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IMPACT OF ALZHEIMER'S DISEASE ON FAMILY CAREGIVERS: SUPPORT GROUP PARTICIPATION AND OTHER PREDICTOR VARIABLES

Straw, Lorraine Beth, Ph.D.

The Ohio State University, 1987

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IMPACT OF ALZHEIMER'S DISEASE ON FAMILY CAREGIVERS:
SUPPORT GROUP PARTICIPATION
AND OTHER PREDICTOR VARIABLES

DISSERTATION

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

By

Lorraine B. Straw, B.A., M.A.

* * * * *

The Ohio State University
1987

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Department of Psychology
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1987
To the Butterfly
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INTRODUCTION

As the proportion of the population aged 65 and older increases in the United States (Bureau of the Census, 1983; McKenzie, 1980), the number of persons in that age group who are at risk for illness or injury increases (Hickey, 1980; Schneck, Reisberg, & Ferris, 1982). When illness or injury does occur, it often falls to family members to provide care at home for the older person when that individual's own physical, economic, or environmental circumstances preclude other options (Brody, 1985; Kaye, 1985; McKenzie, 1980). The number of family caregivers needed, then, increases with the number of older persons in our population. These caregivers are often elderly spouses or adult children who are themselves entering the at-risk stage of adulthood (Mace & Rabins, 1981; Morycz, 1985). The added emotional stress and financial responsibility of caring for an impaired adult can disrupt families, threaten financial status, and cause additional social and psychological complications (Mace & Rabins, 1981; Pagel, Becker, & Coppel, 1985; Robinson, 1983). Not
the least of such complications is the fact that the situation can have a negative impact upon the energy and health of the caregivers, making them less able physically and emotionally to supply adequate care (Brody, 1985; Colerick & George, 1986; Mace & Rabins, 1981; Robinson, 1983).

One condition which almost by definition creates this complex situation is dementia caused by Alzheimer's disease and related neuropathological disorders (Schneck et al., 1982). Alzheimer's disease was named for neuropathologist Alois Alzheimer who, in 1907, first described the condition (see Schneck et al., 1982, for a comprehensive review). The disease is characterized by a gradual decline in many areas of cognitive ability, with an accompanying physical decline as the brain deteriorates (Reisberg, 1981). The victim may first experience memory loss and errors in judgment. Gradually there is disorientation and loss of socially acceptable behavior patterns. The individual with AD may become restless at night and experience behavioral perseveration and loss of coordination. At the same time, the individual often remains physically active, wandering away from caregivers and getting lost in a now unfamiliar world. The complete disorientation necessitates constant attention to minute details normally taken for granted
and problems such as night restlessness require that assistance be available on a 24-hour-a-day basis from exhausted caregivers (Colerick & George, 1986; Mace & Rabins, 1981). These persons must help maintain the confused individual's well-being in a world to which that individual no longer has cognitive access (Schneck et al., 1982). Moreover, amid the pressures of providing care, the caregivers must attempt to maintain their own lives in an already stressful world (Colerick & George, 1986; Mace & Rabins, 1981; Robinson, 1983).

While medical researchers struggle to find potential causes and treatments for AD (Reisberg, 1981; Reisberg & Borenstein, 1986; Schneck et al., 1982), the problems of the existing AD victims and their families demand the attention of all our multidisciplinary resources. More and more, the professionals involved with these people are recognizing that the families are as much victims of the dementia as are the demented persons themselves (Reisberg, Shulman, Steinberg, Rabinowitz, Kahn, & Ferris, 1986; Safford, 1980). The literature along these lines is accumulating as researchers investigate factors which may contribute to the impact of extended caregiving on families (Chenoweth & Spencer, 1986; Mace & Rabins, 1981; Montgomery & Still, 1985; Williams-Schroeder, 1984), as well as investigate different types and forms of
assistance which may be provided to family members (Clark & Rakowski, 1983; Cox, 1985; Safford, 1980; Zarit, Anthony, & Boutsalis, 1987).

Family caregivers of dementia victims face the daily tasks of providing care, as well as the prospect of what amounts to a protracted grieving process as the person under their care gradually approaches death (Mace & Rabins, 1981). Such stressors tend to pervade all of the roles which the caregivers play in their own lives (Colerick & George, 1986; Mace & Rabins, 1981; Rakowski & Clark, 1985). The various aspects of the caregiving situation, in their complex interaction with the lives of the caregivers, usually create a need for formal or informal support systems for the family (Fox, 1986). One means of providing assistance to family caregivers involves support groups formed especially for those caring for individuals with AD. Support groups are being increasingly promoted as forums in which caregivers not only can seek guidance in caring for the AD victim but also receive reinforcement and suggestions related to how to maintain healthy and productive lives of their own (Cox, 1986; Mace & Rabins, 1981; Safford, 1980). Various models of AD caregiver support groups have been tried in a variety of settings (Schmall, 1984). The pilot designs range from psychotherapeutic approaches (Lazarus, Safford,
Cooper, Cohler, & Dysken, 1981), to milieu therapy in a hospital setting (Cox, 1985), to education and discussion formats (Haley, Brown, & Levine, 1987; Safford, 1980; Zarit et al., 1987). Some programs provide limited-time intensive group sessions scheduled, for example, once a week for five to seven weeks (Safford, 1980). Other programs offer more open-ended, loosely-structured formats, such as once-a-month open-forum meetings ("Support Group Meetings," 1986). Many of these various programs and group models are still in the pilot stages, and specific suggestions concerning the design of such programs are accumulating in the literature (Gwyther, 1982; Safford, 1980; Schmall, 1984; Zarit et al., 1987).

A major goal of most of these programs, implicitly or explicitly, appears to be stress reduction (Mace & Rabins, 1981). This may be approached by alleviating fear of the unknown through education; attempting to reduce reactions such as guilt, shame, or anger; sharing caregiving suggestions; teaching potential coping strategies to increase a sense of control; or simply providing an outlet for frustrations and concerns. Whatever the particular design of a support group, however, the assumption is that it will help the
members in some way to reduce the stressful impact of caregiving.

The medical community at this point is unable to provide a cure or effective treatment for AD, leaving the patient and family to search for their own best sources of care for the patient. Support groups exist to help individuals search for options in the community and within themselves. The effect of such a support group will be considered in the present study. The support group style which is of particular interest in this study involves a combination of education, discussion, and explicit stress management through relaxation techniques, presented in a time-limited, intensive format. It is hypothesized that family caregiver participation in a support group of this type will result in decreased anxiety and an increased sense of control over their difficult situation, and therefore a reduction in the overall impact of the caregiving situation.

Support groups for the caregivers, whatever their design, cannot exist without members—persons who have found themselves in the position of having to cope with the issues involved in caring for a family member with AD. Before studying the effectiveness of a group, one question which should be dealt with is that of how the caregivers arrive at that position. Usually by the
time a caregiver seeks out a support group, he or she has already recognized the developing problems and sought the help of the medical professions. Patients and their families typically approach health care professionals hoping for explicit answers to their questions and concrete assistance with the problems. Due to the nature of AD, however, the diagnostic process can be very long and frustrating and still only produce more uncertainties. Some of the factors involved in diagnosing AD, as well as the implications of such a diagnosis, will be discussed below.
In the past decade, our ability to diagnose Alzheimer's disease has progressed very rapidly (Reisberg & Borenstein, 1986). Several years ago, it was difficult to delineate normal aging from pathological aging. In fact, textbooks of adult development published in the 1970's frequently addressed concerns about what constitutes normal aging on social, psychological, and biological levels (e.g., Birren & Schaie, 1977; Kennedy, 1978; Kimmel, 1974). Now, however, we are learning more about the aging process and the diseases associated with it. Reisberg and his associates (Reisberg & Borenstein, 1986; Reisberg, Ferris, & de Leon, 1982) have outlined stages of a Global Deterioration Scale (GDS) to assist physicians and other professionals in recognizing the characteristics, clinical presentation, and course of AD, and to help differentiate it from normal aging.

According to the GDS, Stage 1 represents normal individuals, who show neither subjective complaints of
symptoms nor objective evidence of cognitive deficits. Stage 2, the forgetfulness phase, includes individuals who complain of minor memory deficits but do not necessarily show objective evidence of impairment in occupational or social tasks. Stage 3 represents the early confusional phase. Cognitive deficits become clinically recognizable during detailed evaluation and are serious enough to interfere with complex social and occupational functioning. For example, the salesman may be unable to recall the names of his products, and may forget to make long-standing sales calls. In Stage 4, the late confusional phase, recent memory is seriously affected, to the extent that the person cannot recall major events of the past week, even with prompting. Concentration, orientation, calculation, past memory, and other cognitive abilities may begin to show evidence of decline during this phase, although the person can usually continue to function in the community with limited assistance. Stage 5 represents the early dementia phase, in which the person can no longer survive independently in the community without assistance with basic activities. The person may need help with choosing appropriate clothing or preparing meals, although may still be able to dress and feed him- or herself. By Stage 6, middle dementia, the person usually requires some assistance with basic
living skills of dressing, bathing, eating, and even toileting. The last, Stage 7, is the late dementia stage, in which the person requires major assistance with all activities due to severe cognitive and physical dysfunction.

The use of the GDS requires that the professional have information about the patient's ability to perform daily living functions as well as specific information about the person's cognitive limitations. Therefore, part of the clinical evaluation must include assessment of various areas of cognitive functioning. Reisberg and Borenstein (1986) suggest that deficits in three or more categories would indicate serious deficits, providing that education, IQ, and functioning were previously average. They also suggest some simple tests in several areas of cognition. For example, concentration deficits are indicated if the person cannot count backward serially from 40 by fours. Recent memory is a problem if the person cannot recall his or her current address and phone number, assuming no recent move. If the patient's caregivers have better recall of the patient's personal life events than does the patient, remote memory is assumed to be affected. Asking the patient to give today's date will help determine his or her orientation, which is suspect if the response is wrong by greater than ten days.
Finally, the indicator which is frequently used to suggest whether or not outside assistance is needed is the person's ability to handle personal finances. When this function is affected, other cognitive deficits are usually ready to surface (Reisberg & Borenstein, 1986).

The professional who is examining a patient for clinical evidence of an Alzheimer's-type dementia must keep in mind some critical characteristics of AD as the patient's symptom history is reviewed. In uncomplicated AD, where no other medical conditions are superimposed upon the symptoms, functions are lost in reverse order of their developmental acquisition. This characteristic of the course of AD is referred to as ordinality (Reisberg & Borenstein, 1986). The time course of the disease seems to approximate developmental acquisition, at least until Stage 7, when functions which had been developed in 12-15 months during infancy are lost over a period of years (Reisberg & Borenstein, 1986).

One other area of change in AD patients which should be noted during clinical evaluation is the patient's emotional state. During the fourth stage of dementia, as described by the GDS, there is typically a flattening of affect (Reisberg & Borenstein, 1986). This is a mixture of denial and reactive depression. Often the patient in this state is over-treated with
medications for the depressive symptoms, which may prematurely deprive the patient of some cognitive functions not yet affected by the disease (Jenike, 1986; Mace & Rabins, 1981). Most AD patients also develop some psychotic symptoms later in the disease's progress, as more of the brain is involved in the deterioration (Reisberg & Borenstein, 1986). Typical problems include delusions of being victimized, nonspecific agitation, sleep disturbances, physical violence, verbal outbursts, and constant crying (Mace & Rabins, 1981; Reisberg & Borenstein, 1986).

Clinical assessment allows the diagnostician to determine the severity of the dementia in terms of the GDS continuum. However, the professional has still to determine whether the dementia is actually of the Alzheimer's type. This is largely a process of eliminating other possible conditions which may be causing or contributing to the dementia-like symptoms. For example, hypertension can create confusion in an older adult, which may in turn be labeled as dementia. The primary distinction, however, is that the confusion associated with hypertension can be controlled with appropriate diet, exercise, and medications. Similarly, severe anemia, toxemia, vitamin deficiencies, and systemic infections all have potential for producing dementia-like symptoms, yet all
are treatable conditions which can be identified and eliminated through appropriate intervention (Reisberg, 1981; Reisberg & Borenstein, 1986).

In many cases, identification of the contributing conditions involves relatively simple laboratory tests of blood or urine. There are, however, various conditions which closely resemble dementia of the Alzheimer's type and which require much more complex procedures for identification. However, even if these conditions can be differentiated from AD, they are not always treatable or reversible. One common example is that of multi-infarct dementia, which is the result of multiple cerebral infarctions (strokes) which damage numerous and/or widespread areas of the cerebral cortex (Reisberg, 1981; Reisberg & Borenstein, 1986). Such damage is not reversible but appropriate treatment may help prevent further damage, unlike the unrelenting progression of AD (Reisberg, 1981). Likewise, stroke patients are sometimes able to relearn lost skills by recruiting undamaged cortical areas but this relearning is not seen in AD (Reisberg, 1981).

Several technical procedures are available to assist in the process of differential diagnosis of those persons displaying dementia-like symptoms. For example, electroencephalograms (EEG's) can trace electrical brain activity, possibly allowing
identification of abnormal patterns indicative of contributing conditions such as brain lesions or epilepsy. Computerized tomography (CT) scans can help identify damage from cerebral infarctions. Magnetic resonance imaging (MRI) techniques can be used to diagnose cerebral infarctions or damage from other diseases such as multiple sclerosis. In addition, positron emission tomography (PET) scans can be employed to identify neurometabolic changes that may be missed by CT or MRI. Finally, in extreme situations, a brain biopsy may be performed, although this procedure is dangerous and provides limited information (Reisberg, 1981; Reisberg & Borenstein, 1986; Schneck et al., 1982).

All of these techniques are valuable in making differential diagnoses in dementia cases. The problem, however, is that even with these sophisticated procedures, differentiating confounding conditions from symptoms of an Alzheimer's-type condition, and sometimes even from normal aging processes, is not always possible. Very early results have recently been announced on research to develop a laboratory test specifically for the detection of AD (Davis, 1986). This procedure is still untested and highly controversial, however, and is not available for use by private physicians. The tests which are available, as
described above, can only serve to identify other possible causes of symptoms, some of which may then be eliminated by treatment. Thus, the health care professional who has used the GDS continuum to identify the extent of the problem can only begin to provide some answers to the patient and family as to the nature of the problem. The many tests may allow a narrowing of the diagnosis from possible AD to probable AD through elimination of other possibilities. As yet, however, a definite diagnosis of AD is only possible with a brain autopsy upon death of the patient (Katzman, 1986).

Autopsy of the brain of an AD victim typically reveals a number of characteristic structural changes (Reisberg, 1981). There is a general atrophy of the cerebral cortex, particularly in the frontal and temporal lobes. Atrophy is also occasionally seen in brains of normal aged individuals, with the non-neural supportive cells (glia) decaying, leaving the neurons intact. In AD, however, the neurons themselves decay rather than the glia (Reisberg, 1981).

There are also three characteristic microscopic structural changes in brains of AD victims: the formation of neurofibrillary tangles, formation of neuritic (senile) plaques, and granulovacuolar degeneration (Katzman, 1986; Reisberg, 1981).
Neurofibrillary tangles involve pairs of filaments within a neuron which wrap around each other in a helical pattern (Reisberg, 1981). Such tangles have a characteristic shape and size, and are seen in various medical conditions. As Reisberg (1981) points out, the individual tangles seen in AD are identical to those seen in other conditions with a striking variety of etiologies including chromosomal abnormalities, as in Down's syndrome; injuries, as in dementia pugilistica, seen after repeated head traumas; possible viral sources, particularly postencephalitic Parkinsonism, thought to be a complication from a post-World War I influenza epidemic; genetic diseases such as the hereditary Guam-Parkinsonism seen only in one tribe on Guam; and apparently normal aging. It is the distribution and concentration of the tangles in various areas of the brain, however, which aids diagnosis. In the AD patient, the neurofibrillary tangles are seen in very high concentrations in the hippocampus, an area typically associated with short-term memory, and throughout the neocortex, presumed to be the most advanced part of the cortex (Gardner, 1975; Groves & Schlesinger, 1979; Reisberg, 1981). In normal aging, tangles are frequently found in the hippocampus, neocortex and in the amygdaloid nucleus (associated with emotion) but they are usually
found in lower numbers than in AD. In addition, the brains of those with Down's syndrome display tangles in the neocortex. Reisberg has also noted that although a form of tangles is also seen in aged rhesus monkeys, the type of tangle seen in AD and the conditions described above is found only in humans.

The second major microscopic change in the brains of AD patients, neuritic (senile) plaques, "consist of an amyloid core surrounded by degenerative neuronal processes and reactive non-neuronal cells" (Reisberg, 1981, p. 24). Amyloid material is generally one of two types. One type consists of protein material of unknown origin (Reisberg, 1981). The other type is thought to be composed of immunoglobulin chains, which are protein antibodies produced by the organism in response to foreign proteins (antigens) such as viruses (Reisberg, 1981). The plaques found in AD are thought to be centered around cores of this second type of amyloid. Although the process by which the plaques themselves are formed is uncertain, one possibility is that antigen-antibody complexes are absorbed by white blood cells, then released as amyloids which leak out of blood vessels and develop into plaques as they are enveloped by degenerating neurons and affected glia (Reisberg, 1981). As with neurofibrillary tangles, increasing concentrations of plaques are associated
with dementia but their presence is not uncommon in normal aging. They tend to occur in the same individuals who develop tangles and are generally found in close proximity to those tangles. Unlike tangles, though, plaques are seen in identical form in other species as well as in other human dementia-producing conditions. Adult Down's syndrome patients show these neuritic plaques, as do victims of several transmissible "slow virus" dementias including Scrapie in sheep, encephalopathy in mink, Kuru in humans, and Creutzfeldt-Jakob disease in humans and other primates (Reisberg, 1981). Also, at least one species besides humans, the dog, shows plaque formation in association with apparently normal aging (Reisberg, 1981).

The third microscopic structural alteration characteristically found in the brains of AD victims occurs within brain cells themselves. This particular change is known as granulovacuolar degeneration, which refers to a situation in which the affected cells degenerate in functioning as they become "crowded" with vacuoles (cavities) and granular material (Reisberg, 1981). This degeneration is seen predominantly in the hippocampus and although it occurs in some normal aged individuals, high concentrations of these affected cells are associated with symptoms of dementia (Reisberg, 1981).
Thus, the structural damage in AD appears to occur primarily in the hippocampus, which may account for the observation that short-term memory loss is typically the first symptom of dementia. Additionally, involvement of the amygdaloid nucleus in AD explains the emotional dysfunction in the patients, and damage to the cerebral cortex helps explain the severe cognitive disturbances which develop. It must be kept in mind, however, that these same changes may also occur without symptoms of dementia being present. Evaluation of structural abnormalities in the individual's brain must be considered in combination with evaluation of other factors as well, such as neurochemistry (e.g., Davies, 1986; Davis, 1986; Jenike, 1986).

As noted earlier, one of the characteristic changes in the brains of an AD victim is the decay of neurons. Researchers in neurochemistry have found that it is primarily cholinergic neurons which are lost and that the neurotransmitter for these neurons, acetylcholine, is not efficiently synthesized in AD patients (e.g., Jenike, 1986; Schneck et al., 1982). This deficit in cholinergic potential seems to have a complex relationship to deficits in cognitive functioning, although this relationship is still unclear (Davis, 1986; Reisberg, 1981). One possible
condition which may contribute to the cholinergic loss is inhibited blood flow to areas of the brain. Reisberg (1981) has discussed research which may indicate that problems in blood flow precede neurochemical damage and that acetylcholine seems to be particularly sensitive to this problem. The question of which comes first, however, cholinergic loss or blood flow loss, is controversial (Reisberg, 1981).

A closely related research question pertains to treatment of the symptoms of AD. If acetylcholine is not produced sufficiently, perhaps stimulating its production will be an effective treatment for AD (Reisberg, 1981). This type of research has been pursued with only limited success (Davies, 1986). Likewise, pharmacological treatments designed to inhibit breakdown of existing acetylcholine at neuron receptors have also had very limited success (Jenike, 1986).

Other research has focused on possible external causes of AD. Due to the similarities in structural changes in the brain in AD and in what are called "slow viruses," the possibility that AD actually is caused by a similar virus has received some attention (Reisberg, 1981). However, attempts to isolate and transmit such a virus have been only partially successful and not adequately replicated (Davies, 1986; Reisberg, 1981).
Another possible external etiology involves toxic reactions to specific substances found in the brain. For example, Reisberg (1981) reviewed research on aluminium content in brains of AD victims. Very high concentrations of the metal have been found in the areas of the brain affected by the degeneration associated with AD. The evidence seems to indicate, however, that aluminium poisoning by itself does not cause AD. Rather, some research has indicated that aluminium content may be a by-product of whatever causes the disease (see Reisberg, 1981, for discussion).

For every possible etiology, there is a parallel search for related treatments or cures. These searches have followed a wide variety of courses, including efforts to prevent onset, to halt the disease's progress, and to reverse damage done by the disease (Mace & Rabins, 1981; Reisberg, 1981; Schneck et al., 1982). Usually, these attempts are pharmacologically oriented, although some work is currently being done on transplant grafting techniques to regenerate damaged brain tissue (Davis, 1986). Progress is being made on various fronts but, in general, results of the various treatments have been disappointingly limited (Reisberg & Borenstein, 1986).
What is left to do for a dementia patient, then, when a diagnosis of probable AD has been established? Patient management techniques are limited by the lack of answers from research on etiology and treatment. There is no known cure nor an accepted treatment for the disease itself. Instead, efforts are made to control symptoms which may excessively disrupt the patient's well-being or that of the persons caring for the patient. Patient care, then, is predominantly a matter of making them as comfortable and safe as possible for as long as possible (Mace & Rabins, 1981; Reisberg et al., 1986). How this is accomplished and by whom are decisions which most frequently become the responsibility of the family members. There are, however, numerous resources to assist the family in making decisions and providing various levels of care as the disease progresses. Some of the options and their implications will be covered in the following sections.
Long Term Care Options

When a degenerative disease such as AD creates the prospect of long-term patient care, options for accomplishing this care must be carefully examined. An over-simplification of the most obvious decision facing the family is whether to institutionalize the person with AD, and when that move is appropriate. This decision requires that the family consider their willingness and ability to care for the AD victim outside of the institutional setting and the relative advantages of the institutional alternatives for long term care. Unfortunately, the health-care system in our society is designed much more for acute care than for chronic care (Shanas & Maddox, 1985). Chronic care facilities seem to be almost foreign to the main functioning of the health care professions.

The primary chronic care option associated with health care professions is the nursing home. This option is ideal for the patient who requires non-acute
nursing care with supporting medical care available. While it is true that elderly persons often have multiple problems involving physical, psychological, and social components (Shanas & Maddox, 1985) which may be properly attended to in a nursing home, AD victims frequently do not fit this picture (Mace & Rabins, 1981). A person with AD may remain physically healthy and active for many years but still require constant care. The typical nursing home is usually ill-equipped to care for an active yet demented patient (Mace & Rabins, 1981). Inadequately supervised AD patients may wander off, attack other patients, or accidentally injure themselves. To prevent such occurrences, nursing homes often restrain AD patients physically or with drugs, either of which prematurely deprives the degenerating patient of remaining functional capacities (Mace & Rabins, 1981; Reisberg et al., 1986).

Another consideration with respect to nursing home care as an option for AD victims is financial status. Nursing homes are very expensive. The fees cover not only room and board but also the availability of full nursing care. Most older adults in nursing homes receive financial support from governmental programs such as Medicare and Medicaid (Mace & Rabins, 1981). However, AD victims frequently do not require full nursing care but need what is called unskilled or
nontechnical care (Mace & Rabins, 1981). These custodial care activities are not paid for by Medicare and are only covered by Medicaid after the patient's own assets have been exhausted. This often means that the spouse is then left with no assets, depending on legal ownership of the assets. For patients in this category, then, unless there are health problems which are complicating the dementia, or until the patient is in the very advanced stages of dementia when physical mobility is affected, nursing home care may not be a practical option for these patients (Colerick & George, 1986).

Whatever the reasons, the family may decide against institutionalization in a nursing home, or at least to postpone that option. The alternative is usually home care, which in itself entails a complex series of demanding situations. If keeping the AD victim at home is the option of choice, there are numerous resources which are designed to assist the caregivers in stretching their time, energy, and financial resources in order to provide the necessary care. For example, many communities now have adult day care centers for older adults who need supervision while the family caregivers are unavailable. This is ideal for caregivers who have careers or other activities to pursue but who do not wish to
institutionalize the AD victim. It reduces the isolation and boredom of the patients and releases caregivers from some of the stress and responsibility of constant care (McGivern, 1986). Unfortunately, these facilities sometimes decline to accept persons who are incontinent, violent, or who wander, all of which are common problems in AD (Mace & Rabins, 1981; Reisberg et al., 1986). There are also problems of non-acceptance among caregivers, who may fear having their performance as caregivers judged or feel guilt for not coping with the situation without help or be embarrassed to have the community know about AD in their family (McGivern, 1986). This option for the day-to-day care of the person, however, can help maintain daily living skills for as long as possible, reduce agitation by encouraging activity, and provide adequate supervision, all in cooperation with the caregivers (McGivern, 1986).

If the family has decided to keep the dementia victim at home, and if day care is not considered a viable option, there are still community resources which may be of assistance (Mace & Rabins, 1981). Some communities have agencies which provide respite care for the dementia victim at home. There are community visiting nurse services to help with medical problems or explain medications and their side-effects. There
are often home health aides or visiting practical nurses to assist with such periodic activities as bathing. Even resources such as "Meals-on-Wheels," which brings hot lunches to the person's home, may be appropriate in some situations. Despite the availability of such programs, many family caregivers are left alone with the task of coping with caregiving and the dynamics it creates within the family (Brody, 1985; Chiverton & Goldenberg, 1986; Jarrett, 1985). While many of the issues which develop in families of dementia victims are present whether the person lives at home or not (Colerick & George, 1986), providing care at home increases the immediacy and stress of the situation and produces unique issues within each family context, as will be discussed below (Brody, 1985; Mace & Rabins, 1981).

**Family Issues**

The dynamics of a family can be very easily disrupted by stressful events (Lazarus & Folkman, 1984) and when the stressor is an ongoing situation such as the presence of a degenerative dementia, the pressures can be very destructive (Chiverton & Goldenberg, 1986; Robinson, 1983). For example, one of the most frequent problems encountered when family members must care for a debilitated relative involves the shifts which occur
in familiar roles. When an adult child must become the caregiver for a demented parent, the stress of the apparent role reversal can be severe (Brody, 1985; Mace & Rabins, 1981). A simple task, such as assisting the AD victim with bathing, can come to symbolize the new role and the caregiver may pour all of the associated stress into resenting or fearing that task (Mace & Rabins, 1981). The AD victim also must adjust to new roles. Household or financial duties which were part of former roles must be gradually relinquished to others. Occupational activities may be forfeited to the disease. These role changes are frustrating and disruptive to everyone involved (Mace & Rabins, 1981).

Closely related to this problem of role shifts is the necessity of making decisions for the person. Attending to financial details which the person can no longer handle, deciding when driving is too dangerous, or determining that the person can no longer live alone, all become the responsibility of the family caregivers.

Responsibilities for caregiving affect everyone in the family to some degree. If one person avoids sharing in the responsibility, that decision has a potential effect on everyone (Mace & Rabins, 1981). The spouse caregiver, for example, may feel in need of assistance from adult children who are too far away,
too busy, or too distressed by the situation to actively help. Guilt, resentment, isolation, and frustration become part of the dynamics of the family (Brody, 1985; Mace & Rabins, 1981; Robinson, 1983). The decision-making processes within the family are distorted by these issues, which can in turn hamper appropriate care for the dementia victim. One common situation which may arise from such negative family dynamics is extreme difficulty surrounding the decision to institutionalize the person. Determining when this is appropriate or necessary is very difficult in situations where emotional reactions such as guilt and resentment have influenced the family (Colerick & George, 1986; Mace & Rabins, 1981).

Seeking sources of assistance from the outside may become necessary as the demented person deteriorates. For example, if one person is attempting to care for the dementia victim, simple fatigue can interfere with efficient caregiving. This is especially a problem with the common AD symptom of disturbed sleep/wake cycles (Mace & Rabins, 1981; Reisberg et al., 1986). The caregiver must be on 24-hour alert to the activities of the AD victim. Another situation which may necessitate outside help is poor health of the primary caregiver. An elderly spouse of an AD victim may have physical problems or limitations or may become
ill, especially if exhaustion from caregiving responsibilities is a factor (Chiverton & Goldenberg, 1986). In addition, the caregiver may be an adult child with responsibilities within his or her own family which create time and energy constraints (Chenoweth & Spencer, 1986).

In sum, whether or not community caregiving resources or nursing homes become a necessity in caring for the AD victim, the family must still cope with the disease's effects on the person they care for, on the caregivers themselves, and on the family dynamics. One option for assistance in this coping process is a support group designed for these caregivers. This important option will be discussed in detail below.

Support Groups

Many professionals who work with AD victims and their families are now recognizing the need for support groups to help the caregiving family members deal with the circumstances created by dementia. For example, the medical profession recognizes that the well-being of the patient very often depends on the physical and emotional ability of family members to provide proper care (Chiverton & Goldenberg, 1986; Reisberg et al., 1986). These professionals also know that the paucity of concrete answers which they can offer about this
disease contributes to fear of the unknown and feelings of helplessness in the caregiving family members (Reisberg, 1981; Reisberg et al., 1986). Professionals in mental health fields understand that the caregiver's complex emotional interaction with, and gradual loss of, the affected person as he or she used to be can cause depression and anxiety (Chiverton & Goldenberg, 1986; Jarrett, 1985; Mace & Rabins, 1981; Schmidt & Keyes, 1985). Gerontologists are aware of the additional stress which the situation inflicts on older caregivers during times of normative developmental stress such as retirement, deaths of many same-age peers, and physical changes of normal aging (Leiberman & Tobin, 1983; Mace & Rabins, 1981). Support groups can provide assistance with many of the complications associated with caregiving and "help to normalize the experience of the caregivers" (Schmall, 1984, p. 64).

Support groups vary in design and format. For example, a group may exist solely for education of the caregivers. In this type of group, professionals present information on various aspects of the disease, nutrition, health care, chronic care facilities, legal issues, and financial planning (Schmall, 1984). The information is vital but there is usually no allowance for personal sharing, problem-solving, or emotional support. This type of group may be ideal as a
supplement to other forms of support or for the person who needs information but is not yet able to face the complex emotional implications of AD (Mace & Rabins, 1981; Schmall, 1984). Generally, however, most people who feel the need for a support group want a chance to discuss the problems they face (Glosser & Wexler, 1985; Safford, 1980).

Another type of support group focuses on discharging tension by providing the caregivers with the opportunity to get their frustrations, fears, and angers out in the open (Schmall, 1984). This can be helpful but a group limited to this does not enter the realms of problem-solving or decision-making, which are frequently where help is needed (Gwyther, 1982). There is also a danger that improperly guided groups may turn into "gripe sessions" which only spread misinformation and increase fears (Schmall, 1984; Zarit & Zarit, 1982).

An additional model employed by some groups relies upon psychoanalytic theory, with the emphasis on getting caregivers to resolve their own personality problems in order to be better equipped to deal with the caregiving situation. This approach can take different forms, including getting the participants to confront their own emotional reactions to the disease rather than being ruled by denial (Schmidt & Keyes,
or confronting the members about family dynamics and the history of their relationship with the dementia victim (Lazarus et al., 1981).

All of the above designs serve a purpose and may provide complementary coverage of the needs in the community. Groups which provide a combination of these designs may be of more enduring use to the caregivers, however (Glosser & Wexler, 1985; Mace & Rabins, 1981; Safford, 1980; Schmall, 1984). Individual needs of caregivers must be taken into consideration when looking for an appropriately designed support group.

The exact format of the support group is also an important variable to consider. Groups may meet only occasionally, such as whenever a professional is available to give a presentation, or the group may have a predetermined meeting schedule. The group may be closed-ended or open-ended. Closed-ended groups are scheduled for only a limited number of meetings and usually have specified topics for each session. Members of such groups are expected to attend all sessions in order to maximize benefits. Open-ended groups are usually permanent fixtures which members may attend as needs arise (Mace & Rabins, 1981). As with the different models outlined earlier, the different formats all serve a purpose and each may benefit different persons at varying times. For example,
having access to an open-ended group whenever a new decrement in the AD victim's capacities occurs can be crucial to the caregiver's coping. On the other hand, a person who is just beginning to understand what is involved in the AD situation may need the more intensive format of a closed-ended group.

Support groups for caregivers, then, may follow a variety of models and formats, all with the purpose of aiding each group member in coping with the caregiving situation and its impact on his or her life. While the various strengths of the different types of groups are important to note, it is also worth considering the extent of the impact of the caregiving situation, and what influence support group membership may have on that impact. First, however, it is necessary to specify what is meant by "impact" for the purposes of the current study.

Stress in an individual's life affects that person's functioning at some level. A minor stressful event may only require implementing a basic coping function, yet may still represent a measurable level of impact created by the event. A major stressful situation may require more complex coping responses and interfere with normal functioning in other tasks. Listing what stressors are creating these impacts does not address the level of impairment which may result.
In attempting to improve tools for measuring stress, there has been a move away from the simple listing of recent stressful events in an individual's life, as had been exemplified by life events inventories (e.g., Holmes & Rahe, 1967; Horowitz & Wilner, 1980). For example, Horowitz, Wilner, and Alvarez (1979) developed a scale for measuring self-reported subjective distress in response to a stressful event. In reviewing material from psychotherapeutic interviews, they found that responses could be grouped into two basic types which they labeled "intrusion" and "avoidance" and explained as follows:

Intrusion was characterized by unbidden thoughts and images, troubled dreams, strong waves or pangs of feelings, and repetitive behaviors. Avoidance responses included ideational constriction, denial of meanings and consequences of the event, blunted sensation, behavioral inhibition, counterphobic activity, and awareness of emotional numbness. (Horowitz & Wilner, 1980, p. 366)

The resulting "Impact of Event Scale" consists of two subscales with a total of fifteen statements of impact. For each statement, the respondent assigns a value indicating the frequency with which that indicator of impact applied to a particular event's influence in his or her life. Through their research, Horowitz et al. (1979) established high test-retest reliability and construct validity, and determined the scale's
sensitivity to stress from different kinds of events, stress of ongoing adjustments, and changes in the stress after brief therapy. The scale, then, should be useful in assessing the stress-related impact on the caregiver of caring for an AD victim.

Other factors which affect the level of impact are also of interest. Evidence in the literature is varied as to what factors are important in determining the extent of the individual's response to a stressful event. Basically, three different sources of influencing factors can be outlined: caregiver variables, patient variables, and caregiver/patient interactive variables. Some investigators have found caregiver variables to be of prime importance. For example, Brody (1985) noted that women tend to take on family caregiving responsibilities more easily throughout life than do men. Caregiver age has also been shown to be important. Robinson (1983) found that younger caregivers tend to experience more stress than older caregivers. The caregiver's access to and use of sources of support and assistance can also have a strong modifying effect on their subjective stress (Fox, 1986; Morycz, 1985; Rakowski & Clark, 1985). Moreover, caregiver health is an important factor in determining quality of care provided (Reisberg et al., 1986) and the decision to institutionalize (Colerick &
Caregiver mental health is also widely recognized to be important (Mace & Rabins, 1981; Reisberg et al., 1986). For example, depression and anxiety have been shown to be major predictors of the caregiver’s expressed need for outside support systems and ability to provide care (Lazarus et al., 1981; Safford, 1980) and caregivers with a restricted perspective of their own future have been shown to exhibit greater stress (Rakowski & Clark, 1985).

Research on the effect of other cognitive or personality-related caregiver variables has been very limited, although locus of control has had some attention in this respect (e.g., Lazarus et al., 1981). The caregiver’s locus of control was shown to be related to the stress and coping exhibited by caregivers (Lazarus et al., 1981; Pagel et al., 1985). Krause (1986) reviewed the relationship between stress and locus of control, indicating that persons with internal loci of control should be more able to alter, prepare for, or avoid stressors than those with external loci of control. However, there is also evidence that extreme internal or external locus of control beliefs are associated with high susceptibility to stress (Krause, 1986; Phares, 1976). Also, persons with extreme internal loci of control tend to feel guilty and take too much responsibility for situations
(Krause, 1986). When these findings are related to AD caregiving, the reactions of those with extreme internal loci of control might be expected to be compounded by the guilt which is so frequently reported by caregivers (Lazarus et al., 1981; Mace & Rabins, 1981).

Patient variables are also considered to be important in determining the impact on caregivers. For example, Fox (1986) found the AD patient's level of impairment to be a primary predictor of the caregiver's need for formal sources of support, while others suggest that impairment level is not the critical variable (Mace & Rabins, 1981; Pagel et al., 1985; Zarit & Zarit, 1982). Perhaps this discrepancy is due to the possibly subjective nature of an individual's impairment level. Another patient variable, patient gender, was found by Colerick and George (1986) to influence the decision to institutionalize the patient, although the researchers attributed this to their finding that wives tend to keep demented husbands at home but demented women tend to be institutionalized by husbands or adult children. Thus, what appeared to be a patient variable influence may actually have been a function of an interactive variable—the relationship between patient and caregiver.
Other researchers have also indicated that the caregiver's relationship to the patient is a key factor in caregiving impact. Brody (1985), for example, noted that spouses are usually more emotionally prepared to provide long term care than are other potential caregivers, a finding which could be interpreted as conflicting with a popularly held belief that spouses are usually elderly persons who are often not physically or financially equipped to care for a demented spouse (Mace & Rabins, 1981). Daughters seem to respond more to guilt-associated pressure to perform the caregiving role than do sons or spouses (Reisberg et al., 1986), yet Colerick and George (1986) found that adult children tended to relinquish caregiving roles sooner than spouses. There are, then, complex interactions between age, sex, and relationship of the caregiver to the AD patient.

A related interactive variable was addressed by Lazarus and his colleagues (Lazarus et al., 1981) in attempting to help caregivers resolve previously established interpersonal conflicts with the patient which were interfering with the caregiver's emotional ability to provide care. For instance, a woman may find that the guilt and resentment inherent in the caregiving situation are accentuated and debilitating when she is responsible for the care of a parent who
was abusive years before. Of course, combinations of any of these factors are likely to have a compounding impact on caregiver stress. Fox (1986), for example, found that the caregiver's anxiety level and access to informal sources of support could be combined with the patient's level of impairment to more clearly predict the caregiver's need for formal assistance than did any one of those factors alone. This type of result indicates that utilization of formal and informal support systems, such as caregiver support groups, can be considered as a factor which interacts with other factors in determining the impact of caregiving on the lives of those caring for family members with AD.

As discussed earlier, support groups for caregivers attempt to address the variables which affect the stress experienced by the caregivers. In fact, support groups exist under the assumption that they will mitigate some of the stressful impact of the caregiving situation. The present study was intended to evaluate some of the variables associated with caregiver stress and to assess the value of support group membership as a factor which is assumed to reduce stressful impact. For this purpose, the present study involved a style of support group for caregivers for family members suffering from AD and related disorders which utilized a closed-ended, weekly format, and
combined education, discussion, and explicit stress management. It was anticipated that this combination of various components of support group designs would allow for information exchange, expression of feelings, and problem-solving. Stress reduction techniques were included to provide highly specific skills related to stress management. It was expected that these techniques could then be used privately by the individual to supplement the anxiety-reducing effects of group interaction and information sharing in order to reduce the impact of the caregiving situation on the caregiver's life.
Several preliminary expectations were outlined for the present investigation in anticipation of two primary hypotheses. First, it was expected that impact would be positively correlated with anxiety and depression, based on studies of impact (Horowitz & Wilner, 1980; Horowitz et al., 1979) and stress (Lazarus & Folkman, 1984; Pagel et al., 1985; Williams-Schroeder, 1984). It was also expected that persons with very high internal loci of control would be "overwhelmed" by the externality of the AD situation (Lazarus et al., 1981) and thus have high impact scores. With these initial hypotheses in mind, two primary hypotheses were considered:

1) The level of impact of the stressful caregiving situation may be predicted from measures of depression, anxiety, and locus of control.
2) Participation in a caregiver support group will result in a reduction in the impact of the stressful situation. Associated with this hypothesis is the expectation that, if Impact can be predicted with the independent variables listed in the first hypothesis, then support group membership should also reduce scores on those predictor measures, particularly the depression and state anxiety measures.

Supporting hypotheses were proposed regarding demographic and descriptive variables, based on research with stress and coping. It was hypothesized that kinship relationships between caregiver and patient would be related to impact scores, as suggested by studies of caregiver stress correlates (Brody, 1985; Colerick & George, 1986; Lazarus et al., 1981), although the direction of this expectation was somewhat unclear. Evidence of kinship effects on caregiver stress is confounded by gender and age effects, and previous findings have varied (see discussion above). Also, gender and age factors produced variable effects in the validation studies for the impact scale itself (Horowitz & Wilner, 1980; Horowitz et al., 1979). Finally, patient level of impairment was expected to be positively related to caregiver impact (Fox, 1986; Robinson, 1983), as was time since onset of AD, based
on the sensitivity of the impact scale to type of situation and length of time since occurrence of a stressful event (Horowitz & Wilner, 1980).


CHAPTER IV

METHOD

Participants

All subjects in the present investigation were actively participating in caring for a family member affected by an Alzheimer's-type dementia. Participants were obtained in and around Columbus, OH, through community agencies working with dementia victims and their families. The agencies cooperated in the present study by allowing the investigator to approach the members of scheduled groups regarding research participation. Forty-one individuals, the total membership of four different caregiver support groups, were initially approached about participation in the study. Twenty-five chose to participate in the pretest and 21 of these individuals completed both the pretest and the posttest measures of the current study. The four who did not complete the posttest withdrew for personal reasons including their own illness, death of the dementia patient, or other family crises.
The agencies sponsoring support groups also provided the present investigator with a list of caregivers who had expressed some interest in the groups but who had not enrolled in one as yet. Fifty-five such caregivers were contacted by mail by the investigator to request their participation as control group members. Of 35 who agreed to participate, 26 completed the pretest, and 20 completed both pre- and posttests. Information was not available on the specific reasons for this attrition.

The average age for the 41 participants who completed the study was 53.7, \( \text{SD} = 12.8 \), and most (34) were female. The majority, 24, were caring for a parent, 11 for a spouse, five for a parent-in-law, and one for an aunt. Due to limitations of the present study, matching subjects or randomly assigning individuals to experimental or control conditions was not feasible. Therefore, a more elaborate description of the sample and a comparison of the experimental and control groups will be presented in the Results chapter below.

**Measures**

The participants in this study were predominantly older adults and were, by definition, under emotional stress with limited time and energy. Therefore, major
considerations in choosing instruments for this study were the time required for completion and ease of response. The following measures were employed (see Appendix A for copies of each measure):

**State/Trait Anxiety Inventory - Form Y (STAI)** (Spielberger, 1983). The STAI is a very popular anxiety measure and has been used in a wide variety of studies (for research bibliographies, see Mitchell, 1985, and Spielberger, 1983). The test has proven useful in assessing anxiety levels of individuals and in distinguishing the state and trait components of the anxiety (Mitchell, 1985). Thus, it permits an evaluation of the individual's current level of situation-induced anxiety, in comparison to the more general traits of anxiety-proneness. The State anxiety subscale consists of 20 statements (e.g., "I feel upset") to which the individual responds by marking one of four choices (1 = "Not at all" to 4 = "Very much so"). The Trait anxiety subscale also consists of 20 statements (e.g., "I am a steady person") to which the individual responds by marking one of four choices (1 = "Almost never" to 4 = "Almost always"). Each subscale contains both positively and negatively worded items. The positively worded items are reverse-coded during
scoring, resulting in subscale scores ranging from 20 to 80, with high scores representing high levels of anxiety.

Spielberger (1983) reported in the test manual that stability of the STAI, as measured by test-retest coefficients, was fairly high for the Trait anxiety subscale and low for the State anxiety subscale, which is as expected when situational stressors are a factor. The median Trait anxiety test-retest correlation was .765 in a sample of college students. The median State anxiety test-retest correlation in the same population was .33.

The internal consistency for both subscales of the STAI was very high, as measured by a Cronbach's alpha coefficients. The median alpha coefficients for State anxiety and Trait anxiety were .93 and .90, respectively, in samples of 1,838 working adults, 1,279 students, and 1,964 military recruits. These internal consistency ratings were also uniformly high over the entire age range of working adults. In addition, the two subscales were highly correlated with each other in the working adult sample, $r = .75$ for females and $r = .70$ for men. The correlation between State and Trait anxiety tended to be influenced by the type of stress being experienced, with physical danger or threats to self-esteem increasing the correlation.
The mean State anxiety score for the sample of working adult males was 35.72, SD = 10.4. The mean State anxiety score for working adult females was 35.2, SD = 10.61. On the Trait anxiety measure with the same sample, the mean for males was 34.98, SD = 9.19, and the mean for females was 34.79, SD = 9.22. Spielberger reported that the gender differences were not significant.

The working adult sample did, however, reveal some significant age differences on both subscales, with individuals over age 50 tending to be lower in anxiety than the younger adults. Because the sample in the present study was predominantly in this older age group, those means are of particular relevance here. The mean State anxiety score for males over age 50 was 34.51, SD = 10.34. The State anxiety scores for females in this age group was 32.20, SD = 8.67. On the Trait anxiety measure, the mean scores in this age group were 33.86, SD = 8.86, for males, and 31.79, SD = 7.78, for females.

**Self-rated Depression Scale (SDS)**(Zung, 1965). The SDS was developed to reflect psychological and somatic symptoms of depression. Depression becomes entwined with anxiety during ongoing stressful situations, even though the two conditions are
conceptually distinct (Kanner, Coyne, Schaefer, & Lazarus, 1981; Lazarus et al., 1981). Use of the SDS in the current study allowed an evaluation of depression to be compared to scores on the STAI and used in predicting impact of the stressful situation of caregiving.

The SDS consists of 10 positive statements (e.g., "My life is pretty full") and 10 negative statements (e.g., "I have crying spells or feel like it"). The respondent checks one of four choice, from "none or very little" to "most of the time." The responses are scored from one to four, with positively worded items being reverse-coded. This results in raw scores ranging from 20 to 80, with high scores representing high levels of depression. The raw scores are then converted to SDS scores with the following formula: 
\[
\text{SDS score} = \left( \frac{\text{Raw score}}{80} \right) \times 100.
\]

Using the converted SDS scores, Zung (1969) identified mean scores for different clinical samples. A mean score of 61.4 was given for clinical patients with diagnosed depressive disorders. Clinical patients with a non-depression diagnosis had a mean score of 53.7, and normal adults had a mean score of 37. The normal adults were divided into two age groups of under 65 years and 65 or over, with mean scores of 33 and 48 respectively. From his research, Zung (1965, 1969)
suggests that respondents may be categorized as showing no psychopathology (a score below 50), having minimal to mild depression (50-59), showing moderate to marked depression (60-69), or being severely to extremely depressed (70 and over).

SDS scores were reported to be correlated with psychiatrists' global ratings of patients, with a mean $r$ of .53 for 343 patients with depressive disorder diagnoses, and a mean $r$ of .13 for 590 non-depressive patients (Zung, 1969). The SDS was also used in a study with 320 normal adults (Blumenthal, 1975) and was found to be highly correlated with other depression scales including: the MMPI depression scale, $r = .59$; the Beck scale, $r = .76$; and the Hamilton scale, $r = .56$ (Blumenthal, 1975).

Knight, Waal-Manning, and Spears (1983) have reported normative data for the SDS in which females tended to score higher ($M = 35.56, SD = 7.40$) than males ($M = 31.67, SD = 6.71$). Internal consistency of the scale was reported in that same normative study as being high, with a Cronbach's alpha of .79.

**Attitudes Inventory** (Levenson, 1981). This scale allows a multidimensional evaluation of locus of control (LC), reflected in three subscales. Hence, individuals may display beliefs that control of events
affecting them comes from internal sources (I), powerful others (P), chance (C), or a combination of the three. The three subscales are an elaboration of the unidimensional locus of control scale developed by Rotter (1966), which placed internality and externality on a continuum. In Levenson's measure, the respondent reads 24 statements (e.g., "My life is determined by my own actions"), phrased such that there are eight statements reflecting each of the three subscales. For each item, the respondent marks one of six choices ("Strongly disagree" to "Strongly agree") on a Likert scale from -3 to +3. The subscale scores are then computed by adding 24 points to each subscale, for a possible range of scores from 0 to 48 on each subscale.

Levenson (1972) has reported significant differences in mean scores on the three Locus of Control subscales. The I subscale, with a mean of 35.48, was significantly different from both the P subscale, $M = 16.65$ ($t = 12.41, p < .001$), and the C subscale, $M = 13.94$ ($t = 13.28, p < .001$). Furthermore, the P and C subscales have been found to correlate highly with each other, $r = .59, p < .01$. Finally, both P and C were negatively but not significantly correlated with the I subscale, $r = -.14$, and $r = -.17$. Levenson (1972) pointed out that these correlations supported her concept of the P and C
subscales as both reflecting external locus of control beliefs. In addition, Levenson (1981) reported that, in a sample of 75 college students, Rotter's unidimensional Internal-External scale correlated positively with both the P and C subscales, $r = .25$ and $.56$ respectively, and negatively with the I subscale, $r = -.41$. These findings supported her concept of the need for a multidimensional locus of control measure.

Levenson (1981) reported split-half reliabilities of $.62$, $.66$, and $.64$ for the I, P, and C subscales, respectively. In addition, Levenson (1981) reported that test-retest reliabilities over a one week period ranged from $.60$ to $.79$ for all subscales and also cited studies in which comparable reliability coefficients were obtained for a seven week period or with an elderly sample.

