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RELATION OF SELF-EFFICACY, SOCIAL SUPPORT,
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TO CAREGIVER BURDEN IN AN ALZHEIMER'
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presented by

Paul Cummings Nation

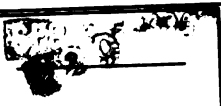has been accepted towards fulfillment
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RELATION OF SELF-EFFICACY, SOCIAL SUPPORT, NEGATIVE AFFECT,

AND COGNITIVE IMPAIRMENT TO CAREGIVER BURDEN IN

AN ALZHEIMER'S DISEASE POPULATION

By

Paul Cummings Nation

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ABSTRACT

RELATION OF SELF-EFFICACY, SOCIAL SUPPORT, NEGATIVE AFFECT,
AND COGNITIVE IMPAIRMENT TO CAREGIVER BURDEN IN
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While dementing disorders of the elderly are devastating to their victims, their adverse effects on family members who provide care can be devastating as well. What remains unclear, however, is the precise nature of burden upon family members caring for these patients.

Despite major gaps in knowledge, available data together with a deluge of descriptive clinical reports lead to the inescapable conclusion that the occurrence of Alzheimer's disease does indeed directly affect family caregivers. While some manage well, others experience a host of burdens, physical and mental health symptoms. Understanding why some caregivers report more burden whereas others remain the same or adapt over time is one of the most important goals of caregiver research (Schulz, 1990; Zarit, 1989).

Few studies have examined caregiver burden using a theoretical model of burden to guide the research. A distress model offered by Vitaliano (1987) is used to guide this

research on the correlates of burden. The application of a theoretical model was seen as a positive step in expanding the knowledge base about the burden of being a caregiver.

The objectives of this study were to describe the correlates of burden among caregivers seen in an ambulatory geriatric assessment unit. Subjects were 92 patient and caregiver dyads being seen at the Turner geriatric clinic at the University of Michigan. A package of questionnaires including measures of caregiver's perception of social support, the caregiver perceptions of role-related self-efficacy, and caregiver's negative affective state were administered to the caregiver subjects. Measures of cognitive impairment from the individual patients were supplied by the clinic's assessment team.

The results of the present study suggests that caregivers at risk for high reported levels of burden may be characterized by their negative affective style, lacking specific elements of social support, low self-efficacy in the caregiving role and perceptions of patient's having low self-efficacy in caring for themselves. This recognition of the multidimensional nature of the stressors associated with caregiving, the mediating factors and caregivers resources increases the knowledge base concerning caregiver burden and the situational demand associated with caring for a relative suffering from Alzheimer's disease.

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in completing it. Special thanks to Dr. Linas Bieliauskas who not only facilitated the data collection but who was instrumental in the construction of the study.

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P. C. N.

1992

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CHAPTER I

INTRODUCTION

Currently some six million persons in the United States are Alzheimer's disease caregivers (Dippel & Hutton, 1988). This number is projected to double or triple in the next fifty years based on the dramatic increase in the number of older persons at risk for developing the progressive dementing disorder. In addition, most people are indirectly affected in that they know a friend or co-worker who suffers from this serious age-related disease.

While the cause of many dementing disorders is unknown and the treatment is limited, family and professional caregivers must struggle to find practical means of dealing with declining performance and behavioral changes. It has become increasingly important to assess carefully and realistically the capacity of the caregiver to provide care. The person providing care may be successful at managing the patient early in the process, but as the demands increase and the primary caregiver attempts to do more and more, re-evaluation of the caregiver's health, resources, and burden becomes very important, otherwise it may well be necessary to provide medical care to both caregiver and dementia patient.

Counseling psychologists are in an important position to focus on preventive work with older persons suffering from dementia of the Alzheimer's type (DAT) and their families (Baltes & Danish, 1980). Since many of the transitions involved with a progressive dementia are highly likely for most Alzheimer's disease victims and their families, they can be anticipated and planned for. The goal of the counseling psychologist in this crisis planning approach is to enable the older client to accurately assess his or her own resources when still able, to structure change in those areas that appear problematic, and empower caregivers to incorporate the entire family and community support system in negotiating the transitions and progression of the disease before they become crises.

Emphasizing anticipatory counseling, however, requires that the counseling psychologist has a clear and present understanding of the Alzheimer's disease process and its consequence on the family members. The understanding of cognitive impairment and burden as perfectly related variables is clearly inappropriate, and crystalline empirical data of the nature of caregiver burden will arm the counseling psychologist with the needed knowledge to accomplish his or her task. The transitions of Alzheimer's disease with regard to caregiver burden can be categorized into four different but interrelated areas: biological, psychological, environmental, and social/cultural. Within each area there are several

transitions which are concomitant of Alzheimer's disease in the elderly population. The counseling psychologist with his or her holistic training is in the unique position of being able to address the interrelated nature of normal aging, Alzheimer's disease, and burden within these consequential domains.

Statement of the Problem

While dementing disorders of the elderly are devastating to their victims, their adverse effects on family members who provide care can be devastating as well. The responsibility of providing care for a physically and/or cognitively impaired older adult can place the caregiver at risk for negative physical, emotional, and social outcomes (Fengler & Goodrich 1979). What remains unclear, however, is the precise nature of burden upon family members caring for these patients. Burden has been broadly defined and measured. The definitions range from burden as emotional costs to feelings of overload (Thompson & Doll, 1982) to specific changes in caregivers' day-to-day lives such as disruption of daily routine. Other areas include financial difficulties, role strain, and physical health deterioration (Robinson, 1983; Zarit & Zarit, 1980).

Despite major gaps in knowledge, available data together with a deluge of descriptive clinical reports lead to the inescapable conclusion that the occurrence of Alzheimer's

disease does indeed directly affect members of the family and the family as a whole. While some manage well, others experience a host of burdens, physical, and mental health symptoms. Understanding why some caregivers report more burden whereas others remain the same or adapt over time is one of the most important goals of caregiver research (Schulz, Visintainer and Williamson, 1990; Zarit, 1989).

Purpose of the Proposed Study

The objectives of the study are to describe 1) burden among caregivers of elderly patients seen in an ambulatory geriatric assessment unit and 2) analyze predictors of caregiver burden of above caregivers. The predictor variables of interest are: 1) perceived caregiver burden; 2) caregiver's social support network; 3) patient's cognitive impairment; 4) caregiver's perceived efficacy of self and patient; and 5) caregiver's affective state. The study used constructed measures of burden and related attributes based on current theory and recent behavioral research.

The study applied a prospective design with caregivers of patients who were undergoing the assessment process at the Turner Clinic. At the time of selection the individual and family caregiver were informed about the study, its purpose, and assurance of strict confidentiality. Those who agreed to participate were asked to sign a consent form. The sample consisted of patients seen at the Turner Clinic and each

patient's family caregiver. They were admitted into the study based on the date of completion of their clinic assessment.

CHAPTER II

REVIEW OF RELATED LITERATURE

Origins and Course of the Illness

Identification of a "progressive, age-related, chronic cognitive dysfunction" known as Alzheimer's disease (Schneck, Reisberg, & Ferris, 1982) was the result of cumulative studies by a number of European researchers. Discovery of the cerebral "plaques" by Blocq and Marinesco (1892) was followed by Alzheimer's (1907) reports on the relationship between autopsy findings of brain neuropathology and the occurrence of psychiatric symptoms during illness, and Simschowicz's (1910) report of a relationship between these "senile plaques" and behavior characteristic of dementia. Additionally, Kraepelin began the tradition of using Alzheimer's name for the progressive disease. More contemporary studies by Roth (1955) and Corsellis and Evans (1965) further clarified this disease, distinguishing between dementias resulting from cerebrovascular disease and those specifically caused by the formation of brain abnormalities, including neurofibrillary tangles and degenerating nerve endings or neuritic plaques (Katzman, 1986; Schneck et al., 1982).

Studies by Terry, Gonatas and Weiss (1964) showed that so-called presenile dementia and senile dementia associated with Alzheimer's disease could be attributed to similar neuropathology. Blessed, Tomlinson and Roth (1968) showed

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that behavioral changes among elderly patients are significantly correlated with later autopsy findings: increased evidence of plaque formation in the cortex is associated with both intellectual deterioration and, in particular, impairment in everyday functioning among afflicted elderly patients.

From the social science perspective, Alzheimer's disease presents several features that are unique among neuropsychiatric disorders. First, the symptoms of the illness defy our culturally defined view of behavior as intentional (Cohler, Grovers, Borden and Lazarus, 1989). Western psychology has long held people accountable for their actions and has viewed mental illness as a moral failing. Patients with Alzheimer's disease display behavior that is socially unacceptable and often unsuitable, and yet the behavior is understood to be beyond the control of the patient. Also, the course of the illness, while strictly progressive, is also completely unpredictable. For reasons that research has not made clear, some victims die in a small span of time after symptoms first appear, while others live for decades. The uncertainty associated with the progressive changes in symptoms or course of the disease is a major reason for the particular adversity reported by caregiver of relatives with Alzheimer's disease (Gubrium, 1987; Pagel, 1985).

To date, no cure, or even effective treatment, has been discovered that can in any way alter the end result of the disease's destructive course of brain degeneration. For family and friends who care for a patient with Alzheimer's disease, learning the diagnosis begins the process of mourning. The process of working through the grief associated with the death of a loved one is made more difficult by both the above mentioned unstable course and the disruptive symptoms that mark the later stages of the disease.

Lastly, and what many consider "the most tragic and difficult symptoms of this disorder" (Cohler et al., 1989), is the inability to recall significant relationships that have been accumulated over a lifetime. Occasional losses in memory, often an early symptom of the disease, are later expressed as lack of orientation to person and place, and still later as an inability to recognize a spouse, children, and close friends. Memory for relationships is central to being human and failure to acknowledge others is among the most painful and crushing responses that persons can show each other. In her discussion of the psychology of parenthood, Benedek (1973) observed that one is a parent as long as there is active memory. Benedek anticipated the problems posed for the parent whom no longer remembers the fact of parenthood; serious problems are posed for adult caregivers when their impaired parent/spouse no longer acknowledges the relationship. No single aspect of caring for a relative with

Alzheimer's disease may be as upsetting as the victim's inability to remember the relationship. For the caregiver, this lack of acknowledgement can be experienced as a major break in empathy.

Caregiver Burden

What are the burdens and resources needed to cope with the stresses associated with caring for a person with Alzheimer's disease? Within empirical research, burden is treated as the dependent variable - hence its operational definition and framework provide key study structure. There appear to be five major models of burden within the reviewed literature. Poulshock and Deimling (1984) suggest that burden be conceptualized and measured as specific to the type of impairment and difficulty in coping with needs. In this model, impairment, burden, and the impact are associated but independent with impairment contributing to burden. Deimling and Bass (1986) address stress effects rather than burden. This includes the impact on family and social life, changes in the caregiver's physical health and depression. Others distinguish between objective, (i.e., the extent of changes in caregiver's life), subjective (i.e., caregiver's attitudes toward and emotional reaction to the caregiving experience), and consequences of burden (Pruchno & Resch, 1986). Burden has also been defined as the caregiver's well-being in the domains of physical health, mental health, social life,

financial resources, or other demographic outcomes (Haley, 1987). Lastly, Robinson measured burden (using the Caregiver Strain Index) as integrated components. The subjective responses are perceived to affect the evaluation of the objective responses, and the degree to which life-style is affected (Robinson, 1983).

Early research on caregiver burden, first conducted by Grad and Sainsbury in Great Britain in the 1960's, did not focus specifically on caregivers of demented persons, but rather included the family caregivers of psychiatric patients who were diagnosed with either functional psychiatric disorders or organic brain syndromes (Grad and Sainsbury, 1963, 1968). Adverse effects on mental health were reported in 63 percent of these caregivers, while 58 percent reported deterioration in their physical health. Social and leisure activities were disrupted in half of these caregivers, and about 19 percent of them reported a decline in income.

In addition, the relationship between the family caregiver and other family members became strained, and domestic routines were altered. The most severe burdens were reported among caregivers who experienced competing demands, such as poor personal health, or poor relationship with the infirmed individual.

The contribution of such early studies lies in their documentation that some form of burden is experienced in an overwhelming majority of family members who take on the

caregiving role. However, any conclusions about the unique role of Alzheimer's disease in the genesis of such caregiver burden is strictly limited. The illness and demographics of those past studies were often aggregated or poorly recorded. Neither objective or subjective measures of caregiver burden were well delineated. Despite these limitations, it appears that those who cared for the mentally impaired were more likely to experience stress and strain than those who cared for physically infirm persons.

Generally, it has been noted that the family plays a considerable role in delaying and preventing institutionalization (Tobin,1976). From one perspective, caregiver stress has been identified as a predictor of institutionalization among chronically disabled older adults. Martin (1984) and Zarit, Todd, & Zarit,(1986) found that nursing home placement was more strongly associated with subjective factors such as caregiver's feelings of burden than with objective indicators of the severity of dementia.

