Reducing Burden and Distress in Caregivers of Dementia Patients.

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REDUCING BURDEN AND DISTRESS IN CAREGIVERS OF DEMENTIA PATIENTS

A Dissertation

Submitted to the Graduate Faculty of the Louisiana State University and Agricultural and Mechanical College in partial fulfillment of the requirements for the degree of Doctor of Philosophy

in

The Department of Psychology

by

Christopher D. Sletten
B.S., Wheaton College, 1985
M.A., Louisiana State University, 1991
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ABSTRACT

As the prevalence and diagnosis of dementia have become more clearly delineated, there has been an increasing focus on the consequences of dementia on the family members that care for these individuals. Much of the attention has focused on who provides care and what impact that caregiving has on them. It has been well documented that the patient's family is responsible for much of the caregiving. These caregivers often experience both a physical and psychological impact from their role. Because of these negative consequences, several studies have investigated interventions designed to reduce caregiver distress. Most of these studies have incorporated group treatments that incorporate education and social support with little attention to cognitive-behavioral interventions. This study was designed to compare a cognitive-behavioral treatment intervention with a social support group in a population of family caregivers of dementia patients. The social support group was similar to those previously described in the literature. The cognitive-behavioral group directly targeted the behaviors of the patient that have been related to caregiver burden as well as addressing the caregiver's reactions to stress. Caregivers were assessed in several domains including burden, depression, anxiety, social support, coping strategies, and cortisol levels. The results indicate that while both groups improved on several of these measures, neither group was superior to the other. The lack of a treatment difference was likely due to
factors associated with this population (i.e., who was able to participate) as well as the potential benefit of components from both treatment approaches. Future investigations will be necessary to further explore the essential components of a group treatment for this population and how to include caregivers who cannot participate without respite assistance.
INTRODUCTION AND LITERATURE REVIEW

Today's society is becoming increasingly aware of the impact of its older citizens. The growth of this segment of the population has affected many aspects of society. Since the beginning of this century, there has been a continuous upward trend in the life expectancy. During the period 1900 to 1985 increases in life expectancy ranged from 25 years for white males to 40 years for black females (Biegel & Blum, 1990). Increasing life expectancy coupled with other social and demographic factors has led to a significant increase in the elderly population. It is estimated that by the year 2000, 13% of the population in the United States will be over 65 years of age (Select Committee on Aging, 1987).

During this century, much of the increase in life span is due to improvements in medical technology and public health interventions. There has been a marked decline in the number of childhood deaths from disease as well as decreased mortality from infections and infectious disease. Unfortunately, concomitant with this decrease there has been an increase in the number of persons with chronic diseases. Diseases such as coronary artery disease, stroke, cancer, and hypertension have replaced infections as the primary causes of morbidity and mortality (Ory, Abeles, & Lipman, 1992). In addition, there is an increased prevalence of conditions generally associated with aging, such as dementia.
There are many degenerative conditions or diseases that can lead to dementia including, Alzheimer's disease, vascular disease, Pick's disease, Cruetzfeld-Jakob's disease, Korsakoff's syndrome, Huntington's chorea, Parkinson's disease, multiple sclerosis, and myasthenia gravis (Kolb & Whishaw, 1990). All of these conditions are characterized by progressive deterioration of brain tissue and associated behavioral changes.

The predominant type of dementia is Senile Dementia of the Alzheimer's Type (SADT) or Alzheimer’s disease (AD). In a recent epidemiological study, Evans and his colleagues (1989) reported that in a sample of individuals with moderate to severe cognitive impairment, 84.1% had AD, 8.8% had a dementia other than AD, and 7.1% had AD and another dementing illness. The other frequently occurring types of dementia reported were multi-infarct dementia, Parkinsonian dementia, and alcohol-induced dementia (Evans et al., 1989). Additional reports estimate that Alzheimer’s disease accounts for 65% and multi-infarct dementia for 10% of all the cases of dementia (Kaplan & Sadock, 1991).

Alzheimer’s disease affects approximately 2.5 million people in the United States (Jenkins, Parham, & Jenkins, 1985). Early estimates for the prevalence of all dementias in the elderly were as follows: 5% over age 65, 20% at age 80, and 30% at age 90 (Rabins, 1984). In more recent studies, the estimates for the prevalence of Alzheimer’s disease alone, are even higher. Evans et al. (1989) estimated rates of 10.3% over age 65, 3% age
65 - 74, 18.7% age 75 - 84, and 47.2% over age 85. Differences in these percentages is likely due to the continuing development of diagnosis and classification. Yet, it is clear that as the total number of elderly increases, the number of those with dementing illnesses will also increase and have a greater impact on society.

Due to the continued rise in the number of elderly in our society and the increased risk for dementia during the later decades of life, many researchers project that the costs due to dementia will continue to rapidly rise. It is estimated that at least half of the patients currently residing in nursing homes have Alzheimer's disease or a similar dementing disorder (Cohen, 1983). In terms of health care expenditures, these patients alone represent approximately $16 billion dollars annually (Oktay & Volland, 1990). It is also estimated that for every elderly person in a nursing home, there are two equally impaired elderly people in the community. These individuals also represent a substantial portion of annual health care expenditures. Nursing home care for a demented individual is reported to be in excess of $25,000 per year and annual costs for family-provided care are around $12,000 annually (Hay & Ernst, 1987). While it is clear that home care is more cost-effective in terms of annual expenditures, the costs to the family can be high, not only financially, but also emotionally (Malonebach & Zarit, 1991).
The remainder of this review will focus on clinical and treatment issues associated with dementia, the effects of caring for a family member with dementia, and interventions for reducing caregiver burden. The final portion of this paper will focus on the results and discussion of a study comparing the relative efficacy of two group treatment programs for reducing stress and distress in primary caregivers of dementia patients.

Dementia

Dementia is characterized by a loss of cognitive abilities severe enough to impair social or occupational performance (Kaplan & Sadock, 1991). Clinically, there is impairment in abstract reasoning, memory, judgement, and varying degrees of personality changes. Alzheimer's disease is by far the most common type of dementia afflicting the elderly, the majority of this review will focus on its course and sequelae. Multi-infarct dementia, the second most frequently occurring dementia in the elderly, will also be briefly reviewed.

Alzheimer's disease is characterized by atrophy of anatomical structures, degeneration of neurotransmitter systems, and three neuropathological developments, neuritic plaques, neurofibrillary tangles, and granulovacuolar bodies (Perry, 1986). The two regions most affected by Alzheimer's disease are the neocortex and the limbic system. The brainstem, cerebellum, and spinal cord are mostly spared from pervasive atrophy (Kolb & Whishaw, 1990). The neuritic plaques are found concentrated in various
cortical regions, particularly the amygdaloid and hippocampus. The proliferation of plaques and tangles in the cortex is associated with significant cognitive decline and ultimately death.

Originally, dementia that began after age 65 was thought to be caused by vascular changes and was often referred to as "hardening of the arteries." The diagnosis of Alzheimer's disease was only used in cases that occurred in the presenium (Reisberg, 1983). It is now widely accepted that both presenile and senile dementia represent a similar degenerative process referred to as Alzheimer's disease.

Several pharmacological interventions have been used in an attempt to halt the disease's progression or ameliorate some of the cognitive deficits associated with the dementing process. There are three general classes of drugs that are used to improve or preserve cognitive functioning: (1) cholinergic agents, (2) nootropics, and (3) vasodilators (McAllister & Powers, 1994). In early studies, cholinesterase inhibitors such as physostigmine, and tetrahydroaminoacridine produced small improvements in memory functioning in some patients with Alzheimer's disease. However, recent double-blind studies have shown no significant improvement on neuropsychological test performance (Cooper, 1991; Summers, Majovski, Marsh, 1986). Hydergine, a vasodilator, was the first drug approved by the Food and Drug Administration as a treatment for Alzheimer's disease (Bennett & Evans, 1992). Recent investigations have indicated that
Hydergine may temporarily improve functioning not through vasodilation, but because it also increases alertness (Cooper, 1991). Like other pharmacological treatments, double-blind clinical trials have not shown any significant differences in cognitive performance between Hydergine and placebo (Thompson, Filley, Mitchell, Culig, Loverde, & Byyny, 1990). Piracetam, a nootropic, used in conjunction with lecithin has been shown to be effective, particularly in patients who have some remaining cholinergic neurons (Hollander, Mohs, & Davis, 1986).

In summary, no drug treatment has yet been proven effective. Moreover, the significant side effects associated with these compounds (e.g., liver and kidney toxicity) appear to outweigh their clinical usefulness (Thompson et al., 1990). Despite uncertainty about etiology, pathophysiology, and treatment, the symptom pattern associated with Alzheimer's disease is quite uniform. The disease is characterized by an insidious onset of mild cognitive and behavioral symptoms. It progresses over a period of 5 to 15 years, with gradual deterioration in all areas of cognitive functioning leading ultimately to a vegetative state and death (Chui, 1989).

There are currently two diagnostic systems for the classification of Alzheimer's disease. The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV; American Psychiatric Association, 1994), describes three types of dementia disorders, Dementia of the
Alzheimer's type (DAT), vascular dementia, and dementia due to other general medical conditions. DAT is further defined as early onset or late onset. Both DAT and vascular dementia can be subtyped as uncomplicated or complicated with delirium, delusions, or depression. Dementia due to other general medical condition is diagnosed when a specific disorder has been diagnosed (i.e., HIV disease, Parkinson's disease, Huntington's disease, etc.). The second main diagnostic system was developed by a work group sponsored by the National Institute of Neurological and Communication Diseases and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA; Niederehe & Oxman, 1994). The NINCDS-ADRDA criteria use the terms "probable" and "possible" Alzheimer's disease. The diagnosis of probable Alzheimer's disease requires the presence of dementia, progressive memory dysfunction, onset between the ages of 40 and 90, and no other brain disorders that would account for the cognitive impairments. Possible Alzheimer's disease is diagnosed when the impairment is mild or not consistent with the typical pattern of Alzheimer's disease (Bennett & Evans, 1992).

The second most common type of dementia is multi-infarct dementia. Unlike Alzheimer's disease, the etiology and mechanism of multi-infarct dementia are more clearly understood. The primary cause of multi-infarct dementia is vascular disease that affects primarily small and medium-sized cerebral vessels. These vessels become infarcted resulting in lesions that
spread over wide areas of the brain (Kaplan & Sadock, 1991). The clinical
course of multi-infarct dementia is characterized by stepwise deteriorations
corresponding to successive episodes of infarction. In most cases, the
cognitive and behavioral symptoms are indistinguishable from Alzheimer's
disease. However, there are two distinctive features of multi-infarct
dementia, fluctuation in symptom severity and significant motor disturbances
(Lezak, 1983).

The earliest signs of Alzheimer's disease include impaired memory
and subtle personality changes. These are often first detected by family
members rather than the patient (Ory et al., 1985). Early memory loss is
characterized by forgetting where items have been placed and having
difficulty in remembering names. These symptoms are often dismissed by
the patient and the patient's family as signs of aging. As the disease
progresses however, the effects on short-term and recent memory become
more pervasive and begin to interfere with many aspects of vocational and
daily functioning (Reisberg, 1983). In the next stage of memory decline,
there are noticeable deficits in the ability to handle personal affairs like
record-keeping, paying bills, and the patient frequently gets lost when
traveling. At this stage, there is still intact remote memory and the patient
frequently recalls past events and uses well-learned material to compensate in
conversation and interactions with others (Bennett & Evans, 1992). Memory
deficits in the latter stages require increasing assistance from others. Patients
become unable to recall significant aspects of their life. For example, a patient may forget his address, telephone number, or the names of close family members. The patients’ memory continues to deteriorate and they are often unable to recall the name of their spouse and are essentially unaware of recent events. At this point, even recall of past events becomes sketchy (Reisberg, 1983).

Language functioning is also frequently affected during the course of Alzheimer’s disease. Early language dysfunction is characterized by occasional difficulty with word- or name-finding ability (Reisberg, 1983). During the course of the disease, the patient’s speech often remains fluent but becomes increasingly vague and meaningless. This is associated with an increase in stereotyped speech and expressive aphasia (Kaplan & Sadock, 1991). Verbal comprehension appears to remain largely intact until the later stages of the disease (Chui, 1989).

Additional cognitive functions that are affected during the course of Alzheimer’s disease include: attention, concentration, orientation, judgement, visuospatial ability, and abstract reasoning (Chui, 1989). These deficits can be quantified on standardized instruments like the Dementia Rating Scale (Mattis, 1976), Mini-Mental State Exam (Folstein, Folstein, & McHugh, 1975), and the Wechsler Adult Intelligence Scale (Wechsler, 1981). These problems are often manifested in disorientation to date, day, and season, poor problem-solving, inability to perform complex tasks, and
perceptual disturbances (Kaplan & Sadock, 1991). One of the most notable
cognitive symptoms associated with Alzheimer's disease is the patient's
limited acknowledgement of his deficits. When patients rate their ability to
perform daily activities or a specified task they consistently under-estimate
their deficits. This tendency has been shown to be positively related to the
severity of the dementia (McGlynn & Kaszniak, 1991).

In addition to the progressive cognitive deterioration associated with
Alzheimer's disease, there are a number of psychological sequelae. In the
early stages of the disease, many patients display depressive symptoms,
especially sad mood, anhedonia, and decreased affective expression. These
symptoms often predate the diagnosis of Alzheimer's disease, and typically
worsen when the individual is formally diagnosed (Drudge, Rosen, Peyser, &
Pieniadz, 1986). Symptoms associated with the progression of Alzheimer's
disease include, increasing apathy, irritability, anxiety, and personality
changes. In the latter stages of Alzheimer's disease, more marked and
severe psychological changes occur, including delusions (often paranoid),
obSESSION, agitation, hallucinations, and confusion (Reisberg, 1983).

A number of behavioral symptoms also characterize the clinical
picture of Alzheimer's disease. The most common behaviors are wandering,
purposeless and repetitive activity, inappropriate sexual and social behavior,
aggressive physical behavior, and verbal outbursts (Carstensen, 1988).
Patients with Alzheimer's disease also lose a number of behavioral
repertoires during the course of the disease. Most notable is the loss of self-care skills, such as eating, dressing, personal hygiene, and toileting. These skills deteriorate throughout the course of the disease leading finally to total dependence on others for feeding, bathing, and toileting. Another behavioral change that is frequently reported is a change in sleep patterns, often a reversal of daytime and nighttime activities (Drinka, Smith & Drinka, 1987).

Caregiving

As the prevalence and diagnosis of dementia have become more clearly delineated, there has been an increasing focus on the consequences of dementia on the family members that care for these individuals. Since the early 1980's, there has been a growing body of literature regarding caregiving. Much of the attention has focused on those who provide care to individuals with dementia and what impact that caregiving has on them. It has been well documented that the patient's family is responsible for much of the caregiving (Malonebach & Zarit, 1991). Initial studies, conducted from a sociological or social psychological perspective, were mainly descriptive. They focused on who provided care, the type of care provided, living arrangements, extent of the patient's disability, and the length of time spent caregiving (Light & Lebowitz, 1989). More recent studies have focused on the psychological and physical impact of caregiving.

Profiles and characteristics of caregivers have accumulated over the past 10 to 15 years. Much of this information has been obtained from
census-type surveys and has included caregivers for several different chronic conditions, including both physical and cognitive decline. Several early studies established that family members provide the majority of primary care. This finding disconfirms the notion that societal trends were causing a decrease in the availability of care from families (Shanas, 1979).

Based on data from several survey studies, caregiving has been conceptualized in four distinct categories: (1) emotional support, (2) direct service provision, (3) connection with formal services, and (4) financial assistance (Horowitz, 1985). In one of the most comprehensive surveys of caregivers, Stone, Cafferata, and Sangl (1987) used data obtained from the 1982 National Long-Term Care Survey conducted by the Bureau of the Census for the Department of Health and Human Services to determine the characteristics of care recipients and their primary caregivers. The mean age of the care recipients was 78 years, 60% were female, 51% were married, 41% were widowed, and only 11% lived alone. Primary caregivers were mostly female (72%), the average age was 57.3 years, with 25% 65 to 74 years old and 10% 75 years or older. The majority of caregivers had been providing primary assistance for one to four years, and one-fifth had cared for a family member for five years or more (Stone et al., 1987). Other surveys based on national samples report similar caregiver characteristics when looking at live-in family caregivers (Soldo & Myllyuoma, 1983),
caregivers of low-income elderly (Cantor, 1983), and caregivers of dementia patients (Chenoweth & Spencer, 1986; Motenko, 1989).

Based on both regional and national surveys of caregivers, there appears to be relative uniformity in the general demographic characteristics of caregivers regardless of the deficits or disorders of the care recipient. Most caregivers are women, who are either married or widowed and who live with the care recipient. As the role of the primary, community-based caregiver has become more defined, researchers have begun to focus on the impact that caregiving has on the caregiver.

Studies of the effects of caregiving have focused both on the amount of distress or burden that the caregiver experiences and the negative consequences the burden has on various aspects of caregiver functioning. The stressors, frequently chronic and often severe in nature, include extreme physical demands, financial burdens, and the disruption of relationships (Schulz, Visintainer, & Williamson, 1990). The caregiver is often required to assist the patient with eating, bathing, and toileting, tasks which frequently require a large amount of physical exertion. In addition, the caregiver often neglects his/her own needs for sleep, nutrition, and health care to meet these constant demands. Finally, in the case of dementia, the caregiver must witness the slow deterioration of a loved one who is increasingly unable to reciprocate emotions or affections (Pearlin, Mullan, Semple, & Skaff, 1990). The literature on caregiving has only recently begun to document the
outcomes of the chronic stress associated with caregiving. Areas that have been identified include, psychiatric and physical morbidity, utilization of formal social and health care, relationship changes, and patient abuse (Zarit, 1990). The most well-established documentation of outcomes is in the area of psychiatric and physical morbidity.

Studies of psychological morbidity have used either standardized self-report measures or clinical assessments. Self-report studies have been used to examine levels of psychiatric symptomatology, such as depression. Standardized clinical assessments have been used to identify actual clinical cases (Schulz et al., 1990). These studies have focused on a variety of caregiving situations including, dementia, Parkinson's disease, and physically impaired elderly.

