



Caregivers of physically and mentally impaired elderly : an investigation of burden and depression
by Susan Churchill Barnett

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Education
Montana State University

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Abstract:

The purpose of this study was to examine differences in burden and depression in caregivers of physically impaired older adults and caregivers of older adults with Alzheimer's disease. The relationship between burden and depression was also examined. It was hypothesized that there would be no differences between caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments in the areas of caregiver age, ill relative age, length of relationship, and length of illness. It was also hypothesized that caregivers of elders with Alzheimer's disease would be found to be experiencing more burden and depression than caregivers of physically Impaired elders. A positive correlational relationship was hypothesized between burden and depression. The caregivers who participated In this study were recruited through area physicians. Eight were caregivers of older adults with Alzheimer's disease and fourteen were caregivers of older adults with chronic physical impairments. The Zarit Burden Interview and the Beck Depression inventory were the Instruments used to measure burden and depression. The caregivers also completed a demographics questionnaire, t-tests for independent samples yielded no significant differences between caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments in the areas of caregiver age, ill relative age, length of relationship, and length of illness. t-tests for Independent samples revealed no significant differences between caregivers of older adults with Alzheimer's and caregivers of older adults with chronic physical impairments in the areas of depression and burden. A statistically significant ($p < .05$) positive correlation was found between burden and depression. In conclusion, caregivers of elders with Alzheimer's disease and caregivers of elders with chronic physical impairments were found to experience similar amounts of burden and depression and high scores on the Zarit Burden Interview were found to be associated with high scores on the Beck Depression Inventory.

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by

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of a thesis submitted by

Susan C. Barnett

This thesis has been read by each member of the thesis committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

8/30/89
Date

Michael W. Wood
Chairperson, Graduate Committee

Approved for the Major Department

29 August 1989
Date

[Signature]
Head, Major Department

Approved for the College of Graduate Studies

9/15/89
Date

Henry L. Parsons
Graduate Dean

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ABSTRACT

The purpose of this study was to examine differences in burden and depression in caregivers of physically impaired older adults and caregivers of older adults with Alzheimer's disease. The relationship between burden and depression was also examined. It was hypothesized that there would be no differences between caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments in the areas of caregiver age, ill relative age, length of relationship, and length of illness. It was also hypothesized that caregivers of elders with Alzheimer's disease would be found to be experiencing more burden and depression than caregivers of physically impaired elders. A positive correlational relationship was hypothesized between burden and depression. The caregivers who participated in this study were recruited through area physicians. Eight were caregivers of older adults with Alzheimer's disease and fourteen were caregivers of older adults with chronic physical impairments. The Zarit Burden Interview and the Beck Depression Inventory were the instruments used to measure burden and depression. The caregivers also completed a demographics questionnaire. t-tests for independent samples yielded no significant differences between caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments in the areas of caregiver age, ill relative age, length of relationship, and length of illness. t-tests for independent samples revealed no significant differences between caregivers of older adults with Alzheimer's and caregivers of older adults with chronic physical impairments in the areas of depression and burden. A statistically significant ($p < .05$) positive correlation was found between burden and depression. In conclusion, caregivers of elders with Alzheimer's disease and caregivers of elders with chronic physical impairments were found to experience similar amounts of burden and depression and high scores on the Zarit Burden Interview were found to be associated with high scores on the Beck Depression Inventory.

CHAPTER 1

INTRODUCTION

This study will examine the subjective experience of caring for a chronically ill parent, spouse, or relative. The experience of caring for an older adult with Alzheimer's Disease will be compared with the experience of caring for a physically impaired older adult. It is hypothesized that a greater degree of burden and level of depression will be experienced by caregivers of older adults with Alzheimer's Disease. It is also hypothesized that there will be a positive relationship between experience of burden and depression.

Mental and physical health care for older adults has become an area of increasing concern for health care giving professionals. Advanced health care and medical knowledge in the past few decades has led to a continually growing population of older adults. The number of persons 65 and older has increased from 16 million to more than 28 million in the past twenty-five years (Statistical Abstract of the United States, 1988). With this growing segment of the population come many medical problems often associated with the infirmities of increased age. This can include physical and mental problems for which the elderly have an increased risk. The incidence of chronic physical impairment tends to increase with chronological age (Dye, 1985). Common chronic physical problems among the elderly population can include arthritis, diabetes, cardiovascular problems, osteoporosis, poor sight and/or hearing, broken bones, and frailty (Knight, 1986; Whitbourne, 1985). These problems can impair the mobility of older adults and often restricts their ability to care for themselves. The chronically impaired older adult can often have difficulty preparing meals, dressing, and doing simple household chores (Branch, 1977). Dementia in the elderly, like chronic physical impairment, can also

restrict the mobility of the older adult. Alzheimer's Disease, a degenerative organic illness accounts for 50 to 65 per cent of dementia cases in older adults (Katzman, 1987). Alzheimer's Disease begins with memory loss and/or personality changes and eventually leaves the afflicted older adult unable to perform even the simplest task. The older adult with Alzheimer's Disease eventually suffers a complete loss of recognition of his/her surroundings and environment (Mace & Rabins, 1981). Each of these physical and organic debilities can range from mild to severe requiring varying amounts of care.

Caring for the mentally and/or physically impaired older adult tends to take place in an institutional or home setting. In an institutional setting care is provided by trained professionals with experience in caring for impaired elderly persons. Caregivers in the home tend to be a spouse, child, or close relative. The care providers in the home setting are often untrained and inexperienced. Spouse caregivers are often elderly themselves and have reduced strength, stamina, and often limited funds. Caregivers who are children of the impaired older person often have a job and family of their own to care for. The physical, financial, and emotional strain of caring for an impaired older adult can be great (Mace & Rabins, 1981).