**Impact of Event Scale** (Horowitz et al., 1979). This scale is a measure of subjective stress and was developed to reflect the impact which an individual experiences as a result of a specific event. The test consists of two subscales. One involves seven statements which represent intrusion of the stressful event into the everyday life of the respondent (e.g., "I thought about it when I didn't mean to"). The other subscale consists of eight statements which reflect the
respondent's avoidance of the situation (e.g., "I tried not to think about it"). For each of the 15 items, the respondent marks one of four response choices ("not at all" to "often") scored 0, 1, 3, or 5. The possible score ranges are 0 to 35 for the Intrusion subscale, 0 to 40 for the Avoidance subscale, and 0 to 75 for the total scale score.

In scale development studies with 66 persons with stress response syndromes, the mean total score was 39.5, SD = 17.2. The mean Intrusion subscale score was 21.4, SD = 9.6, and the mean Avoidance subscale score was 18.2, SD = 10.8 (Horowitz et al., 1979). The authors of the scale have reported high split-half reliability, r = .86, with the same group of 66 stress response syndrome patients. Internal consistency, using a Cronbach's alpha, was also high. The Intrusion and Avoidance alphas were .78 and .82, respectively. A correlation of .42, p<.0002, between the two subscales indicated that they are associated but do not measure identical factors (Horowitz, Wilner, & Alvarez, 1979). Test-retest reliability was assessed with a sample of 25 physical therapy students at two points during cadaver dissection, with one week between administrations of the measure. The reliability coefficient was high for the total scores, r = .87, as
well as for the Intrusion subscale, $r = .89$, and the Avoidance subscale, $r = .79$.

In validating the measure's sensitivity to magnitude of stress, groups with differing levels of stress were identified. Medical school students were compared to stress clinic patients who were believed to have experienced more distressing life events. Group differences were significant: $F(1, 172) = 212.1$, $p<.0001$, for Intrusion scores; $F(1, 172) = 73.0$, $p<.0001$, for Avoidance scores; and $F(1, 172) = 170.8$, $p<.0001$, for total scores. Gender differences on these tests were also significant, with women reporting most of the Intrusion items and all but a few of the Avoidance items more frequently than did men.

The instrument's sensitivity to change in stress after therapy was tested using 32 patients with diagnosed stress response syndromes. Posttreatment scores were significantly improved for the Intrusion subscale, $t = 5.5$, $p<.05$; for the Avoidance subscale, $t = 4.8$, $p<.05$; and for total scores, $t = 5.8$, $p<.05$. These treatment effects were verified with clinical interviews.

**Information Form.** Participants were also asked to fill out a brief questionnaire to provide demographic data on such factors as age, sex, health, education,
and occupational status of the caregivers as well as the persons for whom they provide care. They were also asked about the AD victim's living situation, age of AD onset, current level of functioning, and relationship to the caregiver.

Procedure

Three different agencies sponsored the four experimental support groups included in the present study. Group sponsors included an adult day care center, an Alzheimer's center in a community hospital, and a senior citizen community center. The groups themselves were all led by the same professional facilitator, Ms. D. Jeanne Roberts. Ms. Roberts is a trained crisis group leader, as well as a former caregiver for a family member with dementia.

The four experimental support groups each consisted of six weekly meetings of one-and-a-half hours each. The first meeting of each experimental group was primarily devoted to introducing group members and leaders, outlining the group procedures, and viewing a short film about dementia which served to clarify some of the topics to be considered in the weekly meetings. At this initial gathering, the research was explained to the group members and they were asked to take home a packet containing the pretest
materials and to complete and return it by mail if they were interested in participating in the study. Written, informed consent was obtained from all participants, in keeping with The Ohio State University human subjects research guidelines. A copy of the consent form which was used is included in Appendix B, along with samples of all communications with the participants. Membership in the group was not contingent upon participation in the research.

The subsequent meetings of each group in weeks 2-6 were devoted to topics including information about dementia and available long-term care options and support systems, discussions of common caregiving problems and potential solutions, emotional responses, grieving, communication, stress management techniques, and the necessity of maintaining caregiver physical and emotional health. As noted earlier, the group leader had training and experience in such group discussions. Three of the groups also had a geriatric nurse with training in dementia care as co-leader in order to have medical information available when questions arose in discussions. The fourth group, which had only four members, did not have a nurse co-leader, but medical personnel were available at the meeting site. At the final group meeting, persons who had completed the pretest were given a packet containing the posttest
materials and asked to complete and return the material by mail. The posttest consisted of the same measures as the pretest, with the exception of the information form.

**Analyses**

Demographic and descriptive variables from the Information form were examined in order to determine the level of homogeneity of the participants in the experimental and control groups. Ratio or interval variables, including age, education, and number of other persons assisting with caregiving, were assessed using t-tests to compare the groups. Chi square analyses were used to test the differences between groups on categorical variables including gender, relationship to the patient, nature of the caregiving role, patient's general functioning level, and frequency with which the participant attends other support groups. With the small sample size, it was sometimes necessary to use Fisher's Exact test, which permits analysis when expected cell size is less than 5.

Demographic variables were then included in a Pearson correlation matrix along with pretest scale scores to test the supporting hypotheses related to these variables. The variables of particular interest
included age, gender, relationship to the patient, and the patient's functioning level. Significance levels were set at a value of .05.

Pearson correlation coefficients were also computed for pretest scale scores to allow for confirmation of relationships between the scales, as expected from previous research (as described above). Also, the correlations were intended to provide preliminary information about the validity of using the Impact scale in this context. In addition, t-tests were performed comparing the pretest scale scores of the experimental and control groups, as verification that the groups were statistically similar on those measures prior to the treatment interval. Significance level was set at p<.05.

Multiple regression techniques were used to test the two primary hypotheses of the study. One of the control participants was excluded from these analyses because of missing data on the pretest impact scale. Pretest scores were used to test the first hypothesis, that Impact scores may be predicted from the scores on the other scales in the study. Analyses were conducted using the General Linear Model and Stepwise procedures of the SAS data analysis package at The Ohio State University computer facilities. Initial simultaneous regression analyses were performed with the two Impact
subscales and total Impact scores as the dependent variables, and State anxiety, Trait anxiety, and SDS as the independent variables. This phase permitted a general review of effects and an informal check of the distribution of residuals (i.e., the difference between the predicted value and the obtained value on Impact scores). A stepwise regression analysis was then done to determine the best predictor model for each of the dependent variables and the amount of variance accounted for by that model. The resulting predictive model was then used in a final simultaneous regression to obtain partial sums of squares and to confirm the linear distribution of residuals.

In the first phase of testing the second primary hypothesis (i.e., that membership in a support group program would reduce Impact), the posttest scores were analyzed with a *t*-test procedure to compare the experimental and control participants. Significance level was set at *p* < .05. The same procedure was also used with the pretest scores, the expectation being that significant differences between the groups would be found on posttests but not pretests. In addition, *t*-test comparisons between groups were carried out with the difference scores for each measure (i.e., subtracting pretest from posttest scores). The primary analyses then followed a course similar to that for the
first primary hypothesis above. Initial simultaneous regression analyses were performed with posttest Intrusion, Avoidance, and total Impact scores as the dependent variables. The independent variables were group (experimental versus control) and pretest scores on the Impact subscales, State anxiety, Trait anxiety, and SDS. Stepwise regression provided the best models for predicting posttest scores, which were then used in simultaneous regression analyses to obtain partial sums of squares and review distribution of residuals.

After initial analyses yielded unexpected results, it was decided to once again contact the support group members who had participated in the research. A letter and response card were sent to the experimental group participants, in which they were asked to respond to two statements representing a subjective evaluation of the benefits of support group participation. The statements were "I found the group to be helpful to me" and "I feel that I have reduced my stress as a result of the group" (see Appendix B for a sample letter and response card). The responses were on a five-point scale from "not at all" to "very much so". The means and distribution of responses on these items were of interest in interpreting the results of the original hypotheses testing.
CHAPTER V
RESULTS

Description of Experimental Versus Control Groups

In the present investigation, the experimental and control groups were found to be statistically equivalent on most demographic variables. There was no significant difference between mean ages of the two groups, $t(39) = 1.9, p > .05$. The mean age of experimental group participants was $57.3$ years, $SD = 11.3, n = 21$. The mean age for the control group participants was $50.0$ years, $SD = 13.6, n = 20$. The groups were also equivalent with respect to gender of the caregivers, Fisher's Exact test, $p(1) > .05$. Seventeen in each group were women, which represented $81\%$ of the experimental group participants and $85\%$ of the control group. In addition, caregiver years of education were identical for the two groups, with means of $13.5$ years, $SD = 2.25$, for the experimental group and $13.5$ years, $SD = 2.98$, for the control group, $t(39) = .09, p > .05$. 

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In the experimental group, eight individuals (38.1%) were caring for a spouse, 11 (52.4%) for a parent, and one (4.8%) each for a parent-in-law and an aunt. In the control group, three (15%) were caring for a spouse, 13 (65%) for a parent, and four (20%) for a parent-in-law. The relative distributions of patient-caregiver relationships across experimental and control groups were not statistically compared, however, due to small sample sizes.

The experimental and control groups did not differ significantly on patient descriptive variables such as age, \( t(39) = .23, p > .05 \), or gender, \( \chi^2(1) = 1.43, p > .05 \). The mean age of dementia victims cared for by those in the experimental group was 75.3 years, SD = 10.94; for those in the control group, the mean patient age was 76.1 years, SD = 9.06. The gender composition of the patient group being cared for was predominantly female, with 12 females (57.1%) cared for by those in the experimental group and 15 females (75%) cared for by those in the control group.

The experimental and control caregivers were also similar on important variables reflecting the caregiving situation. For example, all participants were asked to rate the dementia patient’s current level of functioning on a five point scale from "Functions rather well on own" (level one), to "Is completely
dependent at every level" (level five). The reported perceptions were similar in both groups, with medians at level three for both the experimental group and the control group. In order to perform a chi square analysis, the five levels were collapsed into three categories approximating fair (levels one and two), moderate (level three), and poor (levels four and five) levels of functioning. The distribution of functional level of the patients was not significantly different between the two groups, \( \chi^2(2) = 1.34, p>.05 \). The medians and distributions within each group suggested that both groups tended to view those they were caring for as functioning at a level indicating moderate dementia. In addition, data concerning the duration of the dementia, computed as the patient's current age minus age of onset, were collected and were found to be essentially equivalent across groups, \( t(39) = .70, p>.05 \). The mean duration of the dementia for patients cared for by those in the experimental group was 6.38 years, \( SD = 3.97 \). The mean duration for those cared for by control group families was 5.55 years, \( SD = 3.62 \).

In the experimental group, 52.4% of the participants reported medical problems with the dementia patient, compared to 60% of the control group members reporting patient medical problems. This
difference was not significant, \( \chi^2(1) = .27, p > .05 \). The caregivers themselves did not differ with respect to the report of medical problems either, \( \chi^2(1) = 1.98, p > .05 \), although the experimental group members did report taking more prescription drugs, \( M = 1.84, SD = 1.68 \), than did the control group caregivers, \( M = .70, SD = .86 \). Although this latter difference was statistically significant, \( t(26.6) = 2.65, p < .01 \), it is of little practical value due to the small absolute difference in numbers of medications taken.

Furthermore, it is possible that the higher incidence of medication-use among the experimental group is linked to their slightly (but not significantly) older mean age as compared to the control group caregivers. It is also possible that those participating in the pilot support groups felt more comfortable reporting use of medications, due to such factors as personal contact with the experimenter and the presence of a registered nurse in all but the smallest of the support groups.

Information was also obtained on the nature of the participants' caregiving roles, which was indicated by selecting one of four categories (see Information form in Appendix A). Of those in the experimental group, nine were primary caregivers, seven were assistant caregivers, three were primary monitors of
institutional care, and two were assistant monitors. In the case of control family respondents, seven were primary caregivers, two were assistant caregivers, six were primary monitors, and five were assistant monitors. In order to perform a chi square analysis, caregiver role was collapsed in two different fashions. First, the experimental and control groups were compared on roles defined as primary or assistant caregivers/monitors. The groups did not differ on role defined in this manner, $\chi^2(1) = .27, p>.05$. However, when role was defined in terms of direct caregiving versus monitoring of care, the difference between groups was significant, $\chi^2(1) = 4.19, p<.05$. The experimental group consisted mostly of direct caregivers, and the control group was rather evenly divided between caregivers and monitors.

Everyone in both groups had at least one other person assisting them with care or monitoring of a dementia patient on a regular basis. The mean number of caregivers in the family was very similar for the two groups, $t(39) = .21, p>.05$. There were an average of 2.38, $SD = 1.24$, caregivers in the experimental group families and 2.30, $SD = 1.22$, caregivers in the control group families. Also, the caregiver lived with the affected person in eight of the experimental group
families and eight of the control group families, $\chi^2(1) = .02$, $p > .05$. Finally, among experimental group families, 12 of the dementia victims lived in their own homes or apartments, four in the home of adult children, and five in a nursing home or supervised care center. In the control group families, five patients lived in their own homes or apartments, six in an adult child's home, and nine in nursing homes or care centers. Experimental and control group participants did not differ significantly on this variable, $\chi^2(2) = 4.40$, $p > .05$. On the other hand, if this variable is collapsed for a two-by-two chi square analysis comparing the groups for patients being cared for in their own homes versus those being cared for in other places, the groups do differ significantly, $\chi^2(1) = 7.84$, $p < .01$. However, in light of the fact, as noted above, that the caregivers in each group were equally likely to live with the patient, where the patient lives is of limited importance here.

One further potential difference between the experimental and control group participants involved their attendance at other caregiver support groups in the past. Each of the agencies through which participants of the present study were contacted has a policy of informing families of the existence of related support groups in the area. In particular,
individuals are routinely informed about the monthly meetings of the Alzheimer's Disease and Related Disorders Association (ADRDA). Among the experimental group, four individuals said they attended such meetings monthly, six went several times a year, six went once or twice a year, two had attended less than once a year, and three reported never having gone to such a meeting. Three control group participants had been going monthly, two went several times a year, one reported going once or twice a year, and 14 had never gone. In order to perform a chi square analysis, the levels of this variable were collapsed to acquire sufficient cell sizes. Two categories were created by collapsing the three levels representing the lowest frequency of attendance and the two levels of highest attendance. The resulting two-by-two chi square of group by attendance of other support groups was not significant, \( \chi^2(1) = 2.26, p > .05 \). Division of attendance levels in this manner is justifiable in that having gone to another group only one or twice a year represents extremely limited amounts of support, as opposed to having gone several times a year. However, it may also be argued that, especially considering that most such groups meet monthly, the dichotomization should be drawn between those caregivers who report attending other groups to any extent and those who have
never gone to such meetings. A chi square analysis performed on the variable defined in this manner revealed a significant difference between the groups, $\chi^2(1) = 13.10, p < .001$. However, it should also be pointed out that, although the experimental group participants were more likely than control group participants to have attended other groups, they did not differ significantly from each other on the pretest measures, as will be outlined below. Therefore, the experimental group's higher rate of attendance of other groups apparently did not benefit them in terms of stress levels.

From these comparisons between the experimental and control group members, it was ascertained that the groups were relatively similar as caregivers. This assumption of homogeneity of the sample, then, permitted analyses of the present investigation's hypotheses, despite the impracticality of randomly matching the sample or randomly assigning participants to treatment conditions.

**Supporting hypotheses**

Few of the demographic and descriptive variables were significantly correlated with the pretest scores. Table 1 gives the Pearson correlation coefficients for the pairings which were of particular interest. For
Table 1
Correlations of Pretest Scale Scores with Descriptive Variables for All Participants (N = 41)

<table>
<thead>
<tr>
<th>Descriptive Variables</th>
<th>Impact Intrusion</th>
<th>Avoidance</th>
<th>Total</th>
<th>Anxiety State</th>
<th>Anxiety Trait</th>
<th>SDS</th>
<th>Locus of Control Internal</th>
<th>Locus of Control Chance</th>
<th>Locus of Control Powerful others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>.16</td>
<td>.33*</td>
<td>.27</td>
<td>.09</td>
<td>.06</td>
<td>.15</td>
<td>.05</td>
<td>.18</td>
<td>.08</td>
</tr>
<tr>
<td>Gender</td>
<td>.13</td>
<td>-.18</td>
<td>-.03</td>
<td>-.07</td>
<td>-.04</td>
<td>.03</td>
<td>-.18</td>
<td>.33*</td>
<td>.23</td>
</tr>
<tr>
<td>Education</td>
<td>-.11</td>
<td>.08</td>
<td>-.01</td>
<td>-.25</td>
<td>.03</td>
<td>-.07</td>
<td>.34*</td>
<td>-.02</td>
<td>-.09</td>
</tr>
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<td>Medical problems</td>
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<td>-.30</td>
<td>-.28</td>
<td>-.06</td>
<td>-.23</td>
<td>-.21</td>
<td>-.23</td>
<td>-.22</td>
<td>-.13</td>
</tr>
<tr>
<td>Medications</td>
<td>.16</td>
<td>.26</td>
<td>.23</td>
<td>.05</td>
<td>.08</td>
<td>.20</td>
<td>.04</td>
<td>.15</td>
<td>.16</td>
</tr>
<tr>
<td>Number of caregivers</td>
<td>-.24</td>
<td>-.20</td>
<td>-.24</td>
<td>-.55***</td>
<td>-.46**</td>
<td>-.37*</td>
<td>.08</td>
<td>-.36*</td>
<td>.03</td>
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<tr>
<td>Hrs/wk with patient</td>
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<td>.08</td>
<td>-.01</td>
<td>-.17</td>
<td>-.17</td>
<td>.06</td>
<td>-.05</td>
<td>-.33*</td>
<td>-.10</td>
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<tr>
<td>Attendance of other groups</td>
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<td>.21</td>
<td>.12</td>
<td>-.06</td>
<td>.03</td>
<td>.06</td>
<td>-.10</td>
<td>-.09</td>
<td>-.04</td>
</tr>
</tbody>
</table>
Table 1 (continued)

Correlations of Pretest Scale Scores with Descriptive Variables for All Participants (N = 41)

<table>
<thead>
<tr>
<th>Descriptive Variables</th>
<th>Impact</th>
<th>Anxiety</th>
<th>SDS</th>
<th>Locus of Control</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intrusion</td>
<td>Avoidance</td>
<td>Total</td>
<td>State</td>
</tr>
<tr>
<td>Kin Relationship</td>
<td>.25</td>
<td>.32*</td>
<td>.31*</td>
<td>.28</td>
</tr>
<tr>
<td>Patient age</td>
<td>-.04</td>
<td>.00</td>
<td>-.02</td>
<td>-.22</td>
</tr>
<tr>
<td>Patient gender</td>
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<td>.07</td>
<td>-.03</td>
<td>-.02</td>
</tr>
<tr>
<td>Patient level of impairment</td>
<td>.10</td>
<td>.25</td>
<td>.19</td>
<td>.16</td>
</tr>
<tr>
<td>Patient medical problems</td>
<td>-.01</td>
<td>.07</td>
<td>.04</td>
<td>.08</td>
</tr>
<tr>
<td>Duration of dementia</td>
<td>-.10</td>
<td>.01</td>
<td>-.05</td>
<td>-.27</td>
</tr>
</tbody>
</table>

Note: N for Impact scales is 40.
*  p<.05
** p<.01
*** p<.001
example, caregiver age was found to be positively correlated only with Avoidance Impact, $r = .33$, $p < .05$. In addition, caregiver gender was shown to be associated with Chance Locus of Control, $r = .33$, $p < .05$. Also, a positive correlation was found between caregiver years of education and Internal Locus of Control, $r = .34$, $p < .05$. The number of hours per week which the caregiver spent with the dementia patient was negatively related to Chance Locus of Control, $r = -.33$, $p < .05$. The kin relationship between the caregiver and the person with dementia was scored from high to low relationship (5 = spouse, 4 = parent, 3 = parent-in-law, 2 = aunt/uncle, 1 = other). This variable was positively correlated with Avoidance Impact and Total Impact, $r = .32$, $p < .05$, and $r = .31$, $p < .05$, respectively. These results imply that the closer the relationship between caregiver and patient, the higher the impact of the caregiving situation. In addition, the correlation between the pretest measures and caregiver's perception of the patient's functional level was examined. However, no significant correlations were found for this variable, contrary to expectations. Finally, one variable, number of caregivers participating in the caregiving situation, was found to be correlated with several of the scales including: State anxiety, $r = -.55$, $p < .001$; Trait
anxiety, $r = -.46$, $p < .01$; SDS, $r = -.37$, $p < .05$; and Chance Locus of Control, $r = -.36$, $p < .05$.

The number of significant correlations reported above is sparse. As discussed earlier, many of the assumptions which form the basis of support group programs and caregiver research are tied to expectations related to the type of individuals who are caregivers and the degree of distress they are experiencing. Therefore, the lack of significant correlations between demographic variables and scale scores used in this study may indicate a violation of these assumptions, or invalidity of the assumptions.

Intercorrelations between scales and subscales on the pretest met expectations for the most part. Table 2a presents the correlation coefficients for the entire sample. The correlations for the experimental and control groups separately are shown in Tables 2b and 2c. (Similar intercorrelations of posttest measures are given in Tables 12a, 12b, and 12c in Appendix C.) For the total sample of caregivers, the two subscales of the anxiety measure, STAI, were highly positively correlated with each other at pretest, $r = .82$, $p < .001$. This agrees with Spielberger's (1983) findings that situations involving threats to self-esteem and feelings of adequacy result in subscale intercorrelations of .70 or higher.
Table 2a

Intercorrelations of Pretest Scale Scores for All Participants (N = 41)

<table>
<thead>
<tr>
<th>Scale</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Intrusion Impact</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Avoidance Impact</td>
<td>.66***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Impact Total</td>
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<td>.91***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>4. State Anxiety</td>
<td></td>
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<td>.67***</td>
<td>.45**</td>
<td>.61***</td>
<td></td>
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<tr>
<td>5. Trait Anxiety</td>
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<td></td>
<td></td>
<td></td>
<td>.72***</td>
<td>.55***</td>
<td>.70***</td>
<td>.82***</td>
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<tr>
<td>6. SDS—Depression</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>.77***</td>
<td>.55***</td>
<td>.73***</td>
<td>.73***</td>
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<tr>
<td>7. Internal Locus of Control</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td>-.28</td>
<td>-.04</td>
<td>-.17</td>
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<td>8. Chance Locus of Control</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.49**</td>
<td>.25</td>
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<td>9. Powerful others Locus of Control</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.28</td>
</tr>
</tbody>
</table>

Note: N for Impact scales is 40.

*  p<.05
** p<.01
*** p<.001
### Table 2b

**Intercorrelations of Pretest Scale Scores for Experimental Participants (n = 21)**

<table>
<thead>
<tr>
<th>Scale</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Intrusion Impact</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Avoidance Impact</td>
<td>.67***</td>
<td>-</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Impact Total</td>
<td>.93***</td>
<td>.90***</td>
<td>-</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>4. State Anxiety</td>
<td>.62**</td>
<td>.72***</td>
<td>.73***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Trait Anxiety</td>
<td>.65**</td>
<td>.55**</td>
<td>.66***</td>
<td>.77***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>6. SDS—Depression</td>
<td>.72***</td>
<td>.57**</td>
<td>.71***</td>
<td>.65**</td>
<td>.81***</td>
<td>-</td>
<td></td>
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<td>7. Internal Locus of Control</td>
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<td>.42</td>
<td>.27</td>
<td>.39</td>
<td>.20</td>
<td>.14</td>
<td>.39</td>
<td>-</td>
<td></td>
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<tr>
<td>8. Chance Locus of Control</td>
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<td>.35</td>
<td>.01</td>
<td>.22</td>
<td>.31</td>
<td>.41</td>
<td>.37</td>
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<td>-</td>
</tr>
<tr>
<td>9. Powerful others Locus of Control</td>
<td></td>
<td>.35</td>
<td>.30</td>
<td>.35</td>
<td>.27</td>
<td>.40</td>
<td>.35</td>
<td>-.38</td>
<td>.68***</td>
</tr>
</tbody>
</table>

* * * p < .001
** * p < .01
* p < .05
Table 2c

Intercorrelations of Pretest Scale Scores for Control Participants (n = 20)

<table>
<thead>
<tr>
<th>Scale</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Intrusion Impact</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>2. Avoidance Impact</td>
<td>.65**</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>3. Impact Total</td>
<td>.89***</td>
<td>.92***</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<td>-</td>
</tr>
<tr>
<td>4. State Anxiety</td>
<td>.70***</td>
<td>.27</td>
<td>.51*</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<td>-</td>
</tr>
<tr>
<td>5. Trait Anxiety</td>
<td>.79***</td>
<td>.58**</td>
<td>.75***</td>
<td>.87***</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>6. SDS—Depression</td>
<td>.82***</td>
<td>.55*</td>
<td>.74***</td>
<td>.81***</td>
<td>.90***</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>7. Internal Locus of Control</td>
<td>-.12</td>
<td>-.15</td>
<td>-.03</td>
<td>-.20</td>
<td>-.20</td>
<td>-.35</td>
<td>-</td>
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</tr>
<tr>
<td>8. Chance Locus of Control</td>
<td>.62**</td>
<td>.41</td>
<td>.56*</td>
<td>.47*</td>
<td>.51*</td>
<td>.61**</td>
<td>.00</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>9. Powerful others Locus of Control</td>
<td>.21</td>
<td>.27</td>
<td>.27</td>
<td>.09</td>
<td>.09</td>
<td>.24</td>
<td>-.04</td>
<td>.58**</td>
<td>-</td>
</tr>
</tbody>
</table>

Note: n for Impact scales is 19.

* p<.05
** p<.01
*** p<.001
The depression scale, SDS, was positively correlated with both the State anxiety subscale, $r = .73$, $p < .001$, and the Trait anxiety subscale, $r = .85$, $p < .001$. These figures are higher than the equivalent correlations reported by Knight et al. (1983), in which SDS correlated with State, $r = .54$, $p < .001$, and SDS correlated with Trait anxiety, $r = .70$, $p < .001$. The comparison between the two studies is questionable, however. The Knight et al. study used an earlier form of the STAI and tested a normal population in New Zealand. The present study used a refined version of the STAI in a sample of stressed individuals in the United States. This could explain the difference in correlations.

The subscales of the Impact measure, Intrusion and Avoidance, were also positively correlated with each other, $r = .66$, $p < .001$, which is higher than the .42 subscale intercorrelation reported by the authors of the scale (Horowitz et al., 1979). Furthermore, the Intrusion subscale was positively correlated with the State anxiety subscale, $r = .67$, $p < .001$; with the Trait anxiety subscale, $r = .72$, $p < .001$; and with the SDS, $r = .77$, $p < .001$. Finally, the Avoidance subscale was positively correlated with the State subscale, $r = .45$, $p < .01$; with the Trait subscale, $r = .55$, $p < .001$; and with the SDS, $r = .55$, $p < .001$. The only exception to
the trend of significance was for the control group alone, as shown in Table 2c, in which Avoidance Impact and State anxiety were not significantly related. The fact that these two scales were significantly correlated for experimental group participants but not for control group participants may be due to the mind set of the two groups. Perhaps by enrolling in a support group, the experimental group members were put in a position of contemplating the problems of caregiving and, thus, having to put increasing energy into preventing stress from interfering with caregiving responsibilities. Therefore, the higher their level of State anxiety, the higher the Avoidance Impact. The control group members, on the other hand, were not necessarily as involved in preparing to examine their circumstances, so that their current anxiety level was not particularly related to how much effort they had to exert in avoiding the effects of the stress.

In addition, it was found that the two externally-oriented subscales of the Locus of Control measure, Chance and Powerful others, were highly positively correlated with each other, \( r = .63, p < .001 \), as would be expected from Levenson's (1981) theoretical design of the subscales and subsequent research with them. However, the Internal subscale of the Locus of Control measure was not significantly related to either
of the other subscales ($r = -0.13$, $p > 0.05$, for the Chance subscale, and $r = -0.22$, $p > 0.05$, for the Powerful others subscale). Nor was Internal Locus of Control related to any of the other pretest scales except SDS, $r = -0.38$, $p < 0.05$. This latter finding, furthermore, was true only for the entire group of respondents; no relationship between the Internal subscale and the SDS was found for groups separately. This was not the predicted outcome. It had been expected that high internality would be associated with high anxiety and depression due to the frustrations and powerlessness of the dementia caregiving situation. In sum, not only did correlations not appear as expected with anxiety but the significant correlation with SDS was in the wrong direction (i.e., high internality was associated with low depression). This finding will be examined in more detail in the Discussion section.

It should be noted that Chance Locus of Control for the control group was significantly correlated with most of the other pretest measures, unlike the results for the experimental group. This may be important if it indicates that, when a caregiver's strong beliefs in the influence of chance forces are associated with high stress and depression, then those individuals do not as actively seek out support systems.
Prediction of Pretest Impact

The experimental and control groups, as expected, did not differ significantly on any of the pretest scales or subscales. The t-tests comparing the groups at pretest are given in Table 3. The groups were thus collapsed in initial simultaneous regression analyses to test the hypothesis that pretest Impact scores could be predicted from the other pretest measures, including: State and Trait anxiety; SDS (depression); and Internal, Chance, and Powerful others Locus of Control. (One control group participant did not complete the pretest Impact measure correctly and was thus excluded from analyses involving that scale.)

The initial regression analyses carried out to predict pretest Impact scores from the other pretest scores indicated that SDS was the only significant predictor of Intrusion Impact, \( F(1, 33) = 4.83, p<.05 \), with all variables accounting for 63.7% of the variance. SDS was also the only significant variable in the analysis with total Impact scores, \( F(1, 33) = 4.47, p<.05 \), with all variables accounting for 56.6% of the variance. None of the pretest measures was shown on this analysis to be a significant predictor of Avoidance Impact and only 38.2% of the variance was accounted for. Finally, a check of the initial residuals (i.e., the difference between the predicted
Table 3

T-Test Comparison of Experimental and Control Groups on Pretest Scale Scores.

<table>
<thead>
<tr>
<th>Scale</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th>df</th>
<th>t*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intrusion Impact</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experimental</td>
<td>21</td>
<td>19.05</td>
<td>9.45</td>
<td>38</td>
<td>.89</td>
</tr>
<tr>
<td>Control</td>
<td>19</td>
<td>16.21</td>
<td>10.59</td>
<td></td>
<td></td>
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<tr>
<td>Avoidance Impact</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>21</td>
<td>19.39</td>
<td>7.83</td>
<td>29.9</td>
<td>1.49</td>
</tr>
<tr>
<td>Control</td>
<td>19</td>
<td>14.47</td>
<td>12.34</td>
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</tr>
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<td>Impact Total</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Experimental</td>
<td>21</td>
<td>38.44</td>
<td>15.79</td>
<td>38</td>
<td>1.33</td>
</tr>
<tr>
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<td>20.85</td>
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<tr>
<td>Experimental</td>
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<td>46.76</td>
<td>14.92</td>
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<td>.53</td>
</tr>
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<td>Control</td>
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<td>44.35</td>
<td>14.37</td>
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<td></td>
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<td>Experimental</td>
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<td>49.95</td>
<td>13.22</td>
<td>39</td>
<td>.76</td>
</tr>
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<td>46.85</td>
<td>12.78</td>
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<td>Internal Locus of Control</td>
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<td>7.22</td>
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<td>7.71</td>
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<td>Chance Locus of Control</td>
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<td>11.32</td>
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<td>Powerful others Locus of Control</td>
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<td>Experimental</td>
<td>21</td>
<td>18.34</td>
<td>12.06</td>
<td>39</td>
<td>-.25</td>
</tr>
<tr>
<td>Control</td>
<td>20</td>
<td>19.20</td>
<td>9.87</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*All t values were nonsignificant, p>.05.
value and the obtained value on Impact scores) for these analyses indicated that they were basically linearly distributed. This suggested that predictions were equally strong over the entire continuum of scores.

Stepwise regression analyses, with Impact scores as the dependent variable and the other pretest scores entering as independent variables, were subsequently conducted. These analyses confirmed that the SDS comprised the best one-variable model for explaining the variance in Intrusion Impact scores and total Impact scores. No other variables entered either regression equation at a significant level. Subsequent analyses using SDS alone as the independent variable accounted for 59.8% of the variance in Intrusion Impact, $F(1, 38) = 56.44, p < .001$, and 52.6% of the variance in total Impact, $F(1, 38) = 42.18, p < .001$. These analyses are summarized in Tables 4 and 5. Again, an examination of residuals confirmed basic linearity. However, the stepwise analysis of the Avoidance Impact data revealed equivocal findings which contributed to the lack of significant predictors on the initial simultaneous analysis. The complexities arose when Trait Anxiety, which was revealed as the best one-variable regression model for Avoidance Impact, was replaced by SDS in the stepwise regression
Table 4

Pretest SDS (Depression) as Best-Model Prediction of Pretest Intrusion Impact (N = 40)

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>F</th>
<th>R-square</th>
</tr>
</thead>
<tbody>
<tr>
<td>SDS</td>
<td>2321.37</td>
<td>1</td>
<td>2321.37</td>
<td>56.44*</td>
<td>.598</td>
</tr>
<tr>
<td>Error</td>
<td>1563.03</td>
<td>38</td>
<td>41.13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>3884.40</td>
<td>39</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p<.0001

Table 5

Pretest SDS (Depression) as Best-Model Prediction of Pretest Total Impact (N = 40)

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>F</th>
<th>R-square</th>
</tr>
</thead>
<tbody>
<tr>
<td>SDS</td>
<td>7055.14</td>
<td>1</td>
<td>7055.14</td>
<td>42.18*</td>
<td>.526</td>
</tr>
<tr>
<td>Error</td>
<td>6356.66</td>
<td>38</td>
<td>167.28</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>13411.80</td>
<td>39</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p<.0001
as other, non-significant variables were entered. Subsequent simultaneous variance for Avoidance Impact using SDS alone and Trait Anxiety alone show these two measures to be very similar in predictive strength, accounting for 30.5% and 30.8% of the variance, respectively. These results were significant both for the SDS analysis, $F(1, 38) = 16.66$, $p<.001$, and for the Trait Anxiety analysis, $F(1, 38) = 16.88$, $p<.001$. A review of the residuals on these analyses revealed a slight tendency toward nonlinearity, which could explain why the initial multivariate analysis of Avoidance Impact showed no significant main effects of any of the other pretest scales. These problems, however, did not appear to be serious and either of the univariate models would appear to be sufficiently predictive of pretest Avoidance Impact. The results of one-variable model regression analyses using SDS or Trait anxiety are summarized in Tables 6a and 6b.