When the level of depressive symptoms has been assessed, caregivers of dementia patients typically report more symptoms than do caregivers for other patient populations. Dura, Haywood-Niler, and Kiecolt-Glaser (1990) compared levels of depression measured by the Hamilton Depression Rating Scale, the Beck Depression Inventory, and the Brief Symptom Inventory for caregivers of Alzheimer's and Parkinson's patients as well as age and sex-matched comparison subjects. They found that both groups of caregivers had significantly higher depression scores than controls. In comparing the two caregiver groups, caregivers of Alzheimer's patients reported more depressive symptoms and female caregivers of both caregiver groups were
more depressed than male caregivers. In a related study, primary caregivers of Alzheimer's patients endorsed more items on the Beck Depression Inventory than did age-matched controls (Haley, Levine, Brown, Berry, & Hughes, 1987).

Two studies have examined caregiver depression in spouses using the Center for Epidemiologic Studies Depression Scale. The first study, a survey of cognitively impaired elderly and their spouses, found that husbands' report of depression was significantly related to the level of cognitive impairment in their wives. There was a similar trend for wives with cognitively impaired husbands. There was no relation between depression and care demands, social activities or household demands (Moritz, Kasl, & Berkman, 1989). Although not directly assessed, the authors hypothesized that changes in the spouses' personality and ability to participate in the relationship may contribute to increased depressive symptoms, and that men may be more affected than women. The second study assessed spouse caregivers of dementia patients for level of depressive symptoms. Both husbands and wives reported higher rates of depressive symptomatology than age-based norms, and wives were more depressed than husbands (Pruchno & Potashnik, 1989).

The prevalence of clinical levels of depression in caregivers of dementia patients has been examined in four studies. In one study, Cohen and Eisdorfer (1988) found that 55% of the caregivers living with the patient
met DSM-III-R criteria for depression, while no caregivers living apart from the patient were clinically depressed. In another study, Dura, Stukenberg, and Kiecolt-Glaser (1990) compared 86 caregivers of dementia patients with age-matched controls. They reported that 30% of caregivers experienced a depressive disorder compared to 1% of the control group. Importantly, there were no significant differences in the incidence of depression prior to the onset of caregiving. Finally, Gallagher and colleagues conducted two studies using the Schedule for Affective Disorders and Schizophrenia Interview (SADS). In the first study, they compared 158 dementia caregivers enrolled in a caregiver group with 58 non-caregiving relatives of dementia patients. Forty percent of the individuals in the caregiver group met criteria for a depressive disorder, another 22% had depressive features. Eighteen percent of the non-caregivers had a depressive disorder and almost two-thirds had no evidence of depression (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989). The second study compared rates of depressive disorders in distressed Alzheimer’s caregivers to rates in distressed caregivers of other types of medically ill patients (e.g., heart disease, decreased mobility). In this study, 47% of Alzheimer's caregivers and 46% of the caregivers for non-cognitively impaired patients were clinically depressed (Gallagher, Wrabetz, Lovett, Del Maestro, & Rose, 1989).

Based on these reports, family caregivers often exhibit higher rates of depression than non-caregiving peers. There is also evidence that caregivers
of dementia patients experience higher levels of depression than caregivers for other disorders.

Several studies have examined other indices of psychological distress associated with caregiving. Anthony-Bergstone, Zarit, and Gatz (1988) administered the Brief Symptom Inventory to primary caregivers of dementia patients. They reported high levels of anxiety and hostility in female caregivers and high hostility in male caregivers compared to population norms. Other assessments of psychological disturbances have found that female caregivers had significantly higher scores on subscales of hysteria and paranoia on the Minnesota Multiphasic Personality Inventory (MMPI) than did male caregivers (Fitting, Rabins, Lucas, & Eastham, 1986) and higher rates of symptoms of psychological distress compared to a normative sample on the Symptom Checklist 58 (SCL-58; Pruchno & Potashnik, 1989). Caregivers also had higher rates of subjective stress and psychotropic drug use compared to non-caregiving peers (Clipp & George, 1990; George & Gwyther, 1986).

Several investigators have also given attention to the association of caregiving to physical functioning of caregivers. With growing recognition in the literature of the impact of stress on health and illness, it is believed that the chronic stress associated with caregiving can result in impairments of physical functioning. The physical effects of caregiving have been studied
using three types of outcomes: self-report of physical health status, health care utilization, and immune functioning (Schulz et al., 1990).

Data from both self-report and health care utilization studies have generally supported the notion that caregiving is associated with negative effects on caregiver health. Self-report studies have shown that caregivers often report a deterioration in health during the course of caregiving (Pruchno & Potashnik, 1989; Snyder & Keefe, 1985). They also perceive their health to be worse than non-caregivers their age (Stone et al., 1987). Chenoweth and Spencer (1986) reported that caregiver ill health was cited in 21% of the cases of patient institutionalization. Caregivers have also been found to have higher rates of health care utilization and use more prescription medications than age-matched controls (Haley, Levine, Brown, Berry, & Hughes, 1987). Many of these studies are limited by selection biases that likely over-represents more distressed caregivers. They have also sampled several different patient populations, limiting their applicability to any specific caregiver group. Despite these limitations, there is growing evidence that caregiving is associated with an increased risk of physical morbidity.

The impact of caregiving on health has also been measured by assessing alterations in caregivers’ immune functioning. There is growing evidence that various stressors can have negative effects on immune functioning. Research of this kind has received increasing attention over the past 10 years and is currently referred to as “psychoneuroimmunology”
The central focus of PNI is the interaction between the central nervous system and the immune system. The immune system has two primary components: the humoral immune system and the cellular immune system. The humoral system's function is to defend the body against bacterial or viral infections. This is accomplished by the production of immunoglobulin (antibodies) that responds rapidly in reaction to the introduction of antigens. The cellular system, responds more slowly and is responsible for controlling intracellular viruses, foreign materials, cancer cells, fungi, and protozoans (Kiecolt-Glaser & Glaser, 1987). B lymphocytes (B-cells) arise from bone marrow, and when they are stimulated by antigen activity, they differentiate into plasma cells that synthesize and secrete antibodies. T lymphocytes (T-cells) are primarily responsible for cell-mediated immunity. When they are stimulated, they secrete chemicals (lymphokines) that are cytotoxic and aid in phagocytosis (Jemmott & Locke, 1984). There are two important subtypes of T-cells that participate in the regulation of the humoral system. T4 cells bind to B-cells during an antigen response and secrete substances that stimulate B-cell proliferation and their development into immunoglobulin-secreting cells. T8 cells are cytotoxic and respond to specific antigens. A subset of T8 cells is also involved in the down-regulation of the immune response (Geiser, 1989).

The central nervous system affects the immune system in two important ways, direct innervation and neuroendocrine pathways. Direct
innervation of lymphoid tissues like bone marrow, thymus, and spleen can affect lymphocyte development and migration. Indirect evidence indicates that parasympathetic stimulation enhances immunity and sympathetic stimulation suppresses immune responsiveness (Geiser, 1989).

There are two important neuroendocrine pathways that involve the adrenal glands. The first is the hypothalamic-pituitary-adrenocortical system (HA). In this system, the hypothalamus secretes corticotropin-releasing factor (CRF) that stimulates the pituitary to release adrenocorticotropic hormone (ACTH). ACTH then stimulates adrenocortical secretion of corticosteroids (e.g., cortisol; Camara & Danao, 1989). Corticosteroids generally have a suppressive effect on the immune system. They are known to decrease antibody formation, prolong tolerance to antigens, inhibit cytotoxic effects of cells, and suppress the number of circulating monocytes (Ader, Felton, & Cohen, 1990).

The second pathway is the sympathetic adrenal-medullary pathway (SAM). The SAM pathway involves the stimulation of the adrenal medulla, leading to the release of epinephrine and norepinephrine. These hormones are responsible for the classic fight or flight response. Elevations in serum catecholamines are associated with increased susceptibility to acute infections (Geiser, 1989).

These two systems have also been characterized by their activation to specific emotions associated with stressful events. The SAM is most strongly
engaged in situations that involve acute emotional reactions like fear or anger. The HA is activated in situations associated with overwhelming threats, as well as chronic stress and depression (O'Leary, 1990). These patterns are likely oversimplifications but are heuristically useful when studying specific psychological events.

The effects of stress on various aspects of immune functioning have been widely studied. Both specific indicators of immune functioning and/or levels of immunosuppressant agents have been investigated. Many of these studies have examined the immunological sequelae of specific stressful situations. Other studies have examined the effect of psychological interventions on immune system parameters.

The influences of stressful events on immune functioning have received increasing attention. Kiecolt-Glaser and colleagues have studied immunological parameter changes in several populations exposed to various stressors. They found changes in T-lymphocytes and antibody levels in medical students prior to academic examinations (Glaser, Kiecolt-Glaser, Stout, Tarr, Speicher, & Holliday, 1985). In addition, loneliness was shown to be related to impaired immune functioning in both medical students and psychiatric in-patients (Kiecolt-Glaser et al., 1984a; Kiecolt-Glaser et al., 1984b).

Several studies have examined the relation between stressors and cortisol levels. High levels of daily stress have been shown to be related to
increased cortisol secretion (Brantley, Dietz, McKnight, Jones, & Tulley, 1988). Cortisol elevations have also been associated with low levels of perceived control, loneliness, and chronically stressful situations (Irwin, Daniels, Risch, Bloom, & Weiner, 1988; Kiecolt-Glaser, Ricker, George, Messick, Speicher, Garner, & Glaser, 1984; Wiedenfeld, O'Leary, Bandura, Brown, Levine, & Raska, 1990). Wiedenfeld et al. (1990) demonstrated that an increase in self-efficacy from a therapeutic intervention, positively affected levels of cortisol in a clinical population.

The effects of chronic stress have been shown in women experiencing marital distress and caregivers of dementia patients. In the marital disruption study, women who reported poor quality marriages or had recently experienced divorce or separation, displayed significantly poorer response to mitogen challenge than women reporting marital satisfaction (Kiecolt-Glaser, Fisher, Ogrocki, Stout, Speicher, & Glaser, 1987).

Two PNI studies have been conducted using dementia caregivers. In the first study, 34 caregivers were compared to 34 sociodemographically-matched controls, on both immunological and psychological variables. The caregivers reported greater distress and loneliness associated with greater impairment in the Alzheimer's patient. They also displayed lower lymphocyte levels and a higher antibody titer compared to the control group (Kiecolt-Glaser, Glaser, Shuttleworth, Dyer, Ogrocki, & Speicher, 1987). The second caregiver study was an assessment of longitudinal changes in
psychological and immune functioning. During the course of the study, caregivers reported more days of infectious illness, lower levels of social support, and higher levels of depression. They also displayed decreases in cellular immunity as measured by functional assays with concanavalin A (Con A) and phytohemagglutinin (PHA), and antibody titers to latent Ebstein-Barr virus. Overall, caregivers showed deterioration in psychological and immune functioning with no evidence of adaptation over time (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991).

From this review, it is evident that chronic stress does impact specific immune parameters (i.e., antibody response, antibody titers). However, evidence of chronic stress effects on more general physiological parameters remains limited. As discussed previously, cortisol, a centrally mediated corticosteroid, is likely to be affected by exposure to chronic stress. Since cortisol is known to have general immunosuppressive effects, measuring its levels will give an indication of stress effects on several immune parameters (i.e., antibody formation, tolerance to antigens, cytotoxic effects, and monocyte levels; Ader et al., 1990). In addition, cortisol levels have been found to be relatively stable and are thought to represent responses to general levels of stress and not discrete events (Nakamura & Yakata, 1983).

Despite methodological limitations in the study of caregivers, there is strong evidence that caregiving is associated with negative psychological and physical sequelae. For many individuals, caregiving represents a chronic
stressor with negative effects that often worsen over time (Kiecolt-Glaser et al., 1991). Caregiving is associated with alterations in social status, emotional well-being, and intrusion on vocational and recreational activities. This is especially true in the case of caregiving for dementia patients because of their multifaceted needs and the chronic but unpredictable course of their illness. Recently, there has been a heightened interest, based on the growing clinical and empirical evidence regarding the impact of caregiving, in developing interventions that will attenuate the negative effects of caregiving (Zarit & Zarit, 1982).

The use of caregiver interventions was initially reported in association with hospital or community-based geriatric care centers. Many of these studies focused on program and subject description and did not have comparison groups or well-established outcome measures. One of the earliest reports described the format of a community-based support group for families of the elderly (Cohen, 1983). Group components included education, individual "disclosure" of problems and emotions, and discussion of problems associated with the elderly. Although no outcome measures were employed, the author reported a positive response from the group members.

Recent treatment studies have compared individual and group therapies (Barusch & Spaid, 1991; Toseland, Rossiter, Peak, & Smith, 1990; Zarit, Anthony & Boutselis, 1987), different types of group therapies
Several studies have been conducted to examine the efficacy of group interventions for caregivers. One of the first such studies, was a hospital-based group intervention that incorporated both the patient and the family (Winogrond et al., 1987). The patients were diagnosed with Alzheimer's disease and were enrolled in a day hospital program. The group sessions consisted of education regarding the disease process and resource availability, and provided opportunities for caregivers to support one another. Subjects attended the support group for as long as their relative was enrolled in the day program. Caregiver burden, tolerance, and morale were assessed when the subjects joined the group and again when their relative was discharged from the day program. Caregiver burden and tolerance were measured using the Caregiver Burden Inventory (CBI; Zarit, Reever, & Bach-Peterson, 1980) and morale was assessed using the Life Satisfaction Index Z (LSI-Z). The CBI and LSI-Z were administered when the caregivers entered the program and six months later. No significant changes were found on either measure. The findings are limited by a small sample size (n = 18), length of time that
they were enrolled in the group, and widely varying levels of patient
disability (i.e., stage of Alzheimer's disease). Disease stage is important
because the various levels of dementia are associated with different types
and/or degrees of behavioral disturbance and care requirements (Pruchno &
Resch, 1990).

In a regional pilot-program study, caregivers of elderly patients with
chronic physical conditions were enrolled in structured groups that included
education and group discussion of negative feelings associated with
caregiving (Greene & Monahan, 1987). Caregivers were referred by local
social service agencies and enrolled in one of the regional groups. A total of
34 treatment groups were conducted, with 208 caregivers. There was no
control condition. Global anxiety, depression, and hostility were measured
using the Symptom Checklist-90 (SCL-90), and caregiver burden was
assessed using the Caregiver Burden Inventory (Zarit et al., 1980). Results
indicated that the intervention resulted in statistically significant changes on
both psychological functioning (i.e., decreased levels of depression and
anxiety) and lower rates of institutionalization. These and other program
description studies offer preliminary evidence for the efficacy of group
interventions with caregivers (Zarit, 1990). They are limited in their
generalizability, however, because of the inclusion of caregivers of different
patient populations (e.g., physically ill versus dementia), loosely defined
caregiver roles (e.g., spouse versus family; primary versus occasional),
limited use of standard outcome measures, and lack of control group comparisons.

Based on these early reports and clinical observations (Rabins, 1984), several researchers began to study potential psychosocial interventions for caregivers of various populations. These studies have generally applied more rigorous methodology, including the use of control groups, standardized outcome variables, and more well defined interventions.

In a study of family caregivers of dementia patients, Kahan et al. (1985), compared an education/support group (n = 22) with a wait-list control (n = 18). The caregivers in this study reported various levels of involvement with their dementing family member and ranged in age from 16 to 77 years. They conducted eight, weekly two-hour sessions. The first hour was devoted to didactic information about Alzheimer's disease and related disorders. The second hour was used for group discussion of problems associated with caregiving and suggestions of possible solutions. Group members displayed a significant decrease in perceived burden and an increase in knowledge about dementia. In a similar study, Haley, Brown, and Levine (1987) compared two types of support groups and a wait-list control condition in a population of 31 primary caregivers of dementia patients. Both groups met for seven weeks and each session was 1.5 hours. The first group was a support group with two components: information and emotional support. The information component consisted of a specific topic
for each session that was presented by a variety of guest speakers (i.e., nurses, social workers). The topics included causes and stages of Alzheimer's disease, home nursing care, use of community agencies, legal consultation, financial assistance, and psychological reactions to caregiving.

The second group included the support group components plus relaxation training and instruction in managing negative cognitions. Both groups reported high rates of satisfaction with their respective interventions. However, there were no differences between the groups and wait-list subjects on post-treatment measures of depression, life satisfaction, social support, or coping.

Lovett and Gallagher (1988) also compared two group interventions with a wait-list control for caregivers of frail elders. The groups were designed to reduce levels of depression and, unlike the Haley et al. (1987) study, the treatment conditions employed focused on specific skills acquisition. The first group was based on Lewinsohn's (1984) model of increasing pleasant activities and the second on D'Zurilla's (1986) model of problem-solving. Caregiver stress, burden, level of positive activities, self-efficacy, positive affect, and depression were used as outcome measures. Subjects from the treatment groups were not significantly different on any outcome measure, but both displayed significant decreases in depression compared to the wait-list group. No group displayed changes in perceived stress.
In a study of daughters and daughters-in-law of frail elderly patients, Baldwin et al. (1989), compared four groups, didactic/education (n = 20), support/psychotherapy (n = 20), placebo control (n = 20), and no treatment control (n = 20). The educational group was conducted in a classroom format with an established syllabus that included the following topics: family systems and dynamics, stress, and normal versus abnormal aging. The support group consisted of discussion of topics initiated by the subjects and directed by co-leaders and was based on a traditional psychotherapy group model. Although no statistical results were given, the authors reported that both treatment groups experienced reductions in perceived strain in comparison with the control group. Neither group displayed changes in report of stress, depression, or anxiety.

In a study of different therapy settings, Zarit et al. (1987) compared family counseling to a support group for primary caregivers of dementia patients. Both groups received roughly parallel treatment components with the primary difference being the setting and group versus individual therapy. The treatment consisted of education about dementia, problem-solving skills, and identifying formal and informal support systems. No differences were found between the groups on measures of stress or burden. However, a re-analysis of the data controlling for baseline levels of distress and depression, showed that there were significant decreases in measures of distress in both groups compared to the control group (Whitlach, Zarit, & von Eye, 1991).
Two other studies of this type were conducted by Toseland and colleagues. Both were conducted using caregivers of frail elderly patients. In the first study, the caregivers were placed in either a therapist or peer-led support group. The therapist-led group was semi-structured and consisted of education about caregiving, discussion of general problem-solving techniques, and opportunities for group members to "ventilate" about their situation. The peer-led group focused on self-help approaches and generating group support. Neither group displayed any improvement in reports of caregiver burden. Subjects in the therapist-led group did display statistically significant decreases in both the presence and global severity of psychological symptoms as measured by the Brief Symptom Inventory (Toseland et al., 1989). In the second study, caregivers of frail elderly received either group treatment or individual therapy. Subjects in both conditions displayed small, nonsignificant improvements in well-being and decreases in perceived burden, and significant decreases in positive psychiatric symptoms. The group therapy condition led to significant improvements in the number of individuals in their social support network (Toseland et al., 1990).

