

THE EFFECT OF PROLONGED SUPPORT GROUP ATTENDANCE ON DEPRESSION  
AMONG FAMILY CAREGIVERS TO PATIENTS WITH DEMENTIA

by

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ABSTRACT

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Among Family Caregivers to Patients with Dementia

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Decreasing mortality rates and increasing life expectancy are contributing factors in the population growth of those 65 and older. This is of particular importance because research indicates as humans age the probability of developing a dementing illness also increases. The most common irreversible

dementia occurring in later life is senile dementia of the Alzheimer's type.

Family caregivers play an essential role in caring for patients with Alzheimer's disease, but the ability to cope effectively with the demands and strains of caregiving often leads to problems in caregivers' mental and physical health. As many as 80% of caregivers of Alzheimer's patients have been reported to suffer from chronic fatigue, depression, or anger.

Depression, in particular, appears to be significantly more likely among caregivers of Alzheimer's patients than among other noncaregivers of the same age. In an attempt to alleviate some of the symptoms associated with caring for Alzheimer's patients, support groups have become increasingly popular.

Thus, this study examined the effectiveness of support groups in alleviating depressive symptoms in the caregivers of dementia patients by comparing family caregivers that regularly attended support groups to family caregivers that do not regularly attend support groups.

A total of 54 individuals participated in the study: 39%(n=21) making up the control group and 61%(n=33) the experimental group. Descriptive statistics for age, gender, number of years providing care, marital status, employment, and relationship with dementia patients were reported. The research question was answered using a paired t-test.

The results indicated that those caregivers who attend support group meetings more frequently were significantly lower on depression levels than those caregivers who attended fewer meetings. Furthermore, this small exploratory study provides data which allows us to speculate about the cumulative effects of prolonged attendance in support groups.

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# The Effect of Prolonged Support Group Attendance on Depression Among Family Caregivers to Patients with Dementia

## INTRODUCTION

Americans are living longer. In 1900, people over 65 accounted for approximately four percent of the United States population. By 1994, 31.2 million, or 12.6% of the population was age 65 or older (Hooyman & Kiyak, 1999). By the year 2030, the proportion of elderly persons age 65 and older will almost equal that of those persons under the age of 18. By 2050, the "65-plus" group will have almost doubled since 1990 and will account for 22% of the U.S. population (Hoyer, Rybash, & Roodin, 1999).

This growth results from a reduction in infant and child mortality and improved treatment of acute diseases of childhood and adulthood, which in turn increases the proportion of people living to age 65 and beyond (Hooyman & Kiyak, 1999). This is of particular importance because research indicates as humans age the probability of developing a dementing illness also increases (Kramer, 1997).

Dementia includes a variety of conditions that are caused by or associated with damage of brain tissue resulting in impaired cognitive function and, in more advanced stages, altered behavior and personality (Morley, 1997). These changes

in the brain result in progressive deterioration of the individual's ability to learn and recall previous events (Kramer, 1997).

The major types of organic brain syndromes of later life are often distinguished on the basis of reversible or irreversible. The first, often described as delirium, refers to a decrease in cognitive ability which may be caused by nutritional deficiencies, alcohol abuse, and other diseases that may be reversible (Janicki & Dalton, 1999). Irreversible dementias are those that have no discernible environmental cause and cannot yet be cured (Hooyman & Kiyak, 1999). The most common irreversible dementia occurring in later life is senile dementia of the Alzheimer's type (Evans, Frunkenstein, Albert, Scherr, Crook, Chown, Hebert, Hennakans, & Taylor, 1989).

After having conducted an extensive review of literature, this researcher notes that the majority of information about dementia is centered on Alzheimer's Disease (AD). Thus, this review will focus primarily upon AD.

Approximately 80% of the care of AD patients is provided in the community by family members (Haley, 1997). One recent large longitudinal study focusing on Alzheimer's patients and their family caregivers reported that median length of in-home caregiving prior to nursing home placement is 6.5 years (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). The

value of informal (unpaid) care for AD patients by family members averages more than \$34,000 per patient each year (Webber, Max, & Fox, 1995).

Primary family caregivers, usually a spouse who takes on the majority of the responsibility in caring for the AD patient, spend an average of 60 hours per week on caregiving responsibilities (Haley, 1997). As the dementia progresses, the caregivers become increasingly more involved with bathing, dressing, and feeding. Behavioral problems, such as agitation and wandering may develop and often require continuous supervision (Teri, Truax, Logsdan, Uomato, Zant, & Vitaliao, 1992). In addition, caregivers face the progressive deterioration of the personality of a loved one or the "loss of self" that occurs as the disease progresses (Webber et al., 1995). Witnessing this decline, along with the actual death of a relative from dementia, is among the most traumatic aspects of caregiving (Hinds, 1985).

Recently, however, research has suggested that the relationship between depression and caregiving experiences may have less to do with caregiving stressors (the actual task or amount of care) and more to do with the perception of these tasks by the caregiver and the meaning attached to the caregiving situation (Yates, Tennstedt, & Chang, 1999). Yates et al (1999) even proposed an adaptation hypothesis in which

caregivers are seen as adjusting to their situations and experience little change or even improvement in outcomes over time.

Although recent research is revealing a more positive view of caregiving, the ability to cope effectively with the demands and strains of caring for a AD patient may still have a profound effect on the mental health of the family caregiver (Knop, Bergman-Evans, & McCabe, 1998). As many as 80 percent of caregivers of AD patients have been reported to suffer from chronic fatigue, depression or anger (Rabins, Mace, & Lucas, 1982).

Depression, in particular, appears to be significantly more likely among caregivers of AD patients than among other noncaregivers of the same age (Schulz, Visitainer, & Williamson, 1990). In a study by Haley, Brown, & Levine (1987) it was found that family caregivers are more depressed than age-matched controls in the general population and report emotional strain in terms of higher levels of depression, anger, and anxiety. Spouse caregivers, who often times provide most of the primary care, are particularly susceptible to stress and depression (Cantor, 1983; George & Gwyther, 1986). Depression can become a serious problem for caregivers that results in appetite change, sleep disturbances, agitation, lower energy, and poor

concentration (Meshefedjian, McCusker, Bellavance, & Baumgartan, 1998).

In an attempt to alleviate some of the symptoms associated with caring for AD patients, support groups have become increasingly popular. Generally they are designed to provide caregivers with information, education, emotional support, and respite from caregiving responsibilities (Biegel, Sales, & Schulz, 1991). They also may aid in developing the attendee's coping skills and lessen caregiver's perceived burden (Gonyea, 1989).

Thus, the purpose of this study is to examine the role of support groups in alleviating depressive symptoms in dementia patient caregivers by comparing family caregivers who have attended support groups eight or more times to those who have attended support groups two times or less.

## REVIEW OF LITERATURE

Dementia is a condition of deteriorated mentality from any cause (e.g., head injury, stroke, alcoholism) that is often characterized by marked decline from the individual's former intellectual level (Janicki & Dalton, 1999). It includes a variety of conditions that are caused by or associated with damage of brain tissue, resulting in impaired cognitive function and, in more advanced stages, impaired behavior and personality (Hooyman & Kiyak, 1999).

Although dementia is not a normal part of aging, the likelihood of experiencing dementia does increase with advancing age. Approximately five percent of the United States population over the age of 65 experience some degree of cognitive loss (Johnson & Catalano, 1983). By age 85, 20 to 40% of the older population have been shown to have dementia and at 100 years of age 60% are likely to have developed the disorder (Powell, 1994; Skoog, Nilsson, Palmartz, Andreasson, & Svanborg, 1994).

There are many types of age-related dementia that differ in a variety of ways including progression, symptomology and commonality. Pick's disease is a rare, progressive, degenerative disease in which brain atrophy is most conspicuous in the frontal regions (Janicki & Dalton, 1999). The most prominent behavioral features associated with the disease are changes in personality and memory impairment (Hooyman & Kiyak, 1999).

Huntington's Chorea is a genetically transmitted condition that usually appears in a person's thirties and forties (Hooyman & Kiyak, 1999). It involves the ceaseless occurrence of a wide variety of rapid, jerky, but well-coordinated movements performed involuntarily, along with a progressive intellectual deterioration (Erkinjuntti, Ostbye, Steenbuis, & Hachinski, 1997).

Creutzfeldt-Jakob disease is a form of dementia that is caused by a slow-acting virus and may, under certain circumstances, be infectious (Raskind & Peskind, 1992). The symptoms associated with Creutzfeldt-Jakob disease are highly variable, although it appears that

deterioration in the central nervous system is commonly present (Hoyer, Rybash, & Roodin, 1999). The rate of decline in victims is rapid and death generally occurs within two years (Raskind & Peskind, 1992).

Multi-infarct dementia has been estimated to represent 20 to 25% of all nonreversible dementias (Gambert, 1987; Zarit & Zarit, 1983). This dementia arises from series of infarcts or small strokes which result in damage to one or more blood vessels feeding those areas of the brain (Hoyer et al., 1999). The condition is more common in men who often have a history of high blood pressure, strokes, and blackouts (Erkinjuntti et al., 1997). The symptoms of multi-infarct disease may include confusion, difficulty in writing, or weakness in various parts of the body (Hoyer et al., 1999).

Dementia with Lewy Bodies is a recently identified form of dementia which may account for 30% of dementia cases and is now proposed to be the second most common type of dementia (Rojas-Hernandez, 1999). The clinical features of this disease include a progressive cognitive decline affecting normal social or occupational function, recurrent visual hallucinations, spontaneous motor features, similar to Parkinson's disease, systematized delusions, loss of consciousness, and repeated falls (Janicki & Dalton, 1999).

In comparing Alzheimer's disease and Lewy bodies, researchers have reported that patients who display evidence of both AD and Lewy bodies are characterized by faster cognitive decline and possibly earlier mortality rates than those with AD alone (Olichney, Galasko, & Salmon, 1998). Furthermore, researchers have also indicated neurofibrillary tangles and plaques may be less frequent in patients with Lewy bodies than those with AD (Heyman, Fillenbaum, Gearing, Mirra, Welsh-Boher, Peterson, & Pieper, 1999).

However, the most common irreversible dementia in later life is Alzheimer's disease (Hooyman & Kiyak, 1999; Rojas-Hernandez, 1999).

Alzheimer's Disease (AD) is a brain disorder characterized by a progressive dementia (Glickstein, 1988). It usually occurs in middle or later life, although on rare occasions it has occurred in young adults (Dippel and Hutton, 1996). Pathological changes found in autopsy specimens of brains from persons diagnosed as having AD include degeneration of specific nerve cells, presence of neuritic plaques and neurofibrillary tangles (Glickstein, 1988). In AD, plaques are particularly numerous in the cortex and hippocampus of the brain (Brun, 1983).

From the time of diagnosis, the lifespan of the AD patient may range anywhere from three to twenty years, with the average being eight years (Dippel and Hutton, 1996). The disease equally affects men and women and most people are older than age 65 when they become afflicted (Malonebeach & Zaret, 1991).

AD often results in devastating, cognitive, behavioral, and functional impairments (Pierce, Ader, & Peter, 1989). Many persons with AD experience confusion, withdrawal, behavior change, impaired judgment and eventually dependency on others for care (Beisecker, Chrisman, & Wright, 1997). Current estimates suggest that up to four million Americans now have AD and by the year 2030, it is estimated that 14 million people will be diagnosed with the disorder (Koppet, 1998). Since the duration of AD is unpredictable, this makes the problem unique in its implications because the burden of the disease is shared by both the family caregivers and the AD patient for lengths of time uncommon in other conditions (Pierce et al., 1989).

### Family Caregivers

Caregiving, the provision of direct or managed services by one family member to another, is steadily increasing in this society due to the actual increase in the number of dependent persons, and social policies such as Medicare, which are placing more responsibility on families for providing the care for dependent persons (Garity, 1997). In 1997, 22.4 million households in the United States provided an elderly relative with some form of care, compared with only seven million in 1988 (McLeod, 1997).

Providing care to an elderly relative often leads to increased feelings of responsibility, the burden of decision making, and feelings of isolation from other family members and friends, which over time may produce chronic stress in the caregiver (Montgomery, Kosloski, & Brogatta, 1990). According to some researchers, this is particularly true when caregiving for a family member with Alzheimer's Disease (Fitting, Rabins, Lucas, & Eastham, 1986).

Family caregivers to AD patients comprise a critical population given that most caregivers delay placing their aging family member in a nursing home or other institution for as long as possible (Talkington-Boyer, & Snyder, 1994). Approximately half of all caregivers live with the AD patient and more than two-thirds of these caregivers have been providing care for over two years (Malonebeach & Zaret, 1991). Current estimates suggest that there are now more than 25 million family caregivers in America, of which 15% are individuals caring for Alzheimer's patients (Hooyman & Kiyak, 1999).

These caregivers are frequently divided into two categories-primary and secondary. A primary caregiver, often the spouse or adult child, is typically the family member most frequently involved with, and responsible for, the care and management of the patient on a daily basis (Beisecker, Chrisman, & Wright, 1997). Although estimates vary, one survey reported that

55% of caregivers are spouses; 35% are adult offspring; five percent are siblings, and the remainder are other relatives or paid providers (Dippel & Hutton, 1996).

Three-fourths of the AD caregivers are over the age of 65 and are generally composed of women who account for 70 to 80% of the primary caregivers (Malonebeach & Zarit, 1991). Caution, however, is needed in representing caregiving as the primary responsibility of women. Stone, Cafferata, and Sangl (1986) reported that 13% of caregivers are husbands and, while male caregivers are fewer in number compared to other caregiver subgroups, they form a relatively large proportion when only primary caregivers are considered.

Following spouses, daughters of AD patients are the next most likely family members to assume the role of providing primary care (Dippel & Hutton, 1996). These caregivers are typically 30 to 50 years of age and often assume additional roles outside the home including, full-time jobs, raising children, and other social and community responsibilities. (Garity, 1997).

Overall, primary, nonworking caregivers often spend as many as 70 hours a week or more providing care for the AD patient (Internet WWW page, at URL: <[Http://www.Alzheimers.com](http://www.Alzheimers.com)>). An estimated two-thirds of all AD caregivers say that their loved one cannot bathe, dress, or toilet themselves without assistance and seven caregivers out of ten are reluctant to leave their loved one alone even for brief periods (Internet WWW page, at URL: <[Http://www.Alzheimers.com](http://www.Alzheimers.com)>).

Secondary caregivers are frequently other relatives including, aunts, uncles, cousins, and friends (Dippel & Hutton, 1996). Typically these individuals are female, slightly younger than the primary caregiver, less likely to be married and more likely to be employed (Horowitz & Dobrof, 1982). Secondary caregivers tend to provide the most help with less labor-intensive tasks such as providing emotional support, assistance with shopping, and providing

transportation. They are less likely to help with personal care (Horowitz & Dobrof, 1982).

Although secondary caregivers may provide regular assistance (at least one hour a week), their involvement is clearly less intense than that of the primary caregiver (Tennstedt, Mckinlay, & Sullivan, 1989).

### Depression and Family Caregivers

As Alzheimer's disease progresses, the patient's social role in the family is altered. Persons with Alzheimer's may forfeit their autonomy when a child or spouse takes responsibility for their care (Garwick, Detzner, & Boss, 1994). The patient in turn may exhibit frustration, anger, and hostility, often directed at the caregiver. This only compounds an already stressful situation and may add to the family member's feelings of distress and exhaustion caused by the overwhelming day-to-day demands of AD care (Gray-Vickrey, 1988).

Their inability to cope effectively with the demands and strains of caregiving may have a profound effect on both the physical and mental health of the family caregiver (Knop et al., 1998). Studies have found evidence that caregivers of AD patients exhibit impaired immune system functioning compared with noncaregivers (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991). Such immune system alterations have been linked to increased rates of respiratory illness, decreased response to influenza vaccinations (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996), and slower wound healing (Kiecolt-Glaser, Morucha, Malarkey, Mercado, & Glaser, 1995). The caregiving role has also been linked with higher than usual psychotropic drug use, social isolation, family stress, burden, and depression (Clipp & George, 1990; Liberman & Fisher, 1995; Shulz, O'Brien, Bookwala, & Fleissner, 1995; Skaff & Pearlin, 1992; Wright, 1994; Zarit, Reever & Bach-Peterson, 1980).

Depression, in particular, appears to be significantly more likely among caregivers of AD patients than among other noncaregivers of the same age (Schulz & Williamson, 1991). Recent reports suggest that 30 to 55% of AD caregivers report clinically significant depression on self-report instruments. These rates are two to three times higher than those reported in population norms and demographically comparable control groups (Haley, Brown, & Levine, 1987; Haley, West, & Wadley, 1995; Schulz et al., 1995).

Alzheimer's caregivers also have much higher rates of diagnosable mental disorders, particularly depression, than noncaregivers, when assessed through structured diagnostic interviews (Schulz et al., 1995). One study found that although few caregivers had a history of depression before caregiving, 23 percent of spousal caregivers met DSM-III-R (Diagnostic and Statistical Manual of Mental Disorders, Third edition, revised. Washington, DC: American Psychiatric Association, 1987) criteria for a depressive disorder, far in excess of control groups (Dura, Stukenberg, & Kiecolt-Glaser, 1990). Even though many caregivers' symptoms of depression do not meet conventional criteria for depressive disorders, they may still have a significant effect on their ability to function (Baumgarten, Battista, Infante-Rivard, Hanley, Becker, & Gauthier, 1992; Broadhead, Blazer, Georget, Tse, 1990; Dura, Haywood-Niler, & Kiecolt-Glaser, 1990; Kiecolt-Glaser et al., 1991; Schulz & Williamson, 1991; Wells, Stewart, Hays, Brunam, Rogers, Daniels, Berry, Greenfield, & Ware, 1989).

Consistently, depression has been identified as a major mental health problem in husbands and wives caring for spouses with AD (Robinson, 1989). More specifically, female caregivers overall tend to report more depressive symptoms than male caregivers in cross-sectional studies of caregiving for AD patients (Anothony-Bergstone, Zarit, & Gatz, 1988; Fitting, Rabins, Lucas, & Eastham, 1986; Pruchno & Resch, 1989). Also studies have found that

the caregiving relationship to the patient may be an indicator of depression, with spouses reporting more symptoms of stress or depression when compared to adult children or other informal caregivers (Baumgarten et al., 1992; Cantor, 1983; George & Gwyther, 1986). Furthermore, research has found that lower caregiver education levels were significantly associated with increased depression (Kurlowicz, 1993; Stephenson-Cino, Steiner, Krames, Ryan, & Huxley, 1992).

### Support Groups

Coping with the devastation of caring for an AD patient severely taxes the family resources. Stress from personal, social, and economic disruptions alter the family's ability to cope and its subsequent well being. As previously mentioned, home care is frequently the choice most families make as an alternative to institutionalizing the AD patient (Quayhagen & Quayhagen, 1988). Therefore, this responsibility increases the need for effective coping strategies and for periodic relief from the caregiving role (George & Gwyther, 1986; Rapp, 1989). Among the various strategies used, research has indicated that confidence in problem-solving, spiritual support, relief from caregiving, engaging in activities, and utilizing local AD support groups are among the factors related to a caregiver's enhanced well-being (Jivanjee, 1994; Rapp, 1989; Weick, Rapp, Sullivan, & Kistardt, 1989).

Support groups, in particular, have become an increasingly popular and effective resource for families of individuals with Alzheimer's Disease. Emerging as a intervention, support groups are designed to provide caregivers with information, education, emotional support, and respite from caregiving responsibilities (Biegel et al., 1991; Gonyea, 1989; Toseland & Rossiter, 1989; Toseland, Rossiter, & Labrecque, 1989). Support groups provide family members with the freedom to express their emotions without guilt, and let out their frustrations, anger and

sadness, as well as share their successes while at group (Heller, Roccoforte, Hsieh, Cook, & Pickett, 1997).

Support groups are often initiated by family caregivers with the aid and support of the Alzheimer's Association or a local Agency on Aging (Mace & Rabins, 1991). Many groups meet once a month providing the participants with brochures, speakers, referrals, and other potentially beneficial information (Mace & Rabins, 1991). A professional, peer, or family member generally facilitates the groups. Professionally led groups are less common and generally have facilitators who take full responsibility for all meeting tasks and administrative duties while the tasks and responsibilities of a peer led group are more evenly distributed among the group members (Heller et al., 1997). There are a variety of individuals who participate in support groups. Typically, they are white, female, well educated, and middle class (Gidron, Guterman, & Hartman, 1990; Gourash, 1978; Karloff & Friesen, 1991; Norton, Wandersman, & Goldman, 1993; Spaniol, Jung, Zipple, & Fitzgerald, 1987; Videka-Sherman, 1982).

In a systematic study of the effects of a support group that included education about AD and how to manage behavioral disturbance in dementia patients, caregivers expressed increased knowledge and coping ability with day-to-day problems in caring for AD patients (Chiverton & Caine, 1989). Kahan, Kemp, Staples, & Brummel-Smith (1985) found that participation in an AD support group significantly reduced depression and increased the knowledge of dementia in the treatment group as compared with the control group. Additionally, an ongoing large-scale study documented that support groups can help reduce the rates of depression among caregivers (Knight, Lutzky, & Macofsky-Urban, 1993; Mittelman, Ferris, & Shulman, 1995) and can dramatically lower the level of nursing home placement of AD patients (Mittelman, Ferris, & Steinberg, 1996).

Furthermore, research has found that support group members perceive significantly greater benefits in such areas as knowledge about AD, ability to cope with the AD patient, and getting help in solving a problem with that relative (Gage & Kinney, 1995). Specifically, the more active members showed significantly higher scores on such items as feeling more helpful and responsible, perceiving their services as important to the individuals with AD and their families, and obtaining a greater amount of knowledge about Alzheimer's disease (Gage & Kinney, 1995).

Although caregivers' self reports consistently indicate high satisfaction with support groups (Gonyea, 1989), these findings do not always reflect the whole picture. As reported earlier, some studies have found support groups to be effective in lowering depression among caregivers (Knight et al., 1993; Mittelman et al., 1995). However, Biegel et al. (1991) noted that many studies which employ standardized questionnaires (e.g. Beck Depression Inventory) showed limited evidence of significant difference in depression, anxiety, and self-esteem between caregivers attending and not attending caregivers support groups.

In addition, Maton (1989) found that those family members who attended support groups more frequently reported a more positive outlook on their caregiving role as compared to less active members. However, Gage and Kinney, (1995) found only minor differences in coping strategies and anxiety when comparing active and less active support groups members.

Therefore, this study further pursued these inconsistent findings. Specifically, the role of support groups in alleviating depressive symptoms in dementia patient caregivers was examined by comparing family caregivers who attended support groups eight or more times to those who attended support groups two times or less.

## METHODOLOGY

This study examined the effectiveness of support groups in alleviating depressive symptoms in the caregivers of dementia patients by comparing family caregivers who regularly attended support groups to family caregivers who have only recently joined a support group.

Approval for this study was granted by the University of Wisconsin-Stout Human Subjects Review Committee.

### Sample

The criteria for participating in the study were the following: 1) caregivers must be related to the individual with dementia, 2) must be the primary caretaker, and 3) must have consistently provided care for a year or more.

In order to compare differences in support group attendance, the total sample was separated into a control group (Group 1) and an experimental group (Group 2). The criteria for Group 1 participants were as follows: the caregiver has attended two or less meetings of the same support group. The criteria for Group 2 participants were: the caregiver has attended eight or more meetings of the same support group.

Respondents participated in Alzheimer's support groups in seven Northwestern Wisconsin counties: Barron, Buffalo,

Chippewa, Dunn, Eau Claire, Pierce, and Rusk. These support groups were located in courthouses, churches, nursing homes, hospitals, and libraries in their respective communities.

Descriptive statistics for age, gender, number of years providing care, marital status, employment, and relationship with the dementia patient are reported (See Table 1).

A total of 54 individuals participated in the study: 39% (n=21) making up the control group and 61% (n=33) the experimental group.

The mean age of the experimental group participants was 67 years. The mean age of the control group participants was 63 years. The total sample ranged in age from 42 to 86 years. The mean number of years as a family caregiver for a dementia patient was 6.3, with a range from two to 15 years for the total sample (see Table 1). Eighty five percent of the total sample were the spouses of dementia patients; 13% were adult children, and two percent were siblings.

In this study males providing primary care for a dementia patient were completely comprised of spouses (100%) whereas female caregivers were comprised of 75% spouses, 19% adult children, and six percent siblings (see Table 2).

While 52% of the sample did not indicate their education level, it appears this sample did not have extensive college education. Additionally, 15 percent of the participants did not

indicate their marital status, but it appears that the majority of this sample is presently married. Furthermore, while 19% of the participants did not indicate their ethnicity, it seems likely that this sample is largely made up of caucasians. Seventy six percent of the control group participants were female, while men accounted for only 24%. The experimental group participants were again comprised mostly of females (82%) while men accounted for 18%.

Table 1

Background Characteristics of the Study Sample (N=54)

Characteristic	<u>M</u>	<u>SD</u>	Range	Percent
Age	64.76	10.97	42-86	
Years of Care	6.31	3.47	2-15	
Relationship				
Spouse				85% (n=46)
Child				13% (n=7)
Sibling				2% (n=1)
Gender				
Male				20% (n=11)
Female				80% (n=43)
Marital Status				
Single				4% (n=2)
Married				78% (n=42)
Widowed				4% (n=2)
Employed				
Yes				24% (n=10)
No				76% (n=32)

Table 2

Caregiver's Relationship to Carerecipient By Gender

	Spouse	Adult Child	Sibling
<b>Gender</b>			
Male	100%	0%	0%
Female	75%	19%	6%

Procedures

All respondents were participating in Alzheimer's support groups affiliated with the Indianhead Chapter of Alzheimer's Association. The director of the Indianhead Chapter gave permission to the researcher to contact the facilitators of each support group. The facilitators were then contacted by telephone by both the researcher and director of the Indianhead Chapter. Permission was given by each facilitator for the researcher to administer the survey at eight of the Alzheimer's support group meetings. All data were collected from May to July of 1999.

The researcher attended the meetings and was introduced to the group by the facilitator. The researcher then participated

in the group's activities and presented information on caregiving for patients with dementia. At the end of the meeting the researcher explained the purpose of the study and indicated that participation was strictly voluntary. A cover letter, a copy of the consent form, and a questionnaire were distributed to all those in attendance (see Appendices).

Individuals interested in participating in the study completed the survey while those who were not interested (approximately 47%) simply left the forms blank. The researcher then stayed in the room while the subjects completed the survey to answer any questions that may arise. After completion of the survey, the questionnaires were placed into a manila envelope. The researcher then provided the support group members with a list of community resources, including mental health services, which may be beneficial to the caregivers.

#### Dependent Variable Measure

The Short Form Multiscore Depression Inventory (SMDI, Berndt, 1986) is a 47-item, true-false test designed to measure the severity of depression and depressive features (Pantle, Ewart, & Trenerry, 1990). The instrument assesses nine components of depression: low energy, cognitive difficulty, irritability, sad mood, guilt, low self-esteem, social introversion, pessimism, and instrumental helplessness.

The low energy subscale consists of six items with a range of scores from zero to six. Three of the items are keyed positively so that a response of true indicates fatigue and three are keyed negatively. Sample items included "I usually feel lively and energetic" and "I often feel worn out".

The cognitive difficulty subscale is measured by six-items with a range from zero to six. A high score indicates problems with indecision and difficulty in thinking clearly. Sample items include "My thoughts keep going round in circles" and "I always have trouble making important decisions".

The guilt subscale also consists of six items with a range from zero to six and measures feelings of guilt. Four of the items are scored in the positive direction and two items are keyed negatively. Examples of the questions used include "I often feel guilty" and "I hardly ever regret any of my actions".

Six-items assess the low self-esteem subscale with a possible score ranging from zero to six. Four are positively keyed items and two are negatively keyed items. Sample items include "I usually think of myself as well liked" and "I never seem to do anything right".

The social introversion subscale consists of five items with a possible range from zero to five. Sample items include "I am a loner" and "I always enjoy being around people".

Respondents scoring high on this subscale are likely to feel socially withdrawn and isolated.

The pessimism subscale is also measured by five-item with a range from zero to five. These items describe a pessimistic and hopeless outlook (e.g., "I always expect the worst" and "I frequently feel I have nothing to look forward to").

The irritability subscale has five items with possible scores ranging from zero to five. A respondent scoring high on this subscale is likely to be irritable, having a quick temper and intolerance of others. Three items are scored in the direction of irritability (e.g., "I am often annoyed with people"), while two items are keyed negatively (e.g., "It is unusual for me to dislike someone").

Sad mood is indicated by a high score on the four item sad mood subscale with a range from zero to four. Two of the items are keyed positively, while the other two items are keyed negatively. Sample items include "I usually feel pretty down" and "I am a happy person".

The instrumental helplessness subscale has a range from zero to four. Those participants scoring high on this scale are likely to be accustomed to social reinforcement and to find it lacking (e.g., "Nobody ever seems concerned enough about me").

The short form total score consists of 47 items. Scoring of the MDI will result in a raw score, which by itself has

little meaning for those unfamiliar with the test. Therefore, raw scores are converted into standard scores to allow for comparisons of scores between subjects. A standard score less than 51 would fall in the minimal depression category whereas a standard score between 51 and 61 would indicate mild depression; a standard score between 62 and 83 would indicate moderate depression, and a standard score over 83 would indicate severe depression.

Overall, the results of reliability and validity studies support the SMDI as a useful measure of depression. Test-retest reliability of 108 college students given the SMDI on two occasions was in the .80s for half the subscales and in the 70s for the other half (Berndt, Berndt, & Karsar, 1984). Reports of the internal consistency reliability of the total SMDI score were .92 and .88 (Berndt, et al., 1984). Full-scale validity was demonstrated with significant ( $p < .001$ ) correlation between the SMDI and the Beck Depression Inventory (Berndt, Petzel, & Kaiser, 1983). Concurrent validity of the subscales was reported by Berndt et al. (1984) and showed correlations ranging from  $r = .57$  for Sad Mood to  $r = .76$  for Pessimism.

#### Measures of Independent Variables

Control and treatment groups. Family caregiver attendance to the same Alzheimer's support group was measured continuously, asking for the exact number of times in attendance. Those

individuals who had attended the same support group no more than two times were assigned to the control group while those who attended the support group eight or more times were assigned to the treatment group.

Age and gender. The age of the respondents was measured continuously, asking for the exact age in number of years. Gender was measured categorically.

Caregiver's relationship with AD patient. One item assessed the relationship the family caregiver to the AD patient "How are you specifically related to the Alzheimer's patient you are caring for?" Categorical responses included, spouse, child, sibling, and other.

Number of years providing care. The number of years the family caregiver has provided care for the AD patient was measured continuously, asking for the exact number of years.

### Data Analysis

The Statistical Package for the Social Sciences (SPSS) was used to analyze all data.

Descriptive statistics were generated to describe the sample. In addition data were analyzed to compare depression scores between treatment and control groups.

### Research Question

Does a significant difference in depression exist between subjects who participated in the same support groups for no more

than two times compared to those who participated for more than eight times.

This research question was answered using a paired t-test.

Thus, the purpose of this study was to examine the role of support groups in alleviating depressive symptoms in dementia patients by comparing family caregivers who attended support groups eight or more times to those who attended support groups two times or less.

## RESULTS

### Sample

As seen in Table 1, the total sample of caregivers to dementia patients was predominantly female (80%). The vast majority of caregivers (85%) were spouses of the care recipient. The remaining were adult children (13%) or siblings (2%) of the care recipient. The mean number of years as a caregiver was 6.3 years, with a range from two to 15 years. The average number of times the total sample attended the same support group meeting was 12, with a range from one to 84.