Caregiving itself can be physically demanding. Lifting, moving, and transporting impaired adults can be extremely difficult for the caregiver (Mace & Rabins, 1981). The financial strains of caregiving stem from the special needs of the impaired older adult. Quite often caregiving in itself becomes a full-time job which requires the working caregiver to give up his/her job or hire respite care for the impaired older adult.

The financial and physical demands of caregiving often contribute to the emotional strain felt by the caregiver (Silverstone, 1985). The social network of the caregiver is often

restricted due to the limited amount of time that the caregiver has for social and recreational purposes. The home often becomes a type of prison for the caregiver (Mace & Rabins, 1981).

Life events have been connected to the onset of depressive illness for many years (Warheit, 1979, Paykel, Prusoff, & Uhlenhuth, 1971, Vinokur & Selzer, 1975). Life events may be defined as desirable or undesirable occurrences in life that require readjustment. Excessive changes make adjustment difficult and produce stress (Vinokur & Selzer, 1975). Moving, marriage, birth of a child, illness, divorce or separation, death of a spouse or close relative are all occurrences which could be termed life events (Paykel, Myers, Dienelt, Klerman, Lindenthal, & Pepper; 1969). In particular the chronic illness of a loved one can be a stressful life event for the caregiver (Colerick & George, 1986). Chronic illness brings about an irredeemable change in the life of the caregiver and the chronically ill person. When depression results from the stressful life event of caring for a chronically impaired elder the quality of caregiving can deteriorate. The emotional, physical, and financial strain of caregiving can be immense. Becoming a caregiver for a spouse, parent, or relative can be devastating. The news that the loved one is chronically ill can in itself cause stress. It brings about an irredeemable change in the life of the caregiver and the ill person. The chronically ill person must slowly give up his/her independence. The caregiver also gives up his/her independence and freedom. The loss of freedom and independence gives way to a burden of responsibility (Scott, Roberto, & Hutton, 1986). Every waking hour is given to the ill person. The amount of burden experienced by caregivers of chronically impaired older adults has been found to be associated with feelings of depression (Drinka, Smith, & Drinka, 1987). Caregivers in

stressful or depressed states could be unable to provide adequate care for their impaired relatives. This might increase the numbers of impaired elderly being institutionalized (Morycz, 1985).

The physical and emotional needs of the caregiver are often overridden by the needs of the ill family member. The needs of the caregiver are of prime importance both for maintaining their wellbeing and that of the elderly they care for. An exploration of these needs will provide the medical and mental health community with avenues upon which to attempt to meet these needs.

Caring for chronically impaired elders has been associated with feelings of burden and depression in caregivers. It is possible that the amount of burden and depression experienced by caregivers is related to the degree of mental incapacity in the chronically impaired older adult. Caring for a physically impaired older adult relative can be stressful because of the time, financial and physical demands on the caregiver. Caring for an older adult relative who is suffering from Alzheimer's Disease has the potential to be even more stressful because of the stresses mentioned above and the increasing mental incapacity of the older adult. The older adult who is suffering from Alzheimer's Disease can become increasingly unpredictable and often unpleasant. As Alzheimer's Disease progresses the victim suffers from memory loss, the inability to relate to others in a caring fashion, and can often become angry and combative. These problems, coupled with the other stresses normally associated with caregiving, could result in greater burden and depression in caregivers of older adults with Alzheimer's than for other caregivers.

CHAPTER 2

LITERATURE REVIEW

Literature reviewed below examines stress and depression in caregivers of organically and physically impaired elderly.

This chapter is organized to acquaint the reader with the current knowledge of the needs and problems of caregivers. In order to do this the following areas will be explored: the elderly, common chronic physical problems of the elderly, the symptoms, progression, and problems of Alzheimer's Disease, current research concerning the problems inherent in caregiving, stress and depression.

The Elderly

As a growing segment of the population, the physical and mental health needs of the elderly are substantial. Eighty-six percent of the elderly population have some type of chronic health problem (Butler, 1985). However, only an estimated 5 percent of persons over sixty-five currently reside in some type of institution (Siegel, 1977). Elders require more doctor visits and spend more time in the hospital than do the rest of the population. The average hospital stay of an elderly person is 14 days (Butler, 1985). Emotional and mental illness tends to increase over the life cycle. Hypochondriasis is common among the elderly and the incidence of depression tends to increase with age. Elderly white males have the highest suicide rate in the United States (Butler, 1985).

Chronic Physical Impairment and Alzheimer's Disease

Chronic Physical Impairment

The number of adults age 65 and older has steadily increased over the past twenty-five years and is projected to continue to increase (Statistical Abstract of the United States, 1988). The incidence of chronic physical impairments tends to rise sharply with age in those adults aged 45 to 64 and dramatically among older adults age 65 and older (Institute of Medicine and National Research Council, 1985). Seventy-five percent of the population of older adults 65 and older suffer from at least one chronic condition and half of this population suffers from more than one chronic condition (Riley and Foner, 1968).

Common chronic diseases and physical impairments which plague the older adult population are cardiovascular problems, arthritis, problems with sight and hearing, diabetes, and chronic disability due to falls and injuries (Riley and Foner, 1968; Agate, 1970; Dye, 1985).