Despite mixed findings, the results of these studies give preliminary indication that caregivers can benefit from a group intervention. Elements of these interventions, like education and social support appear to be beneficial. However, the benefits are generally nonspecific and have little impact on the enduring caregiving situation (Greene & Monahan, 1989; Winogrond et al., 1989).
Interventions that have focused on specific psychological problems that can result from caregiving (i.e., depression) have shown improvements in that specific domain with little effect on caregiver distress (Lovett & Gallagher, 1988). In conclusion, caregiver studies have used either general psychoeducational interventions or interventions that focus on specific psychological morbidity associated with caregiving. Neither approach has adequately addressed the enduring stress associated with caregiving.

In order to increase efficacy, future interventions should be designed with more emphasis on the stress responses associated with caregiving and enabling the caregiver to better manage the behavioral sequelae of dementia. Such an emphasis would include both improving the caregivers' ability to cope with stress, as well as the acquisition of skills that can directly impact the caregiving situation. This approach would target both the stressful situation and the individual's reactions, thereby ameliorating existing distress and decreasing the frequency of future stressful events.

Caregivers often report that the behavioral problems associated with dementia are the most distressing aspects of caring for a dementia patient (Zarit, 1990). These behaviors include wandering, agitation, abnormal eating, incontinence, shouting/screaming, restlessness, violence, and abnormal sexual activity (Clark & Lancaster, 1994). While a few studies have addressed these behaviors as part of their intervention, no study to date has systematically attempted to help the caregiver manage these behaviors.
Although no group treatments have been reported, management of problem behaviors associated with aging and dementia have been shown to be amenable to change using behavioral techniques (Teri et al., 1992). The application of behavioral techniques with geriatric patients has primarily been done in nursing homes, hospitals, or other specialized settings (Carstensen, 1988), or on a single-case basis using health care professionals and family members in the management of problem behaviors (Alessi, 1991; Wisner & Green, 1986).

A wide variety of behaviors have been targeted including incontinence, wandering, screaming, aggressiveness, inappropriate sexual behavior, poor self-care activities, and memory impairment (Clark & Lancaster, 1994). In general, these behavior problems can be separated into two main categories (Pinkston & Linsk, 1984). The first is behaviors that need to be reduced or eliminated because they are disruptive, ineffective, or dangerous (i.e., aggressiveness, wandering, screaming). The second category includes behaviors that are adaptive and need to be increased or maintained (i.e., hygiene, feeding, dressing).

Intervention approaches with impaired geriatric populations have been similar to those used in other populations (e.g., children, developmentally disabled; Alessi, 1991). They include a careful functional analysis, followed by the application of successively more rigorous techniques. The careful analysis of the behavior problem, its antecedents,
and consequences has been widely advocated (Fisher & Carstensen, 1990; Stewart, 1991) and can be implemented by using the caregiver as the observer and behavior analyst (Alessi, 1991). After the behavior has been defined and analyzed, three general approaches are attempted: environmental alterations, increasing reinforcement for positive behaviors, and removing reinforcement for negative behaviors (Pinkston & Linsk, 1984).

Environmental alterations frequently include changing the amount of stimulation in the environment, making parts of the environment inaccessible, removing dangerous objects, and changing daily routines (Fisher & Carstensen, 1990; Pinkston & Linsk, 1984). Environmental manipulations have been used in the treatment of aggression and agitation (Fisher & Carstensen, 1990), catastrophic reactions (Clark & Lancaster, 1994), restlessness (Stewart, 1991), and memory problems (Alessi, 1991).

More complex interventions have also been implemented and frequently incorporate the establishment of reinforcement schedules and using time out and positive practice (Fisher & Carstensen, 1990). The use of various behavioral contingencies has been successfully applied to several problem behaviors including incontinence (Schnelle, 1983), eating disturbances (Fisher & Carstensen, 1990), and anger management problems (Wisner & Green, 1986).

Thus standard behavioral management techniques have been applied in a variety of geriatric settings, and can be quite effective when used with
dementia patients (Teri, et al., 1992). While these interventions have been implemented primarily in nursing homes or other specialized settings, preliminary reports suggest they may also be efficacious when used by caregivers in the community (Alessi, 1990). To date, no study has been conducted using a systematic application of these techniques as part of an intervention for family caregivers of dementia patients.
THE PRESENT STUDY

It is evident from a review of the literature on caregiving that providing care for a patient with dementia, in the home, often exacts both a physical and psychological toll on the caregiver (Schulz et al., 1990; Zarit, 1990). The most frequently reported psychological problems among caregivers are depression, anger, and anxiety (Pruchno & Potashnik, 1989). Caregivers also report higher rates of medical complaints and medical utilization than non-caregivers (Snyder & Keefe, 1985). Finally, there is preliminary evidence that the chronic stress associated with caregiving leads to altered immune functioning with little evidence of adaptation (Kiecolt-Glaser et al., 1991).

Because of the negative consequences associated with caregiving, investigators have begun to study interventions designed to reduce caregiver distress. These studies have primarily been treatment outcome studies of group interventions (Zarit, 1990). Most of these group treatments have followed a similar structure that incorporates elements of education, social support, and general problem-solving training (Haley, Brown, & Levine, 1987; Winograd et al., 1987; Zarit et al., 1987). Overall, these studies have shown that group interventions for caregivers can be beneficial. However, the strength and generalizability of these findings are limited by the use of different caregiver populations (i.e., physically ill elderly v.
dementia caregivers), varied specificity of treatment intervention, and the use of global or non-standardized outcome measures (see Table 1).

The use of different caregiving populations has limited the conclusions that can be drawn about treatment effectiveness. While all caregiving can be viewed as potentially stressful, the type of patient being cared for is important because of differing daily needs, changes in the caregiver/recipient relationship, and differences in functioning. An elderly patient who is coherent yet requires assistance with bathing or eating represents a different level of caregiver involvement and potential strain than a patient who is agitated, confused, and potentially dangerous to himself and others. Because of these differences in caregiver involvement, the type of intervention chosen will likely vary in its effectiveness according to the caregiving requirements. In addition, many studies have used subjects who are responsible for different types of caregiving (i.e., physically dependent, cognitively impaired) and who may not need or benefit from a specific treatment. There is increasing evidence that type and frequency of caregiving as well as the patient’s relationship to the caregiver can affect caregiver burden and functioning (Anthony-Bergstone et al., 1988).

The efficacy of many of these studies has also been attenuated by interventions that are vaguely defined and implemented. Much of the psychosocial treatment in these studies is based on social psychological or systems-oriented paradigms (Toseland et al., 1990). The common treatment
Table 1

**Summary of Findings from Past Research of Caregiver Treatments**

<table>
<thead>
<tr>
<th>Study</th>
<th>Patient Pop.</th>
<th>Treatment Type</th>
<th>Treatment Meas.</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baldwin et al. (1989)</td>
<td>Frail elderly</td>
<td>Didactic education vs. Support vs. placebo vs. wait-list</td>
<td>Self-report depression, stress, anxiety</td>
<td>No treatment effect in any group</td>
</tr>
<tr>
<td>Greene &amp; Monahan (1987)</td>
<td>Frail elderly</td>
<td>Social support group</td>
<td>SCL-90, CBI, rate of institutionalization</td>
<td>Significant decrease in psychological distress &amp; rate of institutionalization</td>
</tr>
<tr>
<td>Haley et al. (1987)</td>
<td>Dementia</td>
<td>Two social support groups, wait-list</td>
<td>BDI, Life-Z, MBPCL</td>
<td>No treatment effect in any group</td>
</tr>
<tr>
<td>Kahan et al. (1985)</td>
<td>Dementia</td>
<td>Education/support group vs. wait-list</td>
<td>CBI, Zung, program satisfaction rating</td>
<td>Decreased depression and burden, increased knowledge</td>
</tr>
<tr>
<td>Lovett &amp; Gallagher (1988)</td>
<td>Frail elderly</td>
<td>Increasing pleasant events vs. problem-solving vs. wait-list</td>
<td>BDI, SADS, MBPCL, Perceived Stress Scale</td>
<td>Decreased depression, no change in perceived stress</td>
</tr>
<tr>
<td>Study</td>
<td>Patient Pop.</td>
<td>Treatment Type</td>
<td>Treatment Meas.</td>
<td>Results</td>
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<tr>
<td>Toseland et al. (1989)</td>
<td>Frail elderly</td>
<td>Professional vs. peer-led social support groups</td>
<td>CBI, BABS, BSI, Problems with Caregiving Scale</td>
<td>Pro-led decreased psychological symptoms, peer-led increase in social support</td>
</tr>
<tr>
<td>Toseland et al. (1989)</td>
<td>Frail elderly</td>
<td>Group vs. individual</td>
<td>BABS, BSI, social support satisfaction</td>
<td>Individual tx. decreased psychological symptoms, group tx. increased social support</td>
</tr>
<tr>
<td>Winogrond et al. (1987)</td>
<td>Dementia</td>
<td>Support group</td>
<td>CBI, LSI-Z</td>
<td>No treatment effect</td>
</tr>
<tr>
<td>Zarit et al. (1987)</td>
<td>Dementia</td>
<td>Support group vs. family counseling</td>
<td>CBI, BSI, MBPCL, social support rating</td>
<td>No treatment effects compared to wait-list</td>
</tr>
</tbody>
</table>
component in this type of intervention is loosely defined as increasing social support. This frequently refers to group members sharing common problems and complaints regarding their family member and current situation. While this may be reinforcing in the short term, and is associated with high rates of participant satisfaction, there is little evidence of benefit beyond the treatment period (Clark & Raskowski, 1983; Haley, 1989).

More structured interventions have emphasized education and skills training to enable participants to effectively handle stress associated with caregiving. Among studies of this type, there are only a few that have incorporated the training of specific skills (i.e., increasing pleasant activities, anger control, relaxation) into the treatment (Lovett & Gallagher, 1988; Zarit et al., 1987). These treatments incorporated the main components of widely used psychoeducational interventions that were designed primarily to treat depression and other psychological disorders. This has been done based on the notion that caregivers' distress is due to psychopathological reactions to the caregiving situation (Lovett & Gallagher, 1988). While this is an effective approach if the caregivers are experiencing a specific problem (e.g., depression), there is little reason to expect that treatment groups of this sort will be generally effective for the problems associated with caregiving (Zarit, 1990). In addition, there has been only limited attention given to the use of behavioral interventions to manage problem behaviors associated with dementia (Carstensen, 1988; Haley, 1983). No treatment outcome study has
incorporated systematic behavioral management as part of a treatment protocol for caregivers. Since much of the burden associated with caregiving is related to the patient's disruptive and potentially dangerous behaviors, it seems reasonable that decreases in these behaviors would lead to decreased stress for the caregiver.

The final common problem with the intervention studies reviewed here and elsewhere, is the choice of outcome variables. Many studies (e.g., Haley, Brown, & Levine, 1987; Lovett & Gallagher, 1988; Toseland, et al., 1989) have used global psychological measures as outcome variables (e.g., SCL-90, BSI, SADS). The use of such measures may underestimate specific and important treatment effects because of their relative insensitivity to change (Zarit & Toseland, 1989). While these measures assess several global areas of psychological functioning, they are not precise and may not detect changes in targeted domains. Furthermore, other aspects of psychological functioning, like use of coping strategies as well as potentially important physiological parameters have not been studied. It may be important to consider measures of physiological functioning affected by chronic stress exposure (i.e., cortisol level) that are associated with increased susceptibility to disease and physical impairment.

The research indicates that education and increasing social support can be moderately beneficial for some caregivers. However, there have not been any reports that have compared these interventions to more systematic
interventions designed for specific types of caregiver problems (i.e., problems encountered by caregivers of dementia patients). In addition, when follow-up studies have been done (Hayley, 1989; Toseland et al., 1989), they have not assessed caregiver functioning directly. Therefore there is a lack of direct evidence that the effects of a social support group last beyond the end of the intervention. To address these issues, more attention needs to be given to defining the target population to insure a sufficiently homogeneous group that will likely benefit from a specific treatment. Furthermore, the treatment components that are applied should be conceptually related and similar in focus in order to avoid a diffusion of treatment effects (Lovett & Gallagher, 1988). Finally, outcome measures should be sufficiently sensitive to changes in the areas targeted by the intervention.

This study was designed to compare a cognitive-behavioral treatment (CBT) intervention with a social support group (SSG) in a population of family caregivers of dementia patients. The social support group was similar to those previously described in the literature. The cognitive-behavioral group directly targeted the behaviors of the patient that have been related to caregiver burden (Zarit & Zarit, 1982) as well as addressing the caregiver's reactions to stress. The stress management component was based on empirically supported cognitive-behavioral techniques (Meichenbaum, 1990). Specifically, the stressful nature of caregiving was addressed with a combination of cognitive-behavioral techniques including stress management.
training, cognitive restructuring, problem-solving training, and relaxation training. The behavior management component focused on the instruction and practice of behavioral management techniques to reduce the number of caregiving related stressors (Pinkston & Linsk, 1984). The specific components included introduction of social learning theory, behavior monitoring, environmental manipulation, communication, and contingency management.

Similar to previous interventions, cited in the literature, each group met for an hour and a half, once a week for eight weeks. A control condition was not used for two reasons. First, earlier studies have shown social-support interventions can be effective in reducing caregiver distress. Second, previous studies have reported that caregivers who are placed in wait-list conditions often seek assistance from other sources, thus limiting any comparisons with active treatment (Zarit et al., 1987). Comparison of both subjective and objective measures of stress and distress were conducted at baseline, the end of treatment, and at a one-month follow-up.

The study compared two treatments for reducing stress and distress associated with caring for a relative with progressive dementia. In an effort to overcome previous limitations, this study used standardized measures of psychosocial and physiological functioning, and specific measures addressing caregiver burden, and reactions to problems associated with dementia. An attempt was made to select subjects from the caregiving population who were
similar in terms of distress, presenting problems, relationship to care recipient, and whose demented relative was of a similar functional status.

The central questions concerned the relative efficacy of two group interventions designed for primary caregivers of dementia patients. Specifically, the following questions have been addressed: (1) Is social support an effective treatment for reducing stress and distress in primary caregivers of dementia patients? (2) Is cognitive-behavioral therapy an effective treatment for reducing stress and distress in primary caregivers of dementia patients? (3) Is cognitive-behavioral therapy more effective than social support at reducing caregiver burden? (4) Will treatment gains made with social support or cognitive-behavioral therapy be maintained at one-month follow-up?

Hypothesis 1. The first hypothesis was that both a comprehensive cognitive-behavioral group and a nonspecific social support group would significantly reduce physiological manifestations of stress and subjective levels of caregiver distress as compared to pre-treatment baseline levels. Specifically, by receiving either type of group intervention caregivers would experience significantly decreased psychological distress in the areas of depression, anxiety and anger, decreased perception of burden, increased social support, and lower cortisol levels compared to their pre-treatment baseline levels.
Hypothesis 2. The second hypothesis was that subjects in the cognitive-behavioral intervention would display significantly greater decreases in stress and distress than subjects in the social support group. This was expected because they were trained to control stress at its source as well as their reactions to stressful situations. In addition, subjects in the cognitive-behavioral group were expected to display significantly lower levels of perceived burden associated with caregiving and improvements in ability to handle stressful situations. Specifically, cognitive-behavioral group members were expected to report lower levels of depression, anxiety, anger, and caregiver burden, and have lower levels of urinary cortisol as compared to subjects in the social-support group. Following treatment, the cognitive-behavioral group was also expected to display more effective coping through the use active engagement in their coping responses as measured by the Coping Strategies Inventory (i.e., problem-solving, cognitive-restructuring), than subjects in social-support group.

Hypothesis 3. The third hypothesis was that subjects in the cognitive-behavioral group would display better maintenance of treatment gains compared to those in the social support group at one month follow-up. Specifically, it was hypothesized that the acquisition of skills in the cognitive-behavioral group would enable subjects to maintain treatment gains after the formal training ended. Whereas, improvements associated with the social support condition were presumed to be more highly dependent on group
attendance and not associated with the acquisition of skills necessary for ongoing improvements in functioning. It was expected that subjects in the cognitive-behavioral group would have significantly lower levels of distress, burden, and cortisol and higher levels of active coping strategies compared to the social-support group, when re-assessed at follow-up.
METHOD

Subjects were 35 adult caregivers of dementia patients recruited from the Jackson, Mississippi metropolitan area. They were recruited by media announcements (local newspaper and radio), printed announcements sent to local churches and physicians' offices, and announcements at local dementia support agencies.

Caregivers were eligible for participation if: (1) they were the primary caregiver for the dementia patient, in that they provided the majority of care and were responsible for the patient’s daily functioning (i.e. finances, medical care, and activities of daily living; ADL's), and (2) The patient was in the early to middle stages of dementia, as determined by assessment based on the caregiver interview, the Blessed Dementia Scale, and the Clinical Dementia Rating Scale. This was done to exclude patients in the later stages of dementia whose clinical picture is characterized by increased physical dependence and decreased behavioral problems (Pruchno & Resch, 1990). Subjects were also excluded if they evidenced significant cognitive, emotional or physical impairment that would have precluded successful participation in group sessions (e.g., blindness, inability to read and respond to questionnaires, inability to complete homework assignments, or evidence of clinically significant depression or anxiety). This was determined by the interviewer during the intake assessment and was based on DSM-IV criteria (American Psychiatric Association, 1994).
Subjects who met study criteria were grouped by age, sex, and dementia level of care recipient (based on the Blessed Dementia Scale and the Clinical Dementia Rating Scale). Subjects with similar characteristics were placed in one of the two treatment conditions: Cognitive-Behavioral group (n = 19) or Social Support group (n = 14). Two subjects, one from each group, were unable to complete the study.

In addition to the 35 individuals who participated, another 26 contacted the Division of Geriatrics regarding the study. Thirteen of these persons attended the initial screening appointment, six were eligible but unable to attend because of difficulty finding alternative care for their family member, scheduling conflicts, or transportation difficulties. The other seven were ineligible because they were either, not the primary caregiver (5) or were unable to complete the screening process (2). Thirteen individuals were unable to attend the initial interview because of the above mentioned conflicts associated with caregiving.