Group 1 and 2 caregivers were compared with respect to total depression scores as well as the nine components of depression: low energy, cognitive difficulty, irritability, sad mood, guilt, low self-esteem, social introversion, pessimism, and instrumental helplessness.

Control and Experimental Groups. Group 1 participants were predominately female (76%), while men accounted for only 24%. The mean age of Group 1 was 63 years and the mean number of years as a family caregiver was 6.1. Eighty two percent of the Group 2 participants were female, while men accounted for 18%. The average age of Group 2 was 67 years. The mean number

of years as a family caregiver to a dementia patient was 6.4 (see Table 3).

Table 3

Background Characteristics of Control Group (N=21)

Characteristic	<u>M</u>	<u>SD</u>	Range	Percent
Age	63	7	42-83	
Years of Care	6	2	2-12	
Gender				
Male				24%
Female				76%

Background Characteristics of Experimental Group (N=33)

Characteristic	<u>M</u>	<u>SD</u>	Range	Percent
Age	67	8	49-86	
Years of Care	6	2	2-15	
Gender				
Male				18%
Female				82%

### Research Question

Does a significant difference in depression exist between subjects who participated in the same support groups for no more than two times (Group 1) compared to those who participated for more than eight times (Group 2). This research question was answered using a paired t-test.

Overall, as indicated by the MDI Short Form, both the experimental and control groups demonstrated only minimal to mild levels of depression (Control  $\underline{M}$ =58 and Experimental  $\underline{M}$ =48). According to the MDI, a standard score less than 51 would fall in the minimal depression category and a standard score between 51 and 61 would indicate mild depression.

Total depression scores differed by Group 1 ( $\underline{M}$ =58,  $sd=7$ ) and Group 2 ( $\underline{M}$ =48,  $sd=7$ ). Caregivers who attended two or less support group meetings were significantly higher on depression levels than those caregivers who attended eight or more meetings ( $t=5.2$ ,  $p < .001$ , see Table 4).

Comparisons on subscales were also made between Group 1 and Group 2. Seven of the nine subscale scores showed

significant difference. Only instrumental helplessness and irritability were not significant.

Indication of low energy levels differed by Group 1 ( $\underline{M}$ =58,  $sd$ =11) and Group 2 ( $\underline{M}$ =52,  $sd$ =10). Caregivers who attended two or less support group meetings were significantly higher on the low energy scale than those caregivers who attended eight or more meetings ( $t$ =2.1,  $p$  <.05). Cognitive difficulty was also found to differ when comparing Group 1 ( $\underline{M}$ =49,  $sd$ =9) and Group 2 ( $\underline{M}$ =43,  $sd$ =6). Those caregivers who attend support groups two or less times reported significantly higher scores on cognitive difficulty than those caregivers who attended eight times or more ( $t$ =2.6,  $p$  <.05).

Levels of guilt differed by Group 1 ( $\underline{M}$ =51,  $sd$ =7) and Group 2 ( $\underline{M}$ =45,  $sd$ =6). Caregivers who attended two or less support group meetings were significantly higher on guilt levels than those caregivers who attended eight or more meetings ( $t$ =3.5,  $p$  <.001). Feelings of low self-esteem were also found to be significantly different when Group 1 ( $\underline{M}$ =54,  $sd$ =8) and Group 2 ( $\underline{M}$ =48,  $sd$ =4) were compared. Caregivers who attended two or less support group meetings were significantly higher on low self-esteem levels than those caregivers who attended eight or more ( $t$ =3.3,  $p$  <.01).

In assessing the component of social introversion, a difference was found between Group 1 ( $\underline{M}=51$ ,  $sd=7$ ) and Group 2 ( $\underline{M}=47$ ,  $sd=6$ ). Caregivers who attended two or less support group meetings were significantly higher on social introversion levels than those caregivers who attended eight or more meetings ( $t=2.7$ ,  $p < .01$ ). Furthermore, pessimism was found to differ in comparing Group 1 ( $\underline{M}=69$ ,  $sd=11$ ) and Group 2 ( $\underline{M}=60$ ,  $sd=12$ ). Caregivers who attended support groups two or less times as compared to those attending eight or more times reported significantly higher levels of pessimism ( $t=3.0$ ,  $p < .01$ ). Finally, sad mood was found to differ when comparing Group 1 ( $\underline{M}=63$ ,  $sd=10$ ) and Group 2 ( $\underline{M}=55$ ,  $sd=11$ ). Caregivers who attended two or less support group meetings were significantly higher on sad mood levels than those caregivers who attended eight or more ( $t=2.7$ ,  $p < .01$ )

T-test analyses were run to compare each subscale by gender. Only one subscale (low energy) was found to be significantly different for men and women. Specifically, male caregivers ( $\underline{M}=60$ ,  $sd=11$ ) differed from female caregivers ( $\underline{M}=52$ ,  $sd=10$ ) in reported levels of low energy with male caregivers reporting significantly more instances of low energy levels than female caregivers ( $t=2.3$ ,  $p < .05$ , see Table 4).

Table 4

Differences Between Control and Experimental Groups on the MDI

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Variable	Group 1		Group 2		2-tail Probability
	Mean	SD	Mean	SD	
Total Score	58	7	48	7	.000***
Low Engery	58	10	52	10	.045*
Cognitive Difficulty	49	9	43	6	.011*
Guilt	51	7	45	6	.001***
Low Self-Esteem	54	8	48	4	.001**
Social Introversion	51	7	46	6	.009**
Pessimism	69	11	60	12	.004**
Irritability	49	8	46	6	.168
Sad Mood	63	10	55	11	.010**
Instrumental Help.	55	13	50	8	.075

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\*\*\* p < .001

\*\* p < .01

\* p < .05

## DISCUSSION

The purpose of this study was to examine the role of support groups in alleviating depressive symptoms in caregivers of dementia patients by comparing family caregivers who attended support groups eight or more times to those who attended support groups two times or less. Discussion and recommendations for future research and practice are presented here.

In examining caregiver characteristics associated with support group attendance, numerous studies have found that participants are typically white and predominately female which is consistent with the findings of this study (Gidron, Guterman, & Hartman, 1990; Gourash, 1978; Karloff & Frieson, 1991). Furthermore, this study indicated that 85% of caregivers are spouses; 13% are adult offspring; and two percent are siblings, which is also consistent with previous research (Dippel & Hutton, 1996; Haley, 1997).

Furthermore, the literature suggests that almost three-fourths of caregivers are over the age of 65 (Stone, Cafferata, & Sangl, 1986) and that the median length of in-home caregiving before nursing home placement is 6.5 years (Aneshensel et al., 1995) which is also supported by this study.

Previous research has indicated that family caregivers have substantially higher levels of depression when compared to noncaregivers (Rabins et al., 1982; Schulz et al., 1995). This

study, however, reported only mild levels of depression in the respondents. Some possibilities for this occurrence may be due to the small sample size, the limited geographic region, or the ability of the caregivers themselves to find a positive value or meaning in the difficult task of caring for someone with dementia. It is important to note that other researchers have demonstrated that even though a caregiver's symptoms of depression do not meet conventional criteria for depressive disorders, they may still have a significant effect on the caregiver's ability to function (Baumgarten, Battista, Infante-Rivard, Hanley, Becker, & Gauthier, 1992; Broadhead, Blazer, Georget, Tse, 1990; Dura, Haywood-Niler, & Kiecolt-Glaser, 1990; Kiecolt-Glaser et al., 1991; Schulz & Williamson, 1991; Wells, Stewart, Hays, Brunam, Rogers, Daniels, Berry, Greenfield, & Ware, 1989).

In accordance with the relatively few studies (Maton, 1989; Norton, Wandersman, & Goldman, 1993) which have examined the duration of support group attendance, this study found that those caregivers who more frequently attend support group meetings were significantly lower on depression levels than those caregivers who attended fewer meetings.

Furthermore, other research which has compared caregivers who attend group meetings and those that do not suggested that support groups were capable of significantly reducing anxiety

and depression in a caregiver population that was screened for relatively high prior stress levels (Green & Monahan, 1989; Toseland & Rossitar, 1989). While the present study did not control for prior levels of stress, it does support previous research (Knight, Lutzky, & Macofsky-Urban, 1993; Mittelman, Ferris, & Shulman, 1995) which indicates that support group participation seems to be helpful in reducing depressive symptoms in caregivers.

This small exploratory study provides some interesting data which allows us to speculate about the cumulative effects of prolonged attendance in support groups. For example, when caregivers who attended the support group eight or more times were compared with those who attended two times or less, the individuals who attended two or less times reported significantly lower energy and self-esteem, greater cognitive difficulty, and guilt. Moreover, those individuals attending two or less meetings also indicated higher instances of social introversion, pessimism, and sad mood when compared to participants who had attended eight or more meetings.

Perhaps those attending two or less meetings have less time to establish a supportive relationship with other members and have less opportunities for respite, which might contribute to increased levels of depression, as indicated by this study. Additionally, those individuals attending eight or more support

group meetings might learn more about local community resources (i.e., home care services, adult day programs, additional income assistance programs) and how to take advantage of them which might decrease depressive symptoms.

### Limitations

All studies have limitations and although the previous results are interesting, the small sample size and limited geographic region of this study render any conclusions or implications tentative.

In addition several other limitations of the present research should be acknowledged. First, the inclusion of a number of different support groups and lack of measurement of various support group characteristics (e.g., type of dementia of care recipient, type of support group, lack of ethnic diversity) precludes controlling for a number of factors that may have minimized or over exaggerated group differences. For example, Meshefedjian et al (1998) found that decreased functional independence of patients increases the physical burden of care that, in turn, can reduce the psychological well being of the caregiver. On the other hand, Wells et al (1989) found that few behavioral disturbances might create less caregiver distress. Thus, not controlling for the type of dementia of the care receiver nor determining the severity of the dementia may have potentially altered this study's findings.

Additionally, several recent studies suggest that ethnicity has a substantial impact on the caregiving experience.

Comparisons of Caucasian and African-American caregivers of dementia patients have found that African-American caregivers experience lower rates of depression (Haley et al., 1995; Lawton, Rajagopal, Brady, & Kleban, 1992). Because this study included only Caucasians, it cannot be generalized to other cultural and racial groups.

Furthermore, the MDI Short form, which was used to measure the respondents' depression levels, is not an instrument that is specifically designed for older individuals. This perhaps is the most important limitation of this study. It is possible that this instrument did not adequately measure depression in this sample. Future research should use an instrument designed for an older population and use the same sample in order to determine the usefulness of the SMDI for older caregivers.

#### Recommendations for Practice

The results of the present study have implications for local family support group members and facilitators. Having potentially demonstrated the benefits of active support group attendance, it appears that group involvement may help reduce depression as a whole, and also potentially aid in reducing some of the symptoms associated with it.

## Recommendations for Future Research

Future studies should examine frequency of support group attendance as a continuous variable rather than a categorical one. Using a control group which never participated in support group meetings may have also further increased the reliability of this study's findings.

In addition, further research should attempt to understand the impact of group participation on members from a longitudinal perspective. That is, examining change in caregivers over an extended time of support group participation would be a useful next step.

Finally, future research might try to better understand the motivations underlying support group participation, and how these influence the caregiving process. For example there may be a great difference between an individual who attends a support group and wants assistance compared to individuals who attend a support group merely out the obligation they feel towards a family member or doctor who recommended it. Thus, by assessing the motivations which prompt a person to participate in a support group may further add to the reliability of the study.

Overall, this study adds further evidence that active participation in support groups can be beneficial to family caregivers of patients with dementia.

## References

Anthony-Bergstone, C. R., Zarit, S. H., & Gatz, M. (1988). Symptoms of psychological distress among caregivers of dementia patients. Psychology of Aging, 3, 245-248.

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). Profiles in caregiving: The unexpected career. San Diego, CA: Academic Press.

Baumgarten, M. (1989). The health of persons giving care to the demented elderly: A critical review of the literature. Journal of Clinical Epidemiology, 42, 1137-1148.

Baumgarten, M., Battista, R. N., Infante-Rivard, C., Hanley, J. A., Becker, R., & Gauthier, S. (1992). The psychological and physical health of family members caring for an elderly person with dementia. Journal of Clinical Epidemiology, 45, 61-70.

Beisecker, A. E., Chrisman, S. K., & Wright, L. J. (1997). Perceptions of family caregivers of persons with Alzheimer's disease: Communication with physicians. American Journal of Alzheimer's Disease, 2, 73-83.

Berndt, D. J. (1986). Multiscore depression inventory manual. Los Angeles: Western Psychological Services.

Berndt, D. J., Berndt, S. M., & Kaiser, C. F. (1984). Multidimensional assessment of depression. Journal of Personality Assessment, 48(5), 489-493.

Berndt, D. J., Petzel, T. P., & Kaiser, C. F. (1983). Evaluation of a short form of the multiscore depression inventory. Journal of Consulting and Clinical Psychology, 51, 790-791.

Biegel, D. E., Sales, E., Schulz, R. (Eds.). (1991). Family caregiving in chronic illness. Newbury Park: Sage Publications.

Broadhead, E. W., Blazer, D. G., George, L. K., & Tse, C. K. (1990). Depression, disability days, and days lost from work in a prospective epidemiologic survey. Journal of the American Medical Association, 264, 2524-2528.

Brun, A. (1983). An overview of light and electron microscopic changes. In B. Reisberg (Ed.). Alzheimer's disease: The standard reference. New York: The Free Press.

Cantor, M. H. (1983). Strain among caregivers: A study of experience in the United States. The Gerontologist, 23, 597-604.

Chiverton, P., & Caine, E. D. (1989). Education to assist spouses in coping with Alzheimer's disease: A controlled trial. Journal of the American Geriatrics Society, 37, 595-598.

Clipp, E. C., & George, L. K. (1990). Psychotropic drug use among caregivers of patients with dementia. Journal of the American Geriatrics Society, 38, 227-235.

Dippel, H., & Hutton, J. (1996). Caring for the Alzheimer's patient: A practical guide. Pennsylvania: Baywood Publishing Co., Inc.

Dura, J. R., Stukenberg, K. W., & Kiecolt-Glaser, J. K. (1990). Chronic stress and depressive disorders in older adults. The Journal of Abnormal Psychology, 99, 284-290.

Dura, J. R., Haywood-Niler, E., & Kiecolt-Glaser, J. K. (1990). Spousal caregivers of persons with Alzheimer's and Parkinson's disease dementia: A preliminary comparison. The Gerontologist, 30, 332-336.

Evans, D. A., Funkenstein, H., Albert, M. S., Scherr, P. A., Cook, N. R., Chown, M. J., Hebert, L. E., Hennekens, C. H., & Taylor, J. O. (1989). The prevalence of Alzheimer's disease in a community population of older persons. Journal of the American Medical Association, 262, 2551-2556.

Erkinjuntti, T., Ostbye, T., Steenbuis, R., & Hachinski, V. (1997). The effect of different diagnostic criteria on the prevalence of dementia. New England Journal of Medicine, 337, 1667-1674.

Fitting, M., Rabins, P., Lucas, M. J., & Eastham, J. (1986). Caregivers for dementia patients: A comparison of husbands and wives. The Gerontologist, 26, 248-252.

Gage, M. J., & Kinney, J. M. (1995). They aren't for everyone: The impact of support group participation on caregiver's well-being. Clinical Gerontologist, 16(2), 21-34.

Gambert, S. R. (Eds.). (1997). Handbook of geriatrics. New York: Plenum Medical Book Company.

Garity, J. (1997). Stress, learning style, resilience factors, and ways of coping in Alzheimer's family caregivers. American Journal of Alzheimer's Disease, 4, 171-178.

Garwick, A., Detzner, D., & Boss, P. (1994). Family perception of living with Alzheimer's disease. Family Process, 33, 327-340.

George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. The Gerontologist, 26, 253-259.

Gidron, B., Guterman, N. B., & Hartman, H. (1990). Stress and coping patterns of participants and non-participants in self-help groups for parents of the mentally ill. Community Mental Health Journal, 26, 483-496.

Glickstein, J. K. (1988). Therapeutic interventions in Alzheimer's disease. Rockville, Maryland: Aspen Publishers, Inc.