Haley's research (1987) compared personal health ratings of caregivers with controls. Caregivers rated their overall health as poorer than controls and rated their health as "excellent less frequently than controls." Further, burden scores significantly increase for caregivers who rate their health as fair or poor. Reports of increased utilization of drugs by family caregivers are consistent. Haley (1987) report a greater number of prescription medication used among

caregivers (p,.01). George and Gwyther (1986) reports that about 28 percent of the caregivers in their study compared with 19 percent of controls used psychotropic medication, with caregivers who resided with the patient most likely to use these medications. In a number of studies there is a clear relationship between caregiving and depressive symptomatology.

Caregivers, both male and female, consistently score as more depressed on the Beck Depression Inventory than same age controls (Pruncho and Potashnik, 1989). Haley's comparison between caregivers and controls using the Center for Epidemiology Studies Depression scale (CES-D) was significant with 43 percent of the caregivers having scores in the significant range (Haley, 1987). Fitting's (1986) study of spouse caregivers found depression to be higher among wives than husbands. In fact these above mentioned three studies all report significantly higher levels of depressive symptoms for relatives living with the patient. Neither age, duration of illness, nor severity of impairment in the patients differentiated caregiver's depression (Pruncho & Potashnik, 1989, Haley, 1987 and Fitting, 1986).

Rabins, Mace, and Lucas (1982) further documented the psychological distress of Alzheimer's caregivers. In extensive interviews of primary family caregivers of 55 patients suffering from irreversible dementia (60 percent of whom had Alzheimer's disease), these researchers report that 87 percent of the caregivers experienced chronic fatigue,

anger, or depression, and that the caregivers often had difficulty differentiating between these feelings. Fifty-six percent reported family conflicts, and 55 percent reported loss of friends, hobbies, and personal time. Furthermore, 31 percent worried that they themselves would become ill, and 29 percent reported difficulty in assuming new roles and responsibilities as a caregiver for the demented. Only 7 percent reported that they did not experience significant caregiver burden (Rabins et al., 1982).

Not all studies have demonstrated significant psychological distress or depressive symptoms in Alzheimer's caregivers. For example, Gilhooly (1984) studied the impact of caring for a demented relative in 37 separate families. In 20 of the families, the caregiver resided with the demented relative, while in the other 17 families, the caregiver was a "nonresident" caregiver. Co-resident caregivers were significantly older than nonresident caregivers. The demented relative who lived with the co-resident caregiver was also significantly more impaired than the demented relative who lived alone. While Gilhooly hypothesized that co-resident caregivers would show both low morale and poor mental health, their mental health overall was actually either good or only mildly impaired. None of the caregivers had significant psychiatric impairment, and all were capable of performing their daily routines without assistance (Gilhooly, 1984).

Gilhooly's data may reveal several factors that may have fostered relative well-being instead of burden among caregivers. Perceived satisfaction with social support, associated with good morale and mental health, was relatively high in this sample of caregivers. As other researchers have also found, the level of impairment experienced by the demented individual was not associated with caregiver burden. Gilhooly also examined the relationship between caregiver's demographic characteristics and caregiver burden. Male caregivers reported higher morale than females, but not greater mental health. Gilhooly suggested that improved morale in the male caregivers might be accounted for by less emotional involvement with their demented relative's illness (Gilhooly, 1984).

Other studies have examined the measurement of caregiver burden (Robinson 1983, Zarit et al. 1980) and correlates of burden (Paulshock and Diemling 1984, Zarit et al. 1980). A number of factors have been theorized to relate to the level of caregiver burden. Perhaps one of the most obvious issues explored is the relationship between burden and severity of dementia. Surprisingly very few empirical studies of this relationship have been attempted. Poulshock and Deimling (1984) note that the patient's cognitive incapacity (i.e., forgetfulness, confusion) is correlated with perceptions of burden. Zarit reported no relationship between burden and

extent of cognitive impairment and Activities of Daily Living (ADL) function.

Disruptive behaviors have been found to be strongly correlated with a negative impact on the family caregiver relationship. Disruptive behaviors were found to be the single most significant correlation with burden in reports (Deimling & Bass, 1986). Specifically, asocial and disoriented behaviors are directly related to subjective caregiver burden. All caregivers were found to be stressed by repetitive questions, difficulty in cooking, and handling finances. It was also found that as the frequency of these disruptive behaviors increased from occurring "not at all" to "sometimes" and "often," so do the levels of burden. However, the linearity of these relationships reverses itself when higher levels of forgetful behavior are considered (Pruchno & Resch, 1989).

A study by Jenkins and Jenkins (1985) found burden not to be linearly correlated with patient cognitive impairment. The researchers agree that while Alzheimer's disease patients demonstrate decreased functional abilities over time, caregiver perceptions of the meaning and their ability to cope with these losses do not bear a one to one relationship with the course of deterioration. Thus, since all functional losses are not perceived equally by caregivers, perceptions of burden and needed resources vary considerably over time.

Zarit (1980) conducted a study looking at the possible factors contributing to feelings of burden of those caring for older persons with senile dementia. Of the variables considered, including behavioral problems, functional abilities, and duration of illness, only the frequency of family visits had a significant effect upon the degree of caregiver's feelings of burden. That is, in situations where more visits were paid to the impaired older person from family other than the primary caregiver, burden was less (Zarit,1980). The strong relation between visits from family and caregiver's burden is important to the geriatric researcher focusing on the needs of the primary caregiver and the older person with Alzheimer's disease. It suggests that the primary caregiver would be best served by interventions that involve other members of the impaired person's natural social support system and make use of the resources within the network.

Relatives were identified by Quayhagen and Quayhagen (1988) as the most common source of emotional support. Perception of need for more assistance with four dimensions of well-being was measured by George and Gwyther (1987). Pratt (1986) noted that support from the extended family was associated with lower levels of burden for family caregivers. The question of familial relationship to the patient has several different responses. In Zarit's early (1980) study,

burden was similar for husbands and wives as well as daughters and wives.

In Zarit's later study (1986), a first observation found higher reports of subjective burden for wives, but equal measures with husbands at a later second observation point. Zarit interprets this finding to suggest better coping skills, the husband's decrease in difficult behaviors and/or changes in reporting patterns.

Cantor (1983) in a landmark study of four types of caregivers (spouses, children, other relatives and friends/neighbors) of the frail elderly reported more strain among female than among male caregivers. Of the four types of caregivers, spouses were more troubled by financial issues and by the morale of their husband or wife. Spouses also reported the most significant physical and emotional distress. Adult children, on the other hand, expressed relatively more distress over obtaining adequate help for the dependent elderly than the other caregiver groups. While caregivers who were friends/neighbors expressed the least amount of burden, all caregivers expressed anxiety in regards of the Alzheimer's disease patient's physical health (Cantor, 1983). The research observed no overall relation between burden and severity of dementia.

Fitting (1986) even reported that distinct patterns appeared when controlling for age and gender. Higher burden

levels were associated with severity of care recipient's dysfunction only in younger wives and older husbands.

Negative Affect

In a number of recent studies, multidimensional sources of burden in caregivers have been examined and interrelationships have been found among variables that could be classified as personality/trait factors. Morris, Morris, and Britton (1988) reported that caregivers at risk for burden were characterized by their attributional style. Winogrond, Fisk, Kirsling and Keyes (1987) found that caregiver burden was not directly influenced by the cognitive function of the impaired elderly. Rather, the patient's behavior was found to be significantly associated with a measure of the caregiver's intolerance. It was the intolerance that appeared to be in relationship to the caregiver burden, not the patient's impairment.

Gwyther's (1986) survey of 510 caregivers of memory impaired older adults found that patient illness characteristics were minimally related to caregiver well-being, while symptoms of stress, negative affect and low life satisfaction were related. Similarly, Oliver and Bock (1985) account that caregivers prone to responses such as anger, anxiety, guilt and depression exacerbated the burden in caring for their relative, and at the same time caused acute discomfort to themselves.

In this regard, Watson and Tellegen (1985) have summarized a basic, consensual two-factor paradigm of affective organization. In current studies of the structure of affect, positive and negative affect has invariably emerged as two central and relatively autonomous measures.

Briefly, positive affect (PA) mirrors the magnitude to which a person feels enthusiastic, active and alert. High PA is a condition of high vigor, full concentration, and satisfying engagement, whereas low PA is distinguished by melancholy and passivity. In contrast, Negative Affect (NA) is a dimension of subjective distress and unpleasurable engagement that subsumes a multiplicity of aversive dispositional states, including hostility, disdain, loathing, guilt, shame, trepidation, and nervousness. With people experiencing low NA being in a state of calmness and tranquility. These two components illustrate affective state dimensions, but Tellegen (1985) has demonstrated that they are related to corresponding affective trait dimensions of positive and negative emotionality (individual differences in positive and negative emotional reactivity).

Numerous PA and NA scales have been developed and studied in a variety of settings. Generally, the findings from these studies indicate that the two mood factors relate to different classes of variables. NA is related to hostility, anxiety, stress, poor coping, health complaints, and frequency of unpleasant events. In contrast, PA is related to social

activities and satisfaction and to the frequency of pleasant events.

Specifically, for the present study the primary purpose will be to examine whether pervasive individual differences in negative affect underlie the construct of burden observed in many caregivers of Alzheimer's patients.

Watson and Clark (1984) view negative affectivity as a mood dispositional dimension. It reflects pervasive individual dissimilarity in negative emotionality. The negative mood states experienced by persons with high NA include subjective feelings of nervousness, strain and alarm; thus NA has as one of its cardinal attributes what others have called "trait anxiety" (Watson and Clark, 1984). It also includes such affective states as guilt, sadness, scorn and hostility (Watson and Clark, 1984). In distinction, NA is independent to an individual's experience of positive emotions, that is, a high -NA level does not necessarily presuppose a lack of happiness, exhilaration, or enthusiasm.

Watson and Clark (1984) also stress that NA is a very pervasive disposition that manifests itself even in the absence of any overt stress. Although an individual's mood will oscillate broadly, partly in response to distinctive situational considerations, those high in NA will tend to report more negative affect across time and regardless of the circumstances. That is not to assert that high - NA individuals report a consistently high level of negativity.

Rather, such individuals are, in any given situation, more likely to experience a significant level of distress.

Researchers of NA emphasize the conscious, subjective experience rather than the objective condition, that is, it centers on how people feel about themselves and their environment rather than how constructively they may actually manage stressful situations. In addition high - NA individuals interpret ambiguous stimuli more negatively (Goldstein, 1954). This may have significant implications for caregivers of Alzheimer's patients given the course of the disease.

Watson and Clark (1984) examined a number of apparently distinct personality scales to survey the scales' relationship to NA. The tests possessed an assortment of labels and interpretations but their most outstanding characteristic was the extremely high level of relation found among all the tests to NA, despite the diversity of names. The correlations were high enough to cause the researchers to appraise the tests as "Reasonable alternative measures of the NA construct" (Watson & Clark, 1984).

The authors make a special note of the precise association between the Minnesota Multiphasic Personality Inventory and NA. They submit "from the number of Minnesota Multiphasic Personality Inventory tests significantly correlated, it is clear that the MMPI is saturated with NA" (Watson & Clark, 1984). The above literature has important

implications for this study's measure of NA, namely, the Brief Symptom Inventory.

As Campbell and Fiske (1959) illustrated, convergent and discriminant relationships between operational measures are essential to authenticating the empirical framework that fashions the core of construct validation. In plain terms the concept requires that scores from a test designed to measure a definite construct should correlate highly with other measures of that construct, and show relatively low correlations with measures of dissimilar constructs. Such a pattern of relationships should hold if the test is to be considered a valid reflection of the construct of interest.

A study showing impressive convergent validity for the BSI and the MMPI was undertaken by Derogatis (1983),involving the analysis of an study comparing the SCL-90 with the MMPI (Derogatis, Rickels and Rock, 1983) on a sample of 209 subjects. Since the subscales of the BSI are contained within the longer form SCL-90, the data was reanalyzed scoring for the BSI instead of the SCL-90. The correlations for the BSI subscales of Hostility and Anxiety ranged from moderate to high for their corresponding MMPI clinical, Wiggins, and Tryon scores (Derogatis, 1983).

The general findings of high convergence for the dimensions of the BSI subscales of Hostility and Anxiety represents an important confirmation of the fact that subscales retain convergent patterns of relationship with

their counterparts on the MMPI. This relationship is particularly meaningful given the validating research of Watson and Clark (1984) of the MMPI as a measure of NA.

Watson and Clark (1988) present further information regarding the development of scales to measure PA and NA. The Positive and Negative Affect Schedules (PANAS) scales correlate at high levels with measures of related constructs and show the same pattern of relations with external variables that have been seen in previous studies of NA.

Of singular interest to the present study is the reported correlation between the PANAS and the Hopkins Symptom Checklist (HSCL; Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974). The HSCL is a measure of general distress and dysfunction. The HSCL and a subsequent 90-item version, the SCL-90 (Derogatis, Rickels, & Roch, 1976) have been used frequently as measures of clinical symptomatology in both normal and clinical populations (Gottlieb, 1981). Although the HSCL and the SCL-90 each contain several subscales, analyses have repeatedly shown that both instruments reflect the same general distress factor (Dinning & Evens, 1977; Gottlieb, 1981).

Given that the BSI "is essentially the brief form of the SCL-90, measuring the same symptom dimensions", evaluation of the correlations between the PANAS and the HSCL has a direct association with the BSI Hostility subscale and BSI Anxiety

subscale given the interrelated nature of the HSCL, SCL-90 and BSI.

Watson and Clark (1988) report the correlation between the PANAS NA scale and the HSCL to be .74 indicating that the HSCL "is largely a measure of NA." In fact, the authors suggest that the correlations between the HSCL and the PANAS NA scale are high enough to suggest that "the two measures are roughly interchangeable" (Watson & Clark, 1988).

Insofar as the SCL-90 is a subsequent 90-item version of the HSCL and the BSI is essentially a brief form of the SCL-90, it seems reasonable to extend these results to the BSI as an adequate measure of NA.

In summary, recent literature suggests a potential link between the subjective report of burden and the negative affective structure of caregivers. Given the increasingly intensive interactions that exist between patients and adult caregivers over the course of dementia of the Alzheimer's type (DAT), it would appear that data on emotional and personal dynamics may offer valuable sources of information for developing predictive models and designing intervention strategies (Vitaliano, Maiuro, Ochs, & Russo, 1989; Gallagher, Wrabetz, Lovett, Del Maestro, & Rose, S. 1989).

Social Support

Social support networks are widely considered to be an important predictor of stress behavior and illness. Further, the usefulness of social support as a construct among chronically ill and disabled older adults has been emphasized (Antonucci, 1986, Cohen et al., 1985). Caplan (1974) describes social support as formal and informal relationships through which an individual receives emotional, cognitive and material support needed in managing difficult experiences. It has been proposed that an important goal in assessing the "role" behavior of caregivers of such patients is to gain perspective on the person's resources to cope with the chronic illness and functional disability within the elderly recipient.

The possible protective effect of social support in the face of illness is what has been termed the buffering hypothesis. The hypothesis states that stress and illness will have deleterious effects on the health and well-being of those with little or no social support, while these effects will be lessened or eliminated for those with stronger social support systems (Cohen & Mckay, 1984). The buffer hypothesis is based on a multidimensional view of social support and focuses on the functional relationship between the coping requirements of a situation and the resources provided by the elderly's support system, and thus lends itself quite robustly to the realm of caregiver burden.

Thoits (1982) has observed that if a high level of social support is maintained throughout a crisis period, then impact is less damaging to the physical and psychological states than otherwise would be. Holahan and Moos (1982) report that the quality of social support from family members and co-workers influences psychosomatic symptoms during life crises. Cohen and Willis (1985) found that even the perception that social support is available may mediate one's perception of a burdensome event.

The multi-faceted functional importance of social support for individuals was most vividly exemplified by the symptoms suffered by those who lack adequate social support. Empirical research on the relation between stress, social support, and physical and mental health has provided only mixed evidence for the buffering hypothesis (Broadhead et al., 1983; Cohen & McKay, 1984; Thoits, 1982). Although some studies have found that high levels of social support protect the person from the negative effects of stress, other studies have found that supportive relationships with others are associated with good physical and mental health regardless of the presence or absence of stress.

The degree of social support obtainable from the elderly's social support network could be a significant factor in the caregiver's ability to attend to the ill elderly person. (Caplan, 1979; Farquhar, 1978; Haynes, 1979). Greater impairment in the Alzheimer's disease victim has been

significantly correlated with fewer social contacts and greater depression and loneliness. If caregivers experience increased social isolation as their relative's condition deteriorates, it could have important consequences upon caregiver burden. Research with both older and younger adults suggests that social support may moderate stress-related depression or dysphoria, and may also be related to morbidity and mortality (Blazer,1982; Cohen et al., 1985).

Thomas, Goodwin and Goodwin (1985) found low but statistically significant correlations between "satisfying confidant relationships" and two immunological indices, total lymphocyte count and mitogen responsiveness, among a sample of 106 women between 61 to 89 years of age, after controlling for psychological distress and other variables. The correlations were not significant for the 91 men in the sample, suggesting again the greater hazard for the majority of caregivers who are female. If, however, distress and support are causally treated, these limited data may underestimate the magnitude of the effects (Thomas, 1985).

Pilisuk and Minkler (1980) report that the loss or absence of social support from a familiar network has been found to lead to coronary disease, medical disorders in pregnancy, accidents, suicides, mental disorders, school truancy, ulcers, and slowed recovery from certain types of cancer. Concerning caregivers, health and mental well-being are the main aspects of their lives which have been found to

be positively affected by social support (Kaplin, 1977, Henderson, 1979, Berkman and Syme 1979).

The impact of social support on physical health has been evident in the problems which emerge when adequate social support is lacking. Such problems include the increased susceptibility of individuals to various forms of disease (Kaplan, 1977, Henaderson, 1989) as well as a greater mortality rate (Berkman and Syme, 1979). Hibbard (1985) and Berkman and Syme (1979) report that social support among community members is a factor for better physical health among all age groups. Specifically, Hibbard found that frequency of contacts based on reported trust was positively associated with both objective and self-reported health status. Berkman and Syme noted that social support from friends and relatives and, to a lesser extent, support from the community were related to mortality rates.

This impact of social support on physical health, when combined with the close relation between physical and mental health, suggests a possible "indirect effect" of social support on mental well-being. According to this hypothesis, the role of social support for physical health ultimately leads to better mental health through the well-verified impact of physical health on the mental state of the caregiver. For example, Bultena and Oyler (1971), Palmore and Luikart (1972) and Ward (1984) report that poor health (both subjective and objective) causes low levels of mental well-being. Also,

those elderly who have poor health showed lower morale than those with better health (Maddox, 1964). Arling (1987) reports that aged people who have physical impairments tend to show more distress.

Other studies have shown how social support can enhance the mental well-being of a variety of age groups (Holahan and Moos, 1982; Cohen, Terisi and Holmes, 1986). In particular, the impact of social support on the mental well-being of the elderly caregiver spouse is emphasized, since the elderly caregivers are more likely to lose their social network than younger groups. It has been observed that peer group friendships, based on voluntary mutual choice, provides high satisfaction to elderly peoples' lives (Wood and Robertson, 1978; Chappell, 1984).

On the other hand, Cohen and his associates (1986) documented that a decrease in social relationships can increase stress (burden). The studies share a main theme that emotional and material support generated from social relationships, whether among the caregivers themselves or with other social groups, enhances the mental well-being of the elderly.

Behavioral supports in the forms of emotional support and acceptance from family and friends and physical assistance (tangible resources) (Caplin, 1979) contribute significantly to the caregiver's ability to care for the impaired elderly. The concept of social support is important in psychology and

behavioral medicine for two reasons. First, social support appears to moderate the effects of life stress on physical health, mental health and well-being (Berkman, 1985; Cohen & Wills, 1985; Kessler & McLeod,1985). Second, interventions for burdened individuals that include social support seem to hold promise for alleviating distress and facilitating adjustment (Gottlieb,1983).

The research reported clearly relates social support to physical and mental health, but the precise form of the relationship cannot yet be defined. In some studies social support acts only as a moderator variable, counteracting the negative effects of adverse life changes. In other studies, social support acts independently as a positive factor in health status. Holahan and Holahan (1987) report results that indicate that the level of social support in subjects was inversely related to depression. Although further empirical support is needed to verify the precise role of social support under varying conditions, the provision of social support appears to be a promising intervention for reducing perceived burden among caregivers by moderating the stress of caring for an aging relative. (DiMatteo & Hays, 1981).

Zarit and Zarit (1982,1983) describe an integrated model of information giving and emotional support. Their "individual and family counseling" approach utilizes six sessions of individual therapy and a separate weekly family meeting. At the latter, ideas are generated as to how the

family can provide more support for the primary caregiver, and arrangements are made to implement the ideas. Participants in the program have been compared to caregivers participating in a six-session traditional support group. Zarit (1983) reports that both interventions were associated with reduction of caregiver burden and emotional distress in a sample of about 50 caregivers.

Recent studies of caregiver burden and well-being have shown that caregivers have substantial needs and that social support is important to their well-being. Evidence suggests that caring for an elderly demented adult is an arduous task that may lead to financial difficulties, emotional strain, or physical and mental health problems (Brody, 1981; Cantor, 1983; George and Gwyther, 1986; Zarit et al., 1980, 1985, 1986), but that these burdens are less severe for those having a strong support network (Zarit, Reever, and Bach-Peterson, 1980) or the perception of one (George and Gwyther, 1986; George, 1987). Studies also suggest that as the Alzheimer's disease progresses, an important factor for the caregiver's well-being is a supportive other (Cantor, 1983; Hanson, Sauer, and Seelbach, 1983). The data indicates that lack of a close supportive relationship is a factor that increases vulnerability to burden in the face of caregiving (Zarit et al., 1986).

Benefits from social support occur because network arrangements assist in meeting physical, social, emotional,

and psychological needs (Pilisuk and Parks, 1981). Caregivers are provided with feelings of personal affection and opportunities to interact with meaning to others in times of crisis. Simply the presence of another is comforting under adverse conditions (Henderson, Byne, and Duncan-Jones, 1981). Taken together, the studies that have been reviewed suggest that social support may generally serve to promote the universal well-being of the caregiver.

Can the assumption be made, however that all forms of social support have a positive impact upon caregivers of Alzheimer's disease patients? In a recent study by Krause (1987) only emotional support and integration were found to influence caregiver's feelings of control, suggesting that it is important to examine specific types or dimensions of support. This finding is consistent with the work of House (1981), who observed that emotional support is the core element of supportive social relations.

Self-Efficacy

Bandura's theory of self-efficacy postulates that people's perceptions of their capabilities affect how they behave, their level of motivation, their thought patterns, and their emotional reactions in taxing situations. Thus, the theory provides one common mechanism through which people exercise influence over their own motivation and behavior. Self-efficacy also affects the amount of effort devoted to a

task, and the length of persistence when difficulties are encountered. Caregiving for highly impaired elderly might thus be more consistent and long-lasting in those caregivers whose beliefs in their abilities to attend to Alzheimer's disease sufferers are strong (Henry & Sevens, 1977).

Perceived self-efficacy refers to peoples' judgments of their capabilities to execute given levels of performance and outcome expectations and judgments of the likely consequences such behavior will provide. Self-efficacy is measured in terms of three parameters: level, strength, and generality. Level of self-efficacy refers to the person's expected level of performance attainments. Self-efficacy strength expresses the confidence people have that they can attain each expected level. Generality refers to the number of domains of functioning in which people judge themselves to be efficacious. Thus, high self-efficacy leads to greater attainment and further enhanced performance. The importance of raising the spouse's (caregiver's) perceptions of the patient's capabilities following trauma was demonstrated in a study by Bandura (1986). These investigators hypothesized that rehabilitation efforts can be either enhanced or reduced by effects of the spouse's beliefs in the patient's efficacy. A spouse can play a significant role in a patient's recovery either by encouraging physical activity or by communicating worry or concern about the patient's efforts. It seems

reasonable to extend this finding to caregivers of the demented elderly.

An important determinant of caregiving may be the individual's percepts of self-efficacy to carry out the prescribed procedures and thus affect their own caregiving ability. This was demonstrated by Kaplan (1984) who found that perceived self-efficacy to conduct a program of exercise was a better predictor of actual behavior change than was a general health locus of control measure. Other studies report that feelings of self-efficacy were related inversely to depression (Holahan & Holahan, 1987).

The results also report a path analysis relating to self-efficacy and both social support and depression, suggesting a doubly important role for self-efficacy in helping to maintain healthy functioning. Thus, not only does self-efficacy have a direct inverse relation to depression, it also functions indirectly through its influence on social support in fostering positive functioning (Holahan & Holahan, 1987).

With this conceptualization, initial feelings of self-efficacy are central to initiating and maintaining behavior that enables the individual to obtain a sufficient level of social support (Holahan & Holahan, 1987). Additional research has involved an examination of whether self-efficacy adds significantly to activities of daily living (ADL) as a predictor of competence among the oldest old (those over 85). The research reports that self-efficacy contributed to the

prediction of competence in activities of daily living beyond the effects of health. Further, self-efficacy predicted psychosocial competence independently (Abler and Fretz, 1986).

Both of the above findings are consistent with and extend into the social support area Bandura and his associates (Bandura, 1982) conceptualized of self-efficacy as linked to the initiation and maintenance of coping behaviors. Another finding that may have important implications for the study is a commonly held belief that severity of the impairment is the most important factor in caregiving. Such perceptions may also have a debilitating effect on percepts of self-efficacy to control the caregiving process. While high impairment did increase subject's burden level, self-efficacy to perform the caregiving regimen was still a strong predictor of care to the elderly. In fact several investigations have found, that the major discriminator between institutionalized elderly and non-institutionalized elderly was the perception by the family members of their ability to provide care. The research conclusion is that interventions need to be applied in ways that instill and strengthen caregiver's beliefs both in the interventions' effectiveness and in the caregiver's own abilities to effect positive changes in their caregiving routine.

Intervention strategies used with caregivers, such as those developed by Gallagher (1989), are based on the premise that the self-efficacy of caregivers can be enhanced.

Research indicates that the most effective way to enhance efficacy expectations is through experience based inductions that demonstrate to individuals that they possess relevant competencies. Subjects in the Gallagher et al. study were taught a set of specific skills designed to enhance coping and were encouraged to practice these skills in the home setting. They were then provided with performance feedback and encouraged to adjust their behaviors accordingly. Preliminary results suggest that both efficacy expectations and coping ability are enhanced by this intervention and a variety of others (Davis, 1983; Gwyther and Blazer, 1984; Selanand Schuenke 1982).

To help strengthen patient's self-efficacy Bandura (1982) has identified four sources of efficacy information:

1. Enactive; information provided by performance accomplishments is the most reliable and effective source, it provides direct demonstration of the current level of skill.

2. Vicarious; information obtained by observing the effects achieved by others conveys information about task demands and chances of achieving success.

3. Communications; concerning one's capabilities from others. This is the form most often used by health practitioners. The effect of this mode of efficacy induction depends on the degree to which people believe what they are told.

4. In the fourth source people rely on information from their physiological state.

Because performance mastery is an effective way of influencing self-efficacy, quality caregiving should be best achieved by producing feedback of caregiver's capabilities. Caregivers who are fully convinced both of the effects of an intervention and their abilities to carry out the caregiving regimen will be more likely to practice the regimens more carefully.

Implications of these findings are substantial to the study, given Bandura's (1982) suggestion that low perceived self-efficacy may be detrimental to effective coping. He stated "when beset with difficulties people who entertain serious doubts about their capabilities slacken their efforts or give up altogether, whereas those who have a strong sense of self-efficacy exert greater efforts to master the challenges." (Bandura,1982).

Generalizing from this statement to caregivers, it seems that those individuals more at risk in a caregiving

relationship are also more likely to perceive themselves as less competent or capable than others and thus may be more likely to "give up" in terms of their health as well as in general day to day living situations with the impaired elderly.

Michael, Rosenbaum, and Smira (1986) found that underlying process-regulation cognitions are relatively stable competencies such as learned resourcefulness. Persons may possess the necessary skills to cope with certain situational demands, but would not apply these skills unless they think that (a) the situation calls for it, (b) they have these skills, (c) these skills were helpful in similar situations in the past, and (d) they expect to be efficacious in applying these skills. Put in more specific terms, self-evaluation of past caregiving performance and efficacy expectations influences future caregiving performance, which in turn have an impact on subjects' self-evaluations and expectancies for the future.

Clinical observation of caregivers suggests that one of the most frustrating aspects of caregiving is the discovery that behaviors that were effective in the past no longer produce the outcomes desired.

"Changing efficacy-based futility requires development of competencies and expectations of personal effectiveness. By contrast, to change outcome-based futility necessitates changes in prevailing environmental

contingencies that restore the instrumental value of the competencies that people already possess." (Bandura, 1977, p.205).

Given the complexity of the demands placed on caregivers and the fact that the demands change significantly over time, it may well be that caregivers are in a constant state of reevaluating efficacy expectations in regard to themselves as well as to the Alzheimer's disease patient.

Cognitive Impairment

Cognitive variables in the elderly population may also play a significant role in regard to perceived caregiver burden. Cognitive impairment results in setting barriers that may impose upon the elderly's ability to adhere to caregiver's recommendations despite levels of social support. Despite important research efforts, the role of cognitive factors in caregiver burden remains controversial.

The study of burden and cognitive impairment is made more difficult by the often unpredictable progression of Alzheimer's disease. Johnson (1983) reported that some patients showed increased impairment across the two years of the study, while others showed little symptom change. The uncertainty and changes in caregiving demands over time as factors relating to cognitive change in the Alzheimer's patient have received little discussion.

The use of cognitive variables proposes that elderly have an understanding and are able to remember relationships with the caregiver that can impact upon burden either directly and/or indirectly through effects upon the caregiver's social support perceptions. The use of cognitive impairment as a variable obviously requires that there is evidence that (1) the patient has some impairment in understanding, and/or (2) the patient has some impairment in memory. Thus, cognitive impairment within the elderly care recipient could account for barriers to adequate use of social support and have some negative impact upon caregiver burden.

Somewhat surprisingly, research on the relationship between the elderly's cognitive impairment and caregiver burden has been sparse and often contradicting. Poulshock and Deimling (1984) report that cognitive incapacity demonstrated the strongest associations with corresponding caregiver burden ($r=.44$). The authors suggest that the elderly's cognitive incapacity (forgetfulness, confusion and behavior harmful to self) translates quite directly into perceptions of burden. The researchers submit that the moderate to strong correlation is due to the pervasiveness of tasks required to care for a disoriented elder. While it may be possible to ignore or avoid an elder who is withdrawn or isolated, the confused or incontinent elder requires constant surveillance or attention. Other research contradicts this relationship.

As mentioned, Zarit and Reever (1980) found burden not to be linearly correlated with dementia. Their research suggests while some relationship may exist between these two variables, it appears that increases in dementia are not automatically associated with increases in burden.

In summary, this study proposes to examine the behavioral aspects of 1) perceived social support of caregivers, 2) cognitive status of the elderly patient 3) perceived caregiver burden 4) the role of self-efficacy in caregiving and 5) caregiver negative affect. Past major studies on caregiver burden are outlined below. (see Table 2.1)

Table 2.1
Summary of Major Caregiver Studies

Study	N	Variables	Relation to Patient	Mean Age	Results
Zarit, et al, 1980	29	Cognitive Status, ADL's	Spouses 18 Daughters 11	65	No relation Cognitive Staus/Burden
Poulshock Deimling 1984	614	Cognitive Status Demograph.	Spouse 50% Daughters 41% Others 8%	67	Strong Relation Cognition/ Burden
Deimling & Bass 1986	586	Health and Depression in Family	Spouses and Adult Children	57	Lower Health Higher Depression
George & Gwyther 1986	510	Severity of Illness Neg Affect	Spouses and Adult Children	57	Neg. Affect Associated Burden
Fitting, et al., 1986	54	Gender Severity of Illness	Spouse	67	Females More Reported Burden
Zarit & Zarit, 1986	64	Perception of Family Relations	Spouse	68	Family Support Less Burden
Pratt, Wright & Schmall, 1987	240	Extended Family Support	Spouses 139 Children 101	61.3	Family Support Less Burden
Haley, et al., 1987	84	Health of Caregiver Depression	Daughters 22 Sons 3 Wives 8 Husbands 7	65	Lower Health Ratings Increase Depression Ratings
Cohen, 1984	46	Social Support	Spouse 28 Children 18	62	Social Supp Decrease in Burden
Quayhagen 1988	58	Social and Emotinal Support	Wives 26 Husband 17 Daughters 15	66 69 54	Family Emotional Support/Less Burden
Pruchno & Potashnik 1989	315	Depression Demograph.	Spouse	70	Greater Depression Females

Table 2.1 (cont'd.).
Summary of Major Studies

Study	N	Variables	Relation	Age	Results
Robinson 1983	56	Strain	Family Caregiver	68	Caregiver Strain Index
Gilhooly 1984	100	Mental Health Soc. Supp.	Spouse Adult Children	65	Good Soc. Supp = No increase in Mental Impairment
Vitaliano et al, 1989	67	Anger	Family Caregiver	71	Anger Related to Burden
Gallagher 1990	78	Negative Affect	Spouse	72	Neg. Affect Related to Burden

CHAPTER III

METHODS

Subjects

Ninety two elderly patients and their primary caregivers participated in the study. The patients ranged in age from 50 to 91 years, with a mean of 73.4 and a standard deviation of 9.1. Approximately 97% of the cases were white, 55% were women, and 45% were men. The primary caregivers ranged in age from 25 to 84 with a mean age of 58.5 and a standard deviation of 13.7. Sixty eight percent of the primary caregivers were women, 32% were male.

The subjects both patients and caregivers were generally well educated, with the patients averaging a high school education and the caregivers having on the average at least some college education. The range of educational background for the patients ranged from 4 years to doctoral studies, and for the caregivers from high school to doctoral studies.

The patients in the study also showed a high degree of independence. Twenty six percent of the elderly patients lived alone, 58% lived with a spouse, eight percent lived with other family members and 7 percent lived with non-family members. Housing arrangements also suggest a relatively autonomous sample of elderly: 71% lived in single family home, 18% lived in an apartment, and 11% lived in some type of assisted living arrangement (i.e., nursing home, AFC, senior

apartments). All subjects were University of Michigan Hospital patients and were accompanied by a primary family caregiver.

Intake into the study took place during the geriatric assessment process. Upon arrival at the clinic, the elderly patient was given a neuropsychological screen to determine cognitive impairment status. This information was later shared with the primary investigator. Intake of caregivers into the study worked with an exclusion basis, in that only primary family caregiver spouses/adult children were to be caregivers of interest.

This proved not to pose a problem to data collection because the Turner clinic assessment process also relies on a primary caregiver, the vast majority (90%) of these caregivers being spouses/adult children. Thus the study was able to exclude paid caregivers or friends of the geriatric patient and rely on the above mentioned family members only, so as to assure the reliability of the data collected.

During the geriatric assessment process the family caregiver was informed about the nature of the study, its purpose, the nature of the interview, and assurance of strict confidentiality. Those who agreed to participate were asked to sign a consent form. During the patient's examination the primary caregiver was asked to complete a social support questionnaire, caregiver burden inventory, perceived self-efficacy scales and items from the Brief Symptom Inventory

administered by a trained research assistant. The research assistant was instructed to check all sections of the instruments to ensure completeness.

Research Assistants

Five psychological testing technicians (two male, three female) employed at the University of Michigan Hospital, along with the principal investigator gathered data from the primary family caregivers. These five technicians did not know the hypotheses of the research study. They were trained to administer the questionnaire during a group meeting with the primary investigator.

Description of the Model

Few studies have examined caregiver burden using a theoretical model of burden to guide the research. One burden model (Vitaliano et al., 1987) argues that:

$$\text{Burden} = \frac{\text{Exposure to Stressors} + \text{Vulnerability}}{\text{Psychological Resources} + \text{Social Resources}}$$

When applied to this study of caregiver burden, "exposure to stressors" is operationalized in terms of the Alzheimer's patient's cognitive impairment. "Vulnerability" is defined as the caregiver's disposition for negative affect and more global demographic characteristics. "Psychological resources" take into account the caregiver's individual attitudes and

expectations, in this case, measured by caregiver's self-report of caregiving and patient efficacy. Lastly, "social resources" is defined as the caregiver's social support within the caregiving situation. In this model, individuals may improve their emotional state either by decreasing undesirable factors (numerator) or increasing desirable factors (denominator) to strengthen themselves (Vitaliano et al., 1987). Table 3.1 presents the variables, constructs and measures that will make up the model presented in this study.

Such a model has two major advantages in caregiver research. First, the variables represented are well grounded in the theoretical stress literature (Appley and Trumbull, 1967; Hinkle, 1974; Kahn, 1970; McGrath, 1970). The emphasis on vulnerability and resources is supported by extensive research that has examined the importance of these variables in modifying or confounding relationships between stressful events and distress. Second, the model requires that, in examining caregiver burden, the researcher gives operational definitions of caregiver vulnerability and resources (Miettinen,1974).

Table 3.1
Constructs, Variables and Measures used to Operationalize
Proposed Burden Model

Constructs	Variable	Measure
Burden Caregiver Strain	Disruptive Behavior Lifestyle Changes	Caregiver Strain Index
Stressors Having DAT Spouse/ Parent with Cognitive Impairment	Memory, Orientation, Attention	MMSE
Vulnerability Demographics Negative Affect	Sex, Age, Education Hostility/Anxiety	Control Sheet BSI Subscales
Social Resources Social Support	Guidance, Nurtance, Worth, Attachment, Alliance and Social Intergration	SPS Subscales
Psychological Resources Caregivers Efficacy Perception of Patient's Efficacy	Efficacy in Caregiving Task Patient Efficacy	CSE CPPE

It should be stressed that the data collection process did not involve the geriatric patient. The only variable of interest concerning the elderly patient was the patient's cognitive status. The Mini-Mental State Exam is a standard measure designed to measure cognitive functioning. This measure is standard within the Turner clinic assessment battery and was administered by the above mentioned psychological test technicians and the results were shared with the primary researcher. Thus, the measure itself involved no added time, risk or discomfort to the elderly patient. The patient was informed about the need for this measure and asked to give consent for its release to the primary researcher. Because a range of cognitive impairment was seen, at times the family caregiver was asked to give consent for patients with questionable mental competence. It should be noted that it is standard procedure within the Turner clinic for the family caregiver to give proxy consent for dementing patients.

Methods for determining questionable mental status were based on family caregiver's reports, staff interaction with the patient and patient history. The results shared with the principal investigator had no identifying labels with the exception of the patient's ID number which were necessary to match with the family caregiver data.

Procedure

1. <u>Objectives</u>

The objectives of the study are to describe the 1) components of burden among caregivers seen in an ambulatory geriatric assessment unit, 2) analyze the effects on caregiver burden by a) social support, b) cognitive impairment, c) caregiver perceptions of role-related self-efficacy, and d) caregiver's affective state.

2. <u>Study Site and Description of the Assessment Process</u>

The site for the study was the Turner Clinic located at Ann Arbor, Michigan. The clinic operates two half-days per week and services are reimbursed by a combination of third-party payers and out-of-pocket fees charged to the patient. The clinic operates as an assessment, referral, and follow-up unit. Primary care, home care, and emergency services are not provided. The clinic sees patients 65 years of age and older who are functionally limited and have multiple medical problems. A multi-disciplinary team assesses the patient and makes recommendations according to the following process:

a)   Referrals are screened for eligibility
via an intake phone call by the
administrative assistant. When patients are
not eligible for services they are referred
to appropriate community resources. When the
patient is admitted, the following process is
initiated.

b)   Each patient is assigned to a clinical nurse
specialist who coordinates the patient's care while
the individual is in the assessment process.

c)   Within 48 hours of intake the patient's
primary physician is notified of his/her referral
to the clinic and informed regarding the process.

d)   Each patient receives a comprehensive
assessment by a team consisting of a clinical nurse
specialist,   social   worker,   geriatrician,
occupational therapist, and psychologist.

e)   Other backup resources are available and
consulted   as   appropriate   (e.g.   pharmacist,
dietician).

f)   A core data base is completed on each patient and includes information in the following domains: 1) sociodemographics, 2) physical and cognitive assessment (medical history, physical exam, diagnostic studies), 3) basic and instrumental activities of daily living, 4) mobility, 5) mental assessment (cognition and affect), 6) social assessment (social support, patient/care-giver dynamics, care-giver burden), 7) economic, 8) environment (living arrangements, safety of environment).

g)   A team conference is held at the beginning of each clinic day to review data on patients being seen in that clinic.

h)   A weekly case conference at which the entire assessment team participates is held for the purpose of a final comprehensive evaluation and to formulate recommendations for long-term care for those patients who have completed the assessment process.

i)   A conference with each patient and the family care-giver is held at the clinic and is attended by appropriate team members. Each patient and family

care-giver is provided with written recommendations for the patient's long-term care which are discussed and explained. Referrals to appropriate agencies are initiated by the clinic team as needed.

j)   A written summary of the team's findings and recommendations is sent to the patient's primary care physician within two weeks of the family conference.

Quantitative Measures

1)   Perceived social support was assessed using the Social Provisions Scale (SPS; Russell & Curtrona, 1984, 1985). This scale was developed to assess the six functions of social relationships proposed by Weiss (1974). These functions include the following: (a) attachment, a sense of emotional closeness and security; (b) social integration, a sense of belonging to a group of people who share common interests and recreational activities; (c) reassurance of worth, acknowledgement of one's competence and skill; (d) reliable alliance, assurance that one can count on others for tangible assistance; (e) guidance, advice and information; and (f) opportunity for nurturance, a sense of responsibility for the well-being of another person. The measure asks the respondents to rate the degree to which their relationships

with others are currently supplying each of the above provisions. Each provision is assessed by four items, two that describe the presence and two that describe the absence of the provision. Respondents indicate on a 4-point scale (1= not at all true; 4=completely true) the extent to which each statement describes their current social relationships. Internal consistency for the total scale is relatively high, ranging from .85 to .92 across a variety of populations. Alpha coefficients for the individual subscales range from .64 to .76. Factor analysis has confirmed a six-factor structure that corresponds to the six social provisions suggested by Weiss (Russell & Cutrona, 1984,1985). Several studies support the validity of the SPS. Significant negative correlations between the SPS and distressing emotional states have been found both longitudinally and in cross-sectional studies of diverse populations, including postpartum mothers (Cutrona, 1984), public school teachers (Russell, 1986), nurses (Russell & Cutrona, 1984), and the elderly (Cutrona, Russell, & Rose, 1986). Finally, analyses of data from a college student sample has supported the discriminant validity of the SPS against relevant measures of mood (e.g., depression), personality (e.g., neuroticism, self-esteem), and social desirability (Russell & Cutrona,1985).

2) The measure of cognitive impairment included a test of cognitive functions (Mini-Mental State). The Mini-Mental State (MMSE) was designed to test cognitive functions simply and quickly (Folstein et al., 1975). It has no abstraction items, but includes a diagnostically valuable verbal retention test. Administration takes from five to ten minutes. Both administration and scoring are easily learned and standardized. Sixty-three elderly (mean age=73.9) normal control subjects comprised the standardization population. With a maximum obtainable score of 30, the elderly control subjects and younger subjects with functional psychiatric disorders achieved scores in the 24.6 to 27.6 range. Scores of several groups of senile patients ranged from 9.6 to 12.2. There was no overlap between the aged control subjects and the senile patients. The test has proven useful in registering changes in intellectual functioning. The MMSE is one of several cognitive screening tests described by the Work Group on the Diagnosis of Alzheimer's Disease as appropriate for the use in initial screening for the assessment of dementia associated with Alzheimer's disease (McKhann et al., 1984). Fields and Starratt (1985) noted that the MMSE represented the most frequently cited cognitive screening test with 36 citations. Of these, six were directly related to reliability, validity, and/or utility of the MMSE. Test-retest reliability ranged from .85 to .99. Interrater reliability values ranged from .82 to .95. Several concurrent

validation studies have been reported with structural, psychometric, and behavioral indices of impairment used as criteria. A significant correlation (r=-.35) was found between the MMSE and computerized tomography (CT) scan results; thus, high evidence of organic impairment on the CT scan correlated with low scores on the MMSE. Correlations with WAIS verbal I.Q. range from .40 to .78 and with the WAIS performance I.Q. from .56 to .66. A significant correlation (r=.58) between the MMSE and the Wechsler Memory Scale has also been reported. Concerning functional behavior, correlations between the MMSE and the behavioral portion of the Blessed Dementia Rating Scale have been reported to range from .66 to .75. Reisberg (1982) also noted a strong relationship between the MMSE and the Global Deterioration Scale score which is used to stage the level of functional impairment associated with Alzheimer's type dementia (r=.92). The MMSE represents one of the most extensively researched brief screening measures currently available. It has been used in both clinical and research situations and has the advantage of assessing a broader range of cognitive functions than do many other cognitive screening measures. This screen is standard within the Turner Clinic's assessment battery and the data was shared with the primary investigator for those patient's who agreed to participate in the study.

3)   The measure of care-giver burden used was the Caregiver Strain Index (Robinson, 1983).   This self-report scale has thirteen items, using yes-no response categories. Evidence of construct validity was determined by analyzing the relationship between the scale scores and a number of criterion variables which theoretically reflect strain.   A high internal reliability of index items and expected relationships between overall scores and criterion variables indicates that the scale is useful for research.   In scoring the index, a positive response to seven or more items indicate a greater level of strain.   The Caregiver Strain Index (CSI) is computed by summing the 0 (no) and 1 (yes) responses for the 13 items.   Therefore, the CSI has a score that ranges from 0 to 13.   Cronbach's alpha was calculated to assess internal consistency among items.   The reliability coefficient alpha for the 13 items was .86.   The alphas for the scale were not improved with the deletion of any single item.   Construct validity was examined by analyzing the relationships between CSI scores and a number of criterion variables, which theoretically, would reflect strain.   Therefore, the construct validity of the CSI was examined in three areas: ex-patient characteristics; caregivers' subjective perception of the caretaking relationship; and the physical and emotional health of the caregiver.   Items within these areas were selected from the ex-patient and caregiver interviews for their ability to reflect strain.   Analysis of the CSI found that there were

positive correlations between the caregiver's CSI score and the patient's age, hospitalization, and mental status. CSI scores were correlated negatively with elderly patients' ability to perform activities of daily living and satisfaction with progress during convalescence. On the POMS (Profile of Mood States), there was a significant correlation between CSI scores and patients' anxiety factor and a trend ($p < .10$) toward a correlation between CSI scores and the depression factor. CSI scores were related significantly to caregivers' perceptions that they were very involved in helping the impaired elderly. Caregivers' self-reports of experiencing situations that conflicted with their ability to help impaired elderly also were associated significantly with CSI scores, one tailed $t=6.46$, $p < .001$. CSI scores were found to correlate negatively with both the caregivers' satisfaction with the understanding of their own problems by the impaired elderly and their perceptions of how well the caregiver and impaired elderly got along together. A one tailed t test also indicated a significant relationship between CSI scores and the caregivers not having received assistance with their own problems and feelings $t = 4.02$, $p < .001$. The author concluded that emotional strain on the caregiver is evident in the negative correlations between the CSI scores and morale and the positive correlations with the anxiety, depression, and hostility factors on the POMS (Robinson,1983)

4.) Subscales from the Brief Symptom Inventory (BSI) by Derogatis (1974) were used to assess caregiver's level of negative affect. The BSI is a 53 item self-report symptom inventory designed to reflect the psychological systems of psychiatric, medical, and normal individuals. It is designed to provide a multidimensional symptom measurement in a short time. Both the Anxiety and Hostility were used to assess symptoms that are clinically associated with caregiver negative affect. The anxiety dimension is composed of a set of symptoms and signs that are associated clinically with high levels of manifest anxiety. General signs such as nervousness and tension are included in the definition. Cognitive components involving feelings of apprehension, and some somatic correlates of anxiety are also included as dimensional components. The hostility dimension indicates thoughts, feelings or actions that are characteristics of the negative affect state of anger. The selection of items includes all three modes of manifestation and reflects qualities such as aggression, irritability, rage and resentment (Derogatis, 1975) Although the Anxiety and Hostility scales have only 6 and 5 items respectively, the internal consistency reliabilities (Cronbach's alpha) are very acceptable, .81 for the Anxiety subscale and .78 for the Hostility subscale. The test-retest relabilities are also good, .79 for Anxiety and .81 for Hostility. The BSI also reveals an excellent stability coefficient of .90, giving strong evidence that the

BSI is a consistent measure. Concurrent validity is reported by showing the correlation on the symptom dimensions of the BSI with the Wiggins content scales and the Tryon cluster scores obtained on the MMPI. The reported correlations range from .31 to .57 for both scales with most relevant averages scoring correlations averaging .46. A factor analysis on a 1,002 psychiatric outpatient sample was performed. The results confirmed to a remarkable degree the a priori construction of the symptom dimensions (Derogatis, 1982).

5.) Perceived caregiver self-efficacy relating to caregiver burden was assessed by obtaining the caregiver's judgment of two scales the CSE and CPPE. The CSE asked the caregiver how well he or she could help handle disability within a specific function. The CPPE asked the caregiver how well the elderly patient can handle a specific function. The specific functions are described by the Activities of Daily Living Scale (ADL; Katz, Ford, Moskowitz, Jackson & Jaffe, 1963) and Instrumental Activities of Daily Living (IADL; Lawton & Brody, 1969). The ADL measures patient disability in specific basic skills such as dressing, bathing, and feeding oneself. The IADL measures disability in more complex skills such as managing finances and doing household chores. Additional items reflecting existential concerns will be used to examine global functioning. For items on the perceived self-efficacy scales caregivers were asked by questionnaire to

judge the impaired elderly patient's ability in each specific function (i.e. bathing, feeding.), according to the criteria described by the ADL scales' respective published instructions. In addition, for each ADL and IADL item caregivers were asked to rate their perceived self-efficacy in their ability to manage the problem. Subjects' responses to the ADL and IADL self-efficacy management items were coded: 3 = very confident, 2 = reasonably confident and 1 = not at all confident. Questions of global well-being and function supplemented the scale. This procedure has been adapted from a scale used by Holahan and Holahan (1987).

Primary Family Caregiver as Observer of Patient Efficacy

There are many reasons why researchers might wish to assess the viewpoint of a relative or of significant others in research studies with elderly patients. First, the observations of family members may provide a viewpoint on the patient that differs from, and adds something to, professional observations. Blessed and colleagues (1968), for example, in studying associations between behavior and neuropathology in dementia patients, found that the reports of relatives about behavioral deterioration in the patients related strongly to quantitative measures of brain tissue damage, and accounted for greater variance than did cognitive mental status scores.

A related reason for utilizing relatives' reports is that these assessments offer a means of potentially generalizing the findings across a greater breadth of settings than would otherwise be feasible. In other words, family members may constitute an additional "set of eyes" (Niederehe,1988) for the research team and, at least in outpatient studies, may serve as observers of the patients' behavior in natural settings to which the research team would not have access. Schwartz and Loew (1983) suggest that family assessments can uniquely address such aspects of elderly patients' behavior as social, occupational and role functioning, activities of daily living, and sleep, since raters of these aspects must be familiar with the patient's behavior in everyday situations. Not to be neglected as an advantage, the use of data collection measures from family informants may also serve the indirect benefit of strengthening the family's sense of collaboration with the research team, very possibly contributing to better research compliance and enhancing the accuracy of the research information obtained (Fruge and Niederehe, 1985).

A host of methodological issues surround the collection of data on elderly subjects from family informants. There are multiple questions about the inherent sensitivity of untrained family members as observers of human behavior. It has generally been thought that a personal involvement or relationship with the patient might limit one's objectivity,

leading particularly to under-reporting of socially undesirable information about the patient.

Alternatively, it has been said that family members because of stereotyped perceptions of their relatives, may often fail to notice subtle changes in behavior that could be picked up by trained observers. In one empirical study, the estimates of collateral sources about the performance of both healthy and demented aged subjects in such areas as memory, judgement, and problem solving were found to be poor predictors of the elders' actual performance (Edwards & Danziger 1982). Prediction was better when the collateral source was a spouse, rather than nonspouse.

In a study of social adjustment in a non-elderly group of depressed outpatients, however, the reports of relatives generally corresponded well with information obtained from patients themselves and a rater who interviewed them (Weissman & Bothwell 1976). Ratings by the family informants regarding the patients' overall social adjustment correlated .74 with patients' self-ratings and .64 with interviewer ratings. Mean ratings did not differ significantly by the source. Intraclass correlations and comparisons of means also indicated high levels of agreement between patients and family members for various subcategories of adjustment, both at the time of interview and 4 weeks later. These studies suggest that relatives' assessments of patient functioning are sufficiently reliable and accurate for a given project.

Pilot Study: Caregiver and Patient Efficacy Scales Reliability and Validity

Pilot data on 12 elderly patients and their primary family caregivers was collected to examine both the reliability and validity of the patient efficacy and caregiver efficacy scales. Cronbach's alpha for the 12 primary caregivers who completed the 15 items of the perceived caregiver efficacy scale was .83, indicating high internal consistency for the entire scale as a global measure of perceived efficacy in the caregiver role. The perceived patient efficacy scale, completed by the 12 primary family caregivers also achieved very high internal consistency for all 15 items, reflected by a Cronbach's alpha of .93. Thus, the scale showed consistency as a measure of caregiver perceptions of the patients' ability to care for themselves. Concurrent validity was also suggested by the pilot data. Among the two scales the patient efficacy scale correlated significantly (r=.44, p>.001) with the MMSE scale, the scale most descriptive of patients' cognitive behavior, while the caregiver efficacy scale failed to reach any level of significant correlation (r=.02) with the MMSE. Meanwhile, as predicted by a number of researchers (Niederehe & Scott, 1988) caregiver's perceptions of both his/her own and of the patient's efficacy, as measured by the two scales, proved to be consistently negatively correlated with measures of caregiver distress and dysfunction.

Research Questions

1. Will greater levels of social support (SPS) be significantly associated with less caregiver burden (CSI)?

2. Are six SPS subscales of social support differentially associated with caregiver burden?

3. Does cognitive impairment in Alzheimer's patients (as measured by the MMSE) vary linearly with caregiver burden?

4. Does self-efficacy in the caregiving role have a negative relation to caregiver burden?

5. Does the caregiver's perception of the patient's self-efficacy relate negatively to caregiver burden?

6. What is the relation of demographic variables and the caregiver's negative affect to caregiver burden?

Design

The design for the proposed study is a correlational one-group study. Testing the predictive power of three psychosocial variables, along with other global caregiver, patient, and setting characteristics in predicting caregiver reported levels of burden.

Data Analysis

Data analysis will draw on quantitative data describing the factors contributing to caregiver burden.

a.   Quantitative data will first calculate basic descriptive statistics regarding the internal consistencies, intercorrelations, means, and standard deviations of the sociodemographic, social support, cognitive impairment, negative affect, perceived self-efficacy, perception of patient's self-efficacy and caregiver burden measures.

b.   Additional Analysis

Multiple regression analysis will be used to construct a model as follows: Multiple regression analysis will be used to predict the dependent variable caregiver burden (as demonstrated in the Caregiver Strain Index). The independent variables are the caregiver's social support, measure of negative affect, caregiver's perceived self-efficacy, perceptions of patient's self-efficacy and patient's cognitive impairment. The reasons for conducting multiple regression analyses are as follows: (1) major independent variables (social support, caregiver's perceived self-efficacy, perception of caregiver self-efficacy, negative affect and cognitive impairment of the patient), and most of the control

variables (age, education, sex.) are quantitative and interval variables, sex and marital status will be transformed into dummy variables. (2) estimating the effects of the major independent variables on caregiver burden, while controlling for extraneous variables, will require multi-regression analytical technique. The size of the regression coefficient will assess the relative contributions of the independent variables to the dependent variable. Control variables (age, sex, education.) will also be used as blocks. The Statistical Package for the Social Sciences (SPSS-PC) was used for all data analyses. The p < .05 level of significance was used in all analyses.

Specific Aims

This prospective study examines caregivers of older adults who are in need of long term care. The study participants are: 1) males and females suffering from Alzheimer's disease living at home and 2) their family caregiver. The subjects were referred from a treatment team located in the Turner Clinic. Elderly patients are either self or family referrals, or are referred by community physicians and social service agencies to the Turner Clinic.

Study variables are: 1) perceptions of social support, 2) severity of cognitive disability, 3) caregiver burden, 4) perceived self-efficacy of caregivers, and 5) caregiver's

negative affect states. The study will use locally constructed measures of related variables based on current theory and recent empirical research.

Chapter IV

Results

This chapter presents the results of the data analyses conducted to examine the research questions posed for this study. Results are displayed in four principal sections:

a.) descriptive information about the sample;

b.) full reliability data on the Caregiver Self-Efficacy Scale (CSE) and Caregiver Perception of Patient Efficacy (CPPE);

c.) intercorrelations among the various scales and;

d.) the regression analysis predicting the dependent variable caregiver burden.

Description of the Sample

Ninety two elderly patients and their primary family caregivers participated in the study. (See Tables 4.1 and 4.2) The patients ranged in age from 50 to 91 years, with a mean of 73.4 and a standard deviation of 9.1. Approximately 97% of the cases were white, 55% were women, and 45% were men. The primary family caregivers ranged in age from 25 to 84 with a mean age of 58.5 and a standard deviation of 13.7. Sixty eight percent of the caregivers were women, 32% were male. Ninety seven percent of the subjects were Caucasian, three

percent were African American and one percent of the subjects were of Asian decent. Caregivers and patients lived close to one another for the most part, with 77% being less than ten miles apart, 14% ten to twenty five miles apart, and nine percent living twenty five or more miles away from one another.

The subjects, both patients and caregivers, were generally well educated. Patients averaged 12 years of education and the caregivers had on the average at least some college education. The educational backgrounds of the patients ranged from 4 to 20 years, while the caregivers had from 10 years to 21 years of formal education.

The patients in the study also showed a high degree of independence. Twenty six percent of the elderly patients lived alone, 58% with a spouse, 8 percent with other family members and 7 percent with non-family members. Housing arrangements also suggested a relatively autonomous sample of elderly: 71% lived in single family homes, 18% lived in apartments, and 11% lived in some type of assisted living arrangement (i.e., nursing home, adult foster care, senior apartments).

Past and present closeness of relationship among the caregiver and patient dyads were also reported in a demographic questionnaire by the caregiver. Seventy percent of the caregiver subjects reported very close relationships with patients before the onset of the Alzheimer's disease, 21%

reported a close relationship, five percent reported a somewhat close relationship, four percent reported a distant relationship and no caregivers reported a very distant relationship before the onset of the disease. In contrast, in reporting current relationships, 62% of the caregivers rated the relationship as very close, 29% reported close relationships, eight percent reported a somewhat close relationship and two percent of the caregivers reported a distant relationship. Again no caregivers reported a very distant relationship with their impaired family member.

Caregivers were also asked to respond to questions about their religious commitment and the degree to which they felt religious faith helped in caregiving. Eighty two percent of the caregivers reported some degree of religious commitment and 18% felt weak or very weak in religious commitment. Seventy three percent felt that their faith helped to some degree, while 27% felt weak or very weak about the degree of help from their religious faith.

Table 4.1

Description of Patients

$\underline{N}$ = 92

Variable	N	Percentage
Gender		
Male	41	44.6
Female	51	55.4
Education		
Less High School	15	16.3
High School	45	48.9
Some College	13	14.1
College Degree	14	15.2
Graduate School	4	4.3
Doctoral Degree	1	1.1
Living Arrangement		
Lives Alone	24	26.1
Lives with Spouse	53	57.6
Lives with Relation	7	7.6
Lives with Non-relation	8	8.7
Type of Residence		
Single family Home	65	70.7
Apartment	17	18.5
Assisted Living	5	5.4
Adult Foster Care	5	5.4
Distance		
Less than 10 miles	71	77.2
10 - 25 miles	13	14.1
25 or more miles	8	8.7

Age	**Mean**	**SD**	**Range**
	73.4	9.1	50-91

Table 4.2

Description of Caregivers

$\underline{N} = 92$

Variable	N	Percentage
Gender		
Male	30	32.6
Female	62	67.4
Education		
Less High School	4	4.3
High School	25	27.2
Some College	7	7.6
College Degree	40	43.4
Graduate School	13	14.1
Doctoral Degree	3	3.3
Relationship 1 [1]		
Very Close	64	69.6
Close	19	20.7
Somewhat	5	5.4
Distant	4	4.3
Very Distant	0	-
Relationship 2 [2]		
Very Close	57	62.0
Close	26	28.3
Somewhat	7	7.6
Distant	2	2.2
Very Distant	0	-
Religious Commitment[3]		
Very Strong	19	20.7
Strong	41	44.6
Somewhat	17	18.5
Weak	7	7.6
Very Weak	8	8.7
Religious Help		
Very Strong	21	22.8
Strong	34	37.0
Somewhat	12	13.0
Weak	8	8.7
Very Weak	17	18.5

Age	Mean	SD	Range
	58.5	13.7	25-84

Note.

[1] Relationship 1 = Relationship before onset of disease
[2] Relationship 2 = Relationship currently
[3] Religious Commit = Religious Commitment

Reliability Analysis of Developed Instruments

The Caregiver Self-Efficacy Scale (CSE) and the Caregiver Perception of Patient Efficacy Scale (CPPE) both consisted of 15 items. The CSE and CPPE were scored on a 1 - 3 scale, with 1 = not at all confident, 2 = confident, 3 = very confident. All subjects in the study responded to all items, thus, no subjects were excluded from the final analysis (N = 92). Descriptive statistics for the 15 items on both the CSE and CPPE are summarized in Tables 4.3 and 4.4 respectively.

The Caregiver Strain Index (CSI) consists of 13 items measuring caregiver's "enduring problems that have the potential for arousing burden " (Robinson, 1983). Robinson reported an internal consistency of .86 for the CSI. The Social Provisions Scale (SPS) consists of 24 items measuring subjects' perceived social support. The SPS's internal consistency had been reported as ranging from .85 to .92 across a variety of populations (Cutrona, 1984; Russell & Cutrona, 1984). The Anxiety and Hostility subscales from the Brief Symptom Inventory (BSI) are measures of caregiver's negative affect in each respective area. The BSI Anxiety subscale has a reported internal consistency of .81, while the Hostility subscale's internal consistency is reported as .78 (Derogatis, 1982).

Table 4.3

CSE Scale Item Means, Standard Deviations, and Skew
N = 92

ITEM	MEAN	SD	Skew
1. I can help my parent/ spouse use the telephone.	2.81	.47	-2.5
2. I can take my parent/ spouse shopping.	2.77	.49	-2.1
3. I can prepare meals for my parent/spouse	2.65	.65	-1.6
4. I can help my parent/ spouse get house work done.	2.50	.72	-1.0
5. I can give my parent/ spouse their medications.	2.59	.66	-1.4
6. I can help my parent/ spouse handle their money.	2.64	.60	1.1
7. I can bathe my parent/ spouse.	2.19	.85	-.40
8. I can help my parent/ spouse get dressed.	2.40	.68	-.70
9. I can help my parent/spouse move from the bed to the toilet.	2.26	.78	-.50
10. I can help my parent/spouse make it to the bathroom on time.	2.16	.78	-.30
11. I can drive my parent/spouse to different locations.	2.65	.60	-1.5
12. I can feed my parent/spouse at meals.	2.34	.74	-.70
13. I can help my parent/ spouse visit other people.	2.50	.68	-1.0
14. I can help my parent/ spouse remain active.	2.19	.82	-.40
15. I can keep my parent/ spouse from getting sad and lonely.	1.80	.80	.37

Table 4.4
CPPE Scale Item Means, Standard Deviations, and Skew
$\underline{N}$ = 92

ITEM	MEAN	SD	Skew
1. My parent/spouse can use the telephone.	2.01	.74	-.02
2. My parent/spouse can go shopping.	1.57	.68	.78
3. My parent/spouse can prepare his/her own meals.	1.55	.71	.71
4. My parent/spouse can get his/her housework done.	1.54	.67	.85
5. My parent/spouse can take his/her own medications.	1.53	.67	.89
6. My parent/spouse can handle his/her own money.	1.47	.67	1.1
7. My parent/spouse can bathe himself/herself.	2.16	.71	1.0
8. My parent/spouse can get dressed independently.	2.26	.66	-.34
9. My parent/spouse can move from the bed to the toilet.	2.56	.58	-.95
10. My parent/spouse can make it to the bathroom on time.	2.43	.68	-.81
11. My parent/spouse can arrange transportation to locations.	1.52	.70	.99
12. My parent/spouse can feed himself/herself at meals.	2.56	.59	-1.0
13. My parent/spouse can visits other people.	2.06	.75	-.11
14. My parent/spouse can remain active.	1.96	.81	.06
15. My parent/spouse can prevent himself/herself getting sad and lonely.	1.54	.70	.91

In order to estimate the reliability of the CSE, CPPE, CSI, SPS, and BSI Hostility Anxiety subscales, each scale's coefficient alpha was calculated (N = 92). The coefficient alpha presents an estimate of the internal consistency based on the number of items and their mean intercorrelation (Nunnally, 1978). The coefficient alpha reflects the degree to which a scale is homogeneous, i.e., its items represent the same construct. The results of the reliability analysis on the six scales are reported in Table 4.5.

According to Nunnally (1978) an internal consistency of .80 exhibits sufficient reliability for a measure to be used for research purposes. Nunnally also proposed a minimal coefficient alpha of .90 for use of any measure in a clinical setting. The coefficient alpha estimates for the CSE (.92), CPPE (.90), SPS (.89), CSI (.83), BSI Hostility (.82) and BSI Anxiety (.87) indicated a sufficient degree of internal consistency to support their research use.

Descriptive information for all seven measures is presented in Table 4.6. The mean score for the CSE (computed by totaling responses and dividing by the fifteen items) was 2.4 with a range of 1 to 3. Mean score of the CPPE was 1.93 with a range of 1 to 3; mean score for the CSI was 5 with a range of 0 to 12; mean score for the SPS was 81 with a range of 54 to 96; mean score for the BSI Anxiety subscale was 4 with a range of 0 to 19; mean score for the

Table 4.5

Internal Consistency of Research Scales

$\underline{N}$ = 92

Scale	Alpha
CSE	.92
CPPE	.90
SPS	.89
CSI	.83
BSI Hostility	.82
BSI Anxiety	.87

Note.

CSE = Caregiver Self-Efficacy Scale

CPPE = Caregiver's Perception of Patient Efficacy Scale

SPS = Social Provisions Scale

CSI = Caregiver Strain Index

BSI Hostility = Brief Symptoms Inventory subscale (Hostility)

BSI Anxiety = Brief Symptoms Inventory subscale (Anxiety)

Table 4.6
Scale Summary Statistics

$\underline{N}$ = 92

Scale	Mean	Median	Mode	Range	SD	Skew
CSE	2.43	2.53	3	1-3	.48	-.62
CPPE	1.91	1.87	1.6	1-3	.44	.34
CSI	5.02	4	4	0-12	3.2	.31
SPS	80.88	83.04	84	54-96	9.6	.23
MMSE	17.82	19	18	2-30	6.6	-.32
BSI Hostility	.59	.40	.26	0-2.2	.36	.94
BSIAnxiety	.71	.50	.17	0-3.16	.68	1.3

BSI Hostility subscale was 3 with a range of 0 to 11 ; mean
score for the MMSE was 18 with a range of 2 to 30.

Results suggested that the two original measures, the CSE
and CPPE, developed to assess, respectively, self-efficacy for
caregiver behavior and caregiver's perceptions of patient's
efficacy, each had an adequate degree of internal consistency.
The reliability analyses also corroborate the documented
internal consistency of the CSI, SPS, and the BSI Hostility
and Anxiety subscales.

**Research Question 1: Will Greater levels of social
support (SPS) be significantly associated with less
caregiver burden (CSI)?**

Table 4.7 presents the correlations among all measures.
In order to explore the nature of the association between
social support and caregiver burden, the total score of the
SPS and CSI were correlated.   Results demonstrated a weak,
non-significant negative association between total social
support (SPS) and caregiver burden (CSI) (r =.-10).   Thus,
there was no evidence for the expectation that social support
would be predictive of less caregiver burden. However, total
social support was significantly and inversely associated with
anxiety (r =-.38) and hostility (r =-.37).   Thus, there was
limited support for the expectation that social support would
be associated with less negative affect in caregivers.

Table 4.7

Intercorrelation Matrix
N = 92

	2	3	4	5	6	7
1. CSI	-.36**	⊣40**	-.19*	-.10	.47**	.45**
2. CSE	--	.21*	.02	.28**	-.25**	-.23**
3. CPPE		--	.43**	.12	-.16	-.09
4. MMSE			--	-.01	-.04	-.14
5. SPS				--	-.36**	-.38**
6. Hostility					--	.58**
7. Anxiety						--

Note.   * = P< .05   ** = P< .01

CSI = Caregiver Strain Index

CSE = Caregiver Self-Efficacy scale

CPPE = Caregiver's Perception of Patients' Efficacy scale

MMSE = Mini-Mental Status Exam

SPS = Social Provisions Scale

Hostility = BSI Hostility subscale

Anxiety = BSI Anxiety subscale

**Research Question 2: Are the six SPS
social support subscales differentially
associated with caregiver burden?**

Further analyses were undertaken to investigate the association of differing aspects of social support to caregiver burden. Descriptive information for the six SPS subscales (Nurturance, Guidance, Attachment, Alliance, Worth, and Social Integration) is presented in Table 4.8. Correlational results show negligible (r =.-01) to modest (r = -.26) negative associations between the six SPS subscales and the CSI total score. See Table 4.9.

Given the range of correlations between the six SPS subscales and the CSI it appears that certain elements of caregiver social support relate significantly to caregiver burden while others do not.

**Research Question 3: Does cognitive
impairment in Alzheimer's patients (as
measured by the MMSE) vary linearly with
caregiver burden?**

Results showed a significant negative association between total caregiver burden (CSI) and patient cognitive status (MMSE) (r =.-19). The scoring of the MMSE, where higher scores indicated less cognitive impairment, explains the negative correlation between the patient's cognitive status level and total caregiver burden. Thus, this

Table 4.8

Social Provisions Scale
Subscale Statistics
$\underline{N}$ = 92

Variable	Mean	Mode	Median	Range	SD
Nurturance	13.56	16	13	8-16	2.04
Guidance	13.60	16	14	5-16	2.32
Social Integration	13.32	12	13	8-16	2.04
Reassurance Worth	13.48	16	13	7-16	2.08
Attachment	13.28	16	12	5-16	2.32
Reliable Alliance	13.84	16	13	8-16	2.04

Note.
Nurturance = Opportunity for Nurturance

Guidance = Opportunity for Guidance

Table 4.9

Correlations of the SPS Subscales with the CSI
$\underline{N}$ = 92

Subscale	$\underline{r}$
Opportunity for Nurturance	-.26**
Social Integration	-.20*
Reassurance of Worth	-.18*
Reliable Alliance	-.16
Attachment	-.04
Opportunity for Guidance	-.01

Note. * $\underline{P}$ > .05   ** $\underline{P}$ > .01

correlation actually suggests that greater patient cognitive impairment (lower MMSE scores) is associated with increased caregiver burden (higher CSI scores). However, the magnitude of the relationship is quite modest.

Research Question 4: Does self-efficacy in the caregiving role have a negative relation to caregiver burden?

The CSI and CSE scales showed were significantly, negatively related at a moderate level (r =.-36) suggesting that higher caregiver self-efficacy is associated with less caregiver burden.

Research Question 5: Does the caregiver's perception of the patient's self-care efficacy relate negatively to caregiver burden?

Results showed a moderate negative association between the CSI scale and CPPE scale (r =.-40), indicating that caregivers perceive less burden when patients are seen as more efficacious.

Research Question 6: What is the relation of demographic variables and the caregiver's negative affect to caregiver burden?

In order to explore the nature of the relationship between caregiver burden and demographic variables a correlation matrix was constructed. The correlations are presented in Table 4.10. Caregiver and patient demographic characteristics were generally only weakly related to caregiver burden. Caregiver's age (r =.-32) and the current status of the relationship between the caregiver and Alzheimer's patient (r =. 31) were significantly associated with caregiver burden. Thus, older caregivers and caregivers with a better reported relationship with their patients reported lower levels of burden. Interestingly, caregiver age itself was significantly associated with better current relationships between caregiver and patient (r =.-33), with older caregivers reporting on the whole better relationships with relatives with Alzheimer's disease.

Patient's sex was not significantly correlated with caregiver burden, though there was a significant relationship between the caregiver's sex and reported burden (r =.22), with females reporting that they experience greater levels of burden. The data showed a strong positive correlation between caregivers negative affect and burden. The association between

caregiver burden and Hostility scale was ($\underline{r}$ =.47) and for caregiver burden and the Anxiety scale ($\underline{r}$ =.45).

Table 4.10

Correlations of Demographic Variables with the CSI

$\underline{N}$ = 92

Variable	$\underline{r}$
Patient's Age	.02
Patient's Education	-.15
Number of Living Child	.00
Type of Residence	.11
Distance from Patient	.09
Caregiver's Age	-.32**
Caregiver's Education	-.00
Caregiver's Sex	.22*
Patient's Sex	-.07
Past Relationship Status	.15
Present Relationship Status	.31**
Religious Commitment	.02
Faith is Helpful in Coping	.02

Note.
*$\underline{p}$ < .05   **$\underline{p}$ <.01

ADDITIONAL ANALYSIS

A hierarchical regression analysis was performed in order to establish the incremental utility of each theoretical variable in predicting total caregiver burden (CSI).

The results of the regression analysis are presented in Table 4.11. The variables are listed in the order in which they were entered. This order was chosen to facilitate interpretation of the contribution of caregiver negative affect, social support, caregiver self-efficacy, and the caregiver's perception of patient efficacy to the regression equation beyond the effects of caregiver/patient background variables and the patient's cognitive status. The R^2 change value indicates the unique contribution of each variable or block to the prediction model, controlling for variables entered at previous steps.

Demographic variables with significant correlations (see Table 4.11) were entered first into the regression equation as a block. This block accounted for 15% of the variance in caregiver burden.

MMSE scores were entered next to determine the association of the patient's cognitive status to caregiver burden after controlling for the primary demographic variables. The results suggested that the patient's cognitive status (R^2 change =.04) did add significant variance beyond the variables concerned with the caregiver's and patient's demographic background.

Table 4.11

Regression model on Caregiver Burden

N = 92

Variable	R	R^2	R^2 Change	F Change	B
Block Demographics	.43	.18	.18	6.7**	
Caregiver Age					-.05
Current Relationship					.95
Sex of Caregiver					1.2
Mini-Mental Status	.47	.22	.04	4.2*	-.09
Block Negative Affect	.64	.42	.20	14.0***	
Hostility (BSI)					2.3
Anxiety (BSI)					.72
Block Social Support	.72	.52	.10	5.6***	
(SPS) subscales					
Nurturance					-1.6
Social Intergration					-1.8
Feelings of Worth					-1.2
Caregiver Efficacy (CSE)	.75	.56	.04	7.5**	-1.6
Patient Efficacy (CPPE)	.78	.61	.05	11.3**	-2.1

Note.   * P < .05   ** P < .01   ***P < .001

The negative affect block of hostility and anxiety also accounted for significant and substantial proportions of variance beyond that accounted for by the demographic and cognitive variables (R^2 change =.20).

The three SPS subscales with significant correlations with caregiver burden (Nurturance, Social Integration, and Worth) were entered next as a block accounting for significant proportions of the variance (R^2 change =.10) beyond that explained by the previously entered variables.

Finally caregiver self-efficacy and caregivers' perception of patient efficacy were entered sequentially into the regression model. Each of these efficacious variables contributed significant variance to the equation for CSE, R^2 change =.04; for CPPE, R^2 change =.05. Overall, the full model accounted for 61% of the variance in caregiver burden.

Chapter V

Discussion

Chapter V provides a brief summary of the study, a discussion of the results, and implications and limitations of the study.

Summary

This exploratory study investigated the unique interrelationships between caregiver variables, patient variables and the level of burden reported by the primary family caregiver. The primary caregiver's level of burden was defined as the following model:

$$\text{Burden} = \frac{\text{Exposure to Stressors + Vulnerability}}{\text{Psychological Resources + Social Resources}}$$

This study contributes to the current research about factors that may lead to increased levels of burden among caregivers of Alzheimer's patients. Burden among caregivers is a complex process that has received much attention in recent years in the literature, though rarely have theoretical models been applied to this problem. Given that the existing literature has reported mixed results on single variables in predicting or attempting to explain caregiver burden, the application of a theoretical model was seen as a positive step in expanding the knowledge base about the burden of being a caregiver.

Testing the utility of self-efficacy theory relative to levels of burden among caregivers involved developing both the Caregiver Self-Efficacy Scale (CSE) and the Caregiver's Perception of Patient Efficacy Scale (CPPE). Both are fifteen-item measures developed on the basis of the theoretical and empirical literature on self-efficacy theory (Bandura, 1977,1986) and on current caregiver burden literature (Zarit et al., 1986).

The CSE was constructed in order to examine caregivers' perceptions of their ability to assist the impaired relative in Activities of Daily Living (ADL) (Katz et al., 1981). The CPPE was constructed in order to examine the caregiver's perception of the patient's ability to independently perform the Activities of Daily Living. In this way, the two scales (CSE and CPPE) were used to differentiate the effect of the caregiver's perceptions of efficacy involving self and the patient in relation to burden.

A sample of 92 caregivers completed both the CSE and CPPE during the Alzheimer patients' geriatric assessments. Results of the reliability analyses of the CSE and CPPE indicated both scales to be highly reliable measures.

Discussion of the Results

Characteristics of the Sample

This study's descriptive data (caregiver and patient characteristics) were generally consistent with those reported in other studies involving caregivers of Alzheimer patients (e.g., Zarit et al., 1986; Poulshock & Deimling, 1984). The caregiver sample consisted primarily of white spouses and adult children, most of whom were female. The patient sample consisted mostly of white males and females, all of whom resided in a community location. Overall, both patient and caregiver samples were fairly representative of their populations in terms of demographic characteristics such as age, gender, level of impairment and burden.

Reliability of the CSE and CPPE

The obtained alpha coeffients for the CSE and CPPE indicated that both scales were highly homogeneous. Although both scales consisted of only 15 items, the high alphas obtained suggested that the scales would not be appreciably strengthened by including additional items. The high alpha levels on both the CSE and CPPE suggested that measurement error due to item sampling apparently did not affect the scales.

The nonsignificant correlation between the CSE and CPPE (r=.21) supports the discriminant validity of each distinct

scale. That is, a caregiver's perceptions of self-efficacy in tasks was weakly associated with his/her perception of the patient's own efficacy in carrying out the same self care tasks. The finding that the mean score on the CSE was moderately high suggests that, overall, caregivers were confident about their ability to perform Activities of Daily Living for their relatives. In contrast, the lower mean on the CPPE, suggests that, overall, caregivers were less confident about the Alzheimer's disease patient's ability to perform the same tasks. Both scales were found to have a negative correlation with a measure of caregiver burden (CSI).

The reliability information presented suggested that the CSE and CPPE scales are reliable instruments. The CSE is a novel measure developed to assess a caregiver's level of self-efficacy regarding ADL's and other care related tasks. The CPPE, also a novel instrument, was developed to assess caregiver's perceptions about the level of efficacy held by the impaired relative regarding to the same above mentioned tasks. Overall, the preliminary findings about both the CSE and CPPE warrant their continued use for research purposes.

Demographics

Only three significant interrelationships among the many demographic variables were found in the correlational analyses. Caregiver burden level was significantly and negatively associated with the caregiver's age. It was shown that older caregivers, for the most part spouses, reported less burden in caring for their Alzheimer patients. Prior research also suggests that spouses tend to report less burden than do adult children of parents with Alzheimer's disease (Fitting, 1986).

Reported caregiver burden level was also significantly and negatively associated with the current perception of the relationship status between the caregiver and patient. The results suggest that caregivers reporting a strong and positive relationship with the patients also report less burden. This finding is in support of clinical observations that no single aspect of caring for a relative with Alzheimer's disease is as upsetting as the victim's inability to remember relationships (Benedek, 1973).

Not surprisingly, gender of the caregiver was significantly associated with caregiver burden. In general, past research has suggested that female caregivers report more burden then their male counterparts (Zarit et al., 1986, Fitting, 1986). More females are family caregivers and higher reported burden is not surprising given socialization in regard to help-seeking behavior.

Cognitive Impairment

A significant association was found between the patients' cognitive impairment and caregiver burden. This is not consistent with the work of Zarit (1981, 1986), who found no association between burden and cognitive impairment. The findings are consistent with the work of Poulshock and Deimling (1984) who report cognitive incapacity demonstrated the strongest associations with corresponding caregiver burden. The utility of the theoretical variables (social support, negative affect, self-efficacy, patient efficacy and cognitive impairment) along with other caregiver and patient variables were examined in a regression analysis. Regression results indicated that the Alzheimer's disease patient's cognitive status accounted for significant unique variance in the prediction of caregiver burden. It should be noted that the variance accounted for in the model by the patients' cognitive impairment was the least of any given variable or block. Also, the early controlled entry of the cognitive impairment variable into the multiple regression equation before the theoretical variables may have facilitated its significance.

Social Support

A non-significant association between the variables of SPS Total and CSI Total was demonstrated in the correlation analysis. Social support theory posits that an individual's social support is negatively and significantly related to stress and burden experienced in one's life. Unexpectedly, the caregivers' perception of overall level of social support and overall level of burden were not significantly interrelated. According to Cohen and Mckay (1984) stress from difficult experiences will have a deleterious effect on the burden and well-being of those with little or no social support, while these effects will be lessened or eliminated for those with stronger social supports. Findings from the present study indicate that a general measure of social support (SPS) may be unhelpful in accounting for variance within the specific demands and burdens associated with caring for a relative with Alzheimer's disease.

To further investigate the specific role of social support within the context of caring for an elderly person with Alzheimer's disease the six subscales of the SPS: 1) Opportunity for Nurturance; 2) Social Integration; 3) Reassurance of Worth; 4) Attachment; 5) Reliable Alliance and 6) Opportunity for Guidance were examined in association with the CSI.

Literally hundreds of studies have examined the effects of social support and well-being outcomes. However, very

little research has been done on the specific processes through which the exact elements of social support contribute to a caregiver's ability to cope with the stress and burden of caring for a relative with Alzheimer's disease. The current investigation allows for a more micro-analytic approach, allowing specific social support subscales to account for unique variance within caregiver burden.

The regression analysis was consistent with the premise that unique aspects of social support maybe associated with caregiver burden differentially. Regression results indicated that three of the six subscales accounted for significant unique variance in the prediction of caregiver burden. The results indicated that the three SPS subscales with the strongest negative associations in relationship to total burden; 1) Opportunity for Nurturance; 2) Social Integration and 3) Reassurance of Worth all accounted for unique variance within the burden model. The remaining three SPS subscales with weaker associations accounted for nonsignificant variance within the model.

While the specific regression approach designed to account for the individuality of each subscale proscribes direct explanation of the results, certain general results seem clear. Critics have argued that general measures of social support have accounted for only marginal and many times inconsistent results in regard to the buffering hypothesis. This hypothesis holds that when stressful life events occur,

individuals who have adequate support resources are able to mobilize these resources to help them cope effectively with the challenges posed by the stress (Cobb, 1976, 1979). The results of the current study indicate that aspects of social support may in fact be situation specific. It appears that the actual stressful situation may contribute to subjects' evaluations of the need or adequacy of their social support. Alternatively, it may be that the social support behaviors assessed may serve multiple functions, depending on the context in which they are offered. In sum, although total social support was not significant in association with burden, the ability of the individual SPS subscales to account for unique and significant variance within the burden measure allows for some confidence in inferring that specific social support behaviors are in fact associated with lower levels of caregiver burden. Clearly, more comprehensive research on specific social support behaviors, as opposed to more general measures is required.

Perceptions of Self-Efficacy

Regression results indicated that caregivers reported self-efficacy in carrying out ADL's for the impaired relative did account for significant and unique variance in the prediction of caregiver burden. It follows that caregivers who have positive expectations and strong beliefs about their ability to carry out tasks for an impaired relative may be able to remain motivated and positive about the caregiving

role, and thus report less burden. This result is consistent with the evidence in the literature showing that people's perceptions of their efficacy are related to motivation and outcome behavior.

These findings are also consistent with results that suggest that self-efficacy also affects the amount of effort devoted to a task, as well as the duration of persistence when difficulties are encountered. Thus, adherence to a caregiving regimen by family caregivers may be more consistent and long lasting in those people whose beliefs in their abilities are strong. It should be noted that caregiver's self-efficacy accounted for significant variance even when controlling for all other major variables, thus demonstrating the robust characteristic of this highly significant variable.

The results also suggest that the CPPE, a measure of the caregiver's perception of the patient's efficacy, does in fact add unique substantial and significant variance to the prediction of caregiver burden. As expected, the strong relationship between a caregiver's perception of the patient's efficacy and burden was indicated by the fact that the CPPE scale predicted burden even when controlling for demographic, social support, negative affect and caregiver self-efficacy variables.

Bandura (1977) has postulated four principle sources for efficacy information: 1) past and present performance accomplishments; 2) vicarious experience of observing others

perform; 3) verbal persuasion and other kinds of social influence and 4) status of physiological arousal. The importance of the caregiver's perception of the care receiver's efficacy (CPPE) is displayed in the greater negative association with burden than the caregivers reported self-efficacy (CSE). This suggests that the caregiver's perception of the patient's efficacy may be especially potent in relation to levels of caregiver burden. Thus, the Alzheimer's disease patient with a unique pattern of inflicted impairments, may be associated with the caregiver's ability to fully trust his/her judgement concerning the relative's efficacy level. Perceptions of the patient's efficacy in caring for themselves may be especially "at risk" because of unique disease factors which affect all four of the above mentioned sources of efficacy information.

In terms of past performance accomplishments, Alzheimer patients are not likely different from other older adult populations. However, Alzheimer patients' present performance accomplishments are likely dramatically different from the accomplishments of other same age cohorts. Also shifts in individual performance accomplishments may be severe and observations of the individual impaired relative are of little use in forming a lasting perception of observered efficacy. Social influence also holds special implications for caregivers' perceptions of patient efficacy. Caregivers face greater financial, emotional, psychological, informational,

and medical dependence on other family members, counselors and health care professionals. This situation may greatly complicate caregivers' appraisal of the relatives impairment, efficacy and competence.

All of the above information suggests a variable at risk for a caregiver population. The results from this study suggest that perception of the impaired relative's efficacy plays a significant role in predicting caregiver burden. A better understanding of these complex relationships could quite possibly lead to more productive interventions for optimizing caregivers' understanding of the disease factors, leading to more accurate and realistic appraisals of patient efficacy, thus promoting a decrease in caregiver burden.

Negative Affect

Regression analysis demonstrated that caregiver burden was significantly and positively associated with the BSI Hostility and Anxiety subscales; in fact this block accounted for more unique variance than any other. Thus, even with the negative affect scales early entry into the regression model, it seems reasonable to suggest that caregivers at risk for burden may be characterized by their negative affective.

The relationship may be very complex in that caring for a person with Alzheimer's disease places an enormous emotional stress on the caregiver, leading to increases in negative driven coping responses. Those caregivers with negative

affective coping style may display increases in hostility and anxiety. These negative emotions exacerbate the difficulties of caring for the impaired relative while, at the same time, causing acute discomfort to the caregivers themselves (Oliver and Bock, 1985).

Thus, an individual caregiver's negative affect may interact with the specific role the caregiver is forced to play. The data from the present study suggests that individuals prone to more negative emotional styles may experience significantly greater burden when caring for relatives with Alzheimer's disease. This finding is consistent with that of several other researchers who have observed relationships between distress and negative affect in coping with stress (Billings and Moos, 1981; Folkman and Lazarus, 1981; Vitaliano et al., 1986; Watson & Clark, 1984, 1989).

Summary

In summary, the results of the present study suggests that caregivers at risk for high reported levels of burden may be characterized by their negative affect, lacking specific elements of social support, self-efficacy in the caregiving role and perceptions of patient's efficacy in Activities of Daily Living. In short, while Alzheimer's disