo, & Katon, 1990). Additional studies have found that appraisal, coping responses, and social support and activity were significant predictors of caregiver outcomes (e.g., self-reported health and depression; Haley, Levine, Brown, & Bartolucci, 1987). Clearly, the use of appropriate coping styles is an important consideration in the possible outcomes of caregiving such as depression.

In addition to stress models, multiple longitudinal studies have supported an elaborated model of the wear-and-tear hypothesis when examining possible negative effects of caregiving (Alspaugh et al., 1999; Gaugler et al., 2000; Zarit, Todd, & Zarit, 1986). The main implications are that the accumulation of various ADL dependencies, behavior problems, and cognitive impairment can lead to declines in mental health, increased subjective stress, and decreased satisfaction with caregiving. Interventions aimed at targeting these specific ambient stressors, such as educating the caregiver regarding reasons behind various behavioral problems, may assist in preventing frustration and stress from accumulating to such burdensome levels.

Among the numerous stressors that AD caregivers face, behavioral problems have been termed a "primary stressor" and have been linked to increases in burden and depression (Clyburn, et al., 2000; Talkington-Boyer & Snyder, 1994). The frequency of behavior problems has been shown to be a more effective indicator of depressive symptoms compared to other measures related to care recipient (CR) status such as ADLs (Schulz & Williamson, 1991). In a longitudinal study Gaugler and colleagues (2000) examined 137 AD caregivers over a three-year period, finding deleterious long-term impacts of behavior problems. Specifically, the researchers determined the importance of behavior problems when predicting rates of change in depression. These findings provided support for an elaborated wear-and-tear hypothesis of caregiving especially when behavior problems are a recurrent issue (Gaugler et al., 2000). In addition, this study found that constructs such as depression did not appear to intensify much past the middle stages of dementia or caregiving.

Numerous AD caregiver studies have found conflicting results regarding change in depression across time. Specifically, some longitudinal studies have shown stability in depression across time, while others report an increase in depressive symptoms over time

(Powers et al., 2002; Schulz & Williamson, 1991; Wright et al., 1999). Possible reasons for a stabilizing of depression include adaptation to the role of caregiver or adoption of effective coping techniques. Here the importance of examining the longitudinal relationship between depression and AD caregivers is highlighted, as multiple observations allow a non-linear model trajectory to be examined. For example, if a study is conducted to examine the effectiveness of an intervention for AD caregivers utilizing only two waves of data, this may fail to capture the nature of long-term change due to the fact that a linear trajectory is the most complex functional form that can fit the two waves (Rogosa, 1996).

Physical health effects of caregiving. In addition to the possible psychosocial effects of caregiving, a recent meta-analysis examined 23 studies of dementia caregivers over a cumulated 38-year time range, comparing 1,594 caregivers with 1,478 demographically similar noncaregivers; caregivers had 23 percent higher levels of stress hormones and 15 percent lower levels of antibody responses than did noncaregivers (Vitaliano, Zhang, & Scanlan, 2003). It was also found that caregivers took more medications for physical problems and reported poorer global health than did noncaregivers. Although caregiving stress has not been directly linked to causing illnesses, there is sufficient evidence showing that this stress can influence illness progression, risk factors for illness, and various negative health effects.

An additional study examined whether BMI levels of AD caregivers were different compared to those of age matched noncaregivers, finding that caregiver women gained significantly more weight (raw BMI) than did control women (Vitaliano, Russo, Scanlan, & Greeno, 1996). This is particularly noteworthy as the majority of caregivers in the U.S. are female (National Center for Health Statistics, 1999). Further research found that caregivers had a significantly decreased immune function compared to age and sex matched noncaregivers (Pariante et al., 1997). In addition to these specific health consequences, caregiving has been associated with increased risk of mortality (Schulz & Beach, 1999). These findings are significant as they exemplify the deleterious physical health consequences for older caregivers.

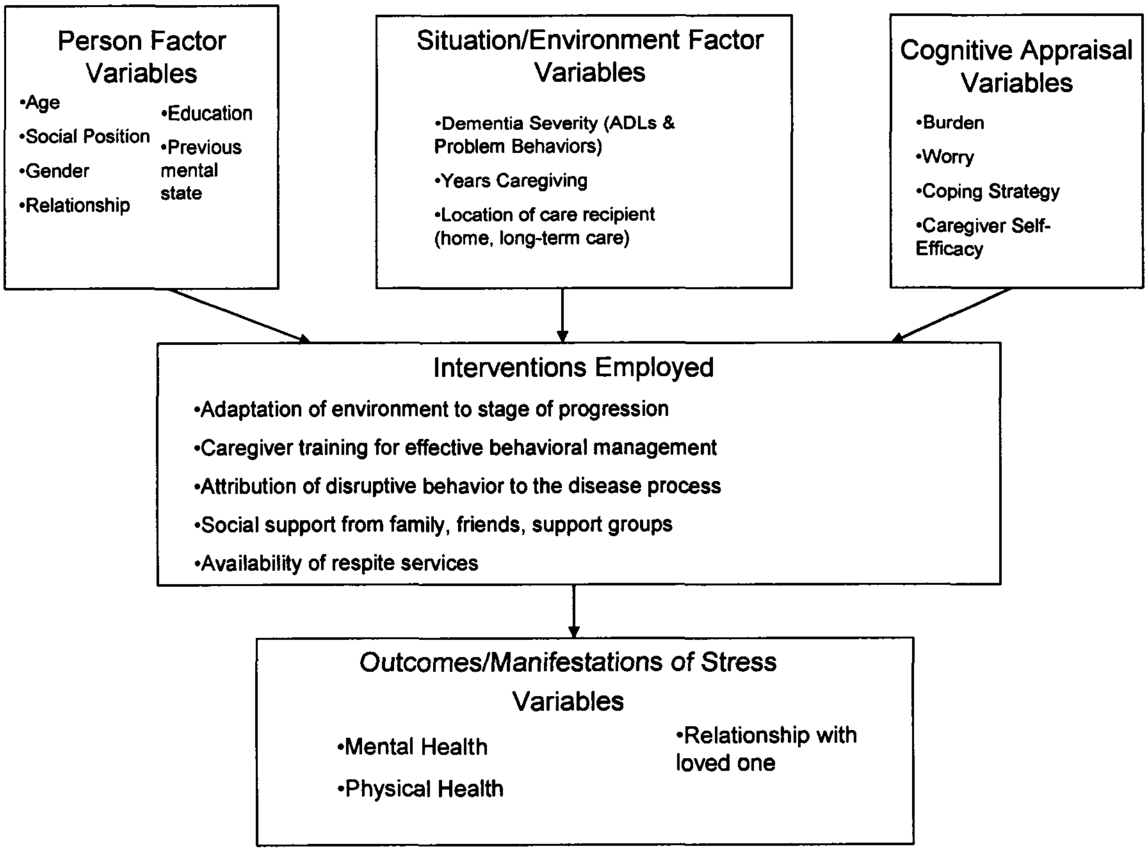
A study that examined the possible links between chronic stress and adverse health effects in women, such as that experienced by AD caregivers, found that among AD caregivers greater depression and distress was related to higher levels of Interleukin-6 (IL-6; Lutgendorf et al., 1999). IL-6 is a multifunctional cytokine that is thought to be involved in normal aging in addition to a variety of age-related conditions (Ershler, 1993). This study suggested that styles of cognitive and emotional processing of life stressors might be related to increases in the cytokine IL-6. This has significant implications in that interventions targeting chronically stressed caregivers may have immune system and health implications (Lutgendorf et al., 1999).

As numerous variables have been associated with both mental and physical health of caregivers, a model of a stress and coping framework applied to dementia caregivers adapted from Sparks and Farran (1998) is shown in Figure 1.

AD Caregiver Interventions

Global interventions. As findings regarding the deleterious effects of caregiver burden and stress are becoming more salient, researchers are responding with specific interventions aimed at alleviating these associated tribulations. A number of intervention methods have been shown to be effective in assisting caregivers in their new role,

Figure 1. Stress and coping framework applied to dementia caregivers adapted from Sparks & Farran (1998).



including: (1) psychoeducational and counseling interventions resulting in increased caregiver well-being and delay of institutionalization of the care recipient (e.g., Bourgeois et al., 2002; Hepburn, Tornatore, Center, & Ostwald, 2001; Mittelman et al., 1996); (2) multisite programs aimed at examining issues of diversity, with various types of interventions such as support strategies and home-based environmental interventions finding positive outcomes on reducing caregiver burden and depression (Schulz et al., 2003); and (3) and the utilization of respite grants, finding that users of the respite grants reported fewer hours of informal assistance and less burden, although care recipient's cognitive status and activities of daily living (ADLs) had deteriorated (Cox, 1997).

A recent review of caregiver interventions found promising results regarding the ability of interventions to produce clinically significant outcomes (Schulz et al., 2002). The review highlighted the need for interventions to obtain data regarding symptomatology, quality of life, social significance, and social validity. Also noted in the review is that AD caregivers seem to clearly benefit from interventions that disseminate knowledge about the disease, the caregiving role, and resources available to them (Schulz et al., 2002). Additional caregiver intervention studies have been reported under the Resources for Enhancing Alzheimer's Caregiver Health (REACH) project. This multisite national research initiative aims to test the effectiveness of various interventions and to evaluate the combined effect of the interventions (Schulz et al., 2003). Recently reported findings show promise in the ability of various interventions to reduce caregiver burden and depression and to highlight the difference between caregivers with regard to intervention effectiveness (Belle et al., 2003; Schulz et al., 2003).

Misattribution. An additional study conducted by Paton and colleagues in 2004 found that a significant number of AD caregivers were making negative attributions regarding their loved one's condition that could result in increased mental distress. For example, 25% of the participants in this study attributed the cognitive, behavioral, and psychological symptoms of their loved one with AD to be under the loved one's control, despite being aware of an AD diagnosis. In addition to these attributions affecting the caregiver's mental health, previous studies have suggested that they can also affect how the caregivers emotionally and behaviorally react toward AD individuals (Hastings, Tombs, Monzani, & Boulton, 2003). These findings suggest that persons with AD might be given a lower level of support because their caregiver does not accept that their problems are a reflection of the illness (Paton et al., 2004). The need for an educationally based intervention for caregivers is highlighted here as it can result in improved mental health of the caregiver and better care for the loved one.

Empowerment. In addition to examining the needs of the caregiver, in recent decades the complex process of empowerment has been discussed with regard to better assessing the needs of the individuals suffering from the disease. There are many ways of defining the concept of empowerment. Gibson (1991) regarded empowerment as more of an interaction between the individual and providers. This is also seen as a developmental process that can take different forms for different people and may be more easily understood in its absence: powerlessness, hopelessness, helplessness, and an external locus of control and dependency (Gibson; Heumann, McCall, & Boldy, 2001). By using a more person-centered approach to dementia care and thus being aware of the significance of the experience and perspective of the individual with dementia, issues such as empowerment can be taken into account (Woods, 2001).

One of the first individuals to emphasize the importance of this approach to dementia care, social psychologist Tom Kitwood, saw as the norm examples of malignant social psychology such as infantilization, disempowerment and objectification (Kitwood, 1990). Kitwood (1993) suggested that the internal and external symptoms of dementia can be affected by a variety of internal, social and environmental factors such as personality, biography, neurological impairment, and social phenomena. If this person-centered approach is neglected it is possible that an individual with dementia may appear more impaired, or even have a more serious level of impairment than is actually the case (Woods, 2001). It has been suggested that an important aspect of empowerment in individuals who suffer from dementia or other types of disability is freedom of choice. Here the idea of aging in place, or the importance of remaining in a particular residence close to those who they care about, is one way to keep a sense of empowerment active in this population (Heumann et al., 2001). The more recent policy of self-directed care is a variation of empowerment (e.g., Bolin, Gamm, Kash, & Peck, 2005); here the individual afflicted with AD is not able to implement self-management so the caregiver is targeted.

Adjusting the environment. In addition to psychoeducational interventions assisting the caregiver role by increasing education and changing attributions regarding the loved one's behavior, another positive influence on caregivers is informing them of specific ways to make the loved one's environment better suited to their unique needs. This may not only enhance the safety of the individuals but it may prolong the amount of time they are able to remain in their home environment, therefore increasing their level of empowerment. The important role that the environment can have on an elderly individual was originally highlighted in a model of environmental press by Lawton and Nahemow (1973). It suggests that individuals have varying levels of competencies that allow them to handle a certain amount of environmental press (i.e., environmental demands). This model has been applied to individuals with dementia finding that as they have less or lowered competencies they are able to deal with fewer environmental demands (Hall & Buckwalter, 1987).

Recent examinations of their model have found that the amount of environmental demands that a person with AD can handle varies depending of their level of functioning. The practical implications have been demonstrated in interventions that assist caregivers in making a more suitable environment for their loved ones, thereby increasing care recipients' quality of life and reducing their stress (Corcoran et al., 2002; Gitlin et al., 2003; Namazi & Johnson, 1991). The use of modifications in the AD individual's environment can decrease disturbing behavior, increase social contact, increase physical activity, increase positive feelings, and decrease negative feelings. Creating suitable environmental features for loved ones with AD will minimize unwanted behaviors and feelings, maximizing those that are desired (Lawton, 2001). Strategies used to make a more suitable environment include but are not limited to: reducing clutter, simplifying tasks, organizing or eliminating objects in the home, using a variety of redundant cueing, and changing daily tasks. A recent study conducted under the REACH project examined the use of such modifications in caregivers' homes and found improvements such as: less upset with memory-related behaviors, less need for assistance from others, and better affect (Gitlin et al., 2003). In addition, spouses using environmental interventions reported less upset with disruptive behaviors compared to controls. As behavior problems have been linked to a variety of negative caregiver outcomes such as burden and depression (e.g., Clyburn, et al., 2000), the benefits of alleviating this particular stressor are apparent.

Examples of how such knowledge can assist both the care recipient and the caregiver is demonstrated in the following examples. If an individual with AD has a particular tendency to wander, the caregiver can make the home environment safer for this particular behavior by installing motion detectors, creating simple leisure activities to address restlessness, or creating a familiar routine. If there is a particular tendency to show resistance to bathing the caregiver can help alleviate potential problems by installing grab bars and a tub seat to reduce fear, choose a time of day when the individual is rested and undistracted, or use blue food coloring in the bath water to increase a visual stimulus (Corcoran et al., 2002). The benefits of giving caregivers knowledge regarding the implementation of simple environmental modifications that can result in positive outcomes for their loved one and themselves are significant.

Savvy Caregiver Program. An example of a psychoeducational intervention covering many of the above strategies and designed to increase caregiver knowledge, skills and confidence, to create reliable and accessible networks of support for caregivers, and to increase access to supportive services is the Savvy Caregiver Program (Savvy). Savvy was originally developed, tested and evaluated as a psychoeducational curriculum for caregivers by the Department of Family Practice and Community Health at the University of Minnesota and the Metro Lakes Chapter of the Alzheimer's Association. The intervention was developed under the stress-mediation theoretical framework

(Lazarus & Folkman, 1984) which was used in order to help address the stressors involved in caregiving. Savvy assists in addressing primary stressors placed on AD caregivers by disseminating information and possibly assisting caregivers in their appraisals of these ambient stressors. For example, by assisting caregivers in the use of effective cognitive problem-focused coping caregivers can learn to react to their loved one's behavioral disturbances in a more effective way.

The training consists of approximately 12 hours of sessions that involve accomplishing various objectives for the caregivers (e.g., acknowledging the disease, developing emotional tolerance, taking control) in addition to providing them with a caregiver manual and educational CD-ROM (Hepburn et al., 2003). The manual contains educational material for the caregivers to review at their pace. The 6 sections include: (1) introduction to dementing disorder, (2) caregiver self-care, (3) the anchors of enjoyable involvement, (4) levels of thinking and performance, (5) strengthening the family as a resource for caregiving, and (6) review and integration of the previous sections.

Tests of the program's effectiveness found favorable results showing that caregivers report substantial increases in skill, knowledge, and confidence after completing the training (Hepburn et al., 2003; Smith & Bell, 2005). Data from a 6-month follow-up interview revealed that participants in Savvy had improved levels of depression, increased use of support services, and increased use of support groups compared to baseline (Smith & Bell, 2006). Of Savvy's many strengths are the involvement of the local AD community and the encouragement to seek social support.

Social support and use of support groups. Social support or coping assistance has been integrated within a general theory of stress-buffering (Thoits, 1986). Here coping assistance, or the active participation of significant others in an individual's stress-management efforts, can help with the relief of stressful situations through instrumental, socioemotional, and informational aid (Turner, 1983). In the case of AD caregivers, often times their particular stressors are seen as uncontrollable and unavoidable (e.g., constant assistance needed with ADLs and problem behaviors). Stress management processes can assist in altering the primary sources of perceived stress such as situations and emotional reactions (Thoits, 1986). For example, if AD caregivers are faced with a loved one who often acts out aggressively, they can reinterpret that existing circumstance so it will seem less threatening and result in less negative emotion attached to it. The importance of support in situations such as AD caregiving is evident as individuals engaging in certain types of stress management can find additional assistance and strength by participation with similar others in their efforts (Thoits, 1986).

Lack of social support in AD caregivers has been linked to negative outcomes such as depression (Coen, O'Boyle, Swanwick, & Coakley, 1999; Wallsten, 2000). The very nature of this disease can lead to great variability in support group usage and resulting benefits from such services. Overall, services such as support groups for caregivers of persons with dementia have been found to have numerous positive outcomes (Karlin, Bell, & Noah, 2001; Millan-Calenti et al., 2000). Researchers have found that many caregivers report positive statements regarding support group usage and that simply being around others was an invaluable experience (Karlin et al., 2001). One study found that caregivers who participated in a help program with a social component had improved well being and improved health status, and reported taking comfort in knowing that they had "back up" (Millan-Calenti et al., 2000). On average, caregivers who adapt to their role effectively often rely on support of family, friends, and health care providers (Karlin et al., 2001; Millan-Calenti et al., 2000).

As the dynamic nature of the caregiving role is becoming apparent, social support is one aspect that should not be overlooked. The use and availability of social support for AD caregivers is believed to play a significant role in the occurrence of clinically relevant outcomes such as symptomatology and service use (Kiecolt-Glaser et al., 1991; Schulz et al., 2002), and thus social support is often used as an outcome measure for effectiveness of interventions. As social support appears to have an ameliorating effect in dealing with caregiver stress, researchers have suggested that future interventions should focus on caregiver support in order to help reduce depression and burden rates (Covinsky et al., 2003; Mittelman et al., 1995).

Use of formal services. Formal supportive services used by AD caregivers include but are not limited to in-home respite, adult day care, home health care, chore or homemaker services, counseling and support groups, transportation services, and group/home delivered meals. Individual factors that influence the use of formal services include the older ages of the caregiver and the care recipient, the caregiver being female, and greater functional impairment of the care recipient (Geldmacher, 2004; Lyons & Zarit, 1999; Monahan, 1993). Use of formal support services can depend on a variety of factors such as judgments that the condition or situation is deficient, that a service will offset this deficiency, and that the benefits will outweigh the costs (Kosloski & Montgomery, 1994).

Various models have been proposed to explain the use and lack of use of formal services with AD caregivers. Models that attempt to explain the often low use of support services look at various environmental factors such as proximity of family and income. A phenomenon referred to as 'kin independence' represents the majority of caregiving situations in the U.S. and explains why there is a low use of formal services by individuals who live close to their elderly relative (Scott & Roberto, 1985). Models examining factors that influence caregiver use of support services suggest that social realities of concerned caregivers--including their perceptions and expectations of appropriate behaviors--affect the use of support services (McAuley et al., 1990).

Irrespective of the reasoning behind support service use, it has been shown to have a positive effect on the caregiving experience. Research shows that use of formal support can have a strong moderating effect on physical disability and depression, health deterioration, and social isolation (Bass, Noelker, & Rechlin, 1996). The importance of utilizing support services is also highlighted in a recent study examining issues related to caregivers' stress and support use, finding lower formal support over time directly associated with worsening cardiovascular health (Musil, Morris, Warner, & Saeid, 2003). Also, despite stressors experienced by AD caregivers, many have a primary goal of delaying institutionalization for their loved one; here the use of formal care can assist in this delay of nursing home placement and therefore directly assist caregivers in achieving this goal (Karlawish, Klocinski, Merz, Clark, & Asch, 2000; Kosloski & Montgomery, 1995). Not only can delaying institutionalization assist in the care recipient's quality of life, but it can also translate into significant economic savings (Geldmacher, 2004).

Respite assistance. Respite can have multiple meanings; one definition used is any situation in which the care recipient is engaged in a perceived safe activity that gives the caregiver a rest from direct supervision (Lund, Hill, Caserta, & Wright, 1995). Included in this can be formal support (e.g., nursing aids) or informal support (e.g., friends and family). Multiple interventions have found that the use of a respite program for caregivers resulted in decreases in subjective burden and increases in morale (Kosloski & Montgomery, 1995). The use of respite services has been shown to have a positive and noticeable effect on caregivers' physical and mental health. Studies have found that respite service use results in fewer hours of informal assistance and positive increases in mental and physical health (Cox, 1997; Kosloski & Montgomery, 1993; Musil et al., 2003). As engaging in respite can lead to both psychological and physiological benefits for AD caregivers, studies have examined how to encourage use of these services, including providing them at low or no cost (e.g., through respite grants), or simply providing information. A recent study found that the use of information and referral to local Alzheimer's Associations significantly increased the amount of human services used by caregivers (McCallion, Toseland, Gerber, & Banks, 2004).

An exploratory study conducted by McGrath and colleagues (2000) reported three major themes with regard to the needs of AD caregivers for respite: prioritizing occupational performance (e.g., having time to garden, socialize, and run errands), taking a mental break from caregiving (e.g., needing time to get away), and having the mutual benefit of respite (e.g., having the care recipient enjoy adult daycare). Two overall findings in this qualitative study were the need for professionals to help caregivers find ways to engage in respite in order to have a mental break in their day, and recognizing that a single type of respite may be insufficient to cover the three needs found to be the most important by the caregivers.

A similar study conducted by Caserta, Lund, Wright, and Redburn (1987) with 888 AD caregivers found that there is a strong and clear need for utilization of respite-oriented services. This study administered a survey to AD caregivers across a variety of states finding that caregivers reported the highest need for some type of respite, daycare, or in-home care, accounting for approximately 71.3% of the responses. When inquiring about knowledge of existence of local formal community services, 36% replied that they did not know whether services were available or not; among those who were aware, the use rate for at least one service was 57.5%. In examining correlates of service utilization it was found that reasons for not using formal services included not wanting to leave the loved one with a stranger, too many behavioral and emotional problems, or the services were too expensive (Caserta et al., 1987). Also mentioned in this study was the need for more longitudinal studies that measure service use to get a better understanding of the individual factors that may be linked to service utilization.

As the use of formal services has been shown to assist the caregiver, interventions aimed at increasing the use of these services are desirable. Examples of effective respite interventions include studies done by Cox (1997) and Kosloski and Montgomery (1993). In both of these studies AD caregivers were either reimbursed for respite care use through a respite grant or they were given access to free or discounted respite services. Both studies found significant positive results in that the caregivers reported significant improvement of their loved one and significant decreases in subjective burden and increased morale.

Here it is clear that interventions providing caregivers with respite, or a service to relieve informal caregivers, have found positive effects (Cox, 1997; Deimling, 1991/1992; Kosloski & Montgomery, 1993). As these services can result in real and significant outcomes, addressing access to these services by areas of the population that are underserved is important. Examples of underserved populations include but are not limited to minority, low socioeconomic status, and rural populations. In a study conducted with rural AD caregivers it was found that what is needed in these areas is the promotion of the use of formal services to help alleviate the strain of family members and friends who are being relied on exclusively (Scott & Roberto, 1985).

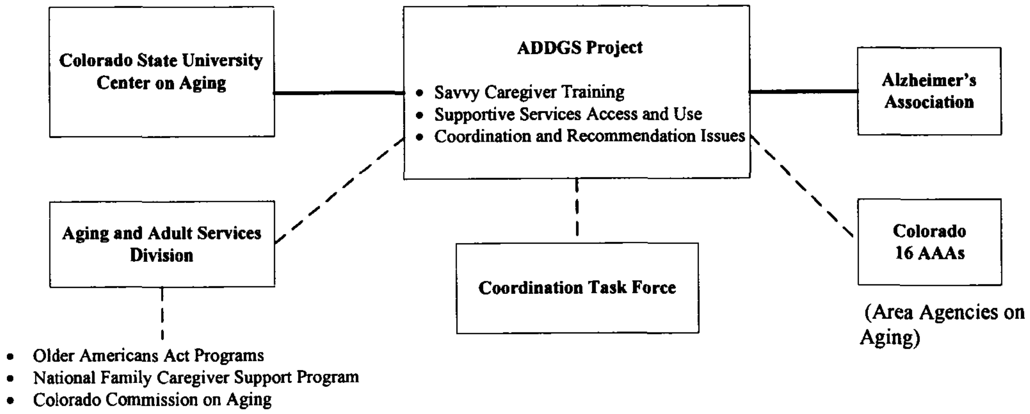
Federal demonstration programs. In response to increasing public recognition of the need for support services for individuals caring for persons with AD, a small service demonstration was established in 1990 with a mission to serve elderly clients; over time this project has grown and its oversight is now under the Administration on Aging (AoA). Under this project numerous Alzheimer's Disease Demonstration Grants to States (ADDGS) projects have been funded in multiple states throughout the U.S. The goals of some of these programs have been to reach certain underserved populations (e.g., rural and minority), increase the understanding of the caregiver career trajectory and when service needs come into play, and to examine client satisfaction with these services (ADDGS Interim report, 2003; Kosloski & Montgomery, 1993; Montgomery, Kosloski, Karner, & Schaefer, 2002). Findings from these studies are promising in showing increased service use in communities and subsequent client satisfaction.

Some studies have examined the dissemination and use of respite grants of a few hundred to a few thousand dollars to help families purchase respite services such as in-home care or adult day care. These studies discuss limitations and provide suggestions for future interventions. For example, past respite programs that have seen low participation rates (Brody, Saperstein, & Lawton, 1989; Montgomery, 1988) often had limitations in the types of respite services available to the participants. Needed to be addressed is the impact that respite can have on caregivers and the need for respite interventions to be individualized to the specific needs of the caregiver (Cox, 1997; Kosloski & Montgomery, 1993). The use of formal services is seen as appropriate and clinically important as the severity of AD increases. Clearly, an examination of the optimal mix of formal and informal services is valuable in order to achieve the best possible caregiver and recipient well-being (Schulz, 2000). Studies also suggest that the implementation and assessment of interventions for AD caregivers is an area that requires further examination (Burgio et al., 2001; Schulz, 2000; Schulz et al., 2002).

Alzheimer's Disease Demonstration Grants to States Project for Colorado

This current study is a continuation of a collaborative project that began in 2002. Colorado State University was awarded the Alzheimer's Disease Demonstration Grants to States (ADDGS) Colorado project for July 2002 through June 2005 by the Administration on Aging; this was a collaborative project with Colorado State University's Center on Aging and the Alzheimer's Association Colorado Chapter. The primary interventions of the project included (1) training in the evidence-based Savvy Caregiver Program (Savvy) for caregivers and professionals in rural areas, and (2) provision of consumer-directed respite grants. Accompanying these interventions, the project gave impetus to new support groups, new adult day programs to increase rural family use of supportive services, coordination of Alzheimer's disease services and

Figure 2. Partners in the Colorado ADDGS Grant, FY 2002-2005.



SOURCE: 2002 ADDGS Grant Application.

access statewide, and dissemination of program impact (Osber & Rabiner, 2005). Figure 2 displays the organizations involved in the Colorado ADDGS grant.

The Savvy Caregiver Program was the primary evidence-based practice on which the 2002-2005 grant was based. Additionally, the Colorado ADDGS project evaluated the effectiveness of the award of $1,000 respite grants. Individuals identified as having a family member with dementia or professional direct care staffs were offered the Savvy training; family members were offered $1,000 to pay for respite services. Throughout the ADDGS grant, 190 individuals participated in the Savvy Caregiver Program, 331 families received the respite grants, and 46 families received both (ADDGS Project Update, 2005).

The training sessions disseminated by this grant help caregivers develop a clearer picture of their new role, give them an understanding of the disease, help them deal with difficult behavior, and teach them how to take control. Using a "train the trainer" approach, the evidence-based Savvy provides basic knowledge and training to family members and professional caregivers to increase their skills and confidence, create reliable and accessible networks of support for caregivers, and increase access to supportive services (Smith & Bell, 2005). An additional goal of this intervention is to increase support networks in the Alzheimer's community, with professionals and family members that completed the Savvy serving as resources for others in the community.

Initial Savvy Evaluation and Outcomes at 6 and 12 Months

The analyses conducted on the ADDGS project found overall support for the effectiveness of the Savvy and the Respite Grant service initially and at a 6-month follow-up with minimal significant differences between varying groups of caregivers, and with no differences between 1-day, 2-day, and 3-day formats for Savvy training (Scharf, Bell, & Smith, 2005). Specifically, the results for the immediate Savvy Overall Evaluation found that participants were overwhelmingly satisfied with the training and felt more confident in their role, in addition to gaining valuable knowledge.

Outcome measures were included on a Client Intake Form (Appendix) developed and required by Administration on Aging (AoA) and completed by participants initially and at 6-month intervals. The three outcomes of average depression score, service usage, and support group usage all showed promising results after 6 months. Caregiver depression scores showed a significant decline regardless of treatment group (Savvy, Grant, or Both). The results also showed a significant increase in support service usage at the 6-month follow-up for all treatment groups (e.g., paid supervision, homemaker services, adult daycare, and transportation services). Support group use also increased. There were no major differences found among various groups of caregivers (e.g., rural/urban, women/men). An additional finding was the increase in reported caregiver health from baseline to the 6-month follow-up (Smith & Bell, 2005). A preliminary examination of the 12-month data showed similar trends with significant improvement between baseline and 12 months in regard to support group use, support service use and depression scores.

Current Project

This current study examines the effectiveness of the three interventions provided to AD caregivers in Colorado--an academic-based caregiver psychoeducational program (Savvy), a voucher-type respite grant, or both--at 18 months after the intervention. There is a need to examine the longitudinal impact of interventions for AD caregivers, especially those in underserved areas. In the past, research in this area was criticized for its use of cross-sectional studies, and longitudinal designs were encouraged (Gaugler et al., 2000; Schulz & Williamson, 1991; Zarit & Leitsch, 2001). As Alzheimer's disease may persist for many years with changing symptoms, examining a complex disease trajectory that assesses the possible lasting effects that certain interventions may have is essential for a better understanding of the dynamics of caregiving. Although psychoeducational and skills-based interventions have resulted in positive caregiver outcomes, there is a need to identify when a treatment regimen is no longer effective so intervention modification or reimplementation can be assessed (Bourgeois et al., 2002).

This initial ADDGS project called for the collection of three waves of data: baseline, 6-month and 12-month follow-up data. Due to the encouraging reports of the participants during the data collection, the promising findings from the initial analysis, and the examination of the literature regarding long-term effects of interventions, continued data collection into a fourth wave (i.e., 18-month follow-up) was conducted. This allowed a longitudinal examination of the possible effectiveness of the two interventions; an additional group--participants who received both the training and the grant--was also included in the analyses to examine the possible effects of a more multicomponent intervention. As problems faced by AD caregivers are considered to be complex in nature the adoption of a multicomponent intervention--one that combines elements of respite, support, and information and referral--is becoming preferred by researchers and practitioners (Czaja, Schulz, Chin Lee, & Belle, 2003; Schulz, Gallagher-Thompson, Haley, & Czaja, 2000).

Specific Aims

Based on the current database and AD caregiver research literature provided in the previous sections, the specific aims for the study included:

> *Specific Aim 1.* To examine change in depression scores over the 18-month follow-up for all participants and the three intervention groups (Savvy, Grant, Both). Also, to examine whether various characteristics of the client (e.g., functional level and relationship to caregiver), caregiver (e.g., age, gender, length of time providing care), and the community (e.g., community size) affect this relationship.
>
> *Specific Aim 2.* To examine change in service usage variety scores over the 18-month follow-up for all participants and the three intervention groups (Savvy, Grant, Both). Also, to examine whether various characteristics of the client (e.g., functional level and relationship to caregiver), caregiver (e.g., age, gender, length of time providing care), and the community (e.g., community size) affect this relationship.
>
> *Specific Aim 3.* To examine change in support group use over the 18-month follow-up for all participants and the three intervention groups (Savvy, Grant, Both).
>
> Specific Aim 4. To examine the relationship between the three outcomes of depression, service usage variety, and support group use with caregiver self-efficacy, contact with the Alzheimer's Association, problem behavior score, and ADL score.

CHAPTER II

METHOD

Participants

Of the 158 participants in the 12-month follow-up, 82 provided data at the 18-month follow-up (these participants were caregivers of persons with Alzheimer's or a related progressive dementia living in Colorado). At $\alpha = .05$ a sample size of 82 yielded a power of 0.55 to detect an effect that accounts for 27% of the variance. Previous longitudinal AD caregiver studies that have resulted in significant findings were conducted with similar or smaller sample sizes (Musil et al., 2003; Powers et al., 2002; Schulz & Williamson, 1991; Wallsten, 2000).

Of the 82 participants, 22 participated in the Savvy training (Savvy intervention), 41 received a voucher-type respite grant for up to $1,000 per family through the Alzheimer's Association as reimbursement for use of community-based respite services (Grant intervention), and 19 participated in both the Savvy and the respite grant (Both intervention). Participation in the Savvy Caregiver workshop was voluntary and free of charge. Reported geographic location of the sample was 44.3% rural (<50,000 population) and 55.7% urban (>50,000). The mean age of the caregiver was 66.3, *SD* = 13, with a range of 44-102; mean age of the loved one with AD was 79.82 years, *SD* = 7.52, with a range of 59-95. Of the caregivers, 52.5% were a spouse/domestic partner, 37.5% a child/child-in-law, 6% a sibling, 2% a friend/neighbor, and 2% "other relative." The caregiver sample was primarily female, with reported gender being 29.3% male and 70.7% female. The majority of both the caregivers and loved ones with AD were English speakers (~98.7%), with reported race as white (~97.4%), and reported ethnicity as not

Hispanic or Latino (~91.3%; ~ 8.8% Hispanic or Latino). Consistent with national statistics on AD caregivers, this sample accurately reflects the majority of caregivers as being either spouse or adult child and female; the sample is slightly older than national samples as would be expected for a high concentration of rural participants.

Materials

Caregiver's Manual. This Savvy manual provides a written version of the skill-building information conveyed in the training. It contains educational material for the caregivers to review at their own pace. The 6 sections include: (1) introduction to dementing disorder, (2) caregiver self-care, (3) the anchors of enjoyable involvement, (4) levels of thinking and performance, (5) strengthening the family as a resource for caregiving, and (6) review and integration of the previous sections.

CD-ROM. Included on the CD along with educational information for the caregivers is a cognitive performance estimation procedure that is embedded in the program, and video clips of experts providing suggested interventions for behavioral problems at multiple stages of dementia.

Client Intake Form (OMB#: 0985-0013) The Client Intake Form, developed by the University of Kansas for the U.S. Administration on Aging-funded evaluation of the ADDGS program (and required for all ADDGS grants awarded in 2002), contains questions regarding demographic information of the caregiver and the client. The questionnaire also inquires about amount of time the caregiver provides care, the employment status of the caregiver, and the amount of services used by the caregiver (see Appendix). As the outcome measure of service usage is taken from this form it should be noted that this is not a measure of frequency of use for various services (e.g., How many days during the month is home health care used?); this is simply a measure of how many types of services are being used (e.g., Home health care and daycare were used this month).

Problem Behavior Scale and Activities of Daily Living Scale. The level of need for assistance and custodial care of the care recipients was assessed at baseline and again during the follow-up interviews by a 15-item measure of problem behaviors and a 17-item measure of need for help with activities of daily living (ADL), and instrumental activities of daily living (IADL), included on the Client Intake Form. The problem behavior scale measures how many days in the past week the caregiver dealt with problem behaviors ranging from 1 = 0/no days to 4 = 5/more days. Examples of questions regarding problem behaviors include, "In the past week, on how many days did you personally have to deal with the following behavior of your relative – keep you up at night, have a bowel or bladder "accident," become irritable or angry, threaten people."

The ADL items included in the measure assessed need for help on a 4-point Likert scale ranging from 1 = needs no help to 4 = can not do it at all; higher overall scores represent more care needed. Examples of questions regarding ADLs include, "How often does the client need help with each of these activities – bathing, using the toilet, dressing, and eating." Examples of questions regarding IADLs include, "How often does the client need help with each of these activities - buying food or clothes, using the telephone, preparing meals, and taking medicine" (see Appendix). Similar measures of patient functioning have been used in previous intervention studies as a means of reliably assessing the functional status of the person with dementia (Montgomery et al., 2002). In the current study internal consistency coefficients for the ADL scale ranged from .90 to

.93 and .70 to .85 for the problem behavior scale, indicating that these were reliable measures of functioning.

Depression Scale. The Client Intake Form includes 10 questions asking the caregiver to report the frequency of feeling a certain way within the past week. Questions include, “I did not feel like eating,” “I felt depressed,” and “I had crying spells.” Answers are given on a 5-point Likert scale ranging from 0 = never to 4 = always. These questions are taken from a larger 20-item self-report scale, the Epidemiological Studies Depression Scale (CESD; Radloff, 1977), with coefficient alpha of .85 to .92, high correlations with other measures of depression, and proven applicability to elderly populations (e.g., Hertzog et al., 1990; Radloff & Teri, 1986). These 10 items were selected by a previous researcher to be on the mandatory Client Intake Form and were not part of the validated shortened CESD scale; therefore, direct comparison of the current study’s depression scores with other CESD findings is not recommended. Measures of depression have been used in numerous studies regarding the effectiveness of various caregiver interventions (Schulz et al., 2002).

Due to some participants not responding to each question on the 10-item scale, 5 items were retained for a depression measure that resulted in the largest sample size possible (*n* = 58; see Table 1). The subsequent potential range of responses was 0 to 20 since depression scores were calculated by summing the 5 items for each participant at each time wave.

Principal components factor analyses to examine the dimensionality of the 5 items were conducted on the data collected at each administration of the Client Intake Form. Three criteria were used to determine the number of factors to rotate: the a priori hypothesis that the measure was unidimensional, the scree test, and the interpretability of the factor solution. The scree plot indicated that the initial hypothesis of unidimensionality was correct. Based on the plot, one factor was rotated using a Varimax rotation procedure. The rotated solution, as shown in Table 1, consistently yielded one interpretable factor. The depression factor accounted for 45% of the item variance. In addition, the internal consistency coefficient for the subsequent 5-item depression scale ranged from .74 to .89 across the four waves of data collection indicating that at each time wave this was a reliable measure of depression. Deleting any one item resulted in almost no change in the coefficient.

Self-efficacy (SE) Questionnaire. Due to time constraints with the interview, caregiver self-efficacy was not assessed prior to the 18-month follow-up. Two items relating to caregiver self-efficacy were added to the 18-month interview protocol in order to assess possible correlations of this measure with various program outcomes and to get a possible picture of how caregivers viewed their role. The two items (i.e., How confident are you in your ability to: "Handle any problems your relative has, like memory loss, wandering, or behavior problems," "Get answers to your questions about your relative's problems") were taken from a 10-point SE scale that was used in a prior study that assessed caregivers' SE with regard to managing their loved one's dementia (Fortinsky, Kercher, & Burant, 2002). The scale's purpose was to measure AD caregivers' perceived ability to manage their relatives' dementia symptoms. The scale has been shown to have good internal consistency ($\alpha = .78$) and to be correlated with global caregiver competence ($r = .49$; Fortinsky et al., 2002). In the current study the two

Table 1

Correlations between the Depression Items and the Depression Factors.

	Factor			
Items	Depression Wave 1	Depression Wave 2	Depression Wave 3	Depression Wave 4
Depression Items				
I felt depressed	0.63	0.68	0.68	0.66
I felt lonely	0.69	0.68	0.68	0.50
I felt that everything I did was an effort	0.64	0.73	0.67	0.67
I had crying spells	0.60	0.71	0.69	0.58
I felt that I could not shake off the blues	0.72	0.78	0.67	0.63

items were correlated ($r = .43, p < .01$). Previous work has shown that even single-item SE measures can be valid (e.g., Staples, Hulland, & Higgins, 1999).

Contact with the Alzheimer's Association. In order to determine the amount of contact that the participants had with the Alzheimer's Association staff a question inquiring about this was added to the 18-month follow-up: "On a scale of 1 to 5, with 1 being no contact and 5 being regular contact, how often are you in contact with people from the Alzheimer's Association?"

Savvy usage questionnaire. This questionnaire was given to the main participant sample during 6-month and 12-month and 18-month follow-up phone interviews. Questions pertaining to the effectiveness of the Savvy training and the use of the materials were asked (e.g., "Since completing Savvy I have used the manual for reference," "Using the manual helped me to structure meaningful household activities for the person with dementia," "I used the Respite Care grant for help in the home") with a 5-point response format (never to always). Literature on effective treatment implementation and assessment regarding caregiver interventions stresses the importance of examining the idea of 'enactment,' or the participant's application of the treatment (Burgio et al., 2001). Assessment of 'enactment' is seen as critical in order to establish the internal validity of a particular intervention. This questionnaire can be seen as a rough attempt to assess the caregivers' long-term use of the information provided in the Savvy training.

Procedure

Participants for both the Savvy and Grant groups were recruited through the seven area offices of the Alzheimer's Association Colorado Chapter (AACC) by the local staff.

Word of mouth, community flyers, and newsletters were used to solicit interest. Consistent with the Alzheimer's Association mission and the requirements of the federal ADDGS program, recruitment was for caregivers dealing with any adult with dementia. Once a critical mass of participants contacted their local Alzheimer's Association office the staff scheduled Savvy training in the area. To accommodate the needs of each community, the local AACC trainer adapted the Savvy to a 1-day, 2-day, or 3-day format. The total hours of training were 6, 12, and 18 hours, respectively. In order to compress the training, various aspects such as discussion time, in-depth information, and content were reduced while still covering all the 6 sections of the Savvy manual and maintaining the overall goals of the training (Scharf, Bell, & Smith, 2006). The respite grants were made available to Savvy participants and to other clients of AACC who requested respite assistance. Each grant was for reimbursement of up to $1,000 of adult day care, in-home care, short-term nursing home care, or any similar service that gave the caregiver a break from the caregiving role.

Training was provided at 36 sites, with 2 to 18 family members per community. For both the Savvy and Grant interventions, participants signed informed consent (consistent with Human Research Committee approval), then completed the Client Intake Form before beginning the training or before filling out the grant paperwork, and again completed a subset of the Client Intake Form items at approximately (i.e., within 2 months of these time frames) 6- , 12- , and 18-month follow-ups via a telephone interview. Participants were called when the 6-, 12-, or 18-month time was appropriate for their individual baseline date, with every attempt made to reach them (i.e., varying call times and day of the week) for up to 8 calls. The subset of questions asked during the telephone interviews included: location of care recipient, ADL scale, problem behavior scale, caregiver's current employment status, amount of time spent caregiving, distance from care recipient, amount of services used, caregiver's annual income, and the depression scale.

Statistical Analyses and Treatment of Missing Data

There were several sets of data in this study, each with a somewhat different sample, and the nature of the data required different types of statistical analyses depending on the data set and the questions being addressed. Data on use of the Savvy manual and CD-ROM at 18-month follow-up are reported as percent of respondents who gave each answer; not all participants in the telephone survey answered each question. Baseline demographic data for the 82 participants in the 18-month follow-up were analyzed with Chi Square or one-way ANOVAs, and item-wise deletion was used for missing data. In examining the outcome variables of depression score, service usage, and support group usage across the four waves, casewise deletion was used for missing data at any wave.

For the first two aims (i.e., depression and service use) factorial repeated measures analysis of variance (ANOVA) was used to determine changes across time and to examine the possible effects of between-subjects factors and covariates on the observed change over time. ANOVA is essentially a technique to analyze the separate and interactive effects of two or more independent variables on a dependent variable (Girden, 1992). This is particularly fitting for this data set as the repeated-measures mixed model design can cross one or more within-subjects factors in a longitudinal design with one or more between-subjects factors. Repeated measures ANOVA has been found to be a robust statistical analysis used across a wide variety of applied settings including longitudinal intervention studies (Looney & Stanley, 1989). In addition, in order to address the first two specific aims demographic measures such as gender or urban/rural were added as additional between-subjects factors (for categorical variables) or covariates (for continuous variables) to examine any effects associated with them. When reporting ANOVA findings η^2 was reported as a measure of effect size or the percentage of variance in the outcome accounted for by that factor. Cohen's (1988) guidelines for small, medium, and large effects as assessed by η^2 are .01, .09, and .25, respectively.

The third specific aim regarding support group use, which was binary in outcome, was analyzed using non-parametric tests. Specifically, Cochran Q tests and Chi Square analyses were used to examine differences between time points, and the non-parametric McNemar test of dependent proportions was used to examine differences between intervention groups.

The fourth specific aim, which assessed the relationship among the outcome variables and other demographic questions in the study, used correlations with pairwise deletion for missing data, a method that is deemed appropriate when exploring relationships between binary and interval or rating scale data (e.g., Chen & Popovich, 2002). In addition, the assumptions of these various statistical tests were examined; specifically, sphericity, homogeneity of variance, multicolinearity effects, and examination of outliers were taken into account.

Although the use of more advanced statistical procedures such as a General Linear Mixed Model has been recommended for these types of studies (e.g., Singer &

Willett, 2003), repeated measures analysis of variance has been commonly employed to look at longitudinal data. Due to the journals and their audience that this study is targeting it is believed that the use of these more common statistical procedures will be more understandable to the practitioners and investigators who would be most interested in the outcomes.

CHAPTER III

RESULTS

Group Differences at Baseline

Baseline demographics for the 18-month participants are shown in Table 2 (n = 82). Statistical analyses were run (χ^2 or univariate ANOVAs) to test for baseline differences in demographic variables between the three groups (i.e., Savvy, Grant, Both).

There was a significant difference in income, χ^2 (2, N = 75) = 7.23, p <.05, η^2 = .10. Here the Grant participants were more likely to fall into the lower income category than were the Savvy participants, χ^2 (1, N = 56) = 5.24, p <.05, η^2 = .09, or the Both participants, χ^2 (1, N = 57) = 4.25, p < .05, η^2 = .07. There were also group differences at baseline with regard to gender, χ^2 (2, N = 82) = 6.26, p < .05, η^2 = .07. There were more men in the Grant group compared to the Savvy group, χ^2 (1, N = 63) = 6.29, p < .05, η^2 = .10. Differences were also found at baseline for medical diagnosis of AD or other dementia, χ^2 (1, N = 79) = 12.58, p < .01, η^2 = .12. Here the Grant group reported a higher percentage of medical diagnosis of AD or other dementia compared to the Savvy participants, χ^2 (1, N = 60) = 7.96, p <.01, η^2 = .11 or the Both participants, χ^2 (1, N = 58) = 13.74, p < .01, η^2 = .17. In addition, a significant difference existed with regard to baseline ADL score, F (2, 50) = 4.34, p < .05, η^2 = .15, with the Grant participants having a higher score than the Savvy participants, F (1, 35) = 8.60, p < .01, η^2 = .20.

There were no significant differences at baseline found between groups with regard to loved one's age, geographic location, initial problem behavior score, employment status, education, relationship with loved one, or length of time as caregiver (p > .05).

Table 2

Baseline Demographic Information for AD Caregivers by Intervention Group

	Savvy (n = 22)	Grant (n = 41)	Both (n = 19)
Age range	44-90	48-102	48-102
Gender	(n = 22)	(n = 41)	(n = 19)
Female	91%	61%	68%
Male	9%	39%*	32%
Diagnosis	(n = 21)	(n = 39)	(n = 19)
Medically diagnosed AD or other dementia	17%	100%**	68%
Other	19%	0%	32%
Income	(n = 18)	(n = 38)	(n = 19)
< 20,000	28%	60%	32%
> 20,000	72%	40%*	68%
Ethnicity	(n = 22)	(n = 40)	(n = 18)
Hispanic or Lation	0%	13%	11%
Not Hispanic or Latino	100%	87%	89%
Race	(n = 21)	(n = 38)	(n = 19)
White	100%	95%	100%
Other	0%	5%	0%
Geographic Location	(n = 21)	(n = 39)	(n = 19)
rural/farm	62%	39%	37%
large city	38%	61%	63%
Relationship	(n = 22)	(n = 39)	(n = 19)
Spouse/domestic partner	41%	62%	47%
Adult Child	41%	31%	47%
Other	18%	7%	6%
Av. Years Caregiving	(n = 21)	(n = 39)	(n = 19)
< 2 years	48%	36%	33%
> 2 years	52%	64%	67%
Education	(n = 21)	(n = 39)	(n = 19)
8th grade or less	5%	2%	0%
High School, did not graduate	11%	13%	5%
High School Graduate	21%	31%	11%
Some College	26%	26%	37%
AA Degree	11%	2%	0%
BA Degree	21%	13%	32%
Graduate Degree	5%	13%	15%
Employment Status	(n = 21)	(n = 40)	(n = 19)
Full-time	29%	7%	26%
Part-time	0%	5%	5%
Retired works part-time	5%	12%	0%
Fully retired	33%	45%	37%
Homemaker	19%	23%	21%
Unemployed	5%	0%	5%
Other	9%	8%	6%
Total Hours of Care	(n = 13)	(n = 36)	(n = 17)
	21.25 (24.47)	70.08 (111.73)	33.38 (25.81)
Activities of Daliy Living (ADL)	(n = 10)	(n = 27)	(n = 16)
	17.06 (10.78)	29.06 (11.14)*	28.14 (11.89)
Depression	(n = 14)	(n = 27)	(n = 16)
	5.71 (4.68)	8.26 (3.72)	6.41 (4.06)
Service Usage	(n = 21)	(n = 40)	(n = 19)
	2.62 (3.11)	2.65 (2.82)	2.37 (2.16)
Support Group Use (% Yes)	(n = 21)	(n = 40)	(n = 19)
	19%	20%	47%

$^{*}p < .05$, $^{**}p < .01$

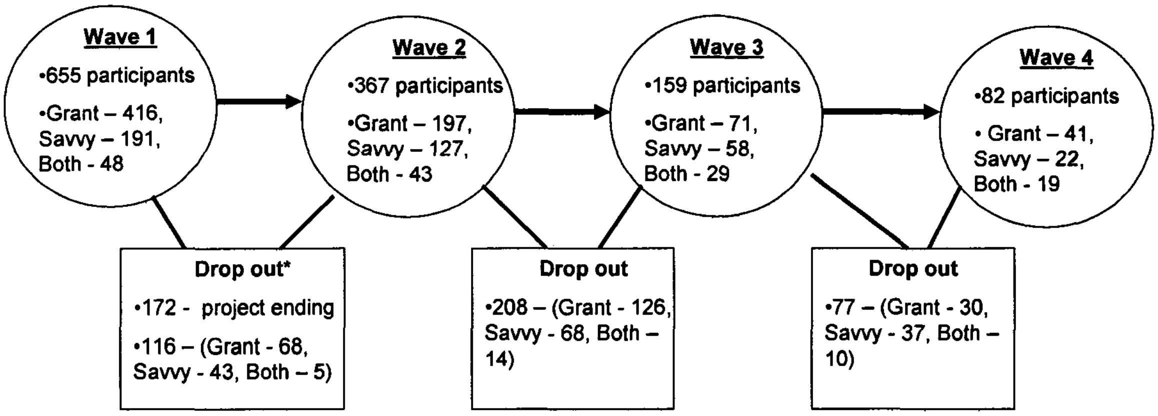
Based on the information from Table 2 it appears as though the Grant group may have been composed of individuals who were caregiving for AD loved ones who were further along with disease progression compared to the other two groups. Specifically, the Grant group reported increased ADLs and medical diagnosis for AD compared to the other intervention groups. These circumstances would be consistent with expectations that respite services are needed most by caregivers dealing at home with more advanced cases of dementia (e.g., Cox, 1997). In addition, the variables shown above were all examined with regard to changes in the outcome variables of depression, service usage variety, and support group use, with no significant differences found ($p > .05$).

Attrition

As is common with longitudinal studies attrition was examined for systematic patterns (see Figure 3). It is of interest to know whether the 82 participants in the 18-month follow-up sample were different in some way in comparison to those who only participated in earlier data collection waves. To scrutinize the effects of possible follow-up bias, basic demographic variables and the three outcome variables were examined with regard to individuals who stayed in the study or dropped out over the four waves. Table 3a gives information for individuals who stayed or dropped out according to the previous interview data obtained. The attrition rate increased from approximately 24% from Wave 1 to Wave 2, to 67% in Wave 3, and ending up at 82% in Wave 4.

In Table 3a, in the Wave 1 to 2 transition the only significant difference was with support group use; here the participants who dropped out reported higher support group use than the participants who stayed in the study, χ^2 $(1, N = 434) = 4.28, p < .05$; $\eta^2 = .009$. There were no differences for Wave 3 participants who stayed in or dropped out of

Figure 3. Continuation and attrition among Participants who received one of the Interventions across the four waves.



*Drop out due to project ending, reported death of loved one, or not being able to contact the participant.

Table 3a

Demographic and Outcome Variables Regarding Attrition across the 4 Waves.