Cardiovascular disease tends to begin at a young age but reaches a severe, chronic stage in older adulthood (Lakatta, 1985). Cardiovascular disease accounts for 72 percent of all deaths of adults over the age of sixty-five (Dye, 1985). Shortness of breath, reduced tolerance for exertion, lethargy, confusion and depression often affect the older adult with cardiovascular disease (Agate, 1970). The activities of twenty-one percent of older adults is limited because of arthritis (Riley & Foner, 1968). Arthritis is a disabling condition of the joint which can be extremely painful. Often older adults suffering from arthritis are at times wheelchair-bound or are in need of some type of walking aid (Agate, 1970). Arthritis can affect joints in the hands, shoulders, hips, knees, feet, spine, and other areas of the body and can often result in deformities of the joint (Agate, 1970). Impairments in vision and hearing affect most older

adults to some degree (Riley & Foner, 1968). Presbyopia, the inability of the crystalline lens of the eye to focus on objects close to the eye, eventually affects all older adults. This is due to thickening of the crystalline lens (Sekular & Blake, 1985). Cataracts, opacity of the crystalline lens, plague many older adults and can at times result in blindness. Failing vision can severely limit the ability of older adults to care for themselves (Agate, 1970). As human beings age, the ability to hear high frequencies tends to decrease (presbycusis). Young humans can hear frequencies as high as 20,000 Hz. By the age of seventy frequencies higher than 6,000 Hz are inaudible (Sekular & Blake, 1985). Loss of hearing often isolates the older adult from the world around him/her (Agate, 1970). Diabetes is common among older adults with fifty percent having some form of diabetes (Dye, 1985). Diabetes can have serious complications for older adults. Some of the more serious complications are those of the visual and vascular systems. Diabetes can lead to blindness and gangrene resulting in amputation from vascular system problems (Agate, 1970). Seventy percent of deaths due to falls occur in those sixty-five and older. Older adults are often severely disabled by falls and other types of injuries (Hogue, 1977). The frailty of older adults often worsens injuries and fractures are common. Hospital stays due to injuries are often long and arduous for the older adult. Injuries tend to sap the confidence of the older adult, severely curtail independence and often lead to further physical breakdown (Agate, 1970).

Alzheimer's Disease

In 1907, Alois Alzheimer reported a peculiar dementing illness which he observed in a 51 year old woman. The woman was forgetful, paranoid and bizarre to a degree requiring hospitalization. The patient became progressively cognitively and emotionally impaired and

died four and a half years after the onset of the disease. Alzheimer termed this malady senile dementia or dementia of the Alzheimer type (Bondareff, 1986; Mace & Rabins, 1981).

Meier (1986) estimated that more than 20% of the people who reach age eighty will suffer from a moderate to severe form of dementia. Very few causes of dementia are treatable or reversible. The most common chronic irreversible form of dementia is Alzheimer's Disease (Nee, Polinsky, Eldridge, Weingarter, Smallberg, & Ebert, 1983). Alzheimer's Disease affects the cerebral cortex of the brain (Bondareff, 1986). It is characterized by senile plaques, neurofibrillary tangles, granulovacuolar structures, and an overall loss of neurons. Senile plaques are masses of degenerated cell matter that occur in the spaces between cells. They interfere with messages which travel from cell to cell in the brain. Neurofibrillary tangles are tangled protein fibers which appear inside brain cells and cause the cells to shrink and atrophy. Granulovacuolar structures are sacs filled with fluid and granular material that accumulate in the hippocampus (Zarit, 1985). Senile plaques and neurofibrillary tangles are found in all people in numbers that increase with age. The number of senile plaques and neurofibrillary tangles is limited in most normally functioning older people. People with Alzheimer's Disease possess abnormally large numbers of senile plaques and neurofibrillary tangles (Wells, 1978).

The clinical features of Alzheimer's Disease were described by Semple, Smith, and Wash (1982). They reported that the onset of Alzheimer's Disease is usually a gradual one. Short term memory is often impaired, while long term memory usually remains intact in the early stages of the disease. The afflicted person's range of interests decreases, affect is blunted, and concern for the welfare of others often diminishes. Depressive symptoms are often common in the early stages of the Alzheimer's Disease. In addition to the memory impairment there tend to be general intellectual deficits. The Alzheimer's Disease patient's vocabulary becomes

impoverished and phrases and tenses are often simplified. There is usually dressing apraxia (the inability to perform a series of purposeful movements); agnosia (the partial or total inability to attach meaning to sensory impression); and geographic, time, space, and person disorientation. The personality itself deteriorates. As the disease progresses the Alzheimer's Disease patient becomes progressively isolated from visual and auditory contact with the environment. Speech is reduced to a babble. During the final stages of Alzheimer's Disease emotional responses tend to be absent or are replaced by loud, abnormal laughter and moaning. Impassivity of expression, rigidity, and disorders of posture, stance, movement, and muscular tone become prominent as the disease progresses. Extreme weight loss has been noted in the final stages of the disease.

Caregivers

Caregivers of Physically Impaired Elderly

Many adults age 65 and older suffer from one or more chronic physical impairment (Riley & Foner, 1968). Older adults with chronic physical impairments often need some type of support from relatives or friends. Cantor (1983) interviewed caregivers of the frail elderly in order to better understand how caregiving impacts the life of the caregiver. The overriding problem was found to be emotional strain of dealing with increasing frailty in a person to whom one is close. It was also found that the closer the emotional bond between the caregiver and frail older adult, the more stressful the caregiving role (Cantor, 1983).

Caregiving support needed by impaired older adults can range from limited to extensive. Sanford (1975) surveyed fifty caregivers of physically and mentally impaired older adults. Incontinence, night wandering, and immobility were found to be problems least tolerated by caregivers. These problems are ones which would require a maximum of time and effort from

the caregiver and therefore are less easily tolerated. This suggests that intolerance for caregiving increases with severity of impairment. Almost half of the caregivers reported a restricted social life and one quarter reported an inability to leave the impaired older person for more than one hour (Sanford, 1975).

The physical demands of caregiving can often be immense. Everyday duties can often include feeding, bathing, lifting, dressing, and often diapering. These simple tasks can be difficult with a baby or small child. The size, weight, and compliance of the older adult can even further complicate these tasks.

Financial strains of caregiving arise from the special needs of the impaired older adult. Quite often caregiving in itself becomes a full-time job which requires the working caregiver to give up his/her job or hire respite care for the impaired older adult.