On the basis of these analyses carried out to obtain a predictive model for pretest Impact scores for caregivers, it appears that depression scores are the most valid overall predictor. Although SDS and Trait anxiety can be used with essentially equal results for predicting Avoidance Impact, SDS did provide the best prediction of Intrusion and Total Impact. The
Table 6a
Pretest SDS (Depression) as Best-Model Prediction of Pretest Avoidance Impact (N = 40)

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>F</th>
<th>R-square</th>
</tr>
</thead>
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<td>SDS</td>
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<td>Error</td>
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<td>38</td>
<td>76.98</td>
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</tr>
<tr>
<td>Total</td>
<td>4208.01</td>
<td>39</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p<.001

Table 6b
Pretest Trait Anxiety as Best-Model Prediction of Pretest Avoidance Impact (N = 40)

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>F</th>
<th>R-square</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trait</td>
<td>1294.09</td>
<td>1</td>
<td>1294.09</td>
<td>16.88*</td>
<td>.308</td>
</tr>
<tr>
<td>Error</td>
<td>2913.92</td>
<td>38</td>
<td>76.68</td>
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<tr>
<td>Total</td>
<td>4208.01</td>
<td>39</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p<.001
caregiver's level of depression, then, is perhaps the best indicator of the extent to which that person's life is disrupted by the caregiving situation.

**Prediction of Posttest Impact**

The treatment effects that were predicted by the second primary hypothesis (i.e., that posttest Impact scores could be predicted from pretest scale scores and membership in an experimental support group versus the control group) were not supported. The experimental and control groups did not differ significantly on any of the posttest measures, as indicated in the *t*-test results presented in Table 7. In addition, the initial simultaneous and stepwise regressions using pretest measures to predict posttest Impact did not show treatment effects for group.

The simultaneous and stepwise regressions did reveal significant pretest predictors of posttest Impact scores. The initial analyses indicated that the only significant predictor of the Intrusion subscale was the pretest of the same subscale, $F(1, 30) = 14.42$, $p < .001$, with all variables accounting for 80.6% of the variance. However, this initial analysis revealed several predictors of Avoidance posttest scores, including pretest Avoidance, $F(1, 30) = 12.08$, $p < .01$;
Table 7

T-Test Comparison of Experimental and Control Groups on Posttest Scale Scores.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Experimental</th>
<th>Control</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th>df</th>
<th>t*</th>
</tr>
</thead>
<tbody>
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<td>Intrusion Impact</td>
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<td></td>
<td>21</td>
<td>17.00</td>
<td>9.90</td>
<td>39</td>
<td>1.61</td>
</tr>
<tr>
<td>Experimental</td>
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<td></td>
<td>20</td>
<td>12.49</td>
<td>7.88</td>
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<tr>
<td>Avoidance Impact</td>
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<td>18.76</td>
<td>7.97</td>
<td>39</td>
<td>1.28</td>
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<tr>
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<td>15.18</td>
<td>9.87</td>
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</tr>
<tr>
<td>Impact Total</td>
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<td>21</td>
<td>35.76</td>
<td>16.43</td>
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<td></td>
<td>20</td>
<td>27.68</td>
<td>16.20</td>
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<td></td>
</tr>
<tr>
<td>State Anxiety</td>
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<td>44.50</td>
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<td>20</td>
<td>40.75</td>
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<td>48.67</td>
<td>10.90</td>
<td>39</td>
<td>.34</td>
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<tr>
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<td>7.53</td>
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<td>.37</td>
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</table>

* All t values were nonsignificant, p > .05.
SDS, $F(1, 30) = 5.95, p<.05$; Trait anxiety, $F(1, 30) = 8.36, p<.01$; and Internal Locus of Control, $F(1, 30) = 10.92, p<.01$. Together, these variables accounted for 72.2% of the variance in posttest Avoidance scores.

The initial analysis of total Impact at posttest also resulted in multiple predictors, including pretest Intrusion, $F(1, 30) = 8.01, p<.01$; Avoidance, $F(1, 30) = 7.64, p<.01$; Trait anxiety, $F(1, 30) = 6.53, p<.05$; and Internal Locus of Control, $F(1, 30) = 11.59, p<.01$. These variables were found to account for 84.2% of the variance. Finally, an examination of the initial distribution of residuals supported the linearity assumption.

A stepwise regression analysis revealed slightly different models than those of the simultaneous regression. The stepwise analysis for Intrusion Impact resulted in a three-variable model including pretest Intrusion, Internal Locus of Control, and Chance Locus of Control, with no other variables entering the equation at a significant level. A subsequent analysis using this three-variable model, summarized in Table 8, indicated that 77.6% of the variance in posttest Intrusion could be accounted for. This model included pretest Intrusion, $F(1, 36) = 55.25, p<.001$; Internal Locus of Control, $F(1, 36) = 3.99, p<.05$; and Chance Locus of Control, $F(1, 36) = 5.96, p<.05$. The
Table 8

Pretest Best-Model Prediction of Posttest Intrusion Impact (N = 40)

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>F</th>
<th>R-square</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model</td>
<td>2589.82</td>
<td>3</td>
<td>863.27</td>
<td>41.68***</td>
<td>.776</td>
</tr>
<tr>
<td>Intrusion Impact</td>
<td>(1144.40)</td>
<td>(1)</td>
<td>-</td>
<td>55.25***</td>
<td></td>
</tr>
<tr>
<td>Internal Locus of Control</td>
<td>(82.62)</td>
<td>(1)</td>
<td>-</td>
<td>3.99*</td>
<td></td>
</tr>
<tr>
<td>Chance Locus of Control</td>
<td>(123.55)</td>
<td>(1)</td>
<td>-</td>
<td>5.96*</td>
<td></td>
</tr>
<tr>
<td>Error</td>
<td>745.70</td>
<td>36</td>
<td>20.72</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>3335.52</td>
<td>39</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* $p<.05$
*** $p<.0001$
residuals on this prediction model were linearly distributed.

The stepwise regression for posttest Avoidance Impact suggested a similar three-variable model, although Intrusion was replaced with Avoidance pretest scores. The subsequent analysis using this model, shown in Table 9, accounted for 62.2% of the variance in posttest Avoidance. This model involved pretest Avoidance, $F(1, 36) = 28.92, p<.001$; Internal Locus of Control, $F(1, 36) = 7.59, p<.01$; and Chance Locus of Control, $F(1, 36) = 8.08, p<.01$. The distribution of residuals on this predictive model were found to be linear.

Finally, for the total Impact scores, a stepwise regression analysis suggested a four-variable model, incorporating the variables which were included in the models for the Impact subscales. The final analysis with this model, shown in Table 10, accounted for 79.3% of the variance in total Impact on the posttest and included pretest Intrusion, $F(1, 35) = 7.55, p<.01$; Avoidance, $F(1, 35) = 13.12, p<.001$; Internal Locus of Control, $F(1, 35) = 9.84, p<.01$; and Chance Locus of Control, $F(1, 35) = 10.90, p<.01$. The distribution of residuals for this model appeared to be linear.

An alternative method of assessing the role of support group participation in determining Impact level
Table 9

Pretest Best-Model Prediction of Posttest Avoidance Impact (N = 40)

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>F</th>
<th>R-square</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model</td>
<td>2013.92</td>
<td>3</td>
<td>671.31</td>
<td>19.72***</td>
<td>.622</td>
</tr>
<tr>
<td>Avoidance Impact</td>
<td>(984.36)</td>
<td>(1)</td>
<td>-</td>
<td>28.92***</td>
<td></td>
</tr>
<tr>
<td>Internal Locus of Control</td>
<td>(259.49)</td>
<td>(1)</td>
<td>-</td>
<td>7.59**</td>
<td></td>
</tr>
<tr>
<td>Chance Locus of Control</td>
<td>(274.98)</td>
<td>(1)</td>
<td>-</td>
<td>8.08**</td>
<td></td>
</tr>
<tr>
<td>Error</td>
<td>1225.34</td>
<td>36</td>
<td>34.04</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>3239.26</td>
<td>39</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

** $p < .01$

*** $p < .0001$
Table 10

Pretest Best-Model Prediction of Posttest Total Impact (N = 40)

<table>
<thead>
<tr>
<th>Source</th>
<th>SS</th>
<th>df</th>
<th>MS</th>
<th>F</th>
<th>R-square</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model</td>
<td>8721.08</td>
<td>4</td>
<td>2180.27</td>
<td>33.59***</td>
<td>.793</td>
</tr>
<tr>
<td>Intrusion Impact</td>
<td>(490.21)</td>
<td>(1)</td>
<td>-</td>
<td>7.55**</td>
<td></td>
</tr>
<tr>
<td>Avoidance Impact</td>
<td>(851.68)</td>
<td>(1)</td>
<td>-</td>
<td>13.12***</td>
<td></td>
</tr>
<tr>
<td>Internal Locus of Control</td>
<td>(638.72)</td>
<td>(1)</td>
<td>-</td>
<td>9.84**</td>
<td></td>
</tr>
<tr>
<td>Chance Locus of Control</td>
<td>(707.51)</td>
<td>(1)</td>
<td>-</td>
<td>10.90**</td>
<td></td>
</tr>
<tr>
<td>Error</td>
<td>2271.73</td>
<td>35</td>
<td>64.91</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>10992.81</td>
<td>39</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* $p < .05$
** $p < .01$
*** $p < .001$
was to perform $t$-tests on difference scores. That is, the two groups could be compared on the direction and extent of change in Impact from pretest to posttest. The results of such an analysis are given in Table 11. The only significant difference between groups involved the change from pretest to posttest on the Chance Locus of Control subscale, $t(39) = -2.20$, $p<.05$, with experimental group members tending to show decreases in Chance beliefs and control group members tending to show increases on this measure. One possible explanation for this finding is that much of the support group discussion focused on reducing feelings of victimization among the caregivers. Such helpless feelings may well be tied to attributing power to chance forces.

An additional test of the changes in scale scores from pretest to posttest involved surveying correlations between the two sets of scale scores for each group. The results of the analyses are given in Tables 13a and 13b in Appendix C. The coefficients of importance to note are those for pretest and posttest of the Impact subscales and total scores. The correlations for the experimental group are not generally different from those for the control group.

The results of the analyses carried out in order to obtain a predictive model of posttest Impact scores,
Table 11

T-Test Comparison of Experimental and Control Groups on Difference Scores: Posttest – Pretest.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Experimental</th>
<th>Control</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th>df</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intrusion Impact</td>
<td></td>
<td></td>
<td>21</td>
<td>-2.05</td>
<td>4.84</td>
<td>38</td>
<td>.93</td>
</tr>
<tr>
<td>Control</td>
<td></td>
<td></td>
<td>19</td>
<td>-3.63</td>
<td>5.98</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidance Impact</td>
<td></td>
<td></td>
<td>21</td>
<td>-.63</td>
<td>8.18</td>
<td>38</td>
<td>-.55</td>
</tr>
<tr>
<td>Control</td>
<td></td>
<td></td>
<td>19</td>
<td>.82</td>
<td>8.32</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact Total</td>
<td></td>
<td></td>
<td>21</td>
<td>-2.67</td>
<td>11.67</td>
<td>38</td>
<td>.04</td>
</tr>
<tr>
<td>Control</td>
<td></td>
<td></td>
<td>19</td>
<td>-2.81</td>
<td>10.78</td>
<td></td>
<td></td>
</tr>
<tr>
<td>State Anxiety</td>
<td></td>
<td></td>
<td>21</td>
<td>-1.75</td>
<td>11.76</td>
<td>39</td>
<td>.12</td>
</tr>
<tr>
<td>Control</td>
<td></td>
<td></td>
<td>20</td>
<td>-2.23</td>
<td>13.27</td>
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<td></td>
</tr>
<tr>
<td>Trait Anxiety</td>
<td></td>
<td></td>
<td>21</td>
<td>-2.26</td>
<td>7.62</td>
<td>39</td>
<td>.49</td>
</tr>
<tr>
<td>Control</td>
<td></td>
<td></td>
<td>20</td>
<td>-3.60</td>
<td>9.88</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SDS-Depression</td>
<td></td>
<td></td>
<td>21</td>
<td>-1.29</td>
<td>7.74</td>
<td>39</td>
<td>-.82</td>
</tr>
<tr>
<td>Control</td>
<td></td>
<td></td>
<td>20</td>
<td>.60</td>
<td>6.93</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal Locus of Control</td>
<td></td>
<td></td>
<td>21</td>
<td>.08</td>
<td>7.28</td>
<td>28.8</td>
<td>.99</td>
</tr>
<tr>
<td>Control</td>
<td></td>
<td></td>
<td>20</td>
<td>-1.66</td>
<td>3.44</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chance Locus of Control</td>
<td></td>
<td></td>
<td>21</td>
<td>-3.05</td>
<td>7.01</td>
<td>39</td>
<td>-2.20*</td>
</tr>
<tr>
<td>Control</td>
<td></td>
<td></td>
<td>20</td>
<td>1.38</td>
<td>5.79</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Powerful others Locus of Control</td>
<td></td>
<td></td>
<td>21</td>
<td>-.24</td>
<td>7.61</td>
<td>39</td>
<td>-.37</td>
</tr>
<tr>
<td>Control</td>
<td></td>
<td></td>
<td>20</td>
<td>.54</td>
<td>5.80</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* p<.05
then, revealed no identifiably important difference between those caregivers who had participated in the experimental support groups and those who had not. However, with an interval of several weeks between pretest and posttest, the best indicator of the impact of caregiving was the person's initial level of impact and the degree of perceived control of the situation derived from internal and chance sources. In other words, those with the highest degree of perceived internal control and the lowest degree of control from chance sources fared the best in the caregiving situation.

Subjective Evaluation of Support Groups

The lack of significant treatment effects with respect to the posttest variables, in contrast to strong impressions of the group leaders that members had valued the groups highly, prompted a follow-up contact with the experimental group participants. As described in the Analyses section above, the former group members were sent a card with two additional questions requesting subjective evaluation of the benefits of group membership. Eighteen of the experimental participants responded to the questions. The first question, whether they found the group
helpful, received very high responses, with a mean of 4.44 out of five, $SD = .78$. The responses to the question of whether they felt they had reduced their stress as a result of the group were also fairly positive, with a mean of 3.83 out of five, $SD = .86$. These findings reinforced the impressions of the group leaders, who were offered gifts and tearful thanks by the group members. The apparent paradox of these results relative to the lack of significant difference between experimental and control participants on the posttest measures will be discussed in the next chapter.
CHAPTER VI
DISCUSSION

The results of the present study can be viewed in terms of two basic foci. First, the measures of impact, anxiety, depression, and locus of control were examined in terms of their correlations with demographic and descriptor variables, and their correlations with each other. Second, the measures of anxiety, depression, and locus of control were examined in terms of their ability to predict scores on the impact measure. This second focus consists of two segments, coinciding with two primary hypotheses: 1) that the pretest scores on the predictor measures could be used as predictors of pretest impact; 2) that all the pretest scores, including pretest impact, could be used as predictors of posttest impact, with membership in a support group as an added predictor.

Variables Related to Impact

Analyses related to the supporting hypotheses which posited correlations between caregiver descriptor variables and pretest scores yielded interesting...
results (see Table 1 and description of results). For example, data indicated that older caregivers tended to put more emphasis on avoiding the impact of caregiving stress than did younger caregivers. This may help illuminate findings of other investigators that younger caregivers experience more stress than older caregivers (Robinson, 1983). It may not be that the older persons feel less stress but may somehow channel more energy into avoiding the impact of that stress.

Caregiver gender was not found to be associated with stress-related impact. Certainly, most of the caregivers in the present study were women. It may, then, be argued by some that women are the persons most in need of stress-reduction. However, women are traditionally expected to assume caregiver roles and, as Brody (1985) indicated, women tend to adapt more easily to caregiving roles than do men. Women are, therefore, more in evidence than men not only as caregivers but also as family members seeking input on how best to fulfill that role.

The caregiver's relationship to the patient was found to be related to avoidance of stress-related behaviors, such that persons who were caring for someone in the immediate family (e.g., parent or spouse) were more likely to have high avoidance impact scores than persons caring for someone outside the
immediate family. Also, persons caring for a parent were higher on avoidance impact than were persons caring for a spouse. These findings are potentially related to Colerick and George's (1986) finding that adult children are more quick to relinquish caregiving situations than are spouses. Perhaps avoiding the situation and its impact is less appropriate for a lifetime spouse than for children who have separate lives to maintain.

The controversy in the literature (Fox, 1986; Mace & Rabins, 1981; Pagel et al., 1985; Zarit & Zarit, 1982) over whether the patient's level of impairment critically affects caregiver stress was not resolved in the present study. Although level of impairment was not found to be associated with either high or low impact, the subjective nature of impairment rating is still an issue. The caregiver's perception of patient functioning is overly contingent upon other factors such as previous personality of the patient and the interpersonal dynamics between caregiver and patient (Lazarus et al., 1981; Mace & Rabins, 1981).

The number of persons sharing the caregiving responsibilities can be seen as an estimate of informal support systems available to the participant in the current investigation. As would be expected from research on stress and caregiving support (Fox, 1986;
Morycz, 1985; Zarit et al., 1987), the number of caregivers available was inversely related to the level of anxiety and depression. This appears to be quite logical in that having other persons to assist in stressful caregiving should reduce some of the emotional impact. However, some professionals working with caregivers (Haley et al., 1987; D. J. Roberts, personal communications, August, 1987; Zarit & Zarit, 1986) believe that the important factor is not just the availability of such support systems but from what perspective and to what extent the caregiver is able to utilize the support. These factors, therefore, deserve more elaborate examination, as described below in the section discussing future research directions.

The correlational results in the present investigation were mixed with regard to relationships between the measures. The Impact scale which was being tested was found to be related to anxiety and depression at pretest, as expected. Another expectation at pretest was that because of the powerlessness often experienced by the caregivers, high internal locus of control would be associated with high scores on depression, anxiety, and impact scales. That is, persons with strong beliefs that power in their lives is derived from within themselves would be more devastated by the caregiving situation in which they
face a loss of self-direction than those with low internal loci of control. In other words, everything becomes controlled by the disease or the dementia victim rather than being controlled from within. The only significant correlational finding with internal locus of control, however, was that high internality was associated with low depression. This is apparently contrary to Krause's (1986) finding that persons with high internality tend to be very susceptible to stress and take on too much responsibility in a caregiving situation. However, Krause also noted that persons with internal loci of control should be more able to adapt to stressors than a person with more external beliefs. This also agrees with Levenson's (1973) finding that the internal locus of control dimension was more adaptively flexible over time and treatment than the externally oriented chance and powerful-other dimensions. One interpretation for the present findings, then, is that the person with high internality is actually able to draw strength from these beliefs while confronting the problems of caregiving. Persons with low internal locus of control may have what little self-governing they did possess taken away by the caregiving situation.
Predicting Impact Levels

The task of identifying variables which could be defined as predictors of stress-related impact yielded limited results. Caregiver age and relationship to the patient were associated with pretest avoidance impact, as discussed above, but no other caregiver or patient descriptive variable was identified as being related to impact. The only instrument which was a useful predictor of pretest impact was the depression measure. The depression and impact scales do touch on similar topics, such as sleep disturbances, interruptions of daily activities, etc. Therefore, the inter-correlations of the scales and variance in impact accounted for by depression are logical findings.

In predicting the posttest impact, the depression influence was apparently subsumed by the pretest impact. The best posttest impact predictive model included pretest impact and the internal and chance subscales of the locus of control measure. As mentioned above in the case of the correlation between internal control and depression, the predictive value of locus of control may be interpreted in terms of the caregiver's ability to maintain a sense of control over the situation for extended periods of time. An individual who believes that chance has significant
influence and who has weak beliefs in self-determination will be more likely to succumb to the stress-related impact of long term caregiving than a person who credits little to chance and much to internal sources of control.

This study also creates questions about the benefits of support groups aimed at reducing the impact of the stressful caregiving situation and about the approaches taken in researching these issues. The participants in the pilot groups studied in this project placed very high value on the groups and even reported moderate to high subjective stress reduction as a result of the groups. Yet, on the objective measures which are assumed to reflect stressful impact, the support group members did not differ from control subjects on posttests. The professionals designing and offering these groups must consider possible explanations for this paradox. Other researchers have begun reporting findings similar to those of the current study and have offered various potential explanations for the objective failure and subjective success of the groups (e.g., Haley, Brown, & Levine, 1987; Zarit et al., 1987). For example, Zarit and his colleagues (1987) point out that their groups were led by professional therapists, rather than by caregiver peers as is commonly the case. The researchers
suggested that the first-hand knowledge of caregiving brought to group leadership by peers might be more effective than the efforts of the professionals. This factor could explain why so many studies have reported significant benefits from support groups and Zarit could not. It does not, however, explain why the group members in Zarit's study believed they had made significant changes through participation in the group. It also does not eliminate the questions raised by the present study, in which the group leader was not a therapist but was a trained group facilitator who had also been a dementia caregiver.

Another methodological issue which Haley et al. (1987) raised is that caregivers are a very heterogeneous population, with a wide variety of needs, skills, distress levels, and coping strategies. Each member of a support group enters the group with individualized needs and expectations and then draws from the group the kind of support which is needed. In addition, a family caring for a dementia victim experiences repeated decrements and plateaus through the course of the disease. These factors make it very difficult to measure specific treatment effects when each participant is applying the group efforts to different and changing situations.
Haley et al. (1987) proposed that researchers have been testing for the wrong changes. Rather than examining depression, stress, and other abstract concepts to test group benefits, perhaps we should be looking for improvement in caregiving skills and resource usage, which would indicate enhanced functional coping. Zarit and his colleagues (Zarit & Zarit, 1982; Zarit et al., 1987) have suggested a similar idea in proposing that caregivers need specific information about dementia and resources, as well as training in patient care skills and behavior management. This could explain the lack of significant treatment effects measured by depression inventories, anxiety scales and related tests. Additionally, the self-reports of high group satisfaction would not be seen as a paradox if, indeed, the group members were drawing the information they need from the groups, even if it is not reflected in the measurements selected by the researchers. Therefore, perhaps a more useful approach to assessing treatment effects would involve concrete measurements of improved knowledge about dementia, increased use of behavior management techniques, and higher skill level in health care.

This problem of appropriate treatment effect measurement is particularly relevant to the present investigation. One of the purposes of this study was
to test the validity of using the Impact measure as a brief indicator of the extent to which the caregiving situation affected the caregiver's general functioning. The assumption was that stress reduces functioning and that stress management training in support groups should reduce the negative impact on functioning. However, the Impact scale used here was highly correlated with factors such as depression and anxiety. Rather than this intercorrelation being a validating feature as hoped, it may have caused the measure to miss the functional components which were critical to the caregivers. Numerous times throughout the support group program, caregivers commented that the items on the scales did not reflect the actual circumstances. After all, is "difficulty sleeping" an adequate indicator of emotional functioning level, when the person cannot sleep because of the dangerous activities of a disoriented family member? In other words, a phenomenon such as sleep difficulty may represent an additional stressful factor related to caregiving, not a symptom of stress itself.

Conclusions

In summary, the present investigation found that although caregivers felt that the support group program was beneficial to them, participation in the groups did
not appear to affect scores on the scales used to measure depression, anxiety, locus of control, and stress-related impact. In addition, although predictive models for impact of caregiving were obtained with the measures of the other constructs, the predictor variables were not found to be strongly related to caregiver descriptive variables. This creates difficulties in using the scales as predictors of differentiation among caregivers on the basis of which family situations present the strongest indications of stress-related impact.

These results underscore methodological concerns which have surfaced in several other recent studies of persons caring for family members suffering from dementing diseases. The implications are that a better understanding of the caregiver's needs is necessary in designing support group programs and research involving the effectiveness of such groups.

**Future Directions**

The questions implied by the methodological problems described above have an impact on several levels of caregiver research. Are we giving the caregivers what they want and is it the same as what they need? Is there a distinction between caregiver stress and coping, and caregiver success? Given those
distinctions, can we measure support group treatment effects appropriately? The ultimate question for researchers, however, may be whether we are approaching the entire problem of family caregivers from an appropriate perspective. This last question may be seen to subsume the others, in that it touches on group design, measurement models, and assumptions about caregiver effectiveness.

Researchers have tended to focus on how to reduce stress, increase coping, or eliminate the negative impact of the immediate situation. It may be unrealistic to expect that in several weeks we can effectively reduce stress in a caregiving situation which involves years of gradual deterioration. The caregivers are attempting to cope with the prolonged phases of grieving which are normally associated with death. These caregivers, however, don't have the benefit of having the event of death to signal the beginning of recovery. They need ongoing support and availability of crisis assistance. It may also be overly optimistic to assume that several weeks of education and training will overcome a lifetime of preestablished coping strategies, even though those strategies may no longer work for the caregivers.

Perhaps the reason for the equivocal results reported by Zarit, Haley, and the current
investigation, is that the research has been focused in the wrong direction. It is possible that we shouldn't be trying to reduce or eliminate caregiver stress although certainly, stress can become overwhelming and professional assistance may become necessary. However, we interact with our internal and external environments through reactions to stressors. The goal is to improve and maintain the ability to cope with stressors as they arise. Most developmental theories include a focus on the tasks which organisms face at different stages of life and how the accomplishment of those tasks affects stage transition and continued development (e.g., Erikson, 1963; Havighurst, 1953). Trying to eliminate the necessity for dealing with the tasks in some form or another does not enhance development. Perhaps, then, we should not attempt to eliminate the stressors in the lives of the caregivers, as those stressors are a form of the adult developmental tasks we all will face, including shifting roles of adult childhood, death of parents or spouse, fears of mortality, and loss of physical and emotional energy. In other developmental stages, difficulties are not resolved for the individual by removing the stress which is created. The approach generally taken is to try to provide the individual with the tools and skills necessary to succeed in these tasks, and success involves emerging
from a task with increased abilities, enhanced understanding of future life tasks and a more highly developed sense of self. The same may be true for the crises faced by the caregivers. This is not to say that their pain is "part of growing up" and must simply be tolerated. Nurturance, guidance, and consolation are provided as an individual passes through other life stages and the same should be true in adulthood. One problem is that comparatively few models exist for "successful aging" and nurturance is very often not available. The older the age group in question, the more diverse the definitions of "success" become. As the adult population becomes older and healthier, we need to develop broader definitions of successful aging and a better understanding of the variety of developmental tasks involved. This normalization of the experiences of older adulthood will in turn help to resolve some of the confusion of situations such as caregiving and thereby answer some of the research difficulties being encountered with these individuals.
APPENDIX A

SAMPLES OF MEASURES
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These consist of pages:

APPENDIX A: Impact of Event; 112-113

Attitude Inventory (Locus of Control); 114-118

Self Rated Depression; 119

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SELF-EVALUATION QUESTIONNAIRE

Developed by Charles D. Spielberger
in collaboration with
R. L. Gorsuch, R. Lushene, P. R. Vagg, and G. A. Jacobs

STA1 Form Y-1

Name______________________________________ Date ________ S __________
Age__________ Sex: M _____ F ____

DIRECTIONS: A number of statements which people have used to
describe themselves are given below. Read each statement and then
blacken in the appropriate circle to the right of the statement to indi-
cate how you feel right now, that is, at this moment. There are no right
or wrong answers. Do not spend too much time on any one statement
but give the answer which seems to describe your present feelings best.

1. I feel calm .............................................................................................................. ©
2. I feel secure .......................................................................................................... ©
3. I am tense .............................................................................................................. ©
4. I feel strained ........................................................................................................ ©
5. I feel at ease .......................................................................................................... ©
6. I feel upset ............................................................................................................ ©
7. I am presently worrying over possible misfortunes ........................................ ©
8. I feel satisfied ........................................................................................................ ©
9. I feel frightened ..................................................................................................... ©
10. I feel comfortable ............................................................................................... ©
11. I feel self-confident ............................................................................................. ©
12. I feel nervous ........................................................................................................ ©
13. I am jittery ............................................................................................................ ©
14. I feel indecisive .................................................................................................... ©
15. I am relaxed .......................................................................................................... ©
16. I feel content ........................................................................................................ ©
17. I am worried ........................................................................................................ ©
18. I feel confused ...................................................................................................... ©
19. I feel steady .......................................................................................................... ©
20. I feel pleasant ....................................................................................................... ©
# SELF-EVALUATION QUESTIONNAIRE  
**STAI Form Y-2**

Name ____________________________________________ Date ______________________

**DIRECTIONS:** A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you generally feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

<table>
<thead>
<tr>
<th></th>
<th>ALMOST NEVER</th>
<th>SOMETIMES</th>
<th>ALMOST ALWAYS</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. I feel pleasant</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. I feel nervous and restless</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. I feel satisfied with myself</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. I wish I could be as happy as others seem to be</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. I feel like a failure</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. I feel rested</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. I am &quot;calm, cool, and collected&quot;</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. I feel that difficulties are piling up so that I cannot overcome them</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. I worry too much over something that really doesn't matter</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. I am happy</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31. I have disturbing thoughts</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. I lack self-confidence</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. I feel secure</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. I make decisions easily</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. I feel inadequate</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. I am content</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>37. Some unimportant thought runs through my mind and bothers me</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>38. I take disappointments so keenly that I can't put them out of my mind</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>39. I am a steady person</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40. I get in a state of tension or turmoil as I think over my recent concerns and interests</td>
<td>0 0 0 0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Information Form

FAMILY CAREGIVER

ID #________

Age______   Sex: M( )  F( )
Patient is your: Husband/wife ( )  Mother/father ( )
Other (specify)_____________________
Patient lives in: Own home ( )  Apartment ( )
Home of children ( )  Senior housing ( )
Nursing/rest home ( )  Other________
Do you live with the patient full time? Yes ( )  No ( )
If not, what other arrangements are involved?
______________________________
Number of persons who share caregiving responsibilities
or who monitor nursing home care ______
Is the person completing this form the:
   Primary caregiver ( )
   Assistant caregiver ( )
   Primary monitor of care ( )
   Assistant monitor of care ( )
Hours per week spent with the patient _________
   Is more time possible? Yes ( )  No ( )
Do you work outside the home?
   Yes ( )  Occupation___________ Hrs/wk______
   No ( )
   Retired ( )  Occupation__________________
What other responsibilities are expected of you?

Care for children ( ) Ages____________________

Take care of your own home including:

Housekeeping ( ) Cooking ( ) Repairs ( )
Yardwork ( ) Laundry ( ) Shopping ( )
Transportation of others ( ) Who?__________

Other duties________________________________

Estimate the hrs/wk spent on these activities_____

Do you have any medical problems? Yes ( ) No ( )

If yes, please specify________________________________________

What medications are you taking?_____________________

What is the highest level of education you have completed?__________

Have you ever attended a support group for families of dementia victims (for example, the Alzheimer's Disease Association)? Yes ( ) No ( )

If so, how often do you attend?

( ) Weekly
( ) Several times a month
( ) Monthly
( ) Several times a year
( ) Once or twice a year
( ) Less than once a year
( ) Never

When did you last attend?__________________
PATIENT

Age_____ Sex: M ( ) F ( )
Approximate age of onset of dementia____________________

Occupational history___________________________________
Highest level of education completed_____________________
Does patient have medical complications?
Yes ( ) Please specify_______________________________
No ( )

What medications is patient taking?_____________________

Based on the behavior and abilities of the patient, which of the following most closely describes that person's current functioning level?

( ) 1. Functions rather well on own.
( ) 2. Needs occasional assistance daily.
( ) 3. Needs frequent assistance daily.
( ) 4. Needs almost constant care to function.
( ) 5. Is completely dependent at every level.
APPENDIX B

SAMPLES OF COMMUNICATIONS WITH PARTICIPANTS
Summary of Introduction and Instructions
to Support Group Members

My name is Lorraine Straw, and I am a doctoral student at The Ohio State University. I am working in cooperation with Jeanne Roberts and the staff here at the Life Center on a research project focused on the attitudes and feelings of persons such as yourself who help provide or monitor the care of family members who are victims of Alzheimer's disease and related dementias. We are interested in how a course like the one you are attending here can help the caregivers manage their stressful lives. We hope that the questions we ask you and ourselves will allow us to better assist you and others like you. The information we collect will be compiled and reported to other professionals. We believe this is an important step toward improving the kinds of resources available to families in this situation.

Participation in the project involves completing a survey designed to reflect your own thoughts, feelings, and opinions. The questions relate to your general frame of mind and the overall effects of the situation, not your personal relationship with the person who has dementia. No identifying information will be
requested, and all information pertaining to the study will remain completely confidential.

The survey is in two parts, one at the beginning of the course and one at the end. Each part will require only about one hour of your time. Participation in the project is highly recommended, but not required for your membership in the course, and you may withdraw from the study at any time.

I will ask you to read and sign a consent form, stating that you understand the project and agree to participate. I then will give you a packet of the survey questions to take home. Your name will not appear or be requested on any of the questionnaires, but you will be assigned a number which will appear on the packet and its contents so that later we can match your two parts of the survey and still preserve your confidentiality.

The first packet will contain a copy of the consent form, a summary of the explanation of the project, and general instructions for completing the survey. Those are for you to keep for your own reference. Please try to complete the questionnaires in the packet and return them to me in the provided envelope within the next 2-3 days. If you have any questions or concerns about the project, or experience
undue stress during the project or the course, please contact me, or the staff here.

Thank you for your time and effort.

Signed:_________________________ Date:_______
Introductory Letter to
Potential Control Group Participants

Dear _____,

As a graduate student at the Ohio State University, I am working in cooperation with the staff at the Reynoldsburg Life Center. It was suggested that you might be interested in assisting us by participating in a survey project on which we are working.

The project focuses on persons who help provide care for family members with Alzheimer's disease or other dementias. We are interested in how we best can help such caregivers manage their stressful lives. We will be studying the caregiver stress management groups offered at the Center and would like to be able to compare the members of the groups with persons such as yourself who have not yet participated in one of the groups. We believe this is an important step toward improving the kinds of resources available to families in this situation.

Participation will be by mail only and will consist of two sets of questionnaires. The sets will be sent about five weeks apart and each will require only about one hour of your time. The questions relate
to your general frame of mind and the overall effects of the situation, not your personal relationship with the person who has dementia. No identifying information will be requested and all information pertaining to the study will remain completely confidential. You may withdraw your consent at any time.

If you are interested in assisting us, please indicate so on the enclosed card and return it as soon as possible. The number you have been assigned on the card will be used to assure confidentiality on the completed forms so do not write your name on the card. If you have any questions about the project, please feel free to contact me or the staff at the Life Center. We do hope that you will agree this is a worthwhile and much-needed project. Thank you for your assistance.

Sincerely,

Lorraine Straw
Department of Psychology
242 Townshend Hall
The Ohio State University
Columbus, OH 43210-1222
Phone: (614) 267-0842
Response Card for Potential Control Participants

ID #____________

Please check one, and mail as soon as possible:

____ Yes, I am interested in helping the project by answering the questionnaires. I understand that two sets of questions will be sent to me about five weeks apart.

____ No, I'm sorry. I do not wish to participate.
Dear Caregiver,

Thank you for consenting to participate in this project. Your answers on the enclosed questionnaires will be summarized with responses from other persons, and the results will be used to improve the assistance available to families of victims of Alzheimer's disease and related disorders.

In order for us to understand and interpret the survey results, the first questionnaire requests information describing your particular situation. Again, no identifying information is requested, and all information pertaining to the survey will remain completely confidential.

The other forms in the survey consist of statements to which you respond by selecting among a choice of answers. Please remember that these are not tests. There are no right or wrong answers, only reflections of your opinions, thoughts, and feelings. Read the brief directions on each form and mark your responses as indicated in those instructions. First impressions are usually best, so don't try to study and second-guess yourself. Please respond to every item.
It should take you about an hour to complete the set. Please try to finish them and return them to me within 2-3 days. You need only return the questionnaires, the other items are for you to keep.

Please take note of the number on your packet contents. This number will be used to match this set of questionnaires with the one you will be given at the end of the course. Do not write your name on any of the forms, so that we can preserve your confidentiality.

If you have any questions, please feel free to call me. My home phone number and my university address are given below.

Thank you for all your cooperation, time, and energy.

Lorraine Straw
Department of Psychology
242 Townshend Hall
The Ohio State University
Columbus, OH 43210-1222
Home Phone: 614/267-0842
Dear ________,

Thank you for consenting to participate in the project I am conducting through the Life Center and the Ohio State University. Enclosed is the first of two parts of the survey. Part two will be sent to you in about five weeks. Your answers on the survey will be summarized with responses from other persons, and the results will be used to better understand the stress the families experience and to improve the assistance available to them.

Included with the packet is a consent form required by the Ohio State University for your protection. Please sign and return one copy with the questionnaires, and keep the second copy for your records. The packet of survey questionnaires begins with a brief form to provide us with information about your particular situation so that we may interpret results of the survey. No identifying information is requested.

The other forms in the survey are designed to reflect your own opinions, thoughts, and feelings. Please remember that these are NOT tests. There are no
right or wrong answers. Read the directions on each form and mark your responses accordingly. First impressions are usually best, so don't try to second-guess yourself. Please respond to every item. It should take you about an hour to complete the set. Please try to complete and return the packet to me in the enclosed mailer within 2-3 days. You need only return the questionnaires and one signed copy of the consent form, the other items are for you to keep. Please take note of the number on your packet contents. This number will be used to match this set of questionnaires with the one you will be sent at the end of the survey. Do not write your name on any of the forms so that we may preserve your confidentiality.

If you have any questions, please feel free to call me or the staff at the Life Center. My home phone number and university address are given below. Your valuable participation in this survey is appreciated. Thank you for all your cooperation, time, and energy.

Lorraine Straw
Department of Psychology
Room 242, Townshend Hall
The Ohio State University
Columbus, OH 43210-1222
Home Phone: 614/267-0842
Consent form

I consent to participate in a project entitled "Stress management for family caregivers of Alzheimer's disease victims," being conducted by Lorraine Straw under the direction of Dr. Andrew Coyne at the Ohio State University. Lorraine has explained the purpose of the study, the procedures to be followed, and the expected duration of my participation. Possible benefits of the study have been described.

I acknowledge that I have had the opportunity to obtain additional information regarding the study and that any questions I have raised have been answered to my full satisfaction. Further, I understand that I am free to withdraw consent at any time and to discontinue participation in the study without prejudice to me. My identity and the information obtained from me will remain confidential.

Finally, I acknowledge that I have read and fully understand the consent form. I sign it freely and voluntarily. A copy has been given to me.

Signed: _____________________________ Date: _____________
(Participant)

Signed: _____________________________
(Investigator)
Dear Caregiver,

Approximately five weeks ago you completed a set of questionnaires as the first part of your participation in a research study. Thank you very much for your assistance on this important study. The second part of that project involves having you complete a second set of questionnaires as a follow-up to the first. The second set is enclosed in this packet. This set should take 45 minutes to an hour of your time. Please try to complete it as soon as possible and return it to me in the enclosed mailer within the next 2-3 days.

Respond to the items as you perceive them at this point in time. As before, remember that these are not tests. There are no right or wrong answers, only indications of your opinions, thoughts, and feelings. First impressions are usually best, so work rather quickly and do not try to second-guess yourself. Please respond to every item.

Do not write your name on any of the questionnaires, but please confirm that the number on this set of forms matches the number you were assigned
on the first set. The assigned number allows us to preserve confidentiality, and to match your two sets of questionnaires.

We sincerely appreciate your cooperation in this project, and hope that the information we collect in the various phases of the study will help us to assist families of dementia victims. If you have any comments or questions, please feel free to contact me. Thank you for your patience and time.

Lorraine Straw
Department of Psychology
Room 242, Townshend Hall
The Ohio State University
Columbus, OH 43210-1222
Home Phone: 614/267-0842
Follow-up Letter to Support Group Participants
Requesting Evaluation of Benefits

Dear Caregiver,

During the past year I have been assisting in conducting support groups for families of dementia victims and in research associated with these groups. You participated in one of the groups and completed two sets of questionnaires for use in my research. Your cooperation was very much appreciated.

We are in the process of putting together the results of the surveys which were done with several different groups over the past months. We are finding some interesting results and would like to be able to evaluate them in terms of your satisfaction with the group and how you benefitted from it. Therefore, I am requesting your assistance once more for this purpose. If you could please complete the two items on the enclosed postcard and return it to me as soon as possible, I would be very grateful.

Notice that the two items on the card ask for your impressions about how the group helped you. Please respond to the items by circling one number (from 1 to 5). To indicate a response of "not at all," circle 1.
To answer "somewhat," circle 3. To indicate something in between those two answers, circle 2. And so on.

Thank you again for your participation in this important research. I hope your Autumn is pleasant.

Lorraine Straw
Department of Psychology
The Ohio State University
Home Phone: 614/267-0842
Evaluation Card
for Support Group Participants

Please circle one number which best describes your experiences with the group you attended.

<table>
<thead>
<tr>
<th></th>
<th>Very much so</th>
<th>Some-what</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found the group to be helpful to me...</td>
<td>5 4 3 2 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that I have reduced my stress as a result of the group...</td>
<td>5 4 3 2 1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Thank you!
APPENDIX C

SUPPLEMENTAL ANALYSES TABLES
Table 12a

Intercorrelations of Posttest Scale Scores for All Participants (N = 41)

<table>
<thead>
<tr>
<th>Scale</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Intrusion Impact</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Avoidance Impact</td>
<td>.67**</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Impact Total</td>
<td>.92***</td>
<td>.91***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. State Anxiety</td>
<td>.66**</td>
<td>.45**</td>
<td>.61***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Trait Anxiety</td>
<td>.77***</td>
<td>.59***</td>
<td>.74***</td>
<td>.89***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. SDS—Depression</td>
<td>.74***</td>
<td>.54***</td>
<td>.70***</td>
<td>.78***</td>
<td>.87***</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Internal Locus of Control</td>
<td>-.17</td>
<td>-.20</td>
<td>-.20</td>
<td>-.26</td>
<td>-.20</td>
<td>-.26</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Chance Locus of Control</td>
<td>.52***</td>
<td>.49***</td>
<td>.56***</td>
<td>.37*</td>
<td>.42**</td>
<td>.41**</td>
<td>-.13</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>9. Powerful others Locus of Control</td>
<td>.46**</td>
<td>.43**</td>
<td>.49***</td>
<td>.28</td>
<td>.41**</td>
<td>.35*</td>
<td>-.10</td>
<td>.71***</td>
<td>-</td>
</tr>
</tbody>
</table>

* p < .05
** p < .01
*** p < .001
Table 12b

Intercorrelations of Posttest Scale Scores for Experimental Participants (n = 21)

<table>
<thead>
<tr>
<th>Scale</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Intrusion Impact</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td>2. Avoidance Impact</td>
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<td>.69***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Impact Total</td>
<td></td>
<td>.94***</td>
<td>.90***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. State Anxiety</td>
<td></td>
<td>.71***</td>
<td>.41</td>
<td>.63**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Trait Anxiety</td>
<td></td>
<td>.77***</td>
<td>.50*</td>
<td>.71***</td>
<td>.92***</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. SDS—Depression</td>
<td></td>
<td>.79***</td>
<td>.57**</td>
<td>.75***</td>
<td>.83***</td>
<td>.90***</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Internal Locus of Control</td>
<td>-.23</td>
<td>-.16</td>
<td>-.22</td>
<td>-.29</td>
<td>-.20</td>
<td>-.28</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Chance Locus of Control</td>
<td></td>
<td>.53**</td>
<td>.53**</td>
<td>.58***</td>
<td>.28</td>
<td>.36</td>
<td>.31</td>
<td>-.27</td>
<td></td>
</tr>
<tr>
<td>9. Powerful others Locus of Control</td>
<td></td>
<td>.56**</td>
<td>.55**</td>
<td>.60**</td>
<td>.31</td>
<td>.46*</td>
<td>.43*</td>
<td>-.28</td>
<td>.84***</td>
</tr>
</tbody>
</table>

*  p<.05
** p<.01
*** p<.001
Table 12c

Intercorrelations of Posttest Scale Scores for Control Participants (n = 20)

<table>
<thead>
<tr>
<th>Scale</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Intrusion Impact</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Avoidance Impact</td>
<td>.66**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Impact Total</td>
<td>.89***</td>
<td>.93***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. State Anxiety</td>
<td>.56**</td>
<td>.49*</td>
<td>.58**</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>5. Trait Anxiety</td>
<td>.76***</td>
<td>.71***</td>
<td>.80***</td>
<td>.84***</td>
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</tr>
<tr>
<td>6. SDS—Depression</td>
<td>.74***</td>
<td>.52*</td>
<td>.68***</td>
<td>.75***</td>
<td>.89***</td>
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<td></td>
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<tr>
<td>7. Internal Locus of Control</td>
<td>-.13</td>
<td>-.26</td>
<td>-.22</td>
<td>-.26</td>
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<td>-.25</td>
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<tr>
<td>8. Chance Locus of Control</td>
<td>.65**</td>
<td>.55**</td>
<td>.66**</td>
<td>.56**</td>
<td>.57**</td>
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</tr>
<tr>
<td>9. Powerful others Locus of Control</td>
<td>.41</td>
<td>.40</td>
<td>.44*</td>
<td>.28</td>
<td>.37</td>
<td>.28</td>
<td>.11</td>
<td>.52*</td>
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</tr>
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</table>

* $p < .05$
** $p < .01$
*** $p < .001$
Table 13a
Correlations of Pretest and Posttest Scale Scores for Experimental Participants (n = 21)

<table>
<thead>
<tr>
<th>Posttest Scales</th>
<th>1</th>
<th>2</th>
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<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
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<tbody>
<tr>
<td>1. Intrusion Impact</td>
<td>.88***</td>
<td>.58**</td>
<td>.81***</td>
<td>.65**</td>
<td>.73***</td>
<td>.77***</td>
<td>-.56**</td>
<td>.49*</td>
<td>.41</td>
</tr>
<tr>
<td>2. Avoidance Impact</td>
<td>.47*</td>
<td>.46*</td>
<td>.51*</td>
<td>.44*</td>
<td>.62**</td>
<td>.37</td>
<td>-.43</td>
<td>.44*</td>
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<tr>
<td>3. Impact Total</td>
<td>.76***</td>
<td>.58**</td>
<td>.74***</td>
<td>.60**</td>
<td>.74***</td>
<td>.64**</td>
<td>-.54**</td>
<td>.51*</td>
<td>.52*</td>
</tr>
<tr>
<td>4. State Anxiety</td>
<td>.71***</td>
<td>.52*</td>
<td>.68***</td>
<td>.74***</td>
<td>.76***</td>
<td>.76***</td>
<td>-.15</td>
<td>.42</td>
<td>.22</td>
</tr>
<tr>
<td>5. Trait Anxiety</td>
<td>.71***</td>
<td>.56**</td>
<td>.70***</td>
<td>.77***</td>
<td>.89***</td>
<td>.89***</td>
<td>-.22</td>
<td>.50*</td>
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<tr>
<td>6. SDS—Depression</td>
<td>.79***</td>
<td>.57**</td>
<td>.76***</td>
<td>.68***</td>
<td>.83***</td>
<td>.81***</td>
<td>-.34</td>
<td>.41</td>
<td>.41</td>
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<td>-.09</td>
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<td>-.01</td>
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<td>.32</td>
<td>.40</td>
<td>.37</td>
<td>.28</td>
<td>.33</td>
<td>-.45*</td>
<td>.81***</td>
<td>.66***</td>
</tr>
<tr>
<td>9. Powerful others Locus of Control</td>
<td>.44*</td>
<td>.48*</td>
<td>.50*</td>
<td>.53*</td>
<td>.39</td>
<td>.46*</td>
<td>-.49*</td>
<td>.70***</td>
<td>.78***</td>
</tr>
</tbody>
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* p < .05
** p < .01
*** p < .001
Table 13b

Correlations of Pretest and Posttest Scale Scores for Control Participants (n = 20)

<table>
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<tr>
<th>Posttest Scales</th>
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<th>6</th>
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<td>.83***</td>
<td>.60**</td>
<td>.77***</td>
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<td>.74***</td>
<td>.79***</td>
<td>.36</td>
<td>.53*</td>
<td>.61**</td>
<td>-.24</td>
<td>.53*</td>
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<td>.74***</td>
<td>.86***</td>
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<td>.64**</td>
<td>.71***</td>
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<td>.47*</td>
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<td>4. State Anxiety</td>
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<td>.64**</td>
<td>.73***</td>
<td>-.28</td>
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<td>5. Trait Anxiety</td>
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<td>.74***</td>
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<td></td>
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<tr>
<td>8. Chance</td>
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<td>.48*</td>
<td>.56**</td>
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<td></td>
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<tr>
<td>9. Powerful others</td>
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<td>.19</td>
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<td>Locus of Control</td>
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</tr>
</tbody>
</table>

Note: n for Impact scales is 19.
* p<.05
** p<.01
*** p<.001
LIST OF REFERENCES


Fox, M. V. (1986). Predictors of dementia caregivers' perceived need for formal support (Abstract). Gerontologist, 26(Special Issue), 129A.