	Wave 1 - 2		**Wave 2 - 3**		**Wave 3 - 4**	
	Stayed	**Dropped out**	**Stayed**	**Dropped out**	**Stayed**	**Dropped out**
N	367	116	158	208	82	71
Dep. Av	7.83 *(4.17)*	7.92 *(4.76)*	5.85 *(4.82)*	5.78 *(4.53)*	5.64 *(4.52)***	8.04 *(5.29)***
Service Use	2.31 *(2.23)*	2.21 *(2.13)*	3.35 *(2.13)*	3.73 *(2.38)*	3.18 *(2.12)*	3.4 *(2.36)*
Support Grp. (% yes)	24.3%**	86%**	51%	47%	45%	54%
AD Age	79.2 *(8.85)*	81 *(8.9)*	79.4 *(8.85)*	79.11 *(8.93)*	79.82 *(7.52)*	77.7 *(10.3)*
% Rural	46%	53%	48%	46%	44%	48%
Gender (%Female)	74%	78%	65%	72%	71%	63%
Income (% < 20,000)	47%	53%	40%	52%	45%	40%
Relationship						
Spouse	47%	52%	46%	55%	53%	42%
Adult Child	37%	40%	44%	38%	38%	48%
Prob. Behavior	14.73 *(8.48)*	14.84 *(8.11)*	15.11 *(7.2)*	14.06 *(5.88)*	13.67 *(7.93)*	14.3 *(8.74)*
ADLs	28.99 *(11.14)*	29.6 *(10.40)*	30.12 *(9.34)*	30.23 *(8.68)*	26.52 *(12.01)*	31.48 *(10.53)*

$^{**}p < .01$, $^{*}p < .05$

~Responses from previous Wave

Table 3b

Comparison of Participants Who Were in Wave 4 with Those Who Dropped Out.

	Baseline Information		**Wave 2 Information**		**Wave 3 Information**	
Participants	Wave 4 Participants	Not Wave 4 Participants	Wave 4 Participants	Not Wave 4 Participants	Wave 4 Participants	Not Wave 4 Participants
N	82	401	82	285	82	77
Dep. Av	7.10 *(4.14)*	7.70 *(4.40)*	5.17 *(4.43)*	5.82 *(4.61)*	5.86 *(4.46)*	8.04 *(5.29)*
Service Use	2.55 *(2.74)*	2.23 *(2.07)*	3.36 *(2.02)*	3.36 *(2.35)*	3.16 *(2.13)*	3.4 *(2.36)*
Support Grp. (% yes)	25%	78%	53%	47%	47%	54%
AD Age	79.82 *(7.52)*	79.42 *(9.22)*	79.82 *(7.52)*	78.93 *(9.32)*	79.82 *(7.52)*	78.68 *(10.57)*
% Rural	44%	49%	44%	47%	44%	50%
Gender (%Female)	71%	75%	71%	74%	71%	83%
Income (% < 20,000)	45%	52%	45%	51%	45%	53%
Relationship						
Spouse	53%	52%	53%	52%	53%	40%
Adult Child	38%	41%	38%	41%	38%	51%
Prob. Behavior	13.67 *(7.93)*	14.83 *(8.33)*	13.77 *(6.57)*	14.81 *(6.61)*	14.46 *(6.78)*	14.59 *(8.84)*
ADLs	26.52 *(12.01)*~	29.58 *(10.80)*~	29.80 *(8.60)*	30.43 *(9.09)*	30.92 *(8.96)*	31.52 *(10.32)*

$\sim p < .1$

the study. However, in the Wave 3 to Wave 4 transition participants who dropped out had higher depression scores than those who stayed in, $F(1, 112) = 6.64, p < .01, \eta^2 = .06$.

Table 3b shows the participants who stayed in for all four waves compared to those who did not across Waves 1 through 3. Wave 4 participants reported a slightly lower ADL score at baseline compared to non-Wave 4 participants, $F(1, 355) = 3.50, p = .06, \eta^2 = .01$. There were no differences between Wave 4 participants and non-Wave 4 participants at Waves 2 and 3.

Overall, these tables show similarity between participants who stayed in or dropped out of the study with regard to the available demographics and outcome measures. Based on the finding that participants who dropped out reported increases in support group use, depression, and ADLs, combined with the information that approximately 21% of the sample reported being unable to participate due to death of their loved one, perhaps one reason why participants dropped out is related to their loved one being at a later stage of the disease or having passed away.

Eighteen-month Follow-up Data on Savvy Usage

The frequencies for the sub-sample's ($n = 82$) 18-month follow-up responses to the Savvy Usage Questionnaire are presented in Figures 4 through 7. The responses show that 90.6% of the participants used the Savvy manual with some frequency since completing the training, 74.2% found the manual helpful in structuring meaningful household activities for the person with AD, 53.8% used the CD-ROM since completion of the training, and 34.8% used the CD-ROM to help them determine their loved one's level of functioning. Regarding use of the grant, 66% reported using it for help in the

Figure 4. Use of Savvy manual at 18-month follow-up ($n = 32$).

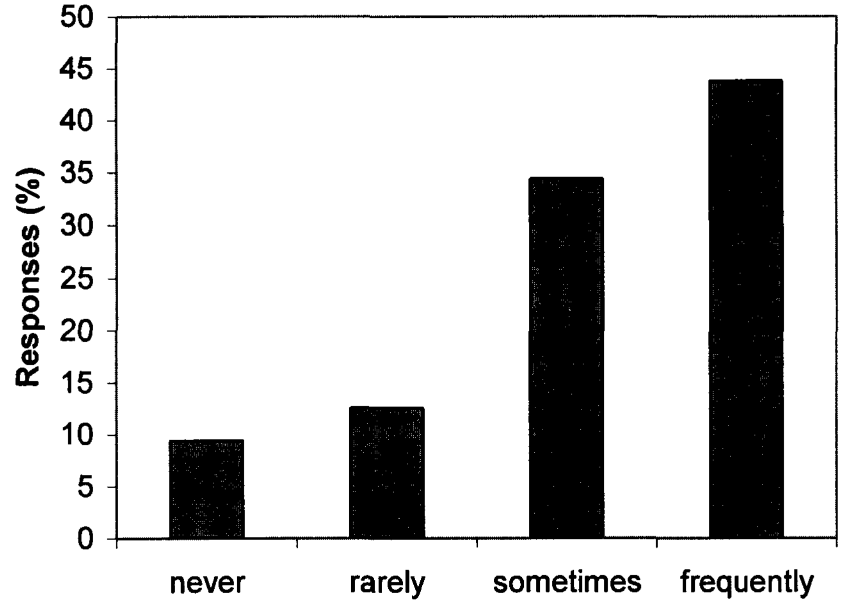


Figure 5. The manual helped to structure meaningful household activities for the AD patient (18-month follow-up: $n = 31$).

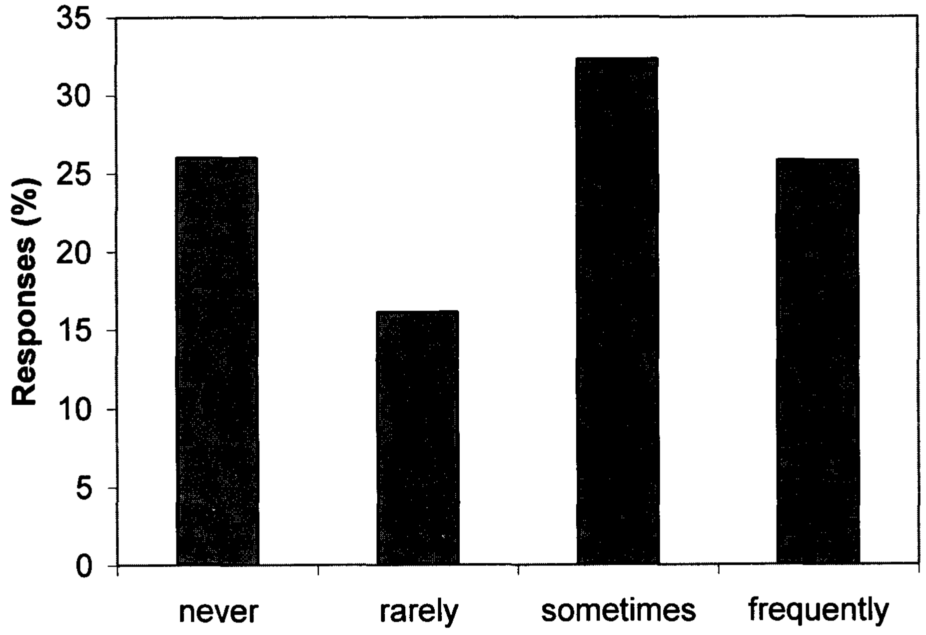


Figure 6. Use of the Savvy CD-ROM at the 18-month follow-up ($n = 27$).

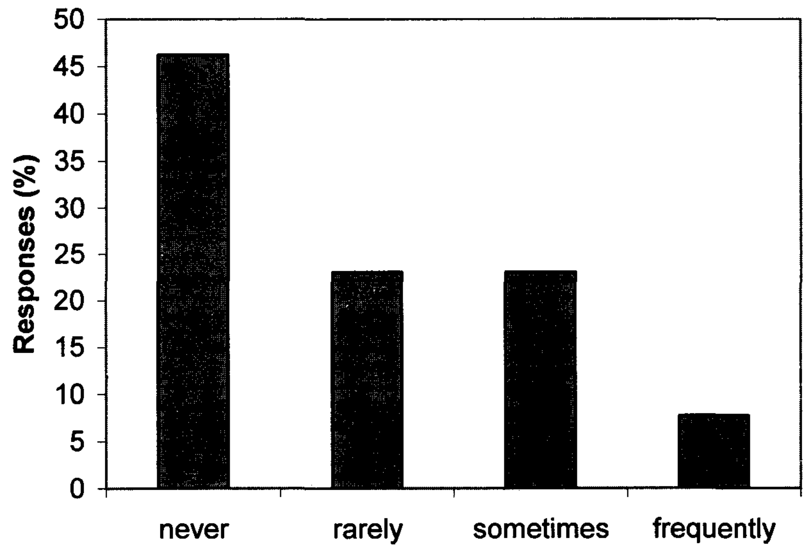
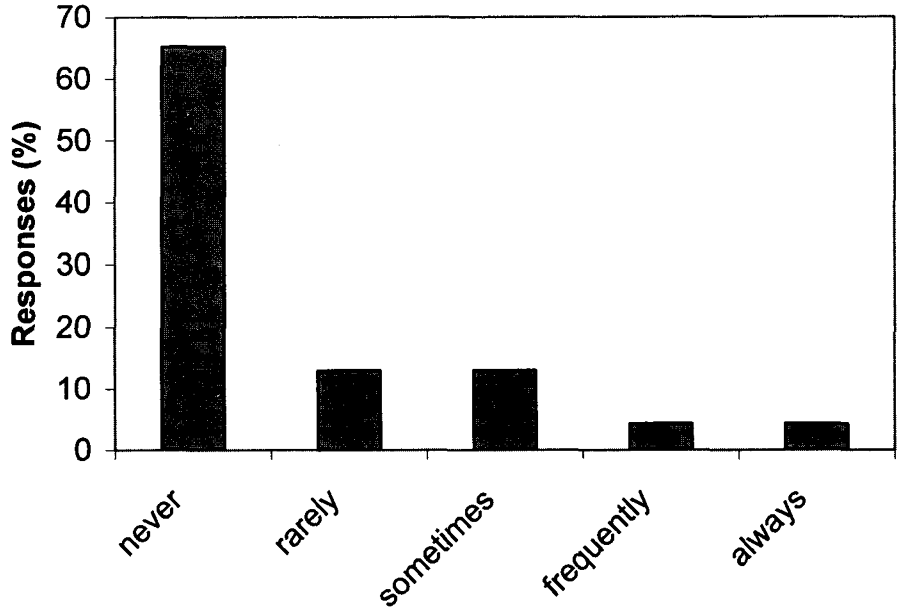


Figure 7. Using the CD at home helped in determining the AD patient's level of functioning (18-month follow-up; *n* = 24).



home, 17% reported using it at a day program, and 17% reported using it for a short stay at a nursing home.

Specific Aim 1 – Patterns of Depression

The primary outcomes (i.e., depression score, service usage variety, and support group use) over time can be seen in Table 4 for all Wave 4 participants. It appears that the improvement in all three measures found in the larger samples at Wave 2 and Wave 3 continues to hold up for the smaller Wave 4 sample. An examination of Table 4 supports this general trend for depression, and indicates that all mean depression scores are below the scale midpoints of 10. The range of depression scores was 0–17 at Wave 1, 0–18 at Wave 2, 0–20 at Wave 3, and 0–15 at Wave 4. Figure 8 depicts the depression score means by intervention group for the Wave 4 participants.

As attrition was a factor in this study, in order to get a clearer look at the trends with regard to depression over time, changes in depression scores at each wave were examined between the three groups using only data from the Wave 4 participants. Any change at all from baseline was counted as a decrease or increase, and the percentages of those increasing, decreasing, or not changing in depression are shown for the different intervention groups in Figures 9, 10, and 11. All three intervention groups either had more or the same amount of participants decreasing than increasing in depression score over time.

A 3 x 4 repeated measures ANOVA with intervention group as the between-subjects factor and the four waves as the within-subjects factor showed a main effect for time, $F(3, 162) = 5.79, p < .01, \eta^2 = .10$. Specifically, participants were decreasing in

Table 4

Descriptive Statistics for the Outcome Variables by Intervention Group (*n* = 82)

	n	Savvy	n	Grant	n	Both
Depression Score						
Baseline (Wave 1)	14	5.71 *(4.68)*	27	8.26 *(3.72)*	16	6.19 *(4.09)*
Wave 2	14	3.00 *(3.51)*	27	6.63 *(4.36)*	16	4.94 *(4.57)*
Wave 3	14	3.78 *(2.89)*	27	7.07 *(5.21)*	16	6.00 *(3.52)*
Wave 4	14	5.00 *(3.78)*	27	5.51 *(3.83)*	16	5.13 *(3.83)*
Service Usage Score						
Baseline (Wave 1)	21	2.61 *(3.11)*	40	2.65 *(2.82)*	19	2.37 *(2.16)*
Wave 2	20	2.60 *(1.85)*	41	3.71 *(1.86)*	19	3.42 *(2.39)*
Wave 3	20	2.70 *(2.34)*	40	3.12 *(2.02)*	19	3.74 *(2.13)*
Wave 4	22	2.82 *(1.65)*	41	3.20 *(1.72)*	19	3.95 *(1.61)*
Support Group Usage (% yes)						
Baseline (Wave 1)	21	19%	40	20%	19	47%
Wave 2	20	45%	41	44%	19	79%
Wave 3	20	40%	40	38%	19	74%
Wave 4	22	41%	41	27%	19	68%

Figure 8. Depression scores across the 4 waves for each intervention group for all Wave 4 participants.

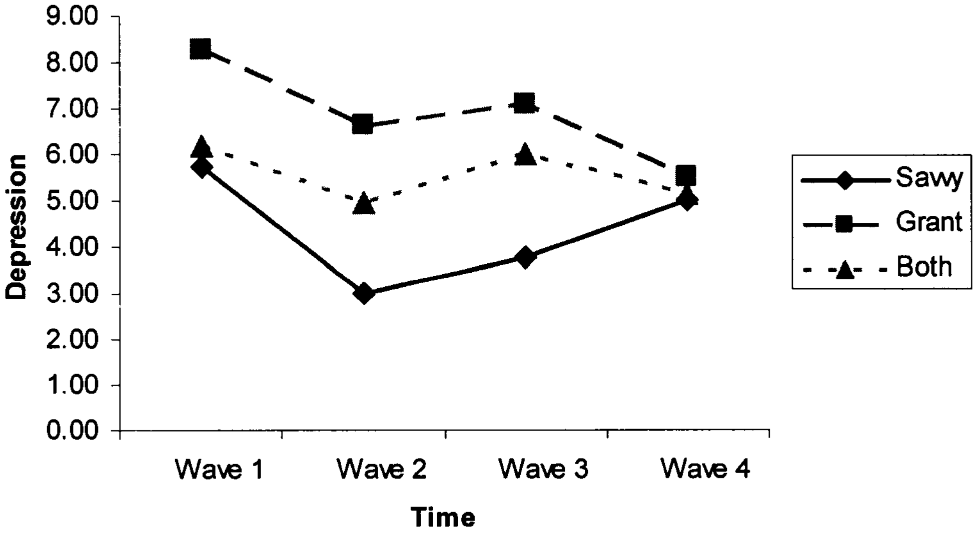


Figure 9. Percent of participants changing in depression scores in the Savvy group (*n* = 14).

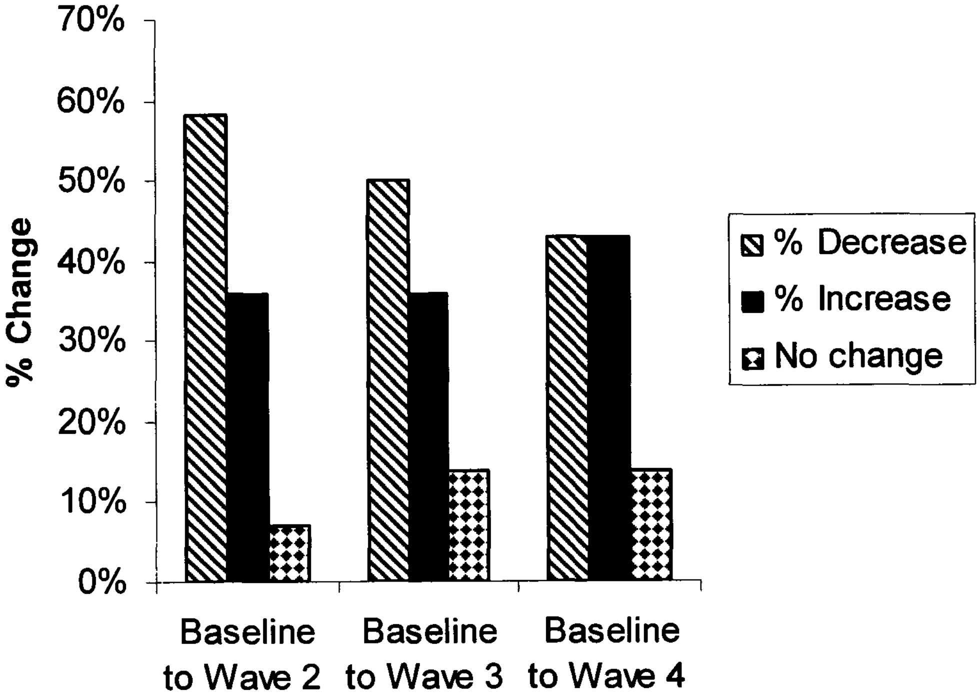


Figure 10. Percent of participants changing in depression scores in the Grant group (*n* = 27).