The financial and physical demands of caregiving often contribute to the emotional strain felt by the caregiver (Silverstone, 1985). Medical costs can include hospitalization, pharmaceuticals, and doctor visits. The impaired older adult often needs special equipment such as; wheelchairs and walkers, commodes, shower and bath equipment, hoists for lifting, and clothing which can be easily put on or removed. The social network of the caregiver is often restricted due to the limited amount of time that the caregiver has for social and recreational purposes. The home often becomes a type of prison for the caregiver (Mace & Rabins, 1981).

Caregivers of Elderly with Alzheimer's Disease

Alzheimer's Disease often begins with memory loss and irritability and results in a complete inability to care for one's self, recognize loved ones, and communicate with others (Semple, Smith, and Wash; 1982). Alzheimer's Disease affects not only the person afflicted with the disease, but the person's family as well. At some point the person with Alzheimer's

Disease requires assistance from a family member or friend. This need for help increases over time until constant care is required. Caring for a person with Alzheimer's Disease becomes a full time job for which most people are not trained (Maletta & Hepburn, 1986). What makes Alzheimer's Disease particularly stressful is a combination of the afflicted person's mental decline and loss of independence. The person with Alzheimer's Disease is intellectually dying (Ory, Williams, Emr, Lebowitz, Rabins, Salloway, Sluss-Radbaugh, Wolff & Zarit, 1985). The caregiver of an Alzheimer's Disease patient experiences a great deal of burden which Ory, et al. (1985) define as the impact of the changes in cognition and behavior of the patient with Alzheimer's Disease on the family, and the patient's subsequent need for care and supervision. In a study designed to investigate the multidimensional properties of burden in caregivers (Poulshock & Diemling, 1984), associations between elder impairment, burden, impact on family life, and depression were explored. Mental impairment in elders and the burden experienced by their caregivers was found to be associated. High levels of burden have been found to be associated with nursing home placement (Zarit, Todd, & Zarit, 1986). The more burden the caregiver experiences the higher the chances the ill relative will be institutionalized.

Cantor (1983) found that the most severe burden was felt in the areas of free time, socializing, leisure pursuits, and household chores. The caregivers no longer had time for outside interests due to the time spent caring for their family member afflicted with Alzheimer's Disease. Social isolation (Wasow, 1985; Morycz, 1980; Maletta & Hepburn, 1986) is another area that causes feelings of burden among caregivers. The actual caregiving is a time consuming job that affords the caregiver very little free time. The long progressive nature of Alzheimer's Disease often causes friends and relatives to avoid the afflicted person.

The avoidance also distances the friends and relatives from the caregiver. As Alzheimer's Disease progresses it becomes increasingly difficult to take the family member out of the home. This tends to isolate the caregivers and make them feel as if they are trapped with the family member afflicted with Alzheimer's Disease. In a study which investigated the association between support and burden in caregivers, Scott, Roberto, & Hutton (1986), found that caregivers who felt they were not receiving support from others tended to experience more burden than did caregivers who felt they were receiving support from others. Support groups for patients and caregivers tended to decrease the amount of burden experienced by caregivers (Winogron, Fisk, Kirsling, & Keyes, 1987).

Spouses, children, and friends of the person afflicted with Alzheimer's Disease most often assume the role of caregiver. The relationship between amount of burden felt by the caregiver and the closeness of the caregiver's relationship with the afflicted person has been explored and differing results have been found. Some studies have found that the closer the relationship between the person with Alzheimer's Disease and the caregiver, the higher the degree of burden felt by the caregiver (Grad & Sainsbury, 1963; Aronson, Levin, & Lipkowitz, 1984; Cantor, 1983). This finding could be due to the emotional strain of watching a loved one slowly deteriorate. Ory et al. (1985), in a review on current research on Alzheimer's Disease and caregivers stated that the better the relationship between caregiver and Alzheimer's victim and caregiver the less burden experienced. No source was given for this finding, therefore the origins of the statement are unknown. Thompson and Doll (1982), in a study which examined the emotional and social costs of caregiving interviewed 125 family caregivers of the mentally ill. No significant relationship between the closeness of the Alzheimer's patient and the caregiver in relation to the amount of burden felt by the caregiver was found.

One of the most difficult problems faced by some caregivers is that of role reversal (Aronson, Teusink & Mahler, 1984). The person afflicted with Alzheimer's Disease becomes more and more dependent on the caregiver. This dependence means that they need to be cared for as if they were small children. Temper tantrums must be dealt with, diapers changed, and the ill person may need to be hand fed. Children often find it very difficult to assume the role of caregiver to a parent with Alzheimer's Disease, a parent that may have been seen as strong and invincible. Strains of children caring for parents with Alzheimer's Disease are often compounded by intergenerational difference (Cantor, 1983). In the case of Alzheimer's Disease the caregiver must, in effect, become parents to their own parents. Husbands typically have trouble assuming the role that their wives once occupied. They tend to have difficulty preparing meals and doing household chores in addition to performing the full time job of caregiving. Wives also have trouble assuming the role of caregiver. Often husbands have taken care of finances and household repairs for years, and it is frequently difficult for the wife to take over those duties. Both spouses incur many problems attempting to take over the role that was once filled by his/her ill spouse. Morycz (1985) found that husbands tend to be much more willing to ask for help outside of the family than are wives. Wives often feel as if they should be able to manage the house, finances, and the person with Alzheimer's Disease. Women tend to be in a caregiving role for most of their lives, caring for their children and their husbands. It is very difficult for them to accept the fact that this type of caregiving is almost impossible to do without some form of help (Morycz, 1985). Conversely, in a comparison of spouse caregivers of dementia patients, Fitting, Rabins, Lucas, & Eastham (1986), found no differences in amount of burden experienced by male and female caregivers.