Gourash, N. (1978). Helpseeking: A review of the literature. American Journal of Community Psychology, 6, 413-423.

Gonyea, J. G. (1989). Alzheimer's disease support groups: An analysis of their structure, format, and perceived benefits. Social Work in Health Care, 14, 61-72.

Grays-Vickrey, P. (1988). Evaluating Alzheimer's patients. Nursing, 18(12), 34-41.

Green, V. L., & Monahan, D. J. (1989). The effect of a support and education program on stress and burden among family caregivers to frail elderly persons. The Gerontologist, 29, 472-477.

Haley, W. E. (1997). The family caregiver's role in Alzheimer's disease. American Academy of Neurology, 48, 25-29.

Haley, W. E., Brown, S. L., & Levine, E. G. (1987). Family caregiver appraisals of patient behavioral disturbance in senile dementia. Clinical Gerontology, 6, 25-34.

Haley, W. E., West, C. A. C., & Wadley, V. G. (1995). Psychological, social, and health impact of caregiving: A comparison of black and white dementia family caregivers and noncaregivers. Psychological Aging, 10, 540-552.

Heller, T., Roccoforte, J. A., Hsieh, K., Cook, J. A., & Pickett, S. A. (1997). Benefits of support groups for families of adults with severe mental illness. American Journal of Orthopsychiatry, 67(2), 187-198.

Heyman, A., Fillenbaum, G. G. Gearing, M., Mirra, S. S., Welsh-Bohmer, K. A., Peterson, B., & Pieper, C. (1999). Comparison of Lewy body variant of Alzheimer's disease with pure (AD). Neurology, 52, 1839-1844.

Hinds, C. (1985). The needs of families who care for patients with cancer at home: Are we meeting them? Journal of Advanced Nursing, 10, 575-581.

Horowitz, A., & Dobrof, R. (1982). The role of families in providing long-term care to the frail and chronically ill elderly living in the community. Final Report, Health Care Financing Administration, Grant No. 18-P-97541120-02. New York: Brookdale Center on Aging.

Hooyman, N., & Kiyak, H. A. (1999). Social Gerontology: A multidisciplinary perspective (5<sup>th</sup> ed.). Needham Heights, MA: A Simon & Schuster Company.

Hoyer, W. J., Rybash, J. M., & Roodin, P. A. (1999). Adult development and aging (4<sup>th</sup> ed.). New York: McGraw-Hill.

Janicki, M. P., & Dalton, A. J. (Eds.). (1999). Dementia, aging, and intellectual disabilities: A handbook. Castleton, NY: Hamilton Printing Co.

Jivanjee, P. (1994). Enhancing the well-being of family caregivers to patients with Alzheimer's disease. Journal of Gerontological Social Work, 23(1/2), 31-48.

Johnson, C. L., & Catalano, D. J. (1983). A longitudinal study of family support to impaired elderly. The Gerontologist, 23(6), 612-618.

Kahan, J., Kemp, B., Staples, F. R., & Brummel-Smith, K. (1985). Adult day care: An integrated model. Journal of American Geriatrics Society, 33(10), 664-670.

Karloff, N. M., & Friesen, B. J. (1991). Support groups for parents of children with emotional disorders: A comparison of members and non-members. Community Mental Health Journal, 27, 265-279.

Kiecolt-Glaser, J. K., Dura, J. R., Speicher, C. E., Trask, O. J., & Glaser, R. (1991). Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. Psychosomatic Medicine, 53, 345-362.

Kiecolt-Glaser, J. K., Glaser, R., Gravenstein, S., Malarkey, W. B., & Sheridan, J. (1996). Chronic stress alters the immune response to influenza virus vaccine in older adults. Proceedings. National Academy of Sciences USA, 93, 3043-3047.

Knop, D. S., Bergman-Evans, B., & Wharton-McCabe, B. (1998). In sickness and in health: An exploration of the perceived quality of the marital relationship, coping, and depression in caregivers of spouses with Alzheimer's disease. Journal of Psychosocial Nursing, 36(1), 16-21.

Knight, B. G., Lutzky, S. M., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. The Gerontologist, 33, 240-248.

Koppet, R. (1998). The business cost of Alzheimer's disease. American Journal of Alzheimer's Care and Related Disorders and Research, 6, 7-9.

Kramer, B. J. (1997). Gain in the caregiving experience: Where are we? What next? The Gerontologist, 37, 218-232.

Kurlowicz, L. H. (1993). Social factors and depression in late life. Archives of Psychiatric Nursing, 7, 30-36.

Lawton, M. P., Rajagopal, D., Brody, E., & Kleban, M. (1992). The dynamics of caregiving for demented elderly among black and white families. Journal of Gerontology, 47, 5156-5164.

Lieberman, M. A., & Fisher, L. (1995). The impact of chronic illness on the health and well-being of family members. The Gerontologist, 35, 92-102.

Mace, N. L. & Rabins, P. V. (1991). The 36-hour day (Rev. ed.). Baltimore, MD: The Johns Hopkins University Press.

Malonebeach, E. E., & Zarit, S. H. (1991). Current research issues in caregiving to the elderly. International Journal of Aging and Human Development, 32(2), 103-114.

Maton, K. I. (1989). Towards an ecological understanding of mutual help groups: The social ecology of "fit". American Journal of Community Psychology, 17, 729-753.

McLeod, B. W. (1997). Introduction: Finding balance in caregiver research. The Gerontologist, 37, 216-217.

Meshfedjian, G., McCusker, J., Bellavance, F., & Baumgarten, M. (1998). Factors associated with symptoms of depression among informal caregivers of demented elders in the community. The Gerontologist, 38(2), 247-253.

Mittelman, M. S., Ferris, S. H., & Shulman, E. (1995). A comprehensive support program: Effect on depression in spouse-caregivers of AD patients. The Gerontologist, 35, 792-802.

Mittelman, M. S., Ferris, S. H., & Steinberg, G. (1996). An intervention that delays institutionalization of Alzheimer's disease patients: Treatment of spouse-caregivers. The Gerontologist, 33, 730-740.

Montgomery, R. J. U., Kosloski, T., & Borgatta, E. (1990). Services use and the caregiving experience: Does Alzheimer's disease make a difference? In D. E. Biegel and A. Blum (Eds.), Aging and caregiving: Theory, research, and policy. Newbury Park, CA: Sage.

Morley, John. Dementia. Internet www page, at URL: <<http://www.cyberounds.com/canferen...5/conferences/1097/conferences.html>> (22, September 1997).

Norton, S., Wandersman, A., & Goldman, C. R. (1993). Perceived costs and benefits of membership in a self-help group: Comparisons of members and nonmembers of the alliance for the mentally ill. Community Mental Health Journal, 29(2), 143-160.

Olichney, J. M., Galasko, D., & Salmon, D. P. (1998). Cognitive decline is faster in Lewy body variant than in (AD). Neurology, 51, 351-357.

Pantle, M. L., Evert, J. M., & Trener, M. R. (1990). The utility of the MAPI in the assessment of depression. Journal of Personality Assessment, 55(3 & 4), 673-682.

Pierce, L., Ader, K., & Peter, P. (1989). Caregiver burden and coping strategies. The American Journal of Alzheimer's Care and Related Disorders and Research, 5, 36-41.

Powell, A. L. (1994). Senile dementia of extreme aging: A common disorder of centenarians. Dementia, 5, 106-109.

Pruchno, R. A., & Resch, N. L. (1989). Husbands and wives as caregivers: Antecedents of depression and burden. The Gerontologist, 29, 159-164.

Quayhagen, M. P., & Quayhagen, M. (1988). Alzheimer's stress: Coping with the caregiving role. The Gerontologist, 28(3), 391-396.

Rabins, P. V., Mace, N. L., & Lucas, M. J. (1982). The impact of dementia on the family. Journal of American Medical Association, 248, 333-340.

Rapp, C. (1989). The strengths model of case management: Results for twelve replications. Journal of Psychosocial Rehabilitation, 13(1), 23-32.

Raskind, M. A., & Peskind, E. R. (1992). Alzheimer's disease and other dementing disorders. In J. E. Birren, R. B. Solane, & G. D. Cohen, (Eds.), Handbook of Mental Health and Aging (2<sup>nd</sup> ed.). San Diego, CA: Academic Press.

Robinson, K. M. (1989). Predictors of depression among wife caregivers. Nursing Research, 38, 359-363.

Rojas-Hernandez, C. (1999). Dementia with Lewy bodies may respond to cholinesterase inhibitors. Brown University Gerontology Psychological Report, 3(7), 1-3.

Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. The Gerontologist, 35, 771-791.

Schulz, R., Visintainer, P., & Williamson, G. M. (1990). Psychiatric and physical morbidity effects of caregiving. Journal of Gerontology: Psychological Sciences, 45B, 181-191.

Schulz, R., & Williamson, G. M. (1991). A 2-year longitudinal study of depression among Alzheimer's caregivers. Psychology and Aging, 6, 569-578.

Skoog, I., Nilsson, L., Palmertz, B., Andreasson, L. A., & Svanborg, A. (1994). A population based study of dementia in 85 year olds. New England Journal of Medicine, 328, 153-158.

Skaiff, M. M., & Pearlin, L. (1992). Caregiving: Role engulfment and the loss of self. The Gerontologist, 32, 656-664.

Spaniol, L., Jung, H., Zipple, A. M., & Fitzgerald, S. (1987). Families as a resource in the rehabilitation of the severely psychiatrically disabled. In A. B. Hatfield & H. P. Lefley (Eds.), Families of the mentally ill: Coping and adaptation (pp. 167-190). New York: Guilford Press.

Stephenson-Clino, P., Steiner, M., Krames, L., Ryan, E. B., & Huxley, G. (1992). Depression in elderly persons and its correlates in family practice: A Canadian study. Psychological Reports, 70, 359-368.

Stone, R., Cafferata, G. L., & Sangl, J. (1986). Caregivers to the frail elderly: A national profile. The Gerontologist, 27, 616-627.

Taking care of the person with Alzheimer's disease. Internet WWW page, at URL:<<http://www.Alzheimer's.com.html>> (18, March 1996).

Talkington-Boyer, S., & Synder, D. K. (1994). Assessing impact on family caregivers to Alzheimer's disease patients. The American Journal of Family Therapy, 22(1), 57-66.

Tennstedt, S. L., Mckinlay, J. B., & Sullivan, L. M. (1989). Informal care for frail elders: The role of secondary caregivers. The Gerontological Society of America, 29(5), 667-683.

Teri, L., Truax, P., Logsdon, R., Uomato, J., Zant, S., & Vitaliano, P. P. (1992). Assessment of behavioral problems in dementia: The revised memory and behavior problems checklist. Psychological Aging, 7, 622-631.

Toseland, R. W., & Rossiter, C. M. (1989). Group interventions to support family caregivers: A review and analysis. The Gerontologist, 29, 438-448.

Toseland, R. W., Rossiter, C. M., & Labrecque, M. S. (1989). The effectiveness of peer-led and professionally led groups to support family caregivers. The Gerontologist, 29, 465-471.

Videka-Sherman, L. (1982). Effects of participation in self-help groups for bereaved parents: Compassionate friends. Prevention in Human Services, 1, 69-77.

Weick, A., Rapp, C., Sullivan, W. P., & Kistardt, W. (1989). A strengths perspective for social work practice. Social Work, 34, 350-354.

Wells, K. B., Stewart, A., Hays, R. D., Brunam, A. M., Rogers, W., Daniels, M., Berry, S., Greenfield, S., & Ware, J. (1989). The functional and well-being of depressed patients: Results from the Medical Outcomes Study. Journal of the American Medical Association, 262, 914-919.

Webber, P. J., Max, W., & Fox, P. (1995). Alzheimer's disease: The unpaid burden of caring. Journal of Aging Health, 7, 179-199.

Wright, L. K. (1994). AD spousal caregivers: Longitudinal changes in health, depression, and coping. Journal of Gerontological Nursing, 20, 35-45.

Yates, M. E., Tennstedt, S., & Chang, B. (1999). Contributors to and mediators of psychological well-being for informal caregivers. Journal of Gerontology, 54(1), 12-22.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. The Gerontologist, 20, 649-655.

Zarit, S. H., & Zarit, J. (1983). Working with families of dementia victims: A treatment manual. Los Angeles: Andrus Gerontology Center, University of Southern California.

Dear Participant,

My name is Ryan Elliott. I am a Graduate student enrolled in the Guidance and Counseling program at the University of Wisconsin-Stout. I am also a certified nursing assistant and have spent numerous hours caring for individuals with dementia. It has been my experience, that caring for these individuals are at times stressful and exhausting, and that talking with others experiencing similar situations tends to alleviate some of the symptoms you experience as a caregiver. Therefore, as the topic for my thesis, I chose to examine the role that the support group plays for caregivers attending to a relative with dementia.

In order to determine the benefits of support groups I need comments from family caregivers, such as your selves. Your participation in this study will contribute to the body of knowledge about caregiving for dementia patients and the role support groups play in caregiver's lives. However, your participation in this study is entirely voluntary. You may choose not to participate without any adverse consequences to you.

Should you choose to participate in the study you will be provided with two forms. The first form is a consent form that discusses various aspects of the study. Please read through this form and sign it if you decide to participate. The second form is the MDI survey, which examines the perceptions, feelings, and reactions common to family members caring for individuals with dementia. Please **ONLY** answer the first 47 questions of the survey. Although all the questions on the survey are valid, the shortened version will take less time to complete. The only demographic information that you need to

Appendix A (Continued)

include on the MDI survey is your gender and age. On **this form**, please also include the following demographic information;

1. The number of years you have been a caregiver for a family member with dementia.
2. The number of times you have attended this particular support group.
3. How are you specifically related to the dementia patient you are currently caring for? Please circle the most appropriate answer.  
A. Spouse B. Adult Child C. Other (Please Indicate)
4. What type of caregiver would you classify yourself as?  
A. Primary Caregiver (Provides the majority of the care to dementia patient)  
B. Secondary Caregiver (Shares caregiving responsibilities equally with others)  
C. Other (Please Indicate)

If you choose to participate in the study, please turn in all three forms to the group facilitators. Once the study is completed a copy of the results will be distributed to the group. Thank you very much for your time and effort. I greatly appreciate it.

## HUMAN RESEARCH SUBJECTS CONSENT FORM

The research examines the perceptions, feelings, and reactions common to those family members caring for dementia patients. The purpose of this research is to examine the role that caregiver support group plays for caregivers attending to a relative with dementia. Before completing the survey, we would like you to read and then sign this consent form, indicating that you understand the potential risks and benefits of participation, and that you understand your rights as a participant. If you have any questions, please contact Ryan Elliott at (715) 232-3202.

### **RISKS**

Participation in this research project may be of some minimal risk to you in that you may find some of the survey questions upsetting. If that happens, a referral to a licensed counselor will be provided.

### **BENEFITS**

By participating in this study you will be contributing to the body of knowledge about caregiving for dementia patients. Also those that choose to participate in the study will receive a list of community resources that may be helpful to caregivers.

### **CONFIDENTIALITY OF RESPONSES**

Your answers are strictly confidential. Only the primary researcher and his academic advisor will have access to the data.

### **RIGHT TO WITHDRAW OR DECLINE TO PARTICIPATE**

Your participation in this study is entirely voluntary. You may choose not to participate without any adverse consequences to you. Should you choose to participate and later wish to

withdraw from the study, you may discontinue your participation at this time without incurring adverse consequences.

**NOTE:** Questions or concerns about participation in the research or subsequent complaints should be addressed first to the research advisor, Dr. Jan Hare, phone (715) 232-2102 and second to Dr. Ted Knous, Chair, UW-Stout Institutional Review Board for the Protection of Human Subjects in Research, 410 BH, UW-Stout, Menomonie, WI 54751, phone (715) 232-1126.

I attest that I have read and understood the above description, including potential risks, benefits, and my rights as a participant, and that all my questions about the study have been answered to my satisfaction. I hereby give my informed consent to participate in this research study.

Signature\_\_\_\_\_Date\_\_\_\_\_