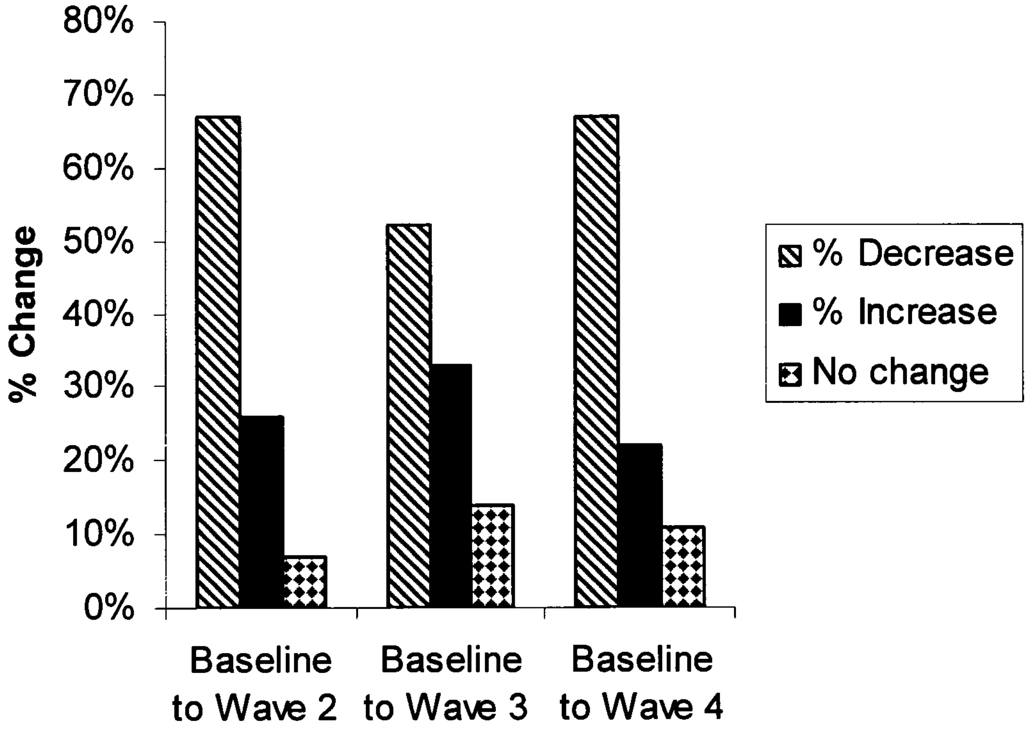
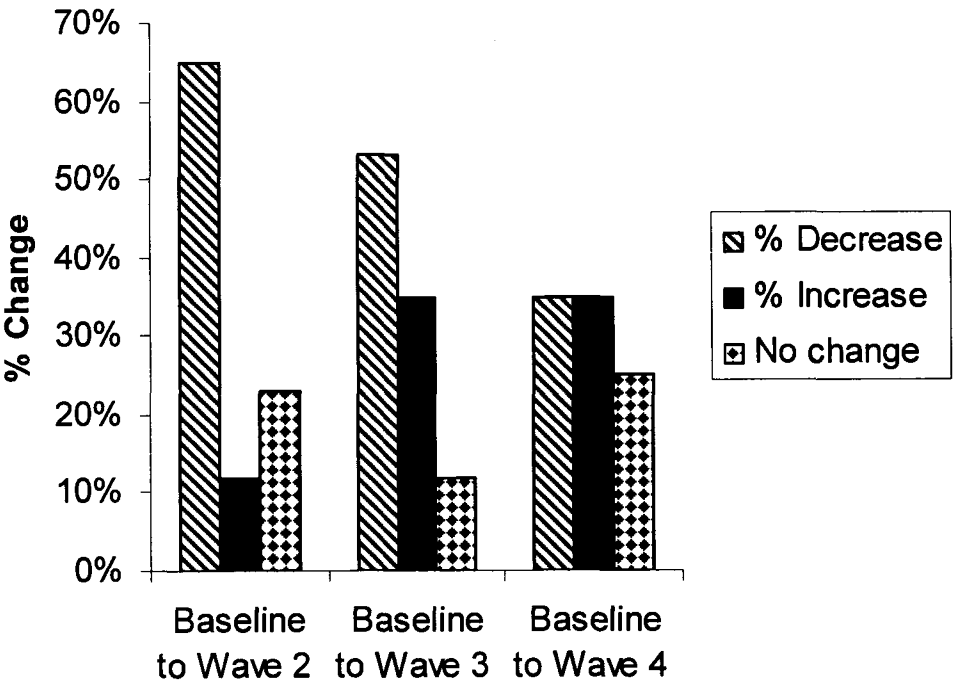


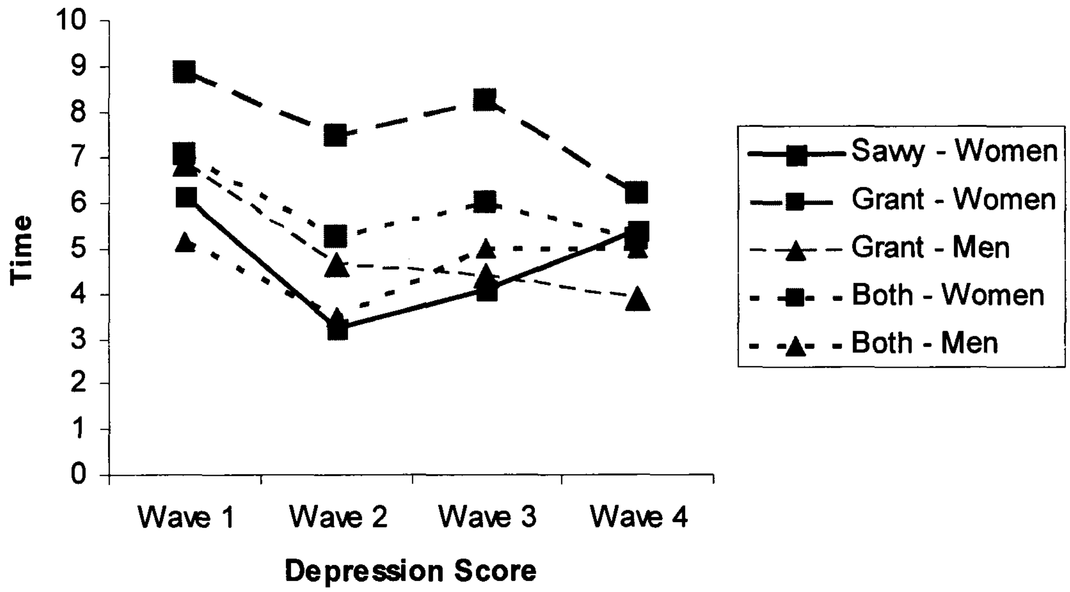
Figure 11. Percent of participants changing in depression scores in the Both group (*n* = 16).



depression over time ($M_1 = 7.05$, $SD_1 = 4.16$; $M_2 = 5.26$, $SD_2 = 4.41$; $M_3 = 5.96$, $SD_3 = 4.43$; $M_4 = 5.28$, $SD_4 = 3.78$). Neither the main effect for group nor the interaction was significant. In subsequent ANOVAs a second between-subjects factor was added, including the client, caregiver, and community characteristics of loved one's gender, community size, age, ADL score, problem behavior score, residence of loved one, relationship with loved one, caregiver gender, length of time caregiving, employment status, and income. Neither main effects nor interactions for these additional variables were significant.

The technique of examining the interventions separately has been suggested as an appropriate tool when assessing longitudinal data (Looney & Stanley, 1989). Since caregiver gender had appeared as a major factor (lower depression for men) with the larger Wave 2 sample, the separate intervention groups were examined by gender across time for the Wave 4 participants. These groups are shown in Figure 12. Note that there were no men shown in the Savvy group because of the small number of men who responded to the depression scale for this sample ($n = 1$). There was a main effect for time for the Savvy women group, $F(3, 39) = 2.87$, $p = .049$, $\eta^2 = .18$. Specifically, participants were decreasing in depression over time ($M_1 = 5.71$, $SD_1 = 4.68$; $M_2 = 3.00$, $SD_2 = 3.50$; $M_3 = 3.78$, $SD_3 = 2.88$; $M_4 = 5.00$, $SD_4 = 3.78$). Women in the Grant group decreased in depression, $F(3, 54) = 3.81$, $p < .05$, $\eta^2 = .17$ ($M_1 = 8.26$, $SD_1 = 3.72$; $M_2 = 6.63$, $SD_2 = 4.36$; $M_3 = 7.07$, $SD_3 = 5.21$; $M_4 = 5.51$, $SD_4 = 3.38$), but men in the Grant group did not, $F(3, 21) = 2.07$, $p > .05$. Women in the Both group showed no change across time, $F(3, 27) = 0.97$, $p > .05$, and men in the Both group also showed no change across time, $F(3, 15) = 2.50$, $p > .05$.

Figure 12. Depression for Wave 4 participants for each intervention group and caregiver gender.



Comparisons of baseline vs. Wave 4 scores for each of these groups found a significant change only for women in the Grant group, $F\,(1, 18) = 8.82, p < .01, \eta^2 = .33$, and men in the Grant group, $F\,(1, 7) = 4.06, p < .01, \eta^2 = .37$. Comparisons of Wave 3 vs. Wave 4 means for each of these five groups found the only significant difference in the Women Grant group, $F\,(1, 18) = 4.82, p < .05, \eta^2 = .21$.

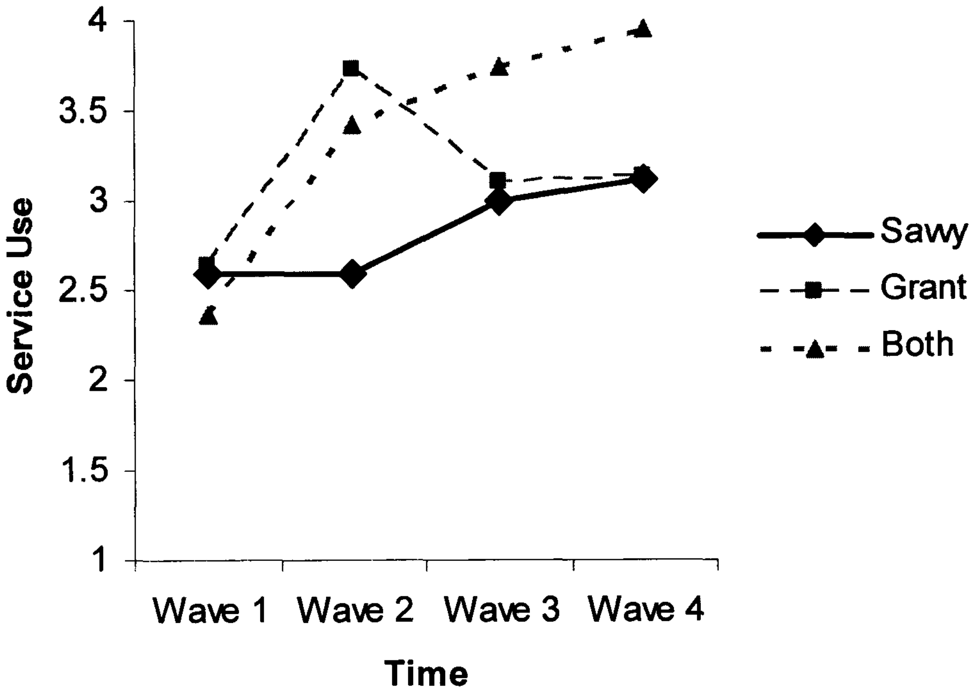
Overall, then, there were no group increases in depression from baseline to Wave 4. Furthermore, the Grant intervention seemed to do the best job of maintaining the improvement in depression initially observed at Wave 2.

Specific Aim 2 – Patterns of Service Usage Variety

Service usage variety across the 4 waves of the study can be seen in Figure 13 for the three intervention groups of the Wave 4 participants. To examine service use change over time repeated measures factorial ANOVAs were used with intervention group and various client, caregiver, and community characteristics as between-subjects factors. A 3 x 2 x 4 ANOVA, using intervention (Savvy, Grant, or Both) and community size--Rural (<50,000) vs. Urban (> 50,000)--as the between-subjects factors and time as a repeated measure (Wave 1, 2, 3, & 4) was found to be the best fitting, most parsimonious model for this variable. Models including loved one's gender, age, ADL score, problem behavior score, residence of loved one, relationship with loved one, length of time caregiving, employment status, and income as between-subjects factors had neither main effects nor interactions for any of these additional factors.

The final model found a significant 3-way interaction between time, group, and community size, $F\,(5.2, 174) = 4.57, p < .01; \eta^2 = .12$, suggesting that changes in service usage over time differed depending upon which intervention group the participants were

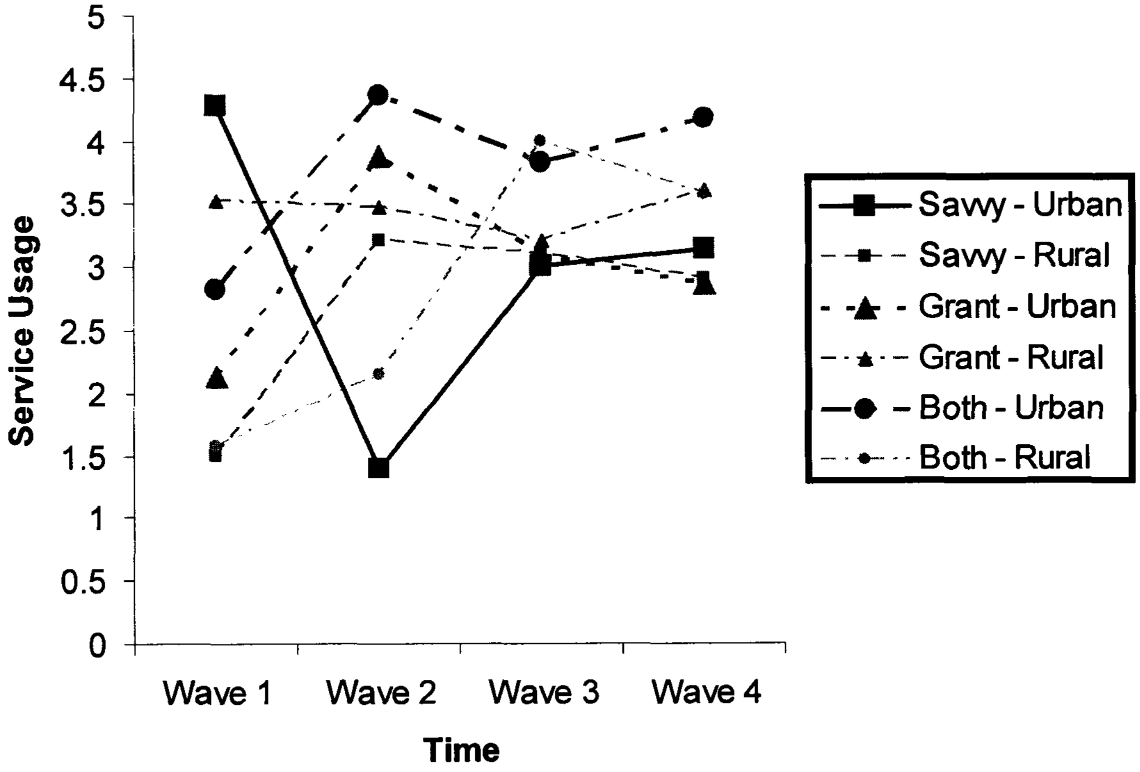
Figure 13. Mean service use scores across the 4 Waves for each intervention group.



in and whether they lived in a rural or urban community (see Figure 14). Here the assumption of sphericity was not met so the more conservative Greenhouse-Geisser estimation of significance was used. Analyses were also run with transformations in order to account for unequal variances, resulting in identical findings. In addition, due to small cell sizes the interaction should be interpreted with caution; therefore additional analyses were run with each of the above client, caregiver, and community characteristics as covariates. The 3-way interaction retained significance ($p < .05$) after each of these variables was added, demonstrating the robust nature of the effect.

Although this 3-way interaction may well be due to the drop in service usage variety by the Savvy-urban group at Wave 2, additional repeated measures ANOVAs were run for each intervention group separately with geographic location as a between-subjects factor. In the Savvy group there was a significant interaction between time (Wave 1 to Wave 4) and geographic location, $F\,(3, 42) = 4.95, p < .01, \eta^2 = .26$. Specifically, rural participants increased in service use, $F\,(3, 27) = 3.01, p < .05, \eta^2 = .25$ ($M_1 = 1.5, SD_1 = 2.12; M_2 = 3.2, SD_2 = 2.20; M_3 = 3.10, SD_3 = 2.64; M_4 = 2.9, SD_4 = 1.97$) but the urban participants did not, $F\,(3, 18) = 2.32, p > .05$. In the Grant group, there was no significant main effect for time or geographic location nor interaction found. In the Both group there was only a significant main effect for time (Wave 1 to Wave 4), $F\,(3, 51) = 4.18, p < .01, \eta^2 = .20$. Tests of baseline vs. Wave 4 means for each of the subgroups in the Figure 14 interaction found increases in service use for rural participants in the Savvy, $F\,(3, 27) = 3.01, p < .05, \eta^2 = .25$, and Both, $F\,(3, 18) = 5.58, p < .01, \eta^2 = .48$, groups and urban participants in the Grant group, $F\,(3, 66) = 5.42, p < .01, \eta^2 = .20$. No group changed in variety of service use from Wave 3 to Wave 4. Overall, then,

Figure 14. Time x group x community size interaction for service use variety for Wave 4 participants.



increases in variety of service usage were especially likely with the Both intervention and for urban participants in the Grant intervention, and there were essentially no changes in usage from Wave 3 to Wave 4.

Specific Aim 3 – Patterns of Support Group Use

Figure 15 depicts percentages of Wave 4 participants who attended support groups at each wave. An examination of Figure 16 suggests that all interventions increased attendance from baseline to all subsequent waves, although due to small sample sizes tests of these changes were not always statistically significant, as described below.