The demographic characteristics of the two groups are summarized in Table 2. The sample consisted of 7 male and 28 female caregivers of dementia patients. Their ages ranged from 35 to 71, with a mean age of 51.5 (SD = 10.7). The sample was predominately Caucasian (85.7% Caucasian, 11.4% African-American, 2.86% Other). All subjects had completed high school, 91.4% had attended college, with 37.1% obtaining a
Table 2.  
Demographic Characteristics of CBT and SSG Group Members.

<table>
<thead>
<tr>
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bachelor's degree or higher. Forty six percent of the subjects reported that they were employed and 74.3% were presently married.

**Measures**

**Medical/Demographic Questionnaire.** A medical/demographic questionnaire was administered at the pretreatment assessment (see Appendix A). It assessed basic demographics of the caregiver such as age, race, marital status, education, annual income, number of persons in the household, and employment status. Modified versions were administered at post-treatment and follow-up to detect any changes in physical functioning or caregiver status (see Appendix A).

**Caregiver Interview.** The caregiver interview was conducted by 1 of 3 interviewers (clinical psychologist, post-doctoral fellow, or psychology intern) to assess level of dementia in the care recipient and screen caregivers for cognitive, psychological, or physical impairment that would preclude participation. The interview consisted of the administration of the Blessed Dementia Scale (BDS; Blessed, Tomlinson, & Roth, 1968) and the Clinical Dementia Rating Scale (CDR; Hughes, et al., 1982).

The BDS was developed to measure the negative changes in a demented person’s abilities across three domains: daily-living, self-care, and personality. Scores can range from 0 to 28, with higher scores representing greater deficits in functioning (Dura, Stukenberg, & Kiecolt-Glaser, 1990). The BDS has adequate inter-rater reliability ($r = .80$), and BDS scores have
been correlated with both senile plaque count at postmortem examination ($r = .64$) and impairments on neuropsychological testing (Erkinjuntti, Hokkanen, Sulkava, & Palo, 1988).

The CDR is a clinician rating measure designed to give an estimate of the level of dementia based on ratings of 6 domains of functioning (Hughes, Berg, Danziger, Coben, & Martin, 1982). The domains are memory, orientation, judgement and problem-solving, community affairs, home and hobbies, and personal care. The rating for each domain may be based on observation or report of significant other. The scale is 0.5 to 3 for each domain with each level of the scale corresponding to a rating of dementia severity from healthy to severe dementia. The CDR has displayed excellent inter-rater reliability ($r = .95$) and correlates highly with other measures of dementia including the Short Portable Mental Status Questionnaire (SPMSQ; $r = .84$), the BDS ($r = .74$), and the Face Hand Test (FHT; $r = .57$; Hughes et al., 1982). The CDR was completed based on the subject's interview and responses on the BDS. The CDR rating was used to determine the level of the care recipient's dementia, which in turn was used as one of the criteria for grouping subjects for placement in one of the treatment conditions. In order to ensure adequate inter-rater reliability 10% of the ratings were conducted with two of the three interviewers. In an alternating fashion one of the interviewers conducted the interview and the other...
completed an independent rating. Inter-rater agreement for both the BDS and CDR was 100% on the total score.

**Revised Memory and Behavior Problems Checklist.** The Revised Memory and Behavior Problems Checklist (RMBPC; Teri, Truax, Logsdon, Uomoto, Zarit, & Vitaliano, 1992), is a 24-item inventory used to assess behavior problems in dementia patients. The items for the RMBPC were drawn from the original Memory and Behavioral Problems Checklist (Zarit, et al., 1987) as well as from a pool of items generated to assess behavior problems associated with dementia (e.g., memory-related, depressive behaviors, and disruptive behaviors).

The RMBPC was adapted to be completed by a caregiver, who rates the frequency of the dementia patient's behaviors during the previous week from never occurred (0) to daily or more often (4) and the impact of those behaviors from not at all (0) to extremely (4). Both a total score and three subscale scores can be obtained for frequency and impact of behavior problems. The total score is a sum of all the items and indicates overall level and impact of the behavior problems. The three subscale scores: Memory-Related Problems, Depression, and Disruption can also be calculated on the basis of frequency and impact (Teri et al., 1992).

The RMBPC has displayed good reliability and validity. It has good internal consistency with Cronbach's alpha ranging from .67 to .84 for the subscales and total scores. There is also low shared variance between the
subscales (.13 for Frequency and .19 for Reaction) indicating independence between the subscales. The RMBPC also displayed adequate concurrent and discriminant validity in comparison to standardized measures of depression (Hamilton Depression Rating Scale) and mental status (Mini-Mental State Exam).

The RMBPC has been designed to assess current behavior problems that are common in dementia patients and their impact on caregivers. Because it rates specific behaviors and their frequency during the previous week, it was used to reflect changes in behavior problems due to treatment effects.

**Caregiver Burden Inventory.** The Caregiver Burden Inventory (CBI) is a 29-item measure of the perceived impact of caregiving and the care recipient's behavior on the caregiver's financial status, physical health, emotional health, and social activities (Zarit & Zarit, 1982). Caregivers are asked to rate each item on a 5-point Likert scale, ranging from 1 = rarely to 5 = nearly always (Anthony-Bergstone, Zarit, & Gatz, 1988). There are three forms of the CBI, these correspond to the person being cared for. The three forms are CBI-Mother, CBI-Father, and CBI-Spouse. These forms differ only in the pronouns used to identify the caregiving recipient. For caregivers of other family members, the appropriate gender form was chosen and the individual was instructed to complete the form replacing their relationship for the one that was designated. Scores are reported as the sum
of all the items with higher scores indicating greater levels of perceived burden (Zarit & Zarit, 1982). Adequate reliability and validity for the CBI have been demonstrated in several studies (Gallagher, Rappaport, Benedict, Lovett, & Silven, 1985; Zarit, et al., 1987; Zarit & Zarit, 1982). Test-retest reliability has ranged from alpha .79 to .89.

The CBI has been designed as a specific measure of perceived burden. As such it gives a direct indication of the impact that caregiving has on the caregiver’s psychological and physical functioning (Zarit et al., 1987). The CBI was used in this study as a measure of caregiver burden.

Geriatric Depression Scale. Because most of the caregivers in this study were middle-aged to older adults, a depression measure specifically designed for this population was chosen. The Geriatric Depression Scale (GDS; Brink, Yesavage, Lum, Heerema, Adley, & Rose, 1982; Yesavage, Brink, Rose, Lum, Adley, & Leierer, 1983) is a 30-item self-report depression scale specifically designed for older individuals. The items on the GDS are primarily directed at measuring cognitive complaints and social behaviors with little reference to somatic complaints (Brink et al., 1982). Subjects were asked to respond yes or no to each of the 30 items. A total score is obtained by summing the responses that are in the depressed direction. Twenty items indicate depression when answered with yes and 10 when answered with no. The “no” items are interspersed throughout the
measure to minimize biasing of responses (Yesavage et al., 1983). A total score of 10 or less is considered to be in the non-depressed range.

The GDS has displayed good reliability and validity in both community and clinical geriatric samples. Good internal consistency has been demonstrated with Cronbach's alpha of .91 to .94. Inter-item correlations have been reported from .36 to .48. Test-retest reliability coefficients of .85 have been reported after one-week and one-month periods (Parmelee, Lawton, & Katz, 1989; Yesavage et al., 1983). Construct validity has been demonstrated by comparing GDS scores with classifications from the Research Diagnostic Criteria (RDC), Hamilton Rating Scale for Depression (HRS-D), and Zung Self-Rating Scale for Depression (SDS). Mean GDS scores corresponding to the RDC categories of normal, mildly depressed or severely depressed, were consistently and reliably different from one another. The GDS scores and classifications were also highly correlated with the HRS-D and SDS (Yesavage et al., 1983). The GDS displayed convergent validity when compared to the Beck Depression Inventory (BDI) and the RDC in both medical and psychiatric patient populations (Norris, Gallagher, Wilson, & Winogrond, 1987; Rapp, Parisi, & Walsh, 1988). It has also displayed good internal consistency (Cronbach's alpha .80 - .87) and convergence with other measures of depression in adults under the age of 55 (Brannan, Pignatiello, & Camp, 1986; Rule, Harvey, & Dobbs, 1989).
State-Trait Personality Inventory. The State-Trait Personality Inventory (STPI) is a self-report scale developed by Spielberger et al. (1979) to assess state and trait anger, anxiety, and curiosity. Both the State and Trait scales consist of 30 items, divided into three 10-item subscales that measure anger, anxiety, and curiosity (Collins & Hailey, 1989). Individuals are asked to rate each item using a four-point scale from not at all (1) to very much so (4), based on how they feel right now (state) or generally feel (trait). Each subscale is scored by adding the weighted responses for the subscale items, giving a possible range of subscale scores from 10 to 40.

In the present study, only the trait-anxiety and trait-anger subscales of the STPI were used to determine current levels of anger and anxiety. These subscales are highly correlated with their respective “parent” scales from the State-Trait Anxiety Inventory and State-Trait Anger Inventory (r = .93 to .96; Schocken, Greene, Worden, Harrison, Spielberger, 1987). They also have good internal consistency, Cronbach’s alpha = .80 to .85 (Spielberger et al., 1979). The use of the trait subscales permitted a measurement of general functioning that is minimally affected by events occurring at the time of the assessment (Schocken et al., 1987). Because of this, using the STPI facilitated the assessment of anxiety and anger in caregivers while minimizing possible elevations because of one (or a few) recent events.

Coping Strategies Inventory. The Coping Strategies Inventory (CSI; Tobin, Holroyd, Reynolds, & Wigal, 1989) is a 72-item self-report inventory
designed to assess coping thoughts and behaviors in response to stress. In this study, it was used to assess initial coping strategies as well as changes due to the group interventions. Subjects were asked to indicate the extent to which they used each item to cope with stressful events on a 5-point scale ranging from not at all (1) to very much (5). The CSI consists of a hierarchical factor structure with eight primary, four secondary, and two tertiary subscales. The primary subscales were used in this study in order to assess the effects of the interventions on specific coping strategies. The eight primary CSI subscales consist of: (a) Problem-Solving (PS; direct behavioral or cognitive attempts to eliminate the source of stress by altering the situation); (b) Cognitive-Restructuring (CR; cognitive strategies employed to manage stressful situations by altering their meaning); (c) Social Support (SS; seeking support from others); (d) Express-Emotions (EE; the expression of feelings about the stressor); (e) Problem-Avoidance (PA; behavioral or cognitive avoidance of the stressor); (f) Wishful-Thinking (WT; wishful thoughts or fantasies which draw attention away from the stressor); (g) Social Withdrawal (SW; avoidance of others); and (h) Self-Criticism (SC; blaming or criticizing oneself). The two higher-order tertiary subscales of the CSI are Engagement and Disengagement. The Engagement scale is composed of PS + CR + SS + EE, and the Disengagement scale is composed of PA + WT + SW + SC.
The CSI has been shown to possess adequate reliability (alpha .71 to .90; Tobin et al., 1989). The factor structure of the CSI has been supported by hierarchical factor analysis (Tobin et al., 1989). In addition, the type of coping strategies endorsed on the CSI have been shown to add unique variance to the presentation of symptoms above and beyond that accounted for by stressful events, alone (Holm, Holroyd, Hursey, & Penzien, 1986; Mosley, Perrin, Neral, Dubbert, Grothues, & Pinto, in press). Specifically, higher scores on the engagement scales of Problem-solving, Cognitive-Restructuring, Express-Emotions, and Social Support, are associated with lower levels of distress and more positive health outcomes.

**Interpersonal Support Evaluation List.** The Interpersonal Support Evaluation List (ISEL; Cohen, Mermelstein, Karmack, & Hoberman, 1985) is a 40-item, self-report scale assessing perceived available social support. The ISEL was specifically designed in light of research implicating perceived support as a primary factor in stress-buffering effects (Cohen, 1988; Cohen & Willis, 1985). Subjects are asked to read each item and then determine the degree to which each item describes him or herself (rated as either definitely true, probably true, definitely false, or probably false). Scoring of the ISEL yields a total aggregate index of social support as well as four factor analytically derived subscales: appraisal, belonging, self-esteem, and tangible. Appraisal support refers to information or advice in dealing with problems. Belonging support is social companionship, like having someone to
go with to dinner or a social event. Self-esteem is support from others indicating that they think the person is valued or important. Tangible support refers to the support of material or effort (e.g., a loan or help with a repair job; Schonfeld, 1991). Consistent with other studies, each scale as well as the total aggregate score for social support was used to determine specific domains as well as a global indication of perceived support.

There are numerous data supporting the reliability and validity of the ISEL for both student and general adult samples (Cohen, 1988). Test-retest coefficients are reported at .87 for the total aggregate score over a four-week period. Internal consistency based on separate samples ranged from .88 to .90. Construct validity, rarely reported for social support measures, has been demonstrated through associations with other measures indicating convergent and discriminant validity. For example, the ISEL correlated .46 with another commonly employed measure of social support, the Inventory of Socially Supportive Behaviors (Barrera, 1981). Cohen and Willis (1985) presented data on the divergent validity of the ISEL with correlations of \( r = -0.52 \) to \( r = -0.64 \) between the ISEL and measures of social anxiety (Cohen & Willis, 1985). Low correlations between the ISEL and a measure of social desirability (i.e., the Marlow-Crowne) suggests that the ISEL is free from a social desirability bias. Further, increases in the ISEL consistently have been shown to be associated with decreases in psychological symptomatology (Cohen, 1988).
24-hour urinary cortisol. Cortisol is one of the corticosteroids that is secreted by the adrenal cortex and is known to be reactive to psychological stress (Forsman & Lundberg, 1982). Increases in cortisol secretion in response to stress have been measured by analysis of plasma and urine (Delahunt & Mellsop, 1987). Because of the additional stress associated with venapuncture, many researchers have used urinary cortisol as a preferred measure of stress response (Bassett & Spillane, 1987; Brantley et al., 1988; Pollard, Ungpakorn, & Harrison, 1992). Urinary cortisol levels have been shown to be relatively stable over the course of 9 or 10 days in the absence of the onset of new stressors or physical illness (Nakamura & Yakata, 1983). However, because urinary cortisol levels may vary during the course of a 24-hour period, a sample of all urine excreted during a continuous 24-hour period is recommended to avoid error associated with differing measurement times (Delahunt & Mellsop, 1987).

Samples were collected at three times during the study, pre-treatment, post-treatment and one-month follow-up. For each collection, the subjects were given a container and instructions for obtaining a 24-hour sample. A preservative, sodium azide, was pre-measured in each container prior to the sampling period. The subjects were instructed to save all of their urine for a 24-hour period just prior to collection time. An effort was made to insure that all samples were collected during the same 24-hour period to minimize
error due to deterioration of the sample or time of day effects (O'Leary, 1990).

Analysis for urinary free cortisol was conducted using the Coat-A-Count® cortisol radioimmunoassay. This procedure employs a solid-phase radioimmunoassay to measure the amount of cortisol present in the urine. The assay has a detection limit of 0.2 μg/dL and is highly specific for cortisol (i.e., extremely low cross-reactivity to other naturally occurring steroids or therapeutic drugs) and has excellent test-retest reliability (r = .98; Diagnostic Products Corporation, 1993).

After each collection the samples were immediately frozen until they were assayed. The assays were conducted in the radioimmunoassay laboratory of the Department of Physiology and Biophysics at the University of Mississippi Medical Center. The samples of each subject were analyzed together to reduce the effects of inter-assay variability. In addition to the laboratories routine reliability sampling, 10% of the assays were duplicated by the investigators to evaluate the reliability of the assay results.

Dementia Questionnaire. Subjects were asked to complete an 11-item “true-false” test to assess knowledge regarding dementia (Appendix B). This questionnaire was developed for this study and used items from two sources, The Alzheimer's Disease Knowledge Test (Dieckmann, Zarit, Zarit, & Gatz, 1988) and items generated by a gerontological social worker and psychologist. The Dementia Questionnaire was used to assess baseline
knowledge and changes in knowledge after the education component of each group.

**Caregiver Satisfaction Survey.** A 7-item survey was written for this study to assess subjects’ satisfaction with the treatment intervention (Appendix C). The items were chosen to address aspects related to participation in a group treatment. Items assessed, appropriateness of the program for the participant’s needs, ability to participate in the group sessions, and clarity and credibility of material. Items were rated on a scale from **strongly disagree** (1) to **strongly agree** (7). A total score was calculated to indicate level of satisfaction. Although written for this study, the survey is similar to previous satisfaction assessments (Hayley et al., 1987; Toseland et al., 1990).

**Procedures**

Potential subjects were asked to contact the Geriatric Division of the Department of Medicine at the University of Mississippi Medical Center. When a potential subject called, a brief phone screening was conducted to determine the subject’s eligibility. During this phone contact, eligible subjects were given a brief overview of the program and information was obtained so that subjects could be called by one of the investigators to schedule an initial appointment.

During the intake appointment, the subjects were told that the current study was designed to assess the benefits of a group intervention for
caregivers of dementia patients. The procedures of the study were thoroughly explained and all questions were answered. Subjects were then asked to read and sign a consent form (Appendix D), indicating that they understood the procedures involved in the study and their rights and privileges as research subjects. The subjects completed a series of questionnaires including the demographic and medical history questionnaire and the Revised Memory and Behavior Problems Checklist (RMBPC). Following the completion of these questionnaires, each subject was interviewed by one of the researchers to determine level and severity of their family member's dementia using the BDS and to assess the caregiver's level of psychological and emotional functioning. The interviewer later rated the patient's dementia using the CDRS. Ten percent of these interviews included a second investigator, who independently completed a dementia rating. Inter-rater reliability was excellent (r = 95). After the interview, subjects were given the remainder of the baseline questionnaires, Geriatric Depression Scale (GDS), State-Trait Personality Inventory - Trait Anger and Anxiety (STPI), Caregiver Burden Inventory (CBI), Coping Strategies Inventory (CSI), and the Interpersonal Support Evaluation List (ISEL). Subjects were also given instructions and a container for the 24-hour urine collection. They were instructed to complete the questionnaires and collect their urine after being contacted by the researchers, just prior to the beginning of the treatment sessions.
As subjects were recruited they were grouped according to age, sex, and care recipient status (i.e., dementia severity). When several subjects with similar characteristics had been screened they were randomly assigned to one of the two treatment conditions. The first three treatment groups were formed and initiated after 29 subjects had been recruited (two CBT and one SSG). The fourth group (SSG) began four weeks later after six additional subjects had been recruited.

Both treatment conditions consisted of eight group sessions that met weekly for an hour and a half. In order to insure consistency and replicability, each group session had an established agenda (see Appendix E). The general format of the group sessions was an initial didactic section followed by group interaction and participation.

The social support group was co-led by a clinical psychologist and a master’s level gerontology specialist. Both leaders had experience in the areas of geriatrics and dementia. The topics that were covered included information about dementia (cognitive and behavioral changes, stages of dementia, self-care problems, and behavioral problems), health care issues (medication management, home nursing), obtaining community and government resources, caregiver’s reactions to their role, dealing with problem behaviors, reducing stress, dealing with nursing home placement, and issues of death and loss. The co-leaders introduced the topics and presented relevant material for background and discussion. The last third of
each group session was unstructured, allowing for group members to interact with one another and the co-leaders. Group members were encouraged to discuss their own situations and offer support and encouragement to each other. Questions or issues that were raised during this part of the session were handled on a group basis, without formal models or plans being presented by the leaders. Although the topics of managing problem behaviors and reducing stress were discussed, they received no particular emphasis compared to the other topics. Both groups received the same educational components regarding dementia.

The cognitive-behavioral treatment group followed a specific treatment outline that incorporated education, behavior management training, and cognitive-behavioral stress management training (see Appendix E). It was co-led by a clinical psychologist and a psychology intern. The first four sessions focused primarily on the use of behavioral techniques to manage problematic behaviors in dementia patients. The framework and content of these sessions are based on Pinkston and Linsk’s (1984) review of behavioral management with elderly populations and components of Forehand and McMahon’s (1982) parent training protocol. Session 1 included an introduction of the group format and rationale, a didactic on the proposed etiologies and general course of Alzheimer’s disease, a review of behavioral problems associated with dementia, and an introduction to behavioral monitoring. At the beginning of this session, group members completed the
Dementia Quiz to establish a baseline for knowledge of dementia and related issues. At the end of the session the quiz was re-administered and reviewed with the group to ensure a consistent knowledge level of dementia and dementia-related issues. In Session 2 the rationale for behavioral interventions was expanded and a brief didactic on the principles of social learning theory and behavior management was presented. During this session subjects were encouraged to present specific behaviors that they had identified as problematic. The group leader then formulated several of these behaviors in terms of likely antecedents and consequences. Session 3 began with a review of behavioral and learning principles and feedback regarding monitoring. The remainder of the session focused on the influence of environmental factors in the initiation and maintenance of behavioral disturbances and the application of environmental manipulation for specific problems. Subjects were instructed to identify one or two of the most disturbing behaviors related to the person they were caring for to target for behavioral intervention. Subjects were also instructed to expand their monitoring to include behavioral strategies attempted and the results of the intervention. Session 4 included a discussion of communication principles and techniques, and an introduction of specific behavioral management strategies. The use of positive and negative reinforcement techniques for specific dementia behaviors was discussed. This included using specific examples presented by group members. Sessions 5 through 7 focused on
stress management. The stress management protocol was based on adaptations from Meichenbaum's Stress Inoculation Training (Meichenbaum, 1990). Session 5 included a didactic on the concept of stress and its impact. This involved defining characteristics of stressful situations, an overview of stress responses, and the identification of specific stressors. A rationale for using relaxation was presented and a progressive muscle relaxation exercise was introduced. Subjects were given cassette tapes that included both a 16-muscle group and a 7-muscle group protocol. They were instructed to practice the 16-muscle protocol daily until the next session. In Session 6, cognitive factors related to stress were discussed. This included a didactic on various coping strategies and cognitive factors related to the stress response. Group members were encouraged to identify coping methods that they frequently used as well as their automatic thoughts and responses to stressful events. Session 7 focused on the description and use of problem-solving to manage stress. A problem-solving model was presented using examples from group members and group feedback. Session 8 included a review of the major principles of the program and specific problem-solving. As part of the review, the rationale for using both stress management and behavioral techniques was reiterated and group members' questions were discussed.

During the course of all the group sessions in the cognitive-behavioral condition, the previous week's topic was reviewed, individual progress was
monitored (through homework and subject feedback), and additional information regarding dementia was provided as requested. After the initial instruction in progressive muscle relaxation and relaxed breathing, subjects were encouraged to choose a preferred method and use it as part of their stress management strategy. Subjects returned on the ninth week and one month post-treatment to complete post-treatment and follow-up measures. A 24-hour urine sample was also obtained on both occasions. All urine samples were frozen immediately upon arrival to the study site. After the last sample was collected, all samples were brought to the University Medical Center endocrinology laboratory for analysis of cortisol level.

Both group conditions were audiotaped for at least 80% of every session. The tapes were reviewed by a clinical psychologist who was not involved in the session. The sessions were evaluated on the percentage of that week's topics that were covered. This percentage was based on the number of topic items covered divided by the number of designated items in that session (see Appendix F).
RESULTS

The primary focus of this study was to determine the relative effectiveness of two group interventions in reducing caregiver distress and burden. Therefore the primary analyses were repeated-measures multivariate analyses of variance (MANOVA). Prior to these analyses, the assumptions of normality, independence of observations, and homogeneity of variance were assessed. Even though multivariate procedures have been demonstrated to be robust to moderate departures from multivariate normality addressing the above assumptions reduces the likelihood of inflated type I error thereby increasing statistical power (Stevens, 1992; Tabachnick & Fidell, 1989). Because the two groups within each treatment condition were close in size (CBT n=11, n=9; SSG n=8, n=7) and the groups were conducted according to an established agenda, individual observations within each condition are presumed to be independent (Stevens, 1992). Normality was assessed by examining skewness and kurtosis of the outcome variables. Absolute values of skewness and kurtosis were within acceptable limits for the majority of the variables except for the Appraisal and Esteem scales of the Interpersonal Support Evaluation List (ISEL), and the Self-Criticism scale of the Coping Strategies Inventory (CSI). A square-root transformation was utilized to normalize their respective distributions. Finally, the assumption of homogeneity of variance and covariance was tested using Bartlett’s-Box
statistic. None of the variables were significant on this statistic indicating normality of variances, therefore no further transformations were conducted.

The two treatment groups were compared on sociodemographic characteristics and caregiving parameters by t-tests or chi-square tests. There were no significant group differences in age, sex, race, marital status, or education (see Table 2). The groups did differ on employment status ($\chi^2(1) = 3.84, p = .05$), with more members from the social support condition being employed (70% for SSG compared to 40% for CBT). Comparisons of caregiving variables are presented in Table 3. There were no significant group differences in years of caregiving, relation to the patient, assistance with caregiving from others, who assists with caregiving, hours a day spent caregiving, and previous assistance from other dementia agencies (e.g., Alzheimer’s Disease Association). These measures were assessed again at post-treatment and follow-up and had not changed significantly over the course of the study.

The groups did differ on whether or not they lived with the patient ($\chi^2(1) = 5.84, p = .016$). Eighty-five percent of the cognitive behavioral group lived with the patient, compared to 47% in the social support condition. They also differed on reported frequency of problem behaviors (RMBPC-F; $t = 2.81, p = .008$). The CBT group reported a higher frequency of dementia related behaviors during the week prior to the first session, than did members of the SSG. This occurred despite efforts to have
Table 3.
Baseline Caregiving Variables for CBT and SSG Group Members.

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<td>4 20</td>
<td>3 20</td>
</tr>
<tr>
<td>daughter</td>
<td>7 35</td>
<td>8 53</td>
</tr>
<tr>
<td>son</td>
<td>3 15</td>
<td>1 7</td>
</tr>
<tr>
<td>in-law</td>
<td>2 10</td>
<td>2 13</td>
</tr>
<tr>
<td>other</td>
<td>4 20</td>
<td>1 7</td>
</tr>
<tr>
<td>Live w/Pt.?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>3 15</td>
<td>8 53</td>
</tr>
<tr>
<td>yes</td>
<td>17 85</td>
<td>7 47</td>
</tr>
<tr>
<td>Assist from Others?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>2 10</td>
<td>3 20</td>
</tr>
<tr>
<td>yes</td>
<td>18 90</td>
<td>12 80</td>
</tr>
<tr>
<td>Who Assists?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>spouse</td>
<td>4 21</td>
<td>0 0</td>
</tr>
<tr>
<td>daughter</td>
<td>1 5</td>
<td>0 0</td>
</tr>
<tr>
<td>other relative</td>
<td>3 16</td>
<td>7 50</td>
</tr>
<tr>
<td>friend</td>
<td>0 0</td>
<td>1 7</td>
</tr>
<tr>
<td>sitter</td>
<td>8 42</td>
<td>3 21</td>
</tr>
<tr>
<td>no one</td>
<td>2 11</td>
<td>3 21</td>
</tr>
<tr>
<td>n/a</td>
<td>1 5</td>
<td>0 0</td>
</tr>
<tr>
<td>Assist/Day (hours)</td>
<td>9.47 8.88</td>
<td>4.63 6.77 2.89 1</td>
</tr>
<tr>
<td>Other Assistance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>no</td>
<td>15 75</td>
<td>11 73</td>
</tr>
<tr>
<td>yes</td>
<td>4 20</td>
<td>4 27</td>
</tr>
<tr>
<td>n/a</td>
<td>1 5</td>
<td></td>
</tr>
<tr>
<td>Freq. of Dem. Beh. (RMBPC-F)</td>
<td>50.7 12.86</td>
<td>38.3 12.68 2.81 32</td>
</tr>
</tbody>
</table>

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similar groups based in-part on the care recipients’ dementia level. These
two findings may be related, because CBT caregivers were more likely to
live with their patient they may also have been exposed to higher rates of
dementia behaviors.

While the differences between the groups in the areas of employment
and living with the patient were statistically significant, neither of these
variables was significantly correlated with the treatment variables or other
baseline variables of interest (see Table 4). The baseline RMBPC-F was
correlated with some of the outcome variables and was statistically controlled
for in subsequent analyses.

A MANOVA was conducted in order to identify any baseline
differences on the outcome variables. There was no overall difference
between the groups (F = 1.73, p = .163). Table 5 shows the means and
standard deviations for the two treatment groups on the outcome variables
Baseline urinary cortisol levels were also compared between the two groups.
There was a significant difference between the two groups (t=2.03, p = .05)
with the CBT group having a higher baseline cortisol level than the SSG.
The range of values was from 1.15 to 13.10 (see Table 6), compared to the
normal range for adults of 1.0 to 7.0 (Merck Manual, 1977). Six
individuals in the CBT group were in the high normal or above normal range
compared to one individual in the SSG.
Table 4  

Baseline Correlation Matrix: Selected Demographic and Outcome Variables.

<table>
<thead>
<tr>
<th></th>
<th>Employ</th>
<th>CgLive</th>
<th>Cortisol</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employ</td>
<td>0.040  (p=.89)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CgLive</td>
<td></td>
<td>0.327  (p=.25)</td>
<td>0.268  (p=.35)</td>
</tr>
<tr>
<td>Cortisol</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.602 (p=.02)</td>
<td>0.257  (p=.36)</td>
<td>-0.400 (p=.16)</td>
</tr>
<tr>
<td>CBI</td>
<td>0.295  (p=.29)</td>
<td>0.222  (p=.43)</td>
<td>-0.017 (p=.95)</td>
</tr>
<tr>
<td>GDS</td>
<td>0.419  (p=.12)</td>
<td>0.483  (p=.07)</td>
<td>0.259  (p=.37)</td>
</tr>
<tr>
<td>RMBPC-R</td>
<td>-0.047 (p=.87)</td>
<td>-0.083 (p=.77)</td>
<td>-0.041 (p=.89)</td>
</tr>
<tr>
<td>STPI-ANG</td>
<td>0.164  (p=.56)</td>
<td>-0.278 (p=.32)</td>
<td>0.284  (p=.33)</td>
</tr>
<tr>
<td>STPI-ANX</td>
<td>0.119  (p=.67)</td>
<td>0.118  (p=.68)</td>
<td>-0.044 (p=.88)</td>
</tr>
<tr>
<td>ISEL-Appraise</td>
<td>-0.410 (p=.13)</td>
<td>-0.025 (p=.93)</td>
<td>-0.545 (p=.04)</td>
</tr>
<tr>
<td>ISEL-Belong</td>
<td>0.154  (p=.58)</td>
<td>-0.361 (p=.19)</td>
<td>0.174  (p=.55)</td>
</tr>
<tr>
<td>ISEL-Esteem</td>
<td>0.172  (p=.54)</td>
<td>-0.137 (p=.63)</td>
<td>-0.243 (p=.40)</td>
</tr>
<tr>
<td>ISEL-Tangible</td>
<td>0.101  (p=.72)</td>
<td>-0.109 (p=.69)</td>
<td>-0.160 (p=.58)</td>
</tr>
<tr>
<td>ISEL-Total</td>
<td>-0.059 (p=.84)</td>
<td>-0.474 (p=.08)</td>
<td>-0.502 (p=.07)</td>
</tr>
<tr>
<td>CSI-Cog-Restr.</td>
<td>-0.169 (p=.55)</td>
<td>0.085  (p=.76)</td>
<td>0.407  (p=.15)</td>
</tr>
<tr>
<td>CSI-Prob.-Solv.</td>
<td>-0.065 (p=.82)</td>
<td>0.054  (p=.85)</td>
<td>0.033  (p=.91)</td>
</tr>
<tr>
<td>CSI-Expr-Emot.</td>
<td>-0.112 (p=.69)</td>
<td>-0.068 (p=.81)</td>
<td>-0.201 (p=.49)</td>
</tr>
<tr>
<td>CSI-Soc. Supp.</td>
<td>-0.243 (p=.38)</td>
<td>0.385  (p=.16)</td>
<td>0.150  (p=.61)</td>
</tr>
<tr>
<td>CSI-Prob. Av.</td>
<td>0.172  (p=.54)</td>
<td>0.059  (p=.84)</td>
<td>0.431  (p=.12)</td>
</tr>
<tr>
<td>CSI-Soc. With.</td>
<td>0.380  (p=.16)</td>
<td>-1.34  (p=.63)</td>
<td>0.385  (p=.17)</td>
</tr>
<tr>
<td>CSI-Wish. Think</td>
<td>0.312  (p=.26)</td>
<td>0.283  (p=.31)</td>
<td>0.284  (p=.33)</td>
</tr>
<tr>
<td>CSI-Self-Crit.</td>
<td>0.179  (p=.52)</td>
<td>-0.039 (p=.89)</td>
<td>0.104  (p=.72)</td>
</tr>
</tbody>
</table>

Note: GDS=Geriatric Depression Scale, RMBPC-F=Revised Memory and Behavior Problems Checklist-Frequency, CBI=Caregiver Inventory, RMBPC-R=Revised Memory and Behavior Problems Checklist-Reaction, STPI-ANG=State-Trait Personality Inventory-Trait Anger, STPI-ANX=State-Trait Personality Inventory-Trait Anxiety, ISEL=Interpersonal Support Evaluation List, CSI=Coping Strategies Inventory.
Table 5. Baseline MANOVA: Means and Standard Deviations of Outcome Variables and Covariates.

<table>
<thead>
<tr>
<th>Variable</th>
<th>CBT Mean S.D.</th>
<th>SSG Mean S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>53.5 11.3</td>
<td>48.7 9.6</td>
</tr>
<tr>
<td>GDS</td>
<td>13.21 6.56</td>
<td>13.35 10.46</td>
</tr>
<tr>
<td>CBI</td>
<td>41.70 14.19</td>
<td>34.93 11.50</td>
</tr>
<tr>
<td>RMBPC-R</td>
<td>32.11 15.91</td>
<td>24.80 16.04</td>
</tr>
<tr>
<td>STPI-ANG</td>
<td>17.85 4.59</td>
<td>15.27 2.92</td>
</tr>
<tr>
<td>STPI-ANX</td>
<td>18.80 5.58</td>
<td>22.13 5.94</td>
</tr>
<tr>
<td>ISEL Appraise</td>
<td>15.11 3.53</td>
<td>14.29 2.89</td>
</tr>
<tr>
<td>ISEL Belong</td>
<td>14.30 1.75</td>
<td>14.20 2.83</td>
</tr>
<tr>
<td>ISEL Esteem</td>
<td>16.26 2.31</td>
<td>14.86 2.32</td>
</tr>
<tr>
<td>ISEL Tangible</td>
<td>14.95 2.35</td>
<td>14.73 1.44</td>
</tr>
<tr>
<td>ISEL Total</td>
<td>60.60 6.90</td>
<td>57.93 3.37</td>
</tr>
<tr>
<td>CSI Cog-Restr.</td>
<td>29.15 6.65</td>
<td>27.40 6.85</td>
</tr>
<tr>
<td>CSI Prob.-Solv.</td>
<td>30.45 5.84</td>
<td>29.07 6.55</td>
</tr>
<tr>
<td>CSI Expr-Emot.</td>
<td>24.00 6.53</td>
<td>20.80 5.28</td>
</tr>
<tr>
<td>CSI Soc. Supp.</td>
<td>27.10 6.24</td>
<td>25.40 7.97</td>
</tr>
<tr>
<td>CSI Prob. Av.</td>
<td>17.00 3.28</td>
<td>17.33 3.92</td>
</tr>
<tr>
<td>CSI Soc. With.</td>
<td>21.15 5.34</td>
<td>22.40 8.04</td>
</tr>
<tr>
<td>CSI Wish. Think</td>
<td>24.15 7.77</td>
<td>24.06 6.14</td>
</tr>
<tr>
<td>CSI Self-Crit.</td>
<td>18.53 7.62</td>
<td>14.29 6.02</td>
</tr>
</tbody>
</table>

Note: GDS = Geriatric Depression Scale, RMBPC-F = Revised Memory and Behavior Problems Checklist-Frequency, CBI = Caregiver Inventory, RMBPC-R = Revised Memory and Behavior Problems Checklist-Revised, STPI-ANG = State-Trait Personality Inventory-Trait Anger, STPI-ANX = State-Trait Personality Inventory-Trait Anxiety, ISEL = Interpersonal Support Evaluation List, CSI = Coping Strategies Inventory

MANOVA by Treatment Condition:

D.F. (1,33) \( F = 1.733 \) \( p = .163 \) 

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### Table 6.

**Baseline Urinary Cortisol Values by Group.**

<table>
<thead>
<tr>
<th>CBT Urinary Cortisol $\mu g/dL$</th>
<th>SSG Urinary Cortisol $\mu g/dL$</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.17</td>
<td>1.23</td>
</tr>
<tr>
<td>1.87</td>
<td>1.15</td>
</tr>
<tr>
<td>3.71</td>
<td>1.59</td>
</tr>
<tr>
<td>1.97</td>
<td>1.81</td>
</tr>
<tr>
<td>2.12</td>
<td>4.14</td>
</tr>
<tr>
<td>5.31</td>
<td>5.06</td>
</tr>
<tr>
<td>3.12</td>
<td>3.20</td>
</tr>
<tr>
<td>2.43</td>
<td>1.42</td>
</tr>
<tr>
<td>6.84</td>
<td>0.87*</td>
</tr>
<tr>
<td>2.53</td>
<td>2.21</td>
</tr>
<tr>
<td>1.42</td>
<td>3.21</td>
</tr>
<tr>
<td>6.84</td>
<td>1.25</td>
</tr>
<tr>
<td>2.53</td>
<td>1.22</td>
</tr>
<tr>
<td>1.42</td>
<td>4.14</td>
</tr>
<tr>
<td>1.72</td>
<td>CBT mean = 3.86, S.D. = 3.06</td>
</tr>
<tr>
<td>7.15</td>
<td>SSG mean = 2.32, S.D. = 1.37</td>
</tr>
<tr>
<td>5.97</td>
<td>* = value too low to be reliable, not used in analysis</td>
</tr>
<tr>
<td>3.57</td>
<td></td>
</tr>
<tr>
<td>1.29</td>
<td></td>
</tr>
<tr>
<td>0.30*</td>
<td></td>
</tr>
<tr>
<td>13.10</td>
<td></td>
</tr>
</tbody>
</table>
In order to assess the clinical significance of the pre-treatment and subsequent scores and compare the current sample with other caregiver samples, mean scores were compared with normative data or previously reported scores for the CBI, GDS, STPI-ANG, and STPI-ANX. The mean score for the GDS was 13.17, which is in the mildly depressed range (Yesavage et al., 1983). The mean for the STPI-ANG was 16.74 which is at the 53rd percentile for adults over 33 years old. The mean for the STPI-ANX was 20.23, which is at 73rd percentile for adults over 33 years old. Finally, the mean CBI score was compared with previous studies of caregivers of dementia patients. The mean CBI score in this study was 38.8 which is very similar to previous studies (mean 42.73; Zarit et al., 1987; 43.9; Toseland et al., 1990).

Four aspects of the treatment process were assessed to control for any effects not due to the treatments and to insure treatment reliability and integrity. The four areas were, dementia knowledge, participant satisfaction, attendance, and reliability ratings of group content.

The groups were given the Dementia Questionnaire before and after the dementia education component of both groups. The groups’ pre-education scores were not significantly different (mean CBT = 8.86, mean SSG = 9.50) and both groups improved significantly from pre to post-education (CBT, t = -3.44, p = .004; SSG, t = -2.71, p = .024). The final mean scores were CBT = 10.2 and SSG = 10.7 out a possible 11.
The two groups' attendance rates were also not significantly different (CBT = 6.7, SSG = 6.07).

Participant satisfaction was used as a measure of treatment credibility and acceptability. It was assessed two times during the treatment, at the beginning of session 3 and session 8. Both groups gave high ratings of satisfaction that remained similar over the course of the treatment. The CBT group's mean ratings, out of a possible 49, were 45.41 and 46.42 respectively. The SSG's mean ratings were 44.67 and 46.08. Using independent and paired t-tests indicated no significant differences between or within the groups.

Finally, treatment reliability was addressed in two ways, analysis of treatment delivery and within session monitoring. The content of the group sessions was rated by an independent judge who was not present during any of the group sessions. The ratings were based on the designated content for that session and scored according to whether specific items were addressed or not (see Appendix F). Each group session was audiotaped and reviewed by the rater. Overall reliability for both treatment conditions was between 92 and 100% (see Table 7). In an effort to minimize the possibility of overlap in content between groups, one of the investigators was present in both groups. This individual monitored each session and intervened when the discussion or presentation in either condition overlapped with the other treatment.
Table 7.

<table>
<thead>
<tr>
<th></th>
<th>CBT</th>
<th>SSG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session 1</td>
<td>95</td>
<td>100</td>
</tr>
<tr>
<td>Session 2</td>
<td>100</td>
<td>94</td>
</tr>
<tr>
<td>Session 3</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Session 4</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Session 5</td>
<td>95</td>
<td>100</td>
</tr>
<tr>
<td>Session 6</td>
<td>92</td>
<td>92</td>
</tr>
<tr>
<td>Session 7</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Session 8</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>
In order to test the first two hypotheses regarding the relative
effectiveness of the two treatment groups and identify the aspects of caregiver
functioning most affected by the treatments, repeated measures analyses were
conducted. The outcome variables were divided into four groups for these
analyses. This was done to maximize the power of each analysis based on
domain of functioning assessed and expected effect size (Stevens, 1992). The
groups of variables analyzed were as follows: Measures of burden and
distress: CBI, GDS, RMBPC-R, STPI-ANG, and STPI-ANX. Social
support; ISEL subscales Appraisal, Belonging, Esteem, Tangible, and Total
Support. Coping strategies; CSI subscales Cognitive-Restructuring,
Problem-Solving, Express Emotions, Social Support, Problem Avoidance,
Social Withdrawal, Wishful Thinking, and Self-Criticism. Because cortisol is
a physiological variable and has never been assessed in this type of study it
was analyzed in a separate series of analyses (Stevens, 1992).

Analysis of covariance was chosen for two reasons, to control
systematic bias, and reduce within group variance. By controlling for
systematic differences between the groups more statistical power is obtained
increasing the likelihood that any differences between the groups will be due
to treatment effects (Tabachnick & Fidell, 1989). The number of covariates
chosen was based on a ratio of the number of groups and sample size
calculated to maximize power without creating unstable adjusted means
(Huitema, 1980). Three covariates were selected, frequency of problem
behaviors (RMBPC-F), age, and baseline depression (GDS). The RMBPC-F was chosen because of significant baseline differences between the groups and because of previously demonstrated correlations between dementia-behaviors and measures of burden and distress (Teri et al., 1992). Age and baseline depression were chosen because it was hypothesized that they could impact the effectiveness of the treatment interventions. All three variables also met the criterion of relatively low inter-correlation (< .80; Stevens, 1992).

A 2 (Group) by 3 (Time) MANCOVA of the measures of caregiver burden and distress was conducted. There was no significant treatment or treatment by time effect (treatment, \( F = 2.53, p = .068 \); treatment by time, \( F = 1.86, p = .118 \)). There was a significant time effect (\( F = 3.56, p = .009 \)) indicating that subjects in both groups reported significantly less burden and distress over the course of treatment and follow-up period.

Perceived social support and coping strategies were also analyzed in separate 2 (Group) by 3 (Time) MANCOVA's. There was no significant treatment or treatment by time effect on the subscales of the ISEL (treatment, \( F = .609, p = .660 \); treatment by time, \( F = 1.18, p = .354 \)). There was a significant time effect (\( F = 79.99, p < .001 \)) indicating an increase in perceived social support over the course of the study.

Analysis of the CSI subscales yielded similar results. There were no significant effects for treatment or treatment by time (treatment, \( F = .503, p \)
time effect ($F = 14.38, p < .001$). To further explore the potential changes in coping, the subscales of the CSI were re-analyzed in groups of four according to the two tertiary subscales, engagement and disengagement. This was done because improved coping could be due to increased engagement (i.e., increased scores on Problem-solving, Cognitive-restructuring, Social support, Express emotions) and/or decreased disengagement (i.e., decreased scores on Problem-avoidance, Social withdrawal, Self-criticism, Wishful thinking). If both of these changes occurred there could be an attenuation of statistical effects. Repeated measures analysis of the four active engagement subscales did not yield any significant effects for treatment, treatment by time, or time. There was, however, a significant time effect for the analysis of the four disengagement subscales ($F = 18.65, p < .001$), indicating a significant decrease on these subscales over the course of treatment.

Urinary cortisol was also analyzed in repeated-measures fashion. Because there was a baseline difference, an ANCOVA model was used with baseline cortisol as the covariate. There were no significant treatment, time or, treatment by time effects (treatment $F = .651, p = .529$; time $F = 3.00, p = .093$; treatment by time $F = .18, p = .675$).

The third hypothesis, that changes observed in the CBT group would be maintained at one-month follow-up could not be directly tested because of
the lack of a treatment effect. However, because of the changes observed over time (i.e., time-effects) further analyses of within subjects factors were conducted.

In order to obtain more information regarding the significant time effects a series of paired t-tests with all subjects in one group was conducted (see Table 8). The t-tests using all of the subjects was done to further explore which variables changed, and at what stage of the study the change occurred. To do this variables were compared between baseline and post-treatment, post-treatment and follow-up, and baseline and follow-up. Alpha was set at .01 to minimize the chance of inflated type I error.

The results of the paired t-tests for all subjects are presented in table 8. Among the measures of burden and distress only caregiver burden (CBI) and reaction to dementia behaviors (RMBPC-R) changed significantly during the active treatment phase. These changes were maintained, as evidenced by the significant differences between baseline and follow-up. Both changes were in the positive direction (i.e., decrease in burden and negative reactions).

All five of the subscales of the ISEL displayed statistically significant increases over the course of the treatment. These changes were also maintained at follow-up when compared to their baseline values. This indicates that all facets of perceived social support that were assessed were positively impacted by the two interventions.
Table 8.

Means and Standard Deviations of Outcome Variables, Pre-treatment, Post-treatment, and Follow-up: Groups combined.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pre</th>
<th>S.D.</th>
<th>Mean</th>
<th>S.D.</th>
<th>Post</th>
<th>S.D.</th>
<th>Mean</th>
<th>S.D.</th>
<th>F/U</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>GDS</td>
<td>13.27</td>
<td>8.29</td>
<td>12.30</td>
<td>8.03</td>
<td>14.53</td>
<td>17.34</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CBI</td>
<td>39.06</td>
<td>13.60</td>
<td>34.45</td>
<td>12.83</td>
<td>32.34</td>
<td>12.58</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RMBPC-R</td>
<td>28.88</td>
<td>16.15</td>
<td>19.68</td>
<td>15.18</td>
<td>15.39</td>
<td>14.32</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>STPI-ANG</td>
<td>16.79</td>
<td>4.17</td>
<td>16.21</td>
<td>5.07</td>
<td>16.22</td>
<td>5.39</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>STPI-ANX</td>
<td>20.03</td>
<td>5.14</td>
<td>19.27</td>
<td>6.09</td>
<td>18.41</td>
<td>6.17</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>ISEL</td>
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</table>

Note: GDS=Geriatric Depression Scale, RMBPC-F=Revised Memory and Behavior Problems Checklist-Frequency, CBI=Caregiver Inventory, RMBPC-R=Revised Memory and Behavior Problems Checklist-Reaction, STPI-ANG=State-Trait Personality Inventory-Trait Anger, STPI-ANX=State-Trait Personality Inventory-Trait Anxiety, ISEL=Interpersonal Support Evaluation List, CSI=Coping Strategies Inventory

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Coping strategies were not as widely affected by the treatments. Only the Social Withdrawal and Wishful Thinking subscales of the CSI, displayed any changes over time. Social Withdrawal decreased significantly from post-treatment to follow-up indicating a decrease in reported use of withdrawal as a coping strategy. Wishful Thinking decreased between baseline and post-treatment and remained lower at follow-up. Therefore, the treatments did not increase active coping strategies but appear to have reduced the use of avoidant, disengagement strategies.

Tables 9 and 10 show the means and standard deviations of the outcome variables for each group. While the lack of a significant treatment effect does not permit formal post-hoc analyses, examination of changes within the groups gives a further indication how the groups changed over time.

Both groups had a decrease in caregiver burden over the course of the study. The CBT group seemed to change most from baseline to follow-up, whereas the SSG changed from baseline to post-treatment. The SSG also had a more notable decrease in reaction to problem behaviors over time.

Both groups appeared to have changed in a similar way with regard to perceived social support (ISEL scales). The SSG also displayed greater reductions in social withdrawal and wishful thinking, on the CSI.

The cortisol data were also examined. In this comparison the CBT group’s mean cortisol decreased markedly from baseline to post-treatment.
Table 9.

Means and Standard Deviations of Outcome Variables for CBT: Pretreatment, Post-treatment, and Follow-up.

<table>
<thead>
<tr>
<th>Variable</th>
<th>CBT</th>
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<tr>
<td></td>
<td></td>
<td>Pre</td>
<td>Post</td>
<td>F/U</td>
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<td>S.D.</td>
<td>Mean</td>
<td>S.D.</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Appraise</td>
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<td>23.79*</td>
<td>5.93</td>
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<tr>
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<td>6.78</td>
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</table>

Note: Values with different superscripts are significantly different at p < .01. GDS=Geriatric Depression Scale; RMBPC-F=Revised Memory and Behavior Problems Checklist-Frequency, CBI=Caregiver Inventory, RMBPC-R=Revised Memory and Behavior Problems Checklist-Reaction, STPI-ANG=State-Trait Personality Inventory-Trait Anger, STPI-ANX=State-Trait Personality Inventory-Trait Anxiety, ISEL=Interpersonal Support Evaluation List, CSI=Coping Strategies Inventory.
Table 10.

Means and Standard Deviations of Outcome Variables for SSG: Pretreatment, Post-treatment, and Follow-up.

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<th></th>
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<td>Pre</td>
<td>Post</td>
<td>F/U</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mean S.D</td>
<td>Mean S.D</td>
<td>Mean S.D</td>
</tr>
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</tr>
<tr>
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<td>4.27</td>
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Note: Values with different superscripts are significantly different at p < .01. GDS=Geriatric Depression Scale, RMBPC-F=Revised Memory and Behavior Problems Checklist-Frequency, CBI=Caregiver Inventory, RMBPC-R=Revised Memory and Behavior Problems Checklist-Reaction, STPI-ANG=State-Trait Personality Inventory-Trait Anger, STPI-ANX=State-Trait Personality Inventory-Trait Anxiety, ISEL=Interpersonal Support Evaluation List, CSI=Coping Strategies Inventory.
and remained stable from post-treatment to follow-up. There were no noticeable changes in the SSG over the course of the study (see Table 11). These data are also represented graphically in figure 1. From this graph it is evident that the CBT group started out with higher cortisol levels than the SSG and ended up with similar levels by follow-up.
Table 11.

<table>
<thead>
<tr>
<th>Group</th>
<th>Pre-treatment mean</th>
<th>Pre-treatment S.D.</th>
<th>Post-treatment mean</th>
<th>Post-treatment S.D.</th>
<th>Follow-up mean</th>
<th>Follow-up S.D.</th>
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<td>1.53</td>
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<td>2.13</td>
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</tbody>
</table>

* = CBT group, + = SSG; * indicates significant difference between groups at p < .05, different superscript letters indicate significant differences within a group at p < .05.

Figure 1.

Urinary cortisol means by group at pre-treatment, post-treatment, and follow-up.
DISCUSSION

This study was designed to compare the use of a social support group versus a cognitive-behavioral treatment group for reducing distress in caregivers of dementia patients. It was hypothesized that the cognitive-behavioral approach would lead to greater improvements in measures of caregiver burden, social support, coping strategies, and urinary cortisol. The primary finding was that there were no group differences; neither group was superior in reducing the targeted variables. However, both groups did show significant improvement on several of the treatment variables over the course of treatment and follow-up.

Despite the lack of significant differences between treatment types, the results of this study indicate that both treatment approaches lead to a reduction in caregiver burden, an increase in perceived social support, and decreases in maladaptive coping strategies. Both groups also displayed improvement in dementia knowledge and reported high rates of satisfaction with the treatments. These findings support previous literature suggesting the efficacy of group interventions for caregivers (e.g., Toseland et al., 1990). Findings also suggest that a cognitive-behavioral approach can reduce distress and burden, and increase perceived social support at least as well as a more commonly used group for caregivers.

The reduction of caregiver burden was evidenced by changes in both the CBI and RMBPC-R. While related, these measures represent different
aspects of caregiver burden and functioning. Changes on the CBI indicate that subjects experienced a decrease in the impact of their family member’s behavior on their emotional, physical, and social functioning. While the decrease in RMBPC-R scores is evidence that the caregiver’s negative reactions to problem behaviors also decreased during treatment.

Subjects’ report of social support also changed over the course of treatment. The levels of support for the four subscales and total score of the ISEL increased from baseline to post-treatment. This indicates that subjects’ perception of overall social support increased as well as support in specific domains. These changes represent improvements in areas such as, getting advice in dealing with problems, social companionship, feeling valued by others, and receiving material or effort from others.

Changes in coping strategies were not as widespread, however there were decreases in two of the disengagement strategies during treatment and follow-up. Subjects’ use of wishful thinking as a coping strategy decreased during treatment, indicating less avoidance of problems and unrealistic solutions. There was also a decrease in social withdrawal from post-treatment to follow-up that is consistent with the previously discussed improvements in social support.

In addition to the decrease in caregiver burden and an increase in perceived social support during the course of the study, these changes were
maintained one month post-treatment. Both groups continued to report less caregiver burden and improved social support even after treatment ended.

The results of the analyses for urinary cortisol did not support a treatment effect. However, the CBT group did display a drop in cortisol levels from pre-treatment to post-treatment and pre-treatment to follow-up. These changes lead to post-treatment and follow-up levels that were similar to the SSG. This trend may have occurred for two reasons. First the CBT group may have been experiencing greater stress at the beginning of the study and the intervention may have reduced caregivers' physiological reactions to the chronic stress associated with caregiving as predicted. This was not directly assessed but should be included in future investigations. A second possibility, is because the subjects in the SSG group had lower baseline cortisol levels, little improvement was possible and the CBT group's improvements might represent a regression to the mean. Neither possibility can be confirmed by the current data, and in fact both may have occurred to some extent. Future studies should consider further assessment of subject's subjective reports of daily stress and hassles as well as the initial cortisol levels.

The lack of significant differences between treatments may be due to the difficulties inherent in studying caregivers, namely the variety and complexity of the caregiving role as well as the various levels of caregiver involvement. Specific aspects of caregiving require different skills and
investment of resources, and can lead to different types of burden and distress. For example a daughter who cares for a dementing parent may experience different concerns related to her role than a wife of a dementia patient (e.g., level of financial commitment, obligations to other family members, job, etc.). While these concerns are all components of caregiver burden, they require different interventions. Concerns about finances and availability of community resources may be more effectively dealt with using a social support/informational approach, whereas, managing stress and dealing with problem behaviors can be addressed from a cognitive-behavioral approach.

The potential effects of these differences were not directly assessed in this study, and despite significant pre-treatment efforts to recruit a homogeneous sample, there were differences between and within groups. Between groups there were statistical differences in the areas of employment, living with dementia patient, and frequency of problem behaviors. Within groups there was a range of caregiver involvement and relationship to the dementia patient (i.e. children, spouses, and in-laws). It is possible that these and related differences may have attenuated the treatment effects because of different potential benefits based on the unique needs of the caregiver. Clinically, this issue may require treatment approaches that are even more specifically tailored to specific types of caregivers (e.g., spouse versus child; live-in versus daily caregiver).
A related factor is the characteristics and problems of participants versus those who attempted to participate but were unable to do so. Many initial respondents were never able to even complete the screening process because of scheduling difficulties and/or inability to leave the dementia patient. It is possible that individuals who were able to attend the treatment sessions had a fewer number of stressors or a more adequate social support network compared to the non-attenders (Dura & Klecolt-Glaser, 1990). Thus, individuals who may have needed the treatment the most were unable to participate because of their caregiving situation. One implication of this for future studies would be the allocation of resources to provide caretakers so that family members could attend a group program. Not only would this extend treatment to a presently under-served group but may also illuminate specific treatment components that are necessary for the most significantly involved caregivers.

The lack of treatment differences may also have been due to factors associated with the implementation of the treatments. The CBT was designed to facilitate the acquisition of specific behavioral management and coping skills. The SSG was designed to provide support and information about the caregiving role. Because of these differences the implementation of the groups was different. The CBT was more directive, with an established set of information to be covered and skills to be applied. In contrast, the more
limited agenda of the SSG allowed for more individual participation and
discussion of topics important to the group.

Related to the differences in group format and structure is the fact that
the skills introduced in the CBT group may not have been immediately
understood or applied by the participants. This may have occurred for two
reasons, subjects’ expectations for immediate assistance with their situation,
and difficulties associated with learning alternative coping skills and
behavioral techniques. Even though many group interventions have been
conducted over a similar number of sessions, the dual goal of teaching
behavioral management and coping with stressors may require more time for
instruction and application.

One final factor that may have affected the results is the limited
number of subjects. Despite rigorous recruiting for over six months, using
media announcements, physician referrals, and presentations to community
groups, only 35 caregivers were qualified and available at the beginning of
treatment. Two of these were unable to complete the study because of
personal problems. A power analysis would suggest that over twice this
number of subjects would be needed to detect further differences based on
the effect sizes of the measures. While that was not practical for this study,
future investigations should include more subjects with consideration given to
the use of multiple sites to achieve an adequate sample size.
Even though neither group proved to be superior in reducing distress and burden, subjects in both groups did exhibit improvements during treatment and follow-up. These improvements are likely a result of the overlapping components of the groups. All subjects were formally exposed to information about dementia, its course and associated problems. For many subjects this was the first formal information about dementia they had received. This information may have lead to a better understanding of the problem behaviors and deficits associated with dementia. The increased understanding likely reduced their sense of burden and distress. This information plus exposure to other caregivers also lead to a decrease in avoidant coping strategies like wishful thinking.

The second common component was increased and regular social contact. Subjects in both groups interacted with persons in similar situations which lead to improvements in perceived social support and decreased social withdrawal.

In considering future interventions, the incorporation of a model like Prochaska’s (1992) stages of change, with the above observations may lead to a more effective treatment for caregivers of dementia patients. The stages of change model considers the individual’s readiness to alter his/her behavior in response to their current problems and distress (Prochaska, DiClemente, & Norcross, 1992). This model has been applied to the stages and processes of change in reducing addictive behaviors, promoting healthy behaviors, and
reducing psychological distress (Prochaska & DiClemente, 1985). The stages of change have been identified as pre-contemplation, contemplation, preparation, action, and maintenance (Prochaska et al., 1992).

The stage the individual is in when they approach treatment has been demonstrated to significantly predict treatment success (Prochaska, Norcross, Fowler, Follick, & Abrams, 1992). That is, individuals in pre-contemplation or contemplation are less likely to initiate significant alterations in their behaviors than those that have been actively preparing to do so.

In the case of caregivers, this may be exemplified by an unawareness of the behavioral and environmental aspects of the caregiving situation and an initial interest in obtaining information and relief from their situation. Because of this, the first phase of an intervention should focus on education and efforts at reducing immediate distress. As the caregivers become more aware of the factors involved in caregiving they may become more receptive to identifying and incorporating changes. This would represent a shift to contemplation and action, and lead to opportunities to incorporate behavioral management and coping skills into the treatment. This graded approach would also allow individuals who have never been exposed to group treatments or psychoeducational interventions, to adjust and prepare to obtain the maximum benefit.

In conclusion, family caregivers of dementia patients face many unique and chronic difficulties. They must manage increasingly difficult
behavioral problems, cope with the gradual decline of a loved-one and maintain the usual activities of life. The results of this study indicate that exposure to education and other caregivers can reduce burden and distress and increase social support. Although the cognitive-behavioral approach was not superior in this instance, observations from this study and the application of a stages of change approach may yield a more successful outcome in future studies.
REFERENCES


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*Psychological Assessment*, **1**, 331-338.


Appendix A

MEDICAL/DEMOGRAPHIC QUESTIONNAIRES
Pre-treatment, Post-treatment, and Follow-up versions

110
Follow-Up

DEMOGRAPHIC AND HEALTH INFORMATION

Please complete the following forms. If you have any questions, mark them and we will go over them with you when we see you. All information will be kept strictly confidential.

1. Full Name: _____________________________________________________________________

2. Please indicate the TYPICAL number of drinks you have for each of the following:
   - Number of cups of coffee each day: _______
   - Number of Cokes (sodas) each day: _______
   - Number of cups/glasses of tea each day: _______
   - Number of alcoholic beverages each WEEK: _______
     (beer, wine, & hard liquor)

3. Do you smoke cigarettes? [ ] Yes [ ] No
   If yes, how many packs do you smoke per day? _______

4. Do you engage in regular physical activity? [ ] Yes [ ] No
   If yes, please rate the intensity of your exercise: (circle one)
   Very Light   1  2  3  4  5  6  Very Intense

5. Please list the MEDICATIONS you are taking. Indicate the name of the drug, how often you take it, and the problem you use it for. Please list both prescription and over-the-counter medications, like aspirin or Advil.

<table>
<thead>
<tr>
<th>Name of Medication</th>
<th>How Often Used</th>
<th>Problem Used For</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example: Digitalis</td>
<td>Twice a day</td>
<td>Heart problems</td>
</tr>
</tbody>
</table>
6. People often go through difficult or stressful times (for example, marital separation, financial crises, death of friends or family). How much STRESS have you experienced over the PAST MONTH? (circle one number)

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Stress</td>
<td>Very Little Stress</td>
<td>Mild Stress</td>
<td>Moderate Stress</td>
<td>A lot of Stress</td>
<td>Extreme Stress</td>
</tr>
</tbody>
</table>

7. How well do you feel that you have handled or COPED with stress over the PAST MONTH?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very Poorly</td>
<td>Poorly</td>
<td>Fairly</td>
<td>Pretty Well</td>
<td>Well</td>
<td>Very Well</td>
</tr>
</tbody>
</table>

8. How often have you been able to CONTROL the stress in your life over the PAST MONTH?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>Seldom</td>
<td>Sometimes</td>
<td>Fairly</td>
<td>Very Often</td>
<td>Almost Always</td>
</tr>
</tbody>
</table>

9. Which of these events happened to you SINCE THE STUDY ENDED? (check all that apply)

[] Death of spouse
[] Death of a close family member
[] You were seriously ill
[] Another member of your family was seriously ill
[] You were divorced or separated
[] You moved
[] You retired
[] Major loss of income
[] Trouble with the law

10. Since the study ENDED, have you received other professional assistance for caregiver stress? (for example, Alzheimer's Association Support Groups)

[] Yes  [] No
Describe: ____________________________________________

11. Caregiving information:

a. Are you still the primary caregiver?  [] Yes  [] No
b. Do you presently live with the care-recipient (patient)?  [] Yes  [] No
c. Is there another person(s) who assists you in caring for the patient?  [] Yes  [] No

Who? ____________________________________________

How many hours per day do you have assistance? ________ hours
Has your assistance from others changed since the study ended?  [] Increase  [] Decrease  [] No change
Post-Tx
DEMOGRAPHIC AND HEALTH INFORMATION

Please complete the following forms. If you have any questions, mark them and we will go over them with you when we see you. All information will be kept strictly confidential.

1. Full Name: __________________________________________

2. Please indicate the TYPICAL number of drinks you have for each of the following:
   - Number of cups of coffee each day: _______
   - Number of Cokes (sodas) each day: _______
   - Number of cups/glasses of tea each day: _______
   - Number of alcoholic beverages each WEEK: _______
     (beer, wine, & hard liquor)

3. Do you smoke cigarettes? [] Yes [] No
   If yes, how many packs do you smoke per day? _______

4. Do you engage in regular physical activity? [] Yes [] No
   If yes, please rate the intensity of your exercise: (circle one)
   
   1  2  3  4  5  6
   Very Light Moderate Very Intense

5. Please list the MEDICATIONS you are taking. Indicate the name of the drug, how often you take it, and the problem you use it for. Please list both prescription and over-the-counter medications, like aspirin or Advil.

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</thead>
<tbody>
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<td>Heart problems</td>
</tr>
</tbody>
</table>
18. People often go through difficult or stressful times (for example, marital separation, financial crises, death of friends or family). How much STRESS have you experienced over the past SIX MONTHS? (circle one number)

0  1  2  3  4  5  
No Stress Very Little Mild Moderate A lot of Extreme Stress Stress Stress Stress Stress

19. How well do you feel that you have handled or COPED with stress over the past SIX MONTHS?

1  2  3  4  5  6  
Very Poorly Poorly Fair Pretty Well Well Very Well

20. How often have you been able to CONTROL the stress in your life over the past SIX MONTHS?

1  2  3  4  5  6  
Never Seldom Sometimes Fairly Very Often Almost Often Always

21. Have you sought assistance for caregiver stress in the past? [ ] Yes [ ] No
(for example, Alzheimer’s Association Support Groups)
Describe:__________________________________________

22. Caregiving information:
   a. Relationship to care-recipient (e.g., spouse, daughter, friend, etc.):_____________________
   b. How long have you been the primary caregiver? _______________________
   c. Do you live with the care-recipient (patient)? [ ] Yes [ ] No
   d. Is there another person(s) who assists you in caring for the patient? [ ] Yes [ ] No
   Who? _____________________________________________________________
   How many hours per day do you have assistance? ________ hours
15. Please list the MEDICATIONS you are taking. Indicate the name of the drug, how often you take it, and the problem you use it for. Please list both prescription and over-the-counter medications, like aspirin or Advil.

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<th>Problem Used For</th>
</tr>
</thead>
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<td>Heart problems</td>
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</tr>
</tbody>
</table>

16. How often do you feel that you have enough money for: (circle response)

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Almost</td>
<td>Never</td>
<td>Some-</td>
<td>Times</td>
</tr>
</tbody>
</table>

a. Food ......... 1  2  3  4
b. Housing ........ 1  2  3  4
c. Clothing ...... 1  2  3  4
d. Medical Care ... 1  2  3  4
e. Medicine ....... 1  2  3  4
f. Small extras ... 1  2  3  4

17. Which of these events happened to you in the last SIX MONTHS? (check all that apply)

[] Death of spouse
[] Death of a close family member
[] You were seriously ill
[] Another member of your family was seriously ill
[] You were divorced or separated
[] You moved
[] You retired
[] Major loss of income
[] Trouble with the law
11. Below is a list of common illnesses. Next to each illness, circle the number which best describes you. Please do not skip any.

<table>
<thead>
<tr>
<th></th>
<th>(0)</th>
<th>(1)</th>
<th>(2)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Do Not Have</td>
<td>Have It But Not Taking Medication</td>
<td>Have It and Taking Medication</td>
</tr>
<tr>
<td>1. Allergies</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2. Anemia (low blood)</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3. Arthritis or Rheumatism</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4. Asthma</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5. Bladder Trouble or Urine Leakage</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>6. Bowel Trouble</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>7. Broken Bones</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>8. Cancer</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>9. Cataracts or Glaucoma</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>10. Chronic back or neck pain</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>11. Circulation Trouble in Arms or Legs</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>12. Diabetes (high sugar)</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>13. Emphysema</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>14. Emotional Disorder (nervous or depression)</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>15. Epilepsy or Seizures</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>16. Encephalitis</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>17. Foot Troubles</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>18. Heart Trouble</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>19. Hepatitis</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>20. High Blood Pressure</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>21. Kidney Disease</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>22. Liver Disease</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>23. Mitral Valve Prolapse</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>24. Osteoporosis</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>25. Parkinson's Disease</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>26. Pressure Sores</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>27. Sexual Difficulties</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>28. Stroke</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>29. Thyroid Disease or other Hormone Disorder</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>30. Tuberculosis</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>31. Ulcers, Stomach or Intestinal Trouble</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>32. Other</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

12. Please indicate the TYPICAL number of drinks you have for each of the following:

- Number of cups of coffee each day: _______
- Number of Cokes (sodas) each day: _______
- Number of cups/glasses of tea each day: _______
- Number of alcoholic beverages each WEEK: _______
  (beer, wine, & hard liquor)

13. Do you smoke cigarettes? [ ] Yes [ ] No
   If yes, how many packs do you smoke per day? _______

14. In the past, have you ever been treated for: depression? [ ] Yes [ ] No
   "nervous"? [ ] Yes [ ] No

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DEMOGRAPHIC AND HEALTH INFORMATION

Please complete the following forms. If you have any questions, mark them and we will go over them with you when we see you. All information will be kept strictly confidential.

1. Full Name: _________________________________________ 2. Sex: M F 3. Age: ___

4. Address: ___________________________________________

5. Telephone numbers where you can be reached: Home: ____ Best times: ______

          Work: _______ Best times: ______

6. Marital Status: [] Single, never married [ ] Separated

          [ ] Married [ ] Widowed

          [ ] Divorced [ ] Living with someone


8. Education: [ ] 8th grade or less

          [ ] Some high school

          [ ] High school graduate or GED

          [ ] Some college

          [ ] College graduate

          [ ] Graduate school

9. Are you currently working outside of your home? [ ] Yes [ ] No

Are you retired? [ ] Yes [ ] No

10. Do you engage in regular physical activity? [ ] Yes [ ] No

If yes, please rate the intensity of your exercise: (circle one)


1 2 3 4 5 6

Very Light Moderate Very Intense

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Inerviewer's Comments:______________________________

________________________________________________

Patient's current dementia level____________________

Most recent medical check-up______________________
Appendix B

DEMENTIA QUESTIONNAIRE
DEMENTIA QUESTIONNAIRE

Please answer the following "true/false" items to the best of your ability. We will use the results ONLY to determine what specific educational information needs to be covered during this study and future sessions.

True False Don't Know

1. Only elderly persons get dementia. ............ T  F  DK
2. Dementia is always inherited. ............... T  F  DK
3. Dementia is caused by the environment. ...... T  F  DK
4. All older persons get dementia. ............... T  F  DK
5. Alzheimer’s disease can only be confirmed after death. .................... T  F  DK
6. There are medicines that can cure dementia. .. T  F  DK
7. Poor nutrition can sometimes make dementia worse  .................... T  F  DK
8. Individuals with dementia don’t get depressed . T  F  DK
9. Frequent reminding can reverse ............... T  F  DK
memory problems
10. Dementia patients don’t experience changes in their personality. ......... T  F  DK
11. Dementia patients should be allowed to drive as long as they have their license. ............ T  F  DK
Appendix C

SATISFACTION SURVEY
CAREGIVER SATISFACTION QUESTIONNAIRE

Date __________

Subject Number ______

This questionnaire is part of our evaluation of the treatment program that you are receiving. It is important that you answer as honestly as possible. The information obtained will help us to evaluate and improve the program we offer.

1 2 3 4 5 6 7

strongly disagree slightly neutral slightly agree agree strongly agree

I feel that this program will help me to more effectively deal with my caregiving situation. 1 2 3 4 5 6 7

Problems with my situation are being addressed in this program. 1 2 3 4 5 6 7

I am receiving adequate attention from the group and group leaders. 1 2 3 4 5 6 7

I have been able to apply skills from this group to my caregiving situation. 1 2 3 4 5 6 7

I would recommend this program to other caregivers. 1 2 3 4 5 6 7

The information and material presented is understandable and helpful. 1 2 3 4 5 6 7

I am able to complete the weekly assignments before the next session. 1 2 3 4 5 6 7

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Appendix D

INFORMED CONSENT FORM
Caregiver Treatment Study
CONSENT FORM

The purpose of the Caregiver Treatment Study is to determine whether an 8-week structured treatment program or an 8-week social support treatment can effectively reduce stress and burden experienced by caregivers of patients suffering from dementia. I understand that I will be expected to participate in all 8 weeks of the group sessions, including completing a battery of questionnaires and providing urine samples before and after treatment. I also understand that upon consenting to participate, I will be assigned to one of two conditions by chance alone: (1) involvement in an 8-week structured group program; (2) involvement in an 8-week social support treatment program. The questionnaires involve measures of stress, burden, coping, mood, and medical history. The urine samples involve the collection of all urine during a 24-hour period at the initial assessment time and after the final group session.

Potential Benefits: It is believed that involvement in this study will provide beneficial caregiving skills to all participants. Specifically:

(1) I understand that I will be offered participation in a beneficial group program at no charge to myself.

(2) I understand that after completion of the project, I will be given information about my own results as well as the findings of the entire project.

(3) I understand that as a participant in the project, I will be allowed access to several health care professionals who can provide individual assistance with specific problems that I may be encounter as a caregiver.

Potential Risks: I understand that there are no recognizable risks involved with participation in this clinical research project.

Confidentiality: I understand that unless I request otherwise in writing, all information gathered will be available only to personnel associated with this project and will remain strictly confidential. In addition, information gathered by the staff of the study will not become part of my UMC medical record.
I understand that I may be excluded from participation in the Caregiver Treatment Study because of the nature of my situation and/or my care recipient, the nature of other physical or psychological problems I may have, insufficient reading level to comprehend written material involved, or failure to comply with all the treatment procedures. I also understand that I may be excluded from the study if I fail to keep to complete assignments or questionnaires, or if I fail to regularly attend group meetings and appointments.

Participation in the study is completely voluntary, and I may discontinue participation at any time without impact on any treatment or benefits to which I am otherwise entitled at the University of Mississippi Medical Center (UMC). Refusal to participate will have no impact on any treatment or benefits to which I am otherwise entitled at UMC.

The University of Mississippi Medical Center has no mechanism to provide compensation for subjects who may incur injuries as a result of participating in biomedical and behavioral research. This means that while all investigators will do everything possible in providing careful medical care and safeguards in conducting this research, there is no way in which the institution can pay for the unlikely occurrence of injury resulting solely from the research itself. We will, of course, provide our best medical treatment to which you are entitled for the illness, if any, for which you consulted us whether or not you participate in this study and whether or not you decide to withdraw from the study.

Any other information regarding this study can be obtained by contacting:

Thomas H. Mosley, Jr., Ph.D.
Department of Medicine (Geriatrics)
University of Mississippi Medical Center
2500 North State St.
Jackson, MS 39216-4505
Phone # (601) 984-5610
Informed Consent: I certify that I am at least 18 years of age. I understand the overview, procedures, potential risks and benefits, confidentiality, and other information associated with the Caregiver Treatment Study. The nature of this treatment study has been carefully explained to me and all my questions have been answered. I understand that I may terminate my participation in the study at any time without penalty. My signature indicates that I give my fully informed and voluntary consent to participate.

______________________________
Name of Participant (Print)

______________________________
Signature of Participant

__________
Date

______________________________
Signature of Witness

__________
Date
Appendix E

TREATMENT OUTLINE
TREATMENT OUTLINE

Session 1: Introduction and Understanding Dementia

I. Class Description and Rationale

A. Dementia Caregiver Stress Model: 3-part stress model
B. Two main strategies: Behavioral management and Stress management
C. Learning and Practicing Skills

II. Class Rules:
   Attendance
   Punctuality
   Class Participation
   Confidentiality

III. Introduction of group members
   Brief mixer exercise to learn names and caregiver situation (or have each group member briefly describe their situation)

IV. Understanding Dementia: "What it is and what it does"

   A. Overview of terms, epidemiology, and history
   B. Brief review of pathophysiology
   C. Hallmark Symptoms of Dementia
   D. Stages of Dementia & What that means to patient and caregiver
      (Stages Handout)
      1. Memory
      2. Emotions
      3. Behavior
      4. Physical functioning

V. Behavioral Disturbances in Dementia

   A. List of Common Behavior Disturbances
      Wandering
      Repetitive/Compulsive Behaviors
      Inappropriate Sexual Behavior
      Inappropriate Social Behavior
      Physical Aggression/Verbal Outbursts
B. Other Behavioral Disturbances

Agitation  Abnormal Eating
Affective Disturbance  Delusions
Klüver-Bucy Syndrome  Hallucinations
Anxiety/phobias/fears  Illusions
Shouting/screaming  Restlessness
Demanding/critical Behavior  Sundowning
Personality Change  Sleep/wake disturbance

(From Rapp, et al., 1992)

C. Behavioral Deficits

Feeding Self
Toileting
Bathing
Dressing
Personal Hygiene

D. Different Behaviors at Different Stages:

1. Stage 1: Driving, becoming lost, poor judgement, gullibility
2. Stage 2: Falls, fire hazards, bathing, poisoning, medication, wandering, pica

VI. Six Myths About Dementia and Alzheimer's Disease

1. Dementia Symptoms are a sign of old age
2. Senility is the usual cause of problems in old age
3. Nothing can be done for the Dementia Patient
4. Dementia is Strictly a Mental Illness
5. Only the family should care for the Dementia Patient
6. All relatives of dementia patients are likely to inherit the disease

VII. Factors Affecting Dementia Patient’s Functioning

A. Medical causes

1. Decreased neurons: CVA, tumor, hematoma
2. Affected blood supply: MI, arrhythmias
3. Altered blood chemistry: Decreased O₂, hypoglycemia, blood-borne toxins

B. Environmental

1. Altered sensory perceptions: vision, hearing
2. Changes in surroundings
3. Pain
4. Restraints
5. Sleep deprivation

VII. Monitoring Behavior (This will be the selection of the first behavior they want to alter, this behavior will be used for the first several sessions)
A. Identifying Target Behavior
B. Operationally Define Behavior
C. Use of monitoring forms

Session 2: Behavioral Principles & Dementia

I. Review of Dementia Quiz and Facts

II. Review of Monitoring Homework

III. Class Examples of Monitoring/ Question & Answer

IV. Rationale for Behavioral Management Strategies

A. During the course of these groups we want to teach you how to reduce the actual occurrence of some the stressors you face as well as how you can reduce your reaction to stressful situations. We will use this two-pronged approach throughout the course of the treatment
B. Uses Pragmatic Problem-Solving Approach
   1. Problem Prevention
   2. Problem Remediation
C. Ways to reduce stress caused by patient’s behavior
   1. Environmental Changes
      a. Daily routines
      b. Physical Environment
   2. Contingency Changes
      a. Increase opportunities for reinforcement
      b. Reduce opportunities for punishment

V. ABC Model of Behavior & Social Learning Theory

A. A - antecedents; what leads up to the behavior
B. B - behavior; what is elicited
C. C - consequence; what happens because of the behavior
D. Emphasize that influences on behavior can go both
ways and that the person being cared for can alter the
caregiver's behavior as easily as the other way around. Also emphasize that there are always antecedents even if they are not immediately obvious. Need to be good investigators

VI. Examples with Dementia Patients
(Class involvement)

VII. Explanation of more detailed monitoring

Session 3: Making Environmental Changes

I. Review of Homework

II. Review of Dementia Behavioral Monitoring
Talk about specifics of monitoring, review social learning principles & ABC's of behavior

III. Environmental Manipulation

A. Rationale: As the disease progresses the patient loses adaptability, changing environmental conditions can lead to increased frustration and behavioral deterioration
B. Goal: To maintain as stable a routine and surrounding as possible to maximize the patients daily functioning. There is a need to balance overstimulation vs. understimulation depending on the problems.
C. Illustration of Principles:
   1. Sundowning: Sundowning is when the person seems to get increasingly confused and/or agitated toward evening. This is often due to a decrease in environmental cues and stimulation. Goal is to decrease the agitation/confusion associated with nightfall. This can be accomplished by increasing environmental stimulation and cues - for example increasing the amount of light in the house, finding a suitable activity etc.
   2. Visitors: The person might get and remain agitated when visitors come into the house. This is likely due to confusion, problems remembering who these people are and being frustrated because social interaction is difficult.
Goal is to decrease agitation and frustration. This can be accomplished by titrating the visitor’s exposure to the person, carefully and calmly explaining their presence, or removing the person periodically and allow them to decompress and calm down.

D. For general day-to-day situations: Make prosthetic changes, introduce gradually but make the person’s living environment less cluttered, safer for ambulation, and appropriately stimulating

IV. Introduce Behavior Monitoring with strategies attempted

Session 4: Caregiving and Behavior Management

I. Review of Monitoring: Brief keep focused on specific problems, save longer discussion for the end

II. Review of Environmental Interventions: Important to be flexible, open to several strategies, make sure you have accurately identified the ABC’s

III. Class Examples of Environmental Management/ Question & Answer

IV. Communicating with Dementia Patients

A. Content of caregiver’s statements
B. Content of patients’s statements
C. Non-verbal behaviors/tone

V. Behavior Change Strategies

A. Increase Opportunities for Rewards/Positive Consequences
   1. Keep level of responsibility as high as possible
   2. Use naturally occurring activities - "daily real activities"
   3. Use frequent, naturally occurring cues and prompts
   4. Maintain as high a level of social contact as possible
B. Increase the Rate of Positive Behaviors: Independent, Socially Appropriate, Useful

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1. Use simple reinforcers: praise, favorite snack, entertainment
2. Break complex tasks into simple components
3. Reinforce consistently, immediately and positively
4. Be on guard for lapses into old patterns

C. Decrease the Rate of Negative Behaviors: Bothersome, Irritating
1. Distraction
2. Reinforce incompatible behavior (DRO)
3. Ignore negative behavior
4. Time out, remove person from problem situation
5. Avoid aversives

VI. Class Examples

VII. Handout 36-Hour Day

Session 5: Stress Management: Identifying Stressful Situations

I. Review Week and Behavioral Strategies

II. Review of Stress and stress management rationale

III. Didactic on identifying stressful situations

A. Common characteristics of stressful situations
   1. Everyday stress, job, people, etc.
   2. Caregiving stress, confused behavior, incontinence, etc.

B. Breaking stressful event into its components
   1. The role of your behavior
   2. The role of other's behavior
   3. The role of cognitive events
   4. The role of past events

IV. Class exercise: Identifying Stressful Situations

A. What's stressful to you?
   1. Elicit individual situations
   2. Identify common aspects of group's situations

B. Identifying Components of the situations
   1. Behavior
   2. other's behavior
   3. cognitions
V. Didactic on stress and tension

A. Brief history of stress concepts and overview of stress responses
B. Presentation of Stress Model:

Stress - Interpretation - Outcomes (physical, behavioral emotional) - psychological problems/physical illness

C. Identifying Stress Arousal Cues
   1. Behaviors
   2. Emotions
   3. Physiological

D. Consequences of Chronic Stress exposure
   1. Increased risk of medical problems
   2. Increased risk of psychological problems

V. Self-monitoring stressful situations
A. Rationale and benefit
B. Introduction of self-monitoring assignment

VI. Didactic on Relaxation and introduction of 16-muscle group technique

Session 6: SOLVE Thoughts - Identifying & Dealing with Unhelpful Thoughts

I. Review of homework and check-in

II. Review of identifying stressful situations & reactions to stress

III. Ways of Coping with Stress (using CSI scales without direct reference to CSI)

A. Explanation of coping strategies
B. Identification of several defined strategies (write on board)
   1. Problem-solving
   2. Cognitive Restructuring
   3. Social Support
   4. Express Emotions
   5. Problem-avoidance
   6. Wishful Thinking
   7. Social Withdrawal
   8. Self-criticism
C. Group focus will be on cognitive restructuring and problem-solving
IV. Cognitive factors in stress response

A. Cognitive Events
1. Identifiable thoughts and images
2. Spontaneous, individual, and almost always believed
3. Often stated in extreme or absolute terms

B. Cognitive Processes
1. Way information is automatically processed
2. Includes assumptions, bias, self-fulfilling
3. Selective perception and recall of information and events

C. Cognitive Structures
1. Tacit assumptions, beliefs and meanings
2. Schemata, inter-related, influences information processing
3. Influences what stimuli are attended to
4. May be triggered by stressful event, readiness to react

IV. Negative Self-Talk

A. Definition: Negative self-talk arises from our automatic thoughts and the way we typically view the world. When negative self-talk begins to dominate it affects how we interact with others and is often associated with an over-response to stressful situations.

B. Types of negative self-statements
1. Polarized Thinking
2. Overgeneralization
3. Filtering
4. Minimizing the Positive
5. Jumping to Conclusions
6. Catastrophizing
7. Reasoning Emotionally
8. Absolute Statements
9. Labelling
10. Personalizing

C. Group Exercise: Identifying Self-Statements
1. Situational Stressor
2. Negative self-statement
3. Problem arising from self-statement
Present dementia or caregiving-related situation and identify the three components

Elicit sample situations from group members, write on board

V. Combating Problematic Thoughts:

A. Thought-catching

B. Situation Analysis
   1. Identify/define the situation
   2. Note automatic thoughts
   3. Note feelings/emotions & mood

C. Changing Automatic Thoughts
   1. Looking for positive as well as negative outcomes of event
   2. What can be learned
   3. Identifying desired outcome

VI. Relaxation Practice: Introduction of 7-muscle group exercise

Session 7: SOLVE - A Problem-Solving Strategy

I. Review of homework and check-in

II. Review of identifying, challenging and changing negative thoughts

III. The use of problem-solving to manage stress
   A. Redefines stress as a problem to be solved
   B. Increases level of personal control

IV. SOLVE - Problem-solving
   A. Use as guideline to analyze and solve stress engendering problems
   B. 5 steps: SOLVE
1. S - State the problem
2. O - Outline the problem
3. L - List possible solutions
4. V - View the consequences
5. E - Execute solution

V. Additional Aspects of Problem-solving
A. Components of the 5-step SOLVE strategy
   1. Carefully and thoroughly define the problem, consider automatic reactions to the stressor
   2. Set realistic goals
   3. Generate a wide variety of solutions
   4. Get input from others if appropriate
   5. Rehearse strategies, both imaginally and behaviorally
   6. Evaluate effectiveness of the solution and re-evaluate problem in light of problem-solving attempt

B. Additional Strategies
   1. Review past coping attempts
   2. Chunk stressful events into smaller, more manageable tasks
   3. Make contingency plans
   4. View failures as feedback and begin again

VI. Group Participation
A. Sample problems
B. Diagram SOLVE strategy

VII. Diaphragmatic breathing

Session 8: Review and Conclusion

I. Review of Relaxation and Homework

II. Review of Coping Procedures
   A. Review of Principles and Strategies
   B. Problem-Solving with Specific Problems

III. Class Examples of Behavioral Management/ Question & Answer

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Appendix F

TREATMENT RELIABILITY RATINGS
### Percentage of Coverage of Designated Session Components

Check to indicate whether topic was covered, 1 = all points on topic covered, .5 = point mentioned, but not completely explained/discussed, 0 = indicates no discussion of agenda item.

**Session 1**

<table>
<thead>
<tr>
<th>Topic</th>
<th>Coverage</th>
</tr>
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<tbody>
<tr>
<td>Dementia Caregiver Stress Model: 3-part model</td>
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<tr>
<td>Behavior Management and Stress Management</td>
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<tr>
<td>Class Requirements</td>
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<td>Dementia Didactic</td>
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<tr>
<td>Terms, History, Definitions</td>
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<tr>
<td>Brief Review of Pathophysiology</td>
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<td>Behavioral Disturbances</td>
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<td>Behavioral Deficits</td>
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<td>Stages and Associated Behaviors</td>
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<td>Myths</td>
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<tr>
<td>Factors That Can Affect Patient’s Functioning</td>
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<tr>
<td>Description of Behavior Monitoring</td>
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**Session 2**

<table>
<thead>
<tr>
<th>Topic</th>
<th>Coverage</th>
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<tbody>
<tr>
<td>Review of Dementia Quiz</td>
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<tr>
<td>Rationale for Behavioral Management Strategy</td>
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<tr>
<td>ABC Model of Behavior &amp; Social Learning Theory</td>
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<tr>
<td>Class Examples</td>
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<td>Detailed Monitoring Assignment</td>
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**Session 3**

<table>
<thead>
<tr>
<th>Topic</th>
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<tbody>
<tr>
<td>Questions/Review of Week</td>
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<tr>
<td>Environmental Manipulation</td>
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<td>Rationale</td>
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<td>Goal</td>
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<td>Illustration</td>
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<td>General Suggestions for Changes</td>
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</tbody>
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Session 4
- Review of Environmental Interventions
- Communication with Dementia Patient
- Behavior Change Strategies
  - Rewards
  - Increasing Rates of Positive Behaviors
  - Decreasing Rates of Negative Behaviors
- Handout 36 Hour Day

Session 5
- Review week and behavioral strategies
- Stress management rationale
- Identifying stressful situations
- Class identification of stressful situations
- Didactic on stress and tension
- Stress model
- Identifying Arousal
- Consequences of chronic stress
- Explanation of monitoring
- 16-muscle group procedure

Session 6
- Coping strategies
- Cognitive factors in stress response
- Negative self-talk
- Thought catching
- Changing Automatic thoughts
- Imaginal relaxation

Session 7
- Review monitoring, week's activities
- Rationale for problem-solving
- Explanation of problem-solving steps
Social Support Group

Session 1

- Group rules
- Defining a support group
- What is Caregiving
  - Demographics
  - Caregiver roles: Physical, administrative, emotional, financial
- Self-assessment of Caregiver Role

Session 2

- Dementia Didactic
  - Terms, History, Definitions
  - Brief Review of Pathophysiology
  - Behavioral Disturbances
  - Behavioral Deficits
  - Stages and Associated Behaviors
  - Myths
  - Factors That Can Affect Patient's Functioning

Session 3

- Defining guilt
- Caregiver guilt
- Defining Grief
Types/Stages of Grieving
Member’s experiences with grief

Session 4
Effects of stress
Benefits of reducing stress
Signs of stress
Discussion of stressful parts of caregiving
Ways to reduce stress (group initiated)
Stress Levels and Experiences

Session 5
The need for Social Services
Reasons for resistance to social services
Available resources
Group member’s experiences

Sessions 6
Making the nursing home decision
Red flags for nursing home placement
choosing a nursing home
Comparing and observing facilities
Moving and adjustment
Financial resources and options

Session 7
Durable power of attorney
Living will
Definitions of conservatorship & guardianship

Session 8
General discussion
VITA

Christopher David Sletten was born on December 26, 1962 in Minneapolis, MN. He grew up in the Minneapolis metropolitan area and attended Minnehaha Academy for junior and senior high school, graduating in June 1981. He attended Wheaton College in Wheaton, Illinois. He was awarded a Bachelor of Science degree in Biology in May 1985. He received a Master of Arts in Psychology from Louisiana State University, Baton Rouge, Louisiana, in May 1991. As part of his graduate training he completed his internship at the Jackson Veterans Affairs Medical Center/University of Mississippi Medical Center Internship Consortium from August 1993 to August 1994. He is currently a post-doctoral fellow at the Mayo Clinic in Rochester Minnesota in the area of Behavioral Medicine.
DOCTORAL EXAMINATION AND DISSERTATION REPORT

Candidate: Christopher D. Sletten

Major Field: Psychology

Title of Dissertation: Reducing Burden and Distress in Caregivers of Dementia Patients

Approved:

[Signatures]

Major Professor and Chairman

Dean of the Graduate School

EXAMINING COMMITTEE:

[Signatures]

Date of Examination:

March 30, 1995