Financial problems may increase burden for many families (Cicirelli, 1984). The cost of institutionalization or hired caregivers is high. Most victims of Alzheimer's Disease eventually reach a state where constant care and supervision is needed. This is often difficult if the caregiver has a job outside the home. Minority and low socioeconomic status families tend to keep the family member with Alzheimer's Disease at home until a very advanced stage of the disease. They tend to make little or no use of formal supports until some catastrophic situation forces them to institutionalize the family member afflicted with Alzheimer's Disease. Families at higher socioeconomic levels are more likely to maintain the family member with Alzheimer's Disease at home through the use of hired caregivers and companions, rather than performing instrumental caregiving tasks themselves or making use of community institutions. The financial resources of the family are an important factor in determining the extent and quality of family caregiving, the hiring and supervision of additional help and the use of institutional alternatives.

Burden experienced by caregivers of chronically impaired older adults has been investigated in several different aspects as stated in the literature cited above. Grad & Sainsbury (1963) investigated burden in caregivers of the mentally ill. Cantor (1983) and Sanford (1985), explored burden in caregivers of chronically impaired older adults. The samples used in these studies contained both mentally and physically impaired older adults in need of care. Studies by Zarit, Todd, and Zarit (1986), Morycz, (1985), Scott, Roberto, and Hutton (1986), Winogron, Fisk, Kirsling, and Keyes (1987), and Fitting, Rabins, Lucas, and Eastham (1986) examined burden only in caregivers of older adults with Alzheimer's disease. Poulshock and Diemling (1984), in an examination of the multidimensional aspects of burden discovered an association between mental incapacity in ill older adults and burden levels.

Increased mental incapacity was found to be associated with increased burden levels. This study will address what seems to be a deficit in the current literature, comparisons between caregivers of the physically and mentally (Alzheimer's afflicted) impaired elders. Mental incapacity can be profound in those suffering from Alzheimer's Disease. Therefore caregivers of older adults with Alzheimer's Disease could be expected to experience higher levels of burden and depression than caregivers of physically ill older adults.

Life Events and Depression

Numerous studies have demonstrated the relationship between stressful life events and depression (Myers, Lindenthal, Pepper & Ostrander, 1972; Lloyd, 1980; Paykel, Myers, Dienalt, Klerman, Lindenthal, & Pepper, 1969). Myers, Lindenthal, Pepper & Ostrander (1972) investigated the relationship between stressful life events and mental status over a two year period with a systematic randomly sampled population in a metropolitan area. Mental status and recent changes in life events were recorded and then again recorded two years later. Increased changes in stressful life events were found to be related to increased pathology on the mental status exam.

Paykel et.al. (1969) compared a control group and a group of depressed patients on recent stressful life events. The depressed patients reported nearly three times as many important stressful life events in the six months prior to the onset of the depressive episode as did the control group.

Support systems have been found to decrease the likelihood of depression following significant life events. Caregivers often find that their circle of social and familial support decreases when their life becomes consumed with caregiving. When high life event scores (Warheit, 1979) showed significant relationships to increased depressive symptomology,

persons with personal, familial, and interpersonal resources had significantly less depressive symptomology than did those without resources.

Paykel, Prusoff, & Uhlenhuth (1971) asked subjects to rate the severity of stress associated with various life events. Their findings suggest that the death of a spouse or close family member, hospitalization of a family member, and the loss of a personally valuable object are extremely stressful events. Financial difficulties, separation from a significant person, and a change in line of work are moderately stressful life events. Each of these life events are not uncommon for caregivers of chronically impaired older adults (Chenowith & Spencer, 1986; Mace & Rabins, 1981).

The burden associated with caring for a family member with Alzheimer's Disease has been linked to depression in caregivers (Poulshock & Deimling, 1984; Pagel, Becker, & Coppel, 1985; Drinka, Smith, & Drinka, 1987). The caregivers tend to feel as if they have lost control over their own lives. It is likely that this feeling of loss of control can lead to depression in caregivers. Also, higher levels of burden can lead to depression, which can in turn, lead to higher levels of burden. This can form a dangerous cycle which affects both the caregiver and ill older adult.

Statement of the Problem

This study is designed to examine burden and depression in caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments. The experience of caring for an older adult with Alzheimer's Disease will be compared with the experience of caring for a physically impaired older adult. It is expected that the experience of these two groups will be different, even when there is no difference between them in the areas of caregiver age, ill relative age, length of relationship, and length of illness. It is expected that

a greater degree of burden and depression will be experienced by caregivers of older adults with Alzheimer's Disease than for caregivers of physically impaired elderly. It is also expected that there will be a positive relationship between experience of burden and depression for both caregivers of physically impaired elderly and caregivers of older adults with Alzheimer's Disease. Areas which appear to be particularly strong sources of burden or depression for caregivers will be explored by examining responses to specific items on the measures of burden and depression.

CHAPTER 3

METHODOLOGY

This section will present the methodology of the study. The sample, research instruments, administration of the instruments, hypotheses, and statistics used to analyze the data will be described.

Research Hypotheses

1. There will be no differences between caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments in the areas of caregiver age, ill relative age, length of relationship, and length of illness.
2. Burden will be greater for caregivers of elders with Alzheimer's Disease than for caregivers of physically impaired elderly.
3. Depression will be greater for caregivers of elders with Alzheimer's Disease than for caregivers of physically impaired elderly.
4. There will be a positive relationship between the amount of burden experienced by the caregiver and depression.

Design Statement

The experimental design used was a static group comparison as defined by Campbell and Stanley (1963). The threats to internal and external validity which are inherent to this design are selection, mortality, interaction of selection and maturation, and the interaction of selection and the experimental treatment.

Sample

Samples from two populations were used in this study. The populations studied were, (a) caregivers of older adults with Alzheimer's Disease and (b) caregivers of physically impaired older adults.

Subjects for both samples were recruited through physicians in the Gallatin and Park County area. Thirty-four area physicians were contacted via a letter (Appendix B) which was followed by a phone call. The names and addresses of all physicians contacted were obtained from the yellow pages of the local phone book. Seven of the thirty-four physicians contacted agreed to participate in the study. Those physicians who did not participate in the study, did not respond to the letter or to repeated phone messages left by the author. The physicians who did participate selected from their patients those who were organically or physically impaired, still resided in their own home, and had a primary caregiver which was a spouse or child. The physicians who chose to participate then supplied the author with the name of the caregiver, nature of relationship to the ill older adult, phone number of caregiver, address of caregiver, name of the ill older adult, and diagnosis of the ill older adult. Twenty-seven subjects were referred to the author. Of these twenty-seven referred subjects twenty-two participated in the study, constituting a return rate of eighty-one percent.

The combined sample consisted of 22 subjects who were caring for a chronically ill older adult (Table 1). The mean age of the caregivers was 62.64, while the mean age of the ill older adults they were caring for was 74.67. The relationship between the caregiver and the ill older adult tended to be long term, an average of 44.05 years. The length of the illness of the ill older adult ranged from one quarter of a year to twenty years with a mean of 6.30 years. The

caregivers in the sample were caring for older adults with the following array of illnesses: Alzheimer's disease, emphysema, heart problems, high blood pressure, cancer, multiple sclerosis, diabetes, dehydration, and frailty.

Table 1. Combined Sample Demographics

Variable	N	\bar{X}	SD	Minimum	Maximum
Caregiver Age	22	62.64	15.67	24.00	83.00
Ill Relative's Age	21*	74.67	11.51	51.00	96.00
Length of Relationship (years)	22	44.05	12.53	20.00	68.00
Length of Illness	22	6.30	5.15	.25	20.00

*Decreased N size due to questions left blank on questionnaire

The two samples were composed of caregivers of elders with Alzheimer's disease and caregivers of elders with chronic physical impairments (Table 2). Eight of the subjects were caring for elders with Alzheimer's Disease, fourteen were caregivers of elders with chronic physical impairments. The mean age of caregivers of elders with Alzheimer's disease was 69.13, while the mean age of the elders with Alzheimer's disease they were caring for was 73.89 (Table 3). The mean age of caregivers of elders with chronic physical impairments was 58.93, while the mean age of the elders with chronic physical impairments they were caring for was 75.15. Fourteen of the caregivers were spouse caregivers and eight caregivers were children caring for a chronically ill parent. Sixteen of the caregivers were female, six were male.

Table 2. Caregiver Demographics

Variable		N	%	\bar{X} Age	SD
Type of Care-giver	C. G.'s of Elders With Alzheimer's	8	36	69.13	10.19
	C. G.'s of Physically Impaired Elders	14	64	58.93	17.32
	Total	22	100	-----	-----
Relation-ship	C. G.'s Caring for a Spouse	14	64	70.36	8.77
	C. G.'s Caring for a Parent	8	36	49.13	16.30
	Total	22	100	-----	-----
C. G.'s of Elders With Alzheimer's	Male	1	12	76.00	-----
	Female	7	88	68.14	10.59
	Total	8	100	-----	-----
C. G.'s of Phys. Impaired Elders	Male	5	36	57.20	22.72
	Female	9	64	59.89	15.05
	Total	14	100	-----	-----

Table 3. III Relative Demographics

Variable		N	%	\bar{X} Age	SD
Type of III Relative	Elders With Alzheimer's	8	36	73.88	2.70
	Physically Impaired Elders	14	64	75.15	14.70
	Total	22	100	----	----
Elders With Alzheimer's	Male	4	50	73.00	2.16
	Female	4	50	74.75	3.20
	Total	8	100	----	----
Physically Impaired Elders	Male	6	43	79.00	8.60
	Female	8	57	72.75	17.63
	Total	14	100	----	----

Questionnaire

This section describes the cover letter, request for information and instruments used to measure caregiving, depression, burden and demographics. The questionnaire (appendices C,D,E,F,G,H) was formatted using the Chicago 12 point font to facilitate easy reading by a predominantly older population.

Cover Letter

The cover letter (Appendix C) was used to introduce the author and the purpose of the study to the caregiver. The cover letter contained a statement of confidentiality and instructions pertaining to completing and returning the questionnaire to the author.

Request for Information

The request for information (Appendix D) was provided so that interested subjects could receive the results of the study. A confidentiality statement was included in the request for information. The return of the request for information form was optional for the subject.

Information Sheet

The information sheet (Appendix E) was designed by the author. It was used to gain information about the caregivers and their relationship with their ill loved one. It contained short answer questions concerning the nature of the relationship, length of the relationship, type of impairment, age of the caregiver, age of the impaired person, support system of the caregiver, gender, hours per day spent caregiving, attitude towards choice about caregiving and average yearly income. A section for comments was also included (Appendix I).

Zarit's Burden Interview

The Burden Interview (Zarit, Orr, & Zarit, 1986) (Appendix F) was especially designed to reflect the stresses experienced by caregivers of dementia patients. It can be used as a self-report measure or as an interview measure. The Burden Interview consists of a series of 22 questions to be answered by the caregiver about the impact of the patient's impairment on the life of the caregiver. The responses are coded on a 0-4 Likert scale, 0 being little or no impact and 4 being severe impact. The Burden Interview is scored by summing the responses of the individual items. Scores range from 0-88. Norms for the Burden Interview have not been

computed, but estimates of the degree of burden have been made from preliminary findings. These are: 0-20 little or no burden, 21-40 mild to moderate burden, 41-60 moderate to severe burden, and 61-88 severe burden (personal correspondence with Steven H. Zarit).

Internal reliability for the Burden Interview has been estimated using Cronbach's alpha at .88 (Hassinger, 1985) and .91 (Gallagher, et al., 1985). Test retest reliability is reported at .71 (Gallagher, et al., 1985). Validity has been estimated by correlating the total score with a single global rating of burden ($r=.71$), and by correlating the total score with the Brief Symptom Inventory (Derogatis, et al., 1970) ($r=.41$).

The Zarit Burden Interview has been used to measure burden in caregivers of older adults suffering from dementia, Alzheimer's Disease, and depression (Drinka, Smith, & Drinka, 1987; Fitting, Rabins, Lucas, & Eastham, 1986; Liptzin, Grob, & Eisen, 1988; Scott, Roberto, & Hutton, 1986; Winogron, Fisk, Kirsling, & Keyes, 1987; Zarit, Todd, & Zarit 1986).

In addition to obtaining a total score Zarit Burden Interview score for each caregiver, individual items will be examined to ascertain which areas appear to be most highly associated with burden in caregivers.

Beck Depression Inventory

The Beck Depression Inventory (Appendix G), is the most frequently used method of assessing severity of depression (Shaw, Vallis, & McCabe, 1985). The scale is clinically derived and designed to measure both attitudes and symptoms of depression. Each category describes a specific behavioral manifestation of depression. Each item consists of a graded series of 4-5 self evaluative statements which are ranked to reflect the severity of the symptom from neutral to maximum severity (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). The Beck Depression Inventory has been shown to be applicable across cultures. Split

half-reliability coefficients have been reported between .58-.93. The concurrent validity of the Beck Depression Inventory has correlated with clinician's ratings of depth of depression resulting in correlations ranging from .62-.77 (Shaw, Vallis & McCabe, 1985).

The Beck Depression Inventory has been used with many different populations. Pagel, Becker, & Coppel (1985) used the Beck Depression Inventory to investigate depression in caregivers of older adults with Alzheimer's Disease. The Beck Depression Inventory was used by Sowa & Lustman (1984) in an investigation of life stress and depression.

In addition to obtaining a total score Beck Depression Inventory score for each caregiver, individual items will be examined to ascertain which areas appear to be most highly associated with depression in caregivers.

Procedures

The study design was submitted to and deemed acceptable by the Human Subjects Committee (Appendix A). Thirty-four area physicians were contacted by letter (Appendix B) in December 1988. Phone contact was made or attempted in January and February 1989. Seven area physicians agreed to participate in the study and referred a total of twenty-seven subjects to the author. Caregiver names and addresses were received by the author in February, March, April, and May 1989. Where possible caregivers were contacted by the referring physician or the author via a phone call to gain consent.

Data collection took place during May and June of 1989. The subjects received a packet through the mail which contained the following:

1. Cover Letter (Appendix C)
2. Request for Information (Appendix D)
3. Information Sheet (Appendix E)

4. Zarit Burden Interview (Appendix F)
5. Beck Depression Inventory (Appendix G)
6. Thank You Sheet (Appendix H)
7. Envelope, addressed to the author

The questionnaire was returned to the author over a three week period in May and June 1989. Twenty-two of the twenty-seven subjects returned the questionnaire which yielded a eighty-one percent return rate.

Data Analysis

The data was analyzed using t-tests for independent samples and the Pearson Product-Moment Correlation Coefficient (Spatz & Johnson, 1984).

1. t-tests for independent samples with a level of significance at or beyond .05 was used to ascertain differences between caregivers of elders with Alzheimer's Disease and caregiver's of elders with chronic physical impairments in the areas of caregiver age, ill relative age, length of relationship, and length of illness.
2. A t-test for independent samples with a level of significance at or beyond .05 was used to determine differences in burden between caregivers of relatives with Alzheimer's and caregiver's of relatives with chronic physical impairments.
3. A t-test with a level of significance at or beyond the .05 level was used to determine differences in depression between caregivers of relatives with Alzheimer's and caregiver's of relatives with chronic physical impairments.

4. A Pearson Product-Moment Correlation Coefficient with a level of significance at or beyond the .05 level was used to determine the relationship between burden and depression.
5. Mean scores on each item in the Zarit Burden Interview and the Beck Depression Inventory will be graphed in order to examine specific areas of burden and depression.

CHAPTER 4

RESULTS

Depression and burden in caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments were studied to test the following alternative hypotheses:

1. There will be no differences between caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments in the areas of caregiver age, ill relative age, length of relationship, and length of illness.
2. Burden will be greater for caregivers of elders with Alzheimer's Disease than for caregivers of elders with chronic physical impairments.
3. Depression will be greater for caregivers of elders with Alzheimer's Disease than for caregivers of elders with chronic physical impairments.
4. There will be a positive relationship between the amount of burden and depression experienced by the caregiver.

The results of the data analyses for each of the hypotheses is reported in the following sections. An explanation and interpretation of these results will be provided in Chapter 5. Firstly, means and standard deviations for the Zarit Burden Interview and Beck Depression Inventory, caregiver age, ill relative age, length of relationship, and length of illness for combined samples will be reported. This will be followed by a comparison of caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments.

Combined Samples

Combined sample statistics for the Zarit Burden Interview, Beck Depression Inventory, caregiver age, ill relative age, length of relationship, and length of illness are reported in Table 4.

The mean age of the caregivers surveyed was 62.64, with a standard deviation of 17.28. The youngest caregiver was 24 and the oldest was 83 years of age.

The mean age of the ill older adults who were receiving care was 74.67, with a standard deviation of 11.51. The minimum and maximum age of the ill older adults was 51 through 96.

Table 4. Combined Sample Statistics

VARIABLE	\bar{X}	SD	N	Minimum	Maximum
Zarit Burden Interview	34.18	17.28	22	6.00	64.00
Beck Depression Inventory	7.96	6.19	22	.00	23.00
Caregiver Age (years)	62.64	15.67	22	24.00	83.00
Ill Relative Age (years)	74.67	11.51	21*	51.00	96.00
Length of Relationship (years)	44.05	12.53	22	20.00	68.00
Length of Illness (years)	6.30	5.15	22	.25	20.00

*Decreased N size due to questions left blank on the questionnaire

The mean length of the relationship between the caregiver and the ill relative was 44.06 years and includes marital and parental relationships. The standard deviation was 12.53. The longest relationship had lasted 68 years and the shortest was a 20 year relationship.

The ill relatives of the caregivers sampled had been ill an average of 6.30 years, with a standard deviation of 5.15. The shortest length of illness was one quarter of a year and the longest was 20 years.

The mean Zarit Burden Interview score for the combined n of 22 subjects was 34.18, standard deviation 17.28, with a minimum score of 6 and a maximum score of 64.

The mean Beck Depression Inventory score for the combined n of 22 subjects was 7.96, standard deviation 6.20, with a minimum score of 0.00 and a maximum score of 23.00.

Tests of Hypotheses

Hypothesis 1

Independent samples t-tests were used to compare caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments on the following variables: caregiver's age, ill relatives age, level of impairment, closeness at present, length of relationship, length of illness, hours spent in care, feelings of having support, and ability to leave the ill relative unattended.

Independent samples t-tests yielded no significant differences between caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments on the previously mentioned variables (Table 5).

Table 5. Comparison of the Two Groups

VARIABLE		N	\bar{X}	SD	t	p
Care-giver Age	Caregiver's of Alzheimer's	8	69.13	10.19	1.51	N.S.
	Caregivers of phys. impaired	14	58.93	17.32		
Ill Relative Age	Alzheimer's	8	73.88	2.70	-.241	N.S.
	Physically Impaired	13	75.15	14.70		
Length of Rela- tionship	Caregiver's of Alzheimer's	8	43.63	12.25	-.116	N.S.
	Caregivers of phys. impaired	14	44.29	13.14		
Length of Illness	Alzheimer's	8	5.56	2.38	-.501	N.S.
	Physically Impaired	14	6.73	6.26		

Hypothesis 2

Burden will be greater for caregivers of elders with Alzheimer's Disease than for caregivers of elders with chronic physical impairments.

Table 6. Comparison of Zarit Burden Interview Scores

VARIABLE		N	\bar{X}	SD	t	p
Zarit	C.G. of Alzheimer's	8	31.88	21.24	-.464	N.S.
Burden						
Interview	C.G. of phys. impaired	14	35.50	15.30		

An independent samples t-test showed no significant difference between caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments and the amount of burden they experienced (Table 6).

Hypothesis 3

Depression will be greater for caregivers of elders with Alzheimer's Disease than for caregivers of elders with chronic physical impairments.

Table 7. Comparison of Beck Depression Inventory Scores

VARIABLE		N	\bar{X}	SD	t	p
Beck	C.G. of Alzheimer's	8	8.50	8.40	.306	N.S.
Depression						
Inventory	C.G. of phys. impaired	14	7.64	4.86		

An independent samples t-test showed no significant difference between caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments and the amount of depression they experienced (Table 7).

Hypothesis 4

There will be a positive relationship between the amount of burden and depression experienced by the caregiver.

Table 8. Relationship Between Burden and Depression

VARIABLE	N	r	p	r ²
Zarit Burden Interview	21	.760	<.05	.578
Beck Depression Inventory	21			

A Pearson Product-Moment Correlation Coefficient for independent samples revealed a significant positive correlation between the amount of burden and depression experienced by the caregiver (Table 8).

Examination of Specific Items

The combined sample mean score, standard deviation, number, and standard error for the items on the Zarit Burden Interview are represented in Table 9 and Figure 1 (Appendices J and K). The items with the highest mean scores were items 3, 7, 8, and 14. Item 3 ($\bar{X}=2.091$) pertained to stress due to caring for an ill older adult while also attempting to meet family and work responsibilities. Item 7 ($\bar{X}=2.091$) pertained to fear of what the future holds for the ill relative. Item 8 ($\bar{X}=3.727$) asked the caregiver how dependent they feel the ill relative is on them. Item 14 ($\bar{X}=2.455$) asked the caregiver if the ill relative felt they were the only one who could care for him/her. The items with the lowest mean score on the Zarit Burden Interview were items 4, 5, and 6. Item 4 ($\bar{X}=.773$) pertained to embarrassment over the ill

relatives behavior, item 5 ($\bar{X}=1.000$) to anger felt toward the ill relative, and item 6 ($\bar{X}=.810$) to negative effects on the family.

The combined sample mean score, standard deviation, number, and standard error for the items on the Beck Depression Inventory are represented in Table 11 and Figure 2 (Appendices M and N). The items with the highest mean score were P, Q, and U. Item P ($\bar{X}=.995$) denotes problems with insomnia, item Q ($\bar{X}=.864$) with fatigability, and item U ($\bar{X}=1.000$) with loss of libido. The items with the lowest mean score on the Beck Depression Inventory were E, G, and I. Item E ($\bar{X}=.955$) concerns feelings of guilt, item G ($\bar{X}=.000$) feelings of self-dislike, and item I ($\bar{X}=.000$) concerns suicidal ideation.

CHAPTER 5

DISCUSSION

The purpose of this research study was to examine burden and depression in caregivers of elders with Alzheimer's Disease and caregivers of elders with chronic physical impairments. This chapter will discuss major findings, limitations, and conclusions of the study. Implications of these findings and suggestions for future research will also be discussed.

Combined Samples

The people studied were primary caregivers (spouses and children) of chronically ill older adult relatives. The mean age of the caregivers was 62.64, while the mean age of the older adults they were caring for was 74.67. The age difference between caregivers and ill older adults can be attributed to the fact that some of the caregivers were spouses and some were children of the ill older adult which lowered the mean age of the caregivers. The fact that the mean age of the caregivers surveyed was 62.64 indicates that caregivers of chronically impaired older adults tend to be older adults themselves. Caregivers who are themselves older adults, may suffer from decreased stamina and poor health themselves, which can make caregiving an even more strenuous task. The average length of the relationship between caregivers and the ill older adult was 44.05 years. Sixty-four percent of these relationships were spousal and 36 % were parental. The ill older adults had been chronically ill for an average of 6.30 years, which means the caregivers sampled had been caring for an ill older adult an average of over six years.