As support group use was categorical in nature (yes/no), an initial Cochran Q test was run to assess differences across time. Chi Square analysis was then used to examine significant differences between time points, and the non-parametric McNemar test of dependent proportions was used to examine differences between intervention groups. There was an increase in support group use across the four Waves, Cochran Q 22, df 3, $p = .00$. Specifically, at Wave 1 25% of participants reported they were attending a support group compared to 51.3%, 45.6%, and 40.2% at Waves 2, 3, and 4, respectively. These percentages were significantly different from each other based on results of a Chi Square test, Wave 1 to Wave 2, χ^2 $(1, N = 78) = 12.24, p < .01, \eta^2 = .16$; Wave 1 to Wave 3, χ^2 $(1, N = 77) = 10.5, p < .01, \eta^2 = .14$; Wave 1 to Wave 4, χ^2 $(1, N = 80) = 6.21, p < .05, \eta^2 = .08$.

To examine possible differences in these percentages between intervention groups, a McNemar test of dependent proportions was used with Fisher's Exact Test (see Figure 16). For Wave 1 to Wave 2 the Grant group showed significant change, χ^2 $(1, N = 40) = 7.30, p < .01, \eta^2 = .18$, but the Both group, χ^2 $(1, N = 19) = 4.56, p > .05, \eta^2 = .24$,

Figure 15. Percent of Wave 4 participants who attended a support group across time.

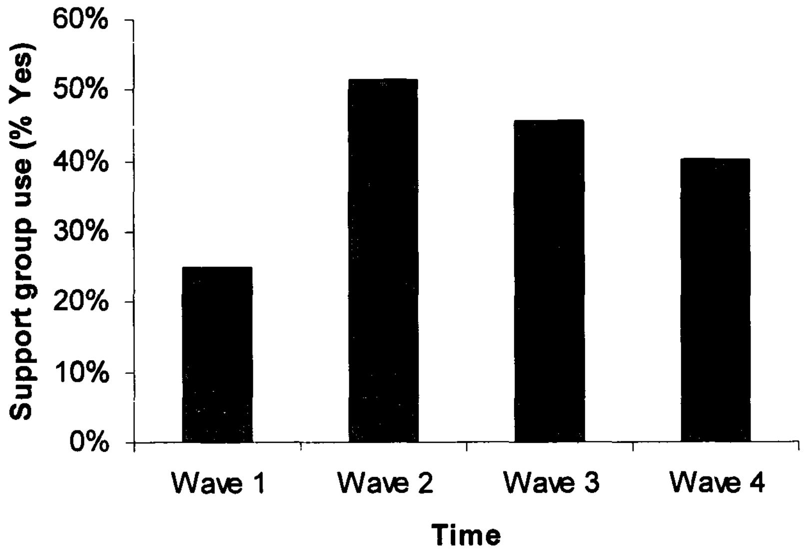
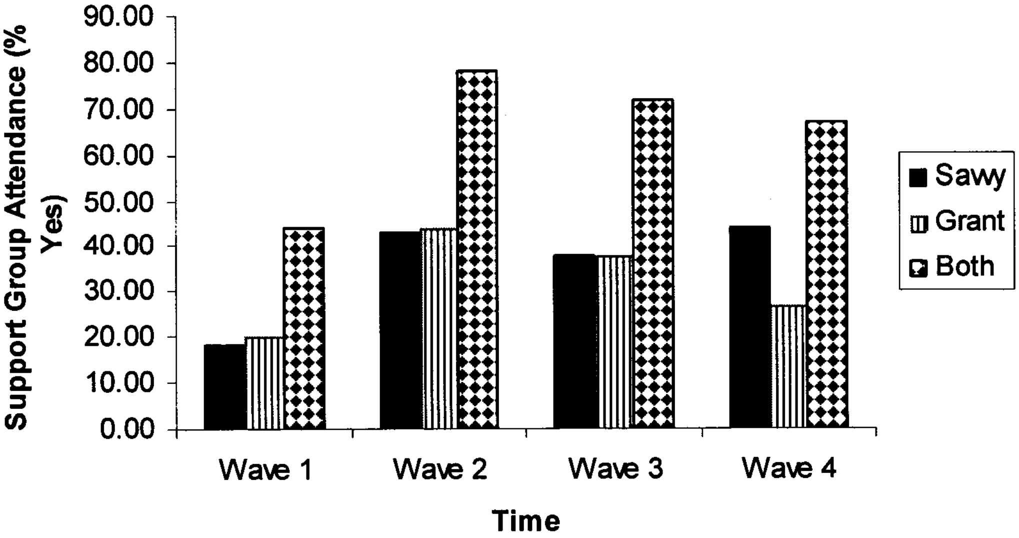


Figure 16. Percent of Wave 4 participants who attended a support group across time according to intervention group.



and the Savvy group, χ^2 (1, N = 19) = .13, $p > .05$, did not. For Wave 1 to Wave 3 no group showed significant change, Savvy - χ^2 (1, N = 19) = 4.90, $p > .05$, $\eta^2 = .25$, Grant - χ^2 (1, N = 39) = 2.46, $p > .05$, $\eta^2 = .06$, and Both - χ^2 (1, N = 19) = 2.04, $p > .05$, $\eta^2 = .11$. For Wave 1 to Wave 4 no group showed significant change, Savvy - χ^2 (1, N = 21) = 2.08, $p >.05$, $\eta^2 = .10$; Grant - χ^2 (1, N = 40) = 2.54, $p >.05$, $\eta^2 = .06$; and Both - χ^2 (1, N = 18) = .45, $p >.05$, $\eta^2 = .04$. It should be noted that effect sizes in these tests are often moderate even if the small sample sizes preclude statistical significance. Figures 17, 18, and 19 show participants who started, stopped, never used, or always used support groups for Wave 1 to Wave 2, Wave 2 to Wave 3, and Wave 3 to Wave 4. All three interventions appeared to be reasonably effective in getting caregivers to attend support groups by the 6-month follow-up, as seen in the Wave 1 to Wave 2 frequencies.

Specific Aim 4 – Relationships between Variables

Correlations were run between the three main outcomes of depression, service use, and support group use, and key demographic variables across the four time waves (see Table 5). Correlations among the outcome measures were strong within each measure across waves, indicating considerable stability. Depression score at Wave 1 was found to be positively correlated with service use at Wave 2, $r = .28$, $p < .05$; here it appears that higher depression scores at Wave 1 were associated with increased service usage at Wave 2. Depression score at Wave 2 was positively correlated with service use at Wave 2, $r = .26$, $p < .05$. Depression score at Wave 3 was positively correlated with service use at Wave 2, $r = .25$, $p = .06$; here it appears that higher depression scores at Wave 3 are associated with increased service use at Waves 2.

Figure 17. Percent of Wave 4 Savvy participants who started, stopped, never used, or always used support groups across the four waves ($n = 20$).

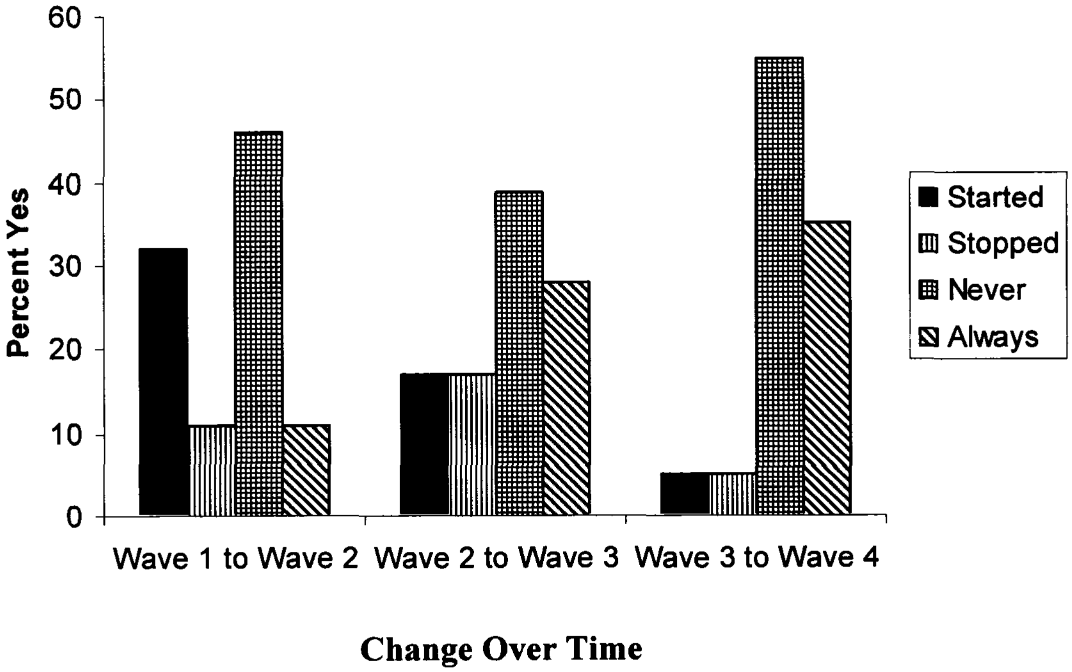


Figure 18. Percent of Wave 4 Grant participants who started, stopped, never used, or always used support groups across the four waves ($n = 40$).

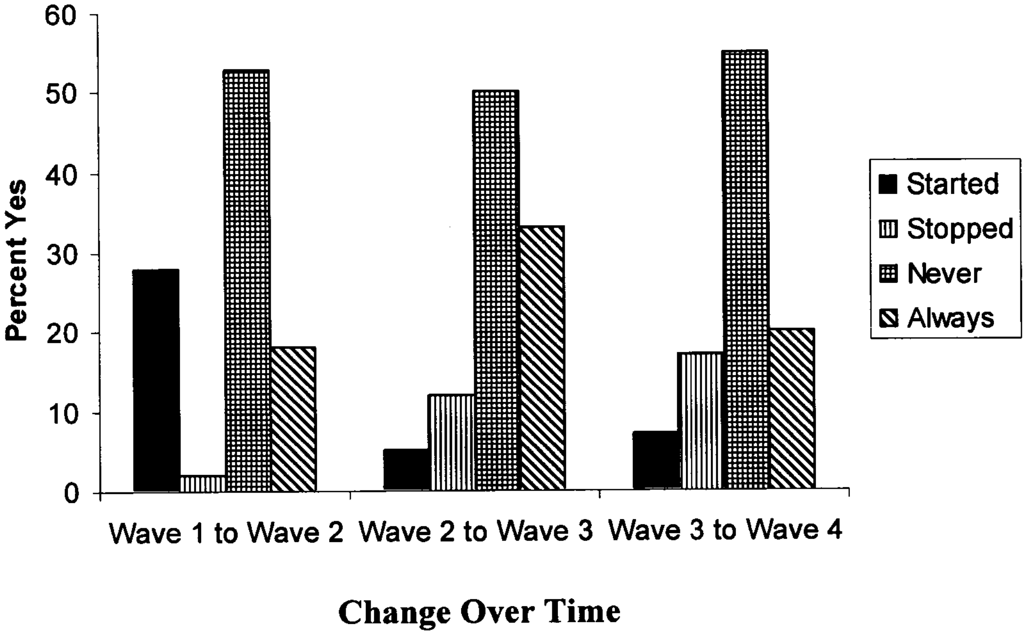
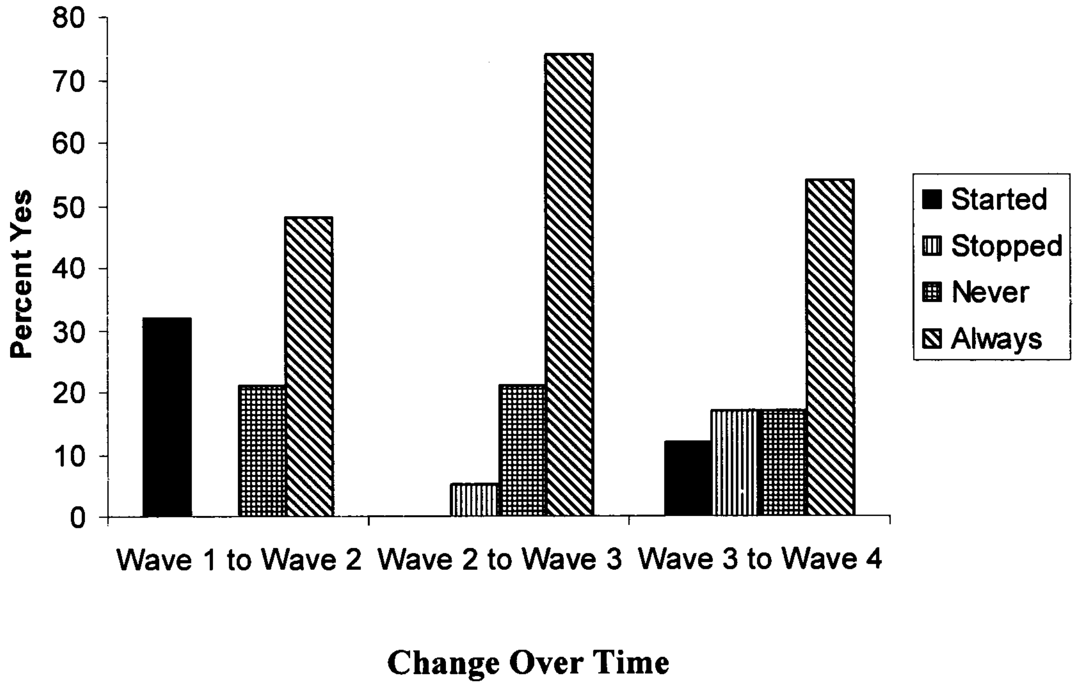


Figure 19. Percent of Wave 4 Both participants who started, stopped, never used, or always used support groups across the four waves ($n = 19$).



Support group use was generally not correlated with depression. Service use at Wave 1 was found to be positively correlated with support group use at Wave 1, $r = .32, p < .01$; here it appears that the more services individuals used at Wave 1 the more likely it was that they attended a support group. Also, support group use at Wave 1 and Wave 3 was positively correlated with service use at Wave 4, $r = .22$ and $r = .23$ respectively, $p < .05$.

It was also found that reports of contact with the Alzheimer's Association were related to the outcome variables mentioned above. Specifically, service use at Wave 3 and Wave 4 was positively correlated with contact with the Alzheimer's Association ($r = .32$, $r = .34$, respectively), with higher service usage scores at Wave 3 and 4 corresponding to more contact with the Alzheimer's Association (measured at Wave 4; $p < .01$. Regarding support group use, contact with the local Alzheimer's Association was positively correlated with support group use at Waves 1, 3, and 4 ($r = .36$, $r = .42$, $r = .63$, respectively, $p < .01$). The measure of self-efficacy was not found to be consistently correlated to any of the three outcome variables ($p > .05$).

Problem behavior score and ADL were also examined in order to better understand possible disease progression. Indicative of the decline in functioning level associated with Alzheimer's disease, both the problem behavior score, $F(2, 42) = 5.52, p < .05, \eta^2 = .21; M_1 = 12.6, SD = 5.96; M_3 = 15.83, SD = 6.8$, and the ADLs, $F(3,33) = 10.03, p < .01, \eta^2 = .23; M_1 = 26.88, SD = 12.6; M_4 = 32.27, SD = 8.7$, of the individual with AD increased over time (problem behavior not reported for Wave 4 due to insufficient data).

Correlations in Table 5 also show associations with problem behavior and ADLs and the three outcome variables. Specifically, problem behavior at Wave 1 was positively correlated with depression at Waves 1, 2, 3, and 4 ($r = .59$, $r = .43$, $r = .43$, $r = .45$, respectively, $p < .05$). Problem behavior at Wave 2 was positively correlated with depression at Waves 2, 3, and 4 ($r = .29$, $r = .30$, $r = .41$, respectively, $p < .05$). Also, problem behavior at Wave 3 was positively correlated with depression at Waves 1, 2, 3, and 4, ($r = .40$, $r = .54$, $r = .56$, $r = .58$, respectively, $p < .05$).

Problem behavior scores were also correlated with service use, with Wave 1 problem behavior correlated with service use at Wave 2, $r = .35$, $p < .05$, and Wave 2 problem behavior correlated with service use at Wave 1, $r = .32$, $p < .05$, indicating that as the loved ones increased in problem behaviors the number of services used increased. Problem behavior scores were not generally correlated with support group use. Activities of daily living (ADL) scores were not consistently correlated with depression or support group use. However, ADLs at Wave 1 were correlated with service usage at Wave 2, $r = .32$, $p < .05$, and ADLs at Wave 4 were correlated with service usage at Waves 2, 3, and 4, $r = .27$, $r = .30$, $r = .26$, respectively, $p < .05$. Here it appears that as the need for assistance with activities of daily living increased, use of services also increased in this particular population.

Table 5

Correlations for the Three Main Outcome Variables and Demographics across the 4 Waves.

		Depression				**Service Use**				**Support Group Use**			
		Wave 1	Wave 2	Wave 3	Wave 4	Wave 1	Wave 2	Wave 3	Wave 4	Wave 1	Wave 2	Wave 3	Wave 4
Depression	Wave 1	-	.55**	.55**	.54**	-.00	.28*	.12	.00	.12	.03	-.07	-.16
	Wave 2	.55**	-	.78**	.78**	.24	.26*	.13	.09	.21	.18	.02	-.07
	Wave 3	.55**	.78**	-	.69**	.19	.25~	.18	-.03	.25	.14	-.05	-.04
	Wave 4	.54**	.78**	.69**	-	.16	.07	.07	.14	.21	.16	-.04	-.00
Service Use	Wave 1					-	.30**	.43**	.39**	.32**	.05	.16	.18
(minus support	Wave 2					.30**	-	.47**	.36**	-.03	.15	.22~	.11
group use)	Wave 3					.43**	.47**	-	.58**	.19	.13	.14	.14
	Wave 4					.39**	.36**	.58**	-	.22*	.10	.23*	.12
Support Group Use	Wave 1									-	.40**	.38**	.31**
	Wave 2									.40**	-	.64**	.39**
	Wave 3									.38**	.64**	-	.57**
	Wave 4									.31**	.39**	.57**	-
Problem Behavior Score[t]	Wave 1	.59**	.43**	.43**	.45**	.20	.35*	.27	.17	-.13	.19	.30*	.04
	Wave 2	.18	.29~	.30*	.41**	.32*	.10	.19	.10	.14	-.06	.14	.00
	Wave 3	.40*	.54**	.56**	.58**	10	.20	.24	-.00	.25	.24	.30	.03
ADLs	Wave 1	.20	.17	.29	.15	.19	.32*	.23	.24	-.14	-.12	-.12	.00
	Wave 2	.15	.12	.17	.15	.10	.22	.17	.21	-.19	-.05	-.13	-.10
	Wave 3	.17	.20	.30*	.21	.02	.22	.17	.12	-.19	-.03	.07	-.05
	Wave 4	.13	.23	.23	.17	.10	.27*	.30**	.26*	-.15	.07	.10	-.02
Contact with AA		-.08	-.20	-.06	-.18	.22	.11	.32**	.34**	.36**	.22	.42**	.63**
Self-efficacy		.12	-.15	-.02	-.05	.18	.10	.30*	.05	.14	.10	.12	.18

** p < .01, * p < .05, ~ p < .10, [t] inadequate data for Wave 4

CHAPTER IV

DISCUSSION

The current longitudinal follow-up study of three varying interventions for AD caregivers found overall encouraging findings. Specifically, caregivers reported significant decreases in depression scores over time, significant increases in service usage over time, and significant increases in support group usage over time. In general, these outcomes held up 18 months after the intervention, although there were differences regarding these outcomes associated with certain caregiver and community characteristics.

Specific Aim 1 – Patterns of Depression

The first specific aim of the current study was to examine how depression scores changed over the 18-month follow-up for all participants and the three intervention groups (Savvy, Grant, Both). The results for the depression scores differed depending on intervention group and gender. There was an improvement in depression for the women in the Savvy group. There was also an improvement in depression for women in the Grant group across the 18-month follow-up. Here it is important to note that the Grant participants consisted of individuals with significantly lower income, 100% medical diagnosis of AD, and reporting significantly more problems with ADLs compared to those in the other two intervention groups. In addition, the problem of depression is more prevalent in women as females are twice as likely to experience a major depressive episode compared to males (Sonnenberg, Beekman, Deeg, & van Tilburg, 2000). The Both intervention appeared to have little effect on men's and women's depression. It should be noted that small sample size and subsequent power may have contributed to these findings; specifically, the Both group had a significantly smaller sample size and thus less power to detect significant change.

A second part of this aim was to examine how specific client, caregiver, and community characteristics might affect depression over the 18-month follow-up. Gender and intervention group were the only variables found to assist in understanding the depression trajectory. There were no significant effects found for other caregiver characteristics (community size, problem behavior, ADLs, employment status, relationship with loved one, length of time caregiving, age, and income). These findings suggest that with regard to depression women should be targeted more aggressively. The Grant group (both men and women) was the only intervention that maintained the declines in depression at the 18-month follow-up, implying that enabling the use of respite services has long-term impact on depression. In addition, women in the Grant group reported the only significant declines in depression from Wave 3 to Wave 4, perhaps showing that depression may continue to decrease long after the intervention has expired (i.e., the grant ended at 12 months).

Although variability existed among the caregivers, the overall depression trajectory across the 18-month follow-up period showed no increases in depression. The last objective of this specific aim was to examine whether the effects on improving depression scores (from baseline to Wave 2) held up after 18 months, or whether the progression of the disease takes its toll on the caregiver regardless of the intervention. Although the Grant group had the only significant decrease in depression from baseline to Wave 4, all three groups had more or equal amounts of participants decreasing compared to increasing in depression from baseline to Wave 4.

Additionally, these findings should be interpreted with caution as the Grant individuals and women started with higher depression scores, so a ceiling effect may be occurring with results showing statistical regression. As the trends of depression decline did not last to the 18-month follow-up for all groups, repeating the intervention after 12 months may prove beneficial. In addition, it is important to note that the depression scores did not significantly increase for any of the intervention groups; this is noteworthy as other studies have found significant increases in depression across time for AD caregivers (e.g., Schulz & Williamson, 1991). Since the scale used in this study was a shortened version of a larger validated depression scale, direct comparisons to other studies are not feasible.

Perhaps the knowledge that was gained by the Savvy participants played a role in helping to buffer against increases in their depression levels, in addition to the Grant and Both groups finding possible relief from the use of support services and a possible lessening of financial burden. In addition to education and monetary assistance, information about support services and making possible contacts via the Alzheimer's Association could also have aided in these overall positive findings. It is important to note that although there was a natural decline of the caregivers' loved ones with regard to needing more assistance with ADLs along with a significant increase in problem behaviors, either an improvement in caregiver depression or a lack of significant deterioration was achieved.

Additionally, the majority of studies examining intervention effectiveness have failed to report 12- or 18-month follow-up data; this study, although it cannot be causally linked, found that caregivers' scores either significantly improved or did not significantly increase after a substantial amount of time. The implications of this go beyond the caregiver's own mental health and can be seen to possibly affect the caregiver's physical health and the caregiving relationship. For example, Paton and colleagues (2004) found that a significant number of AD caregivers were making negative attributions regarding their loved one's condition that could result in increased mental distress. In addition to these attributions affecting the caregiver's mental health, previous studies have suggested that they can also affect how the caregivers emotionally and behaviorally react toward AD individuals (Hastings et al., 2003). These findings suggest that persons with AD might be given a lower level of support because their caregiver does not accept that their problems are a reflection of the illness (Paton et al., 2004). Here a psychoeducational intervention such as the Savvy program or connections made via the Alzheimer's Association may have helped with giving caregivers a better understanding of their loved one's behavior.

Specific Aim 2 – Patterns of Service Usage Variety

The second specific aim of the current study was to examine how service usage changed over the 18-month follow-up for all participants and the three intervention groups (Savvy, Grant, Both). It should be noted again that the dependent measure employed is in essence variety of types of supportive services used and not overall quantity of service usage. That is, a higher score indicates more types of services used and not a larger quantity of a service. A significant interaction was found between time, group, and community size (rural vs. urban). Specifically, rural participants in the Savvy and Both groups increased types of services used across the 18-month time period, and urban participants in the Grant group showed a significant increase in types of service use. Presumably, the grant enabled caregivers to purchase more services, and more services were available in larger communities. It should be noted that this study was not able to measure the amount of services that were available to participants; therefore any findings with regard to the rural/urban differences could be a reflection of amount of services that were available in the respective community.

With regard to the Savvy/rural group this finding is particularly noteworthy as these participants were not provided with additional monetary assistance. Specifically, the Savvy group maintained increases in types of service use across the 18-month follow-up and ended with the same variety of service use as the Grant group. Here it may be that contact with the Alzheimer's Association and others in a similar situation was enough to bring about awareness and to increase types of usage of support services. Another possible reason this increase in service use might exist has been highlighted in the literature explaining that reluctance by the caregiver appears to be a major obstacle in service utilization (Gwyther, 1994). The Savvy training may have aided in making the caregivers feel like the local care available to them was adequate and dependable. These increases in service use are encouraging as an AD caregiver study by Cox (1997) found that of those who received respite assistance only 54% used services for 6 months. The current findings of increased use up to 18 months after the initial program began are clinically meaningful for this population.

An additional purpose of this aim was to get a better understanding of the longitudinal nature of service use between these intervention groups. From these 18-month follow-up results it appears that although this was only a 12-month respite grant, service use for the Grant and Both groups did not significantly decline from 12- to 18-

months. On the contrary it actually continued to increase for the Both group participants across the 18-month period. As problems faced by AD caregivers are considered to be complex in nature the adoption of a multicomponent intervention is becoming preferred by researchers and practitioners (e.g., Czaja et al., 2003). It appears that the combination of the psychoeducational intervention and the respite grant was the optimal mix for increasing types of service use in this population.

In addition, it was a goal of this study to examine the caregiver's service use by examining how specific client, caregiver, and community characteristics might affect service usage across the 18-month follow-up. The current study found that when designing a respite intervention considerations of community size may need to be considered. For the Savvy and the Both participants individuals living in more rural locations seemed to benefit the most from the $1,000 respite grant. Possible reasons for these findings may be an increase in knowledge of available services, a better understanding of the services thus making caregivers feel more comfortable using them, and possible creation of services such as adult day care or support groups in the area.

Interventions that increase service use in this population are beneficial, as the need for AD caregivers to use supportive services has been highlighted in multiple studies (Caserta et al., 1987;McGrath et al., 2000). The use of respite services has been shown to have a positive and noticeable effect on caregivers' physical and mental health. Studies have found that service use results in increased morale and decreases in subjective burden. Fewer hours of informal assistance and less formal support use over time have been associated with a decline in cardiovascular health (Cox, 1997; Kosloski & Montgomery, 1993; Musil et al., 2003). In addition to the physical and mental benefits from increased service use another possible positive ramification is the delay of institutionalization of the AD loved one; this can result in reduced stress for the caregiver and better quality of life for the loved one (Karlawish et al., 2000; Kosloski & Montgomery, 1995).

The current findings of increased service use with the rural participants have particularly powerful implications as this population is considered an at-risk population for lower than average service use. As rural communities are considered understaffed settings, significant effects such as increased psychological vulnerability, decreased health, and hopelessness and helplessness are valid concerns (Norris-Baker, 1999). In addition, although the reasons for not using services in this population vary widely, studies with rural AD caregivers found that cost was consistently reported as a major barrier to service utilization (Buckwalter, Russell, & Hall, 1994); perhaps the combination of the psychoeducational training and the monetary assistance was optimal for this group of rural caregivers.

The findings that the Savvy and Both interventions resulted in increased service use for rural individuals across the 18-month follow-up period are encouraging and can perhaps be used by future Alzheimer's Associations that serve rural communities. However, it is important to distinguish that although these findings are positive for this particular group of rural individuals, diversity exists among rural areas in the country and an examination of each area's needs should be conducted before assuming similar interventions would impact other rural caregivers the same. Additionally, the use of services by AD caregivers is a complex behavior that requires changes in not only financial areas but also attitudes regarding care and various internal cues (e.g., caregiver health and competency); therefore, future interventions should closely examine these other important determinants of service utilization.

Specific Aim 3 – Patterns of Support Group Use

The third specific aim of the current study was to examine how support group use changed over the 18-month follow-up for all participants and the three intervention groups (Savvy, Grant, Both). Particularly notable regarding support group use from this study was that an increase in support group use was found for participants, regardless of intervention, across the 4 waves. Also, support group attendance was not consistently found to be related to changes in depression or service usage. When changes in support group use were examined among the three intervention groups a significant increase was found for the Grant group from baseline to 6 months, with trends showing increases among all groups for each wave. It is important to note the differences in sample sizes when interpreting these analyses, specifically that the Grant group had a significantly larger sample compared to the Savvy and Both groups.

Services such as support groups for caregivers of persons with dementia have been found to have numerous positive outcomes. A study conducted by Millan-Calenti et al. (2000) found that AD caregivers who participated in a help program with a social component had improved well being, improved health status, and reported taking comfort in knowing that they had “back up.” Additionally, participation in support groups is known to create a positive peer-supported environment and to help ease the stress on the caregiver (Molinari et al., 1994). This increase in support usage can be particularly beneficial to rural participants as many rural communities are small and may lack other services that caregivers can use to establish supportive relationships.

It is interesting to note that support group use appeared to be on a slight decline from Wave 2 to the 18-month follow-up. One of the many strengths of this longitudinal data set is the ability to see if some type of reimplementation or change is needed after the initial intervention. Perhaps with regard to support group use the participants would benefit from more direct contact with the Alzheimer's Association around the 6- or 12-month follow-up to monitor support group attendance and assess personal concerns. The Alzheimer's Association Colorado Chapter does attempt to contact all clients periodically by phone. One possible reason for drop-off in support group use could be that participants are not getting what they need from these meetings. Although support groups have been found to have positive effects, some studies have shown that these meetings can also be "double-edged swords." For example, Wright and colleagues (1987) used both quantitative and qualitative data from a nationwide sample of AD caregivers finding both positive and negative effects from participation in support groups. Of the negative effects found were content of meetings (e.g., too general, too much talk, information does not help emotions), logistics (e.g., difficulty arranging for care, meeting place is not easily accessible), and emotions/feelings (e.g., depressing, not wanting to relive old problems). Future studies should examine the need for more tailored support groups or perhaps use of qualitative measures to better understand why a caregiver no longer attends a support group.

Specific Aim 4 – Relationships between Variables

Also examined in this study were possible relationships between the caregiver's self-efficacy and contact with the Alzheimer's Association measured at Wave 4 and the outcome variables of depression, service use, and support group use. Measuring self-efficacy has been suggested in order to have a better understanding of the dynamics of the caregiving role and also as a possible tool in looking at intervention outcomes (Bourgeois et al., 2002). It is believed that the nature of the current study's self-efficacy measurement and the one-time assessment may have been a factor in the lack of association between self-efficacy and the outcome variables. Although the current study did not find consistent effects of self-efficacy on important caregiver outcomes, it is believed that the use of theories such as Bandura's social cognitive theory should be used as more of a theoretical base for future interventions. For example, complex behaviors such as use of services by AD caregivers need to be explored in a broader psychological framework. In addition to the shortened version of the self-efficacy questionnaire, perhaps the shortened format of the trainings limited the amount of feedback that has been recommended to increase self-efficacy.

The one-time assessment of contact with the local Alzheimer's Association was found to be related to both service use and support group use; here increased contact resulted in increased variety of service use. This is consistent with recent findings that the use of information and referral to local Alzheimer's Associations significantly increased the amount of human services used by caregivers (McCallion et al., 2004). Here the importance of contact with a local organization such as the Alzheimer's Association is highlighted as it can lead to substantial favorable outcomes. Also, problem behavior scores were consistently correlated with depression scores, with caregivers who reported more problem behaviors with their loved one reporting higher depression. This finding supports a recent longitudinal study that examined 137 AD caregivers over a three-year period, finding deleterious long-term impacts of behavior problems (Gaugler et al., 2000). Specifically, the researchers determined the importance of behavior problems when predicting rates of change in depression. The findings of that study in addition to the current study provide support for an elaborated wear-and-tear hypothesis of caregiver depression.

Integration

Outcomes. In addition to examining each of the three outcome variables over time, another goal of this study was to better understand how depression scores, service use, and support group use relate to one another across the 18-month study. It appears that depression scores were repeatedly related to service use, in that the more depression caregivers reported the more services they were using. This could have been the case if those using more services were caregiving for a loved one in the later stages of the disease. As Alzheimer's disease progresses individuals move through a series of stages ranging from minimal cognitive decline to very severe cognitive decline (Reisberg et al., 1982), with increasing loss of normative social behavior and progressive dependence on others for care. It is clear that as the disease progresses and services are needed to assist with care, the amount of stress for the caregiver can also increase.

In addition to service use being related to depression, it was found to be related to support group use. Here it was often the case that as caregivers used more services they were also more likely to be in a support group. This finding can be beneficial in better understanding the information that caregivers have and how knowledge of local community services can cut across a variety of domains. As recent studies have found that contact with local organizations such as the Alzheimer's Association can increase the amount of human services used by caregivers (McCallion et al., 2004), perhaps additional methods of information dissemination should be explored to further increase the knowledge of services.

Interventions. As there were three intervention groups in this study an examination of each intervention's strengths and weakness is appropriate. With regard to the psychoeducational Savvy Caregiver Program there were significant decreases in depression over the course of this study with the women sub-sample, although the baseline to 18-month change was not significant. It appears that this type of intervention has positive short-term effects regarding depression but may need some type of booster around the 6- or 12-month follow-up point. The fact that depression did not increase across time despite the deterioration in the loved one's condition may convey a major benefit of Savvy and the respite grant. Service use showed significant increases, with rural participants increasing over time; as previously noted there are limitations with regard to not being able to know amount of services offered in communities. And support group attendance showed promising trends with increases in frequencies to the 12-month follow-up. The rural vs. urban increase with regard to variety of services used may point to the dearth of available services in rural communities and be a particular strength of this type of intervention for this demographic difference.

The Grant intervention participants showed a significant decrease in depression scores; essentially this intervention group was superior to the others in that it showed the only significant decrease in depression across the 18 months. Service and support group use also showed a significant increase for the urban participants with regard to service use and a significant increase overall in support group use at the 6-month follow-up. This intervention has positive outcomes in the longer term with regard to both depression and service use for the urban participants, with the support group use falling off by 12 months.

The Both group showed no changes in the depression means across time. One possible explanation for this finding could be the fact that if AD caregivers were seeking both of these services their loved one could have been farther along with the disease trajectory, therefore leading to higher depression. There was also a significant finding for the outcome of service use, with a significant increase for the rural individuals in service use across the 4 waves. In addition, positive trends were shown for increases in support group use at the 6-month follow-up. The strengths of having a multicompoment intervention appear to be the increased service usage over time, and the promising finding that depression scores did not increase over time.

When examining the three intervention types there are strengths and weaknesses of each with more variation occurring over time; essentially, the 6-month follow-up showed similar effects of the interventions on the outcome variables, and as time progressed the differences between groups became more apparent. As client, caregiver, and community characteristics were explored with each outcome variable over time the only ones that made a significant impact in these outcomes were gender and community size. When examining which intervention is appropriate for various populations perhaps there are only a few characteristics that separate the majority of AD caregivers with regard to intervention effectiveness.

Implications

Although this study was correlational in nature, there are numerous possible implications of the findings. The Savvy group had positive overall findings supporting the efficacy of psychoeducational interventions for AD caregivers, specifically showing decreases in depression and increases in service usage variety. With these types of interventions knowledge can really translate into power for AD caregivers. For example, negative attributions can lead to negative stress appraisal and a downward cognitive coping style that can have significant psychological, physiological, and relationship implications for the AD caregiver (Paton et al., 2004). Information regarding the disease can have a powerful and long-lasting effect on the caregiving role. In addition to assisting with appraisals, interventions such as Savvy can assist in forming meaningful social relationships. As contact with the Alzheimer's Association is initiated in this process the caregivers can rely on this established relationship for future questions and advice. This contact may have been the impetus that was needed to boost service usage. Also, the use of a more person-centered approach to dementia care, emphasizing the significance of the experience and perspective of the individual with dementia, allows other important issues such as empowerment to be taken into account (Woods, 2001).

The Grant intervention, although greatly differing from Savvy, found similar positive outcomes. As was expected the participants in this group reported increased service use over time; what was surprising was that even after the grant was over (i.e., at 18-month follow-up) caregivers still reported higher service usage compared to baseline reports. This is significant as studies examining barriers to service use in this population highlight the complexity of the service use process, with multiple factors contributing to use. Perhaps the grant was the impetus that these caregivers needed not only financially but also psychologically to actually feel the value that respite care can have in their lives. An additional finding was the significant decrease in depression found for these caregivers across the 18-month follow-up and the initial increased support group attendance. This might speak to the value that respite can have for primary caregivers. For example, it has been noted that service use results in increased morale and decreases in subjective burden (Cox, 1997); perhaps this grant enabled caregivers to experience these significant benefits resulting in long-lasting behavior change. Also, in addition to the physical and mental benefits from increased service use another possible positive ramification could be the delaying of institutionalization of the AD loved one; this can result in reduced stress for caregivers and better quality of life for their loved one (Karlawish et al., 2000).

This study addresses the recent REACH concerns regarding the importance of tailoring interventions for specific individuals or groups (e.g., Schulz et al., 2003). The respite grant was designed for use by participants for respite services they felt were appropriate for their individual needs. Additionally, the shorter versions of the Savvy presentation were designed with rural participants in mind who might not be able to commit to the full 6-week training process. A particularly noteworthy finding from this study is the ability to examine a multicomponent intervention group (i.e., the Both group), as these have been recently suggested as possible solutions in addressing the complex nature of the disease (e.g., Czaja et al., 2003). Although the Both group in this study was of a smaller size than the other two interventions examined, implications can nevertheless be drawn from the findings. It is interesting to note that the Both group had the biggest change in service use across the four waves. It appears that the combination of the psychoeducational intervention and the respite grant was the optimal mix for increasing service use in this sample. Again this finding implies that since the problems dealt with by AD caregivers are multifaceted, multicomponent interventions are more effective.

With regard to the longitudinal nature of this study the outcomes do support limited long-term effectiveness. All three of these interventions could benefit from some type of reimplementation or booster after the original implementation. Future intervention studies should explore this idea of reimplementation to determine the extent of reimplementation needed; for example, perhaps a simple phone call or one-time meeting with the original group at 6 or 12 months would be an effective way to assist caregivers in maintaining proper contact with their community and increase positive outcomes.

Limitations

As previously mentioned there were limitations of this study including absence of random assignment to interventions, absence of a no-intervention control group, lack of ethnic diversity in the sample, and constraints in the format of the Client Intake Form questions required by the ADDGS program. One concern with absence of random assignment in this study was the fact that individuals in certain groups could have been caring for loved ones who were significantly farther along with disease progression. What is recommended for future intervention studies is the use of various measures such as the Functional Assessment Staging Measure (FAST) which is part of the Global Deterioration Scale that provides caregivers an overview of the stages of cognitive functioning for those suffering from a progressive dementia such as Alzheimer's disease (Reisberg, 1985). This would give researchers important information regarding accurately quantifying the nature and magnitude of impairment in Alzheimer’s disease, thus leading to a better understanding of the caregiving trajectory. It would also provide a quantitative means to explore mediating and moderating effects of stage of progression.

Given the large empirical foundations showing that interventions have major benefits for caregivers, it would be unethical to have a no-intervention control group. The limitation of lack of a no-intervention comparison group was addressed by the use of previous literature with AD caregivers in order to make general and broad comparisons. Constraints in the format of the Client Intake Form questions required by the ADDGS program were most notably a concern with the three outcome measures of depression, service use, and support group use. The depression measure was limited in that there were no questions regarding the caregiver's current medication intake or any way to account for issues that were affecting the caregiver that were unrelated to the caregiving role. For example, if an individual between Wave 3 and Wave 4 begins medication for depression or experienced a death in the family this should be taken into account. Here if an individual reported a decrease in depression over the course of the study but also began taking a psychotropic that was effective in reducing depression, then this study may have overestimated the effects of the interventions to reduce depression. In addition, if an individual experienced the death of a friend or loved one during the course of the study and reported an increase in depression this study may have underestimated the effects of the interventions on depression scores. With regard to the depression scale available for this study, every attempt was made to maintain the validity of the measure in addition to keeping as many participants as possible in the analyses. As the larger validated and previously used CESD scale or the validated shortened version was not used, no direct comparisons were made with regard to numerical changes in this study and those in previous studies.

Limitations with the service use measure were most notably that it did not inquire about the frequency of service use and it did not ask about various other types of services such as more informal services. In addition, data were not available with regard to the amount of services that were offered in the participants' communities, making it unclear if the interventions aided in increased service use or if there was simply an increase in services offered across the 18-month follow-up; here the interventions' effectiveness could have been over- or underestimated depending upon amount of services in the community.

The support group use measure was lacking with regard to frequency of attendance and other measures of social support such as the caregiver's social network. Some type of qualitative reports would be helpful with this particular population as this may lead to a more thorough understanding of service use and support group use or lack thereof.

With regard to attrition, this particular study had a loss to follow-up of approximately 82%; based on the finding that participants who dropped out reported increases in support group use, depression, and ADLs, combined with the information that approximately 21% of the sample reported being unable to participant due to death of their loved one, perhaps one reason why participants dropped out is related to their loved one being at a later stage of the disease or having passed away. This presents problems with regard to under- and overestimating the effects of these interventions. For example, it is possible that if individuals who were in the Wave 4 sample were caregiving for loved ones who were in the beginning stages of AD then perhaps their depression scores were lower than caregivers who had loved ones with more advanced AD, thus leading to an underestimation of the effects that were found with regard to depression. This loss to follow-up and the small nature of the sample size present concerns regarding the generaliziability of the findings. Specifically, if individuals who stayed in the study had loved ones who were only in the beginning stages of AD, that would have significant implications with regard to generalizing these findings to all caregivers. It is recommended that additional studies are needed to better explore the effect that these interventions have in addition to examining the impact that various demographic characteristics have. Nevertheless, the positive outcomes of the interventions at 18-month follow-up are encouraging.

Conclusions

It should be mentioned that the majority of participants who were interviewed (i.e., an estimated 70%) reported that they were very satisfied with the services they received from the intervention in which they participated. For example, caregivers who received the grant reported that it, “helped me out immensely,” “was very much appreciated,” and “was a valuable resource.” Although the nature of this study was exploratory and changes were difficult to assess with the measures and information available, it is believed that these interventions made a real and meaningful impact in the lives of the majority of caregivers in this study. Participants sometimes became emotional during the phone interviews and expressed appreciation to the interviewers for being available to listen, so even the data collection process appeared to be beneficial to some participants.

As positive outcomes were found across the three intervention groups, possible implications of these findings suggest that what may be most beneficial to caregivers in this particular sample is the contact that was made with the Alzheimer's Association and the community resources in general. Various other moderating variables should be explored to better understand factors that contribute to reducing caregiver depression (e.g., feelings regarding support from others in the local Alzheimer's community). The fact that most demographic and community variables had little or no impact on the outcomes suggests that the positive effects of the interventions are fairly robust. Alzheimer's caregivers are a precious resource not only to our economy but to a generation of individuals that represent our nation. Additional longitudinal intervention studies can provide meaningful assistance to this caring population.

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Appendix

Client Intake Form & Questionnaires

AoA ALZHEIMER'S DISEASE DEMONSTRATION GRANT TO STATES PROGRAM

CLIENT INTAKE FORM

NOTE: For this form, *CLIENT* refers to the individual with memory difficulties.
CAREGIVER, refers to the person most responsible for client's care

What is the Date of intake? _____ / _____ / _______
Month Day Year

CLIENT's First Name I. CLIENT's Last Name

Number & Street Address

City State Zip Code

Phone Number
(_____) ______ - _______

CAREGIVER's First Name I. CAREGIVER's Last Name

(Name of person most responsible for client's care.)

Number & Street Address

City State Zip Code

Phone Number
(_____) ______ - ________

OMB#: 0985-0013 **Client Family ID#** _________

PART 1: *INFORMATION ABOUT CLIENT*

Q1. What is *CLIENT'S* gender? ○ Male ○ Female

Q2. What is *CLIENT's* marital status?
○ Single ○ Married/Domestic Partner
○ Widowed ○ Other

Q3. What is *CLIENT's* birth date? _____ / _____ / ______
Month Day Year

Q4. Does *CLIENT* have Alzheimer's disease?
- ○ Yes, probable Alzheimer's disease or other dementia has been medically diagnosed
- ○ Probable Alzheimer's disease or other dementia is suspected, but is not medically diagnosed
- ○ Memory or cognitive problems suspected
- ○ No (Record other diagnosis if known.) ___________________

Q5. What is the type of geographic location of the *CLIENT's* residence?
- ○ A rural or farm community (fewer than 2,500 people)
- ○ A small city or town that is not suburb of a larger city (fewer than 50,000 people)
- ○ A medium sized city or suburb of medium size city (50,000 to 100,000 people)
- ○ A large city or suburb of large city (more than 100,000 people)
- ○ An Indian reservation

Q6a. Where does *CLIENT* live?
- ○ Lives in a group environment with assistance (not a nursing home)
- ○ Lives in a nursing home
- ○ Lives alone in a house or apartment
- ○ Lives with other in a house or apartment

Q6b. If CLIENT lives in a house or apartment, how many people reside in the household? (Include the Client in the total number.)

_______ Total Persons in household

Q7. How often does *CLIENT* need help with each of these activities? (Shade one.)

	Needs no help (No supervision)	Needs some help (Occasional Supervision)	Needs a Lot of help (Constant Supervision)	Can not do it at all
(a) Eating	○	○	○	○
(b) Getting in and out of bed	○	○	○	○
(c) Getting around inside	○	○	○	○
(d) Dressing	○	○	○	○
(e) Bathing	○	○	○	○
(f) Using the toilet	○	○	○	○
(g) Doing heavy housework	○	○	○	○
(h) Doing light housework	○	○	○	○
(i) Doing laundry	○	○	○	○
(j) Cooking / preparing meals	○	○	○	○
(k) Buying / getting food / clothes	○	○	○	○
(l) Getting around outside	○	○	○	○
(m) Going places outside of walking distance	○	○	○	○
(n) Managing money	○	○	○	○
(o) Taking medicine	○	○	○	○
(p) Using telephone	○	○	○	○
(q) Nursing services	○	○	○	○

Q8. Which of these categories is closest to *CLIENT's* total annual income? (If *CLIENT* is married include income of spouse.)

○ under $8,000

○ $8,000 - $11,999

○ $12,000 - $14,999

○ $15,000 - $19,999

○ $20,000 - $29,999

○ $30,000 and over

○ Not Reported

Q9. What is the CLIENT's ethnicity?

○ Hispanic or Latino ○ Not Hispanic or Latino

Q10. What is the CLIENT's race? (Shade all that apply.)

○ Black or African American ○ Native Hawaiian or Other Pacific Islander

○ Asian ○ White

○ American Indian or Alaska Native

Q11. In which language(s) is the CLIENT fluent? (Shade all that apply.)

○ English ○ Spanish ○ Other (Please specify.) ____________

OPTIONAL: This question is state-sponsored and is NOT required under the AoA Alzheimer's Program. Completion is voluntary and will not affect eligibility for or provision of Alzheimer's Demonstration services.

Q12. In the past week, on how many days did you (the caregiver) personally have to deal with the following behavior of your relative?

	0 (no) days	1-2 days	3-4 days	5/more days
(a) Keep you up at night	○	○	○	○
(b) Repeat questions / stories	○	○	○	○
(c) Try to dress the wrong way	○	○	○	○
(d) Have a bowel or bladder "accident"	○	○	○	○
(e) Hide belongings and forget about them	○	○	○	○
(f) Cry easily	○	○	○	○
(g) Act depressed or downhearted	○	○	○	○
(h) Cling to or follow you around	○	○	○	○
(i) Become restless or agitated	○	○	○	○
(j) Become irritable or angry	○	○	○	○
(k) Swear or use foul language	○	○	○	○
(l) Become suspicious or believe someone is going to harm (him/her)	○	○	○	○
(m) Threaten people	○	○	○	○
(n) Show sexual behavior or interest at wrong time / place	○	○	○	○
(o) Wander	○	○	○	○

PART 2: *INFORMATION ABOUT CAREGIVER* *(Person most responsible for Client's care.)*

Q12a. Is caregiver a professional care manager?

- ○ Yes **(STOP! DO NOT CONTINUE.)**
- ○ No **(CONTINUE with the next question.)**

Q12b. What is *CAREGIVER's* relationship to the *ELDER CLIENT*? ○ No caregiver identified ○ Spouse / domestic partner ○ Child / child-in-law ○ Sibling ○ Other relative ○ Friend / neighbor	**Q13. How long has *CAREGIVER* provided assistance?** ○ Less than 6 months ○ 6 to 12 months ○ 13 to 24 months ○ More than 24 months but less than 5 years ○ 5 years or more ○ Not reported
Q14. What is *CAREGIVER's* birth date? _____ / _____ / ______ Month Day Year	**Q15. What is *CAREGIVER's* gender?** ○ Male ○ Female

Q16. What is *CAREGIVER's* marital status?

- ○ Single
- ○ Married / Domestic partner
- ○ Widowed
- ○ Other

Q17. What is the *CAREGIVER's* ethnicity?

- ○ Hispanic or Latino
- ○ Not Hispanic or Latino

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Q18. What is the CAREGIVER's race? (Shade ALL that apply.)

○ Black or African American
○ Asian
○ American Indian or Alaska Native
○ Native Hawaiian or Other Pacific Islander
○ White

Q19. In which language(s) is the *CAREGIVER* fluent? (Shade ALL that apply.)

○ English
○ Spanish
○ Other (Please specify.) ____________

Q20. What is *CAREGIVER's* employment status?

○ Works full-time
○ Works part-time
○ Retired but works part-time
○ Fully retired
○ Homemaker
○ Unemployed
○ Other

Q21. What is the highest grade in school that *CAREGIVER* completed?

○ 8th grade or less
○ Attended high school, did not graduate
○ High school graduate (Diploma or GED)
○ Some college / post high school training
○ Associate or technical degree (AA, AS, etc.)
○ Bachelor's degree (BS, BA, etc.)
○ Graduate degree (MS, MA, etc.)

Q22. During the past week, about how many hours total did the *CAREGIVER* help *CLIENT* with ...
(Round to the nearest HOUR; Enter '0' is activity was not performed.)

a. Eating, bathing, dressing or helping with toilet functions? _______
b. Meal preparation, laundry or light housework? _______
c. Providing transportation to appointments and/or shopping? _________
d. Legal matters, banking or money matters? _________

Q23. Approximately how far away in driving time does *CAREGIVER* live from *CLIENT*?

__________ Minutes (Enter '0" if CAREGIVER lives with CLIENT.)

Q24. Which of the following services is the *CLIENT FAMILY* currently using?
(Shade ALL services that are used by either the *CLIENT* OR the *CAREGIVER*.)

○ Companion or friendly visitor	○ Case management
○ Paid supervision	○ Transportation services
○ Chore services	○ Support groups
○ Homemaker services	○ Caregiver training program
○ Personal care services	○ Psychological counseling
○ Home health services	○ Group meals / home delivered meals
○ Adult daycare center / adult day health	○ Other services, list: ________________
○ Respite care given in a nursing home, adult foster home, or someone else's home	

Q25. Which of these categories is closest to the *CAREGIVER's* total annual HOUSEHOLD income excluding any income of the *CLIENT*?

○ Under $8,000	○ $20,000 - $29,999
○ $8,000 - $11,999	○ $30,000 - $39,999
○ $12,000 - $14,999	○ $40,000 and over
○ $15,000 - $19,999	○ Not Reported

OPTIONAL: These questions are state-sponsored and are NOT required under the AoA Alzheimer's Program. Completion is voluntary and will not affect eligibility for or provision of Alzhiemer's Demonstration services.

Q26. (Optional) How do you rate your overall health at the present time?

○ Very good ○ Good ○ Fair ○ Poor ○ Very Poor

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Q27. (Optional) How often have you felt this way during the past week?

	Never	Rarely	Sometimes	Frequently	Always
(a) I did not feel like eating; my appetite was poor.	○	○	○	○	○
(b) I felt depressed.	○	○	○	○	○
(c) I had trouble keeping my mind on what I was doing.	○	○	○	○	○
(d) I felt lonely.	○	○	○	○	○
(e) I felt that everything I did was an effort.	○	○	○	○	○
(f) I had crying spells.	○	○	○	○	○
(g) My sleep was restless.	○	○	○	○	○
(h) I felt sad.	○	○	○	○	○
(i) I could not get "going."	○	○	○	○	○
(j) I felt that I could not shake off the blues.	○	○	○	○	○

Q28. (Optional) As a result of assisting your elder, how have the following aspects of your life changed? Do you have ...

	A lot less	A little less	The same	A little more	A lot more
(a) time to yourself?	○	○	○	○	○
(b) stress in your relationship with your relative?	○	○	○	○	○
(c) personal privacy?	○	○	○	○	○
(d) attempts by your relative to manipulate you?	○	○	○	○	○
(e) time to spend in recreational activities?	○	○	○	○	○
(f) unreasonable requests made of you by your relative?	○	○	○	○	○
(g) tension in your life?	○	○	○	○	○
(h) vacation activities and trips?	○	○	○	○	○
(i) nervousness and depression concerning your relationship?	○	○	○	○	○
(j) feelings that you are being taken advantage of?	○	○	○	○	○
(k) time to do your own work and daily chores?	○	○	○	○	○
(l) demands made that are over and above what he/she needs?	○	○	○	○	○
(m) anxiety about things?	○	○	○	○	○
(n) time for friends and other relatives?	○	○	○	○	○

Additional Longitudinal Questions

How confident are you in your ability to:

1 – Handle any problems your relative has, like memory loss, wandering, or behavior problems.

____

2 – Get answers to your questions about your relative's problems.

____

Responses for each question are on a 5-point scale ranging from 1 (not at all certain) to 5 (very certain).

3 - On a scale of 1 to 5 – with 1 being no contact and 5 being regular contact how often are you in contact with people from the Alzheimer's Association?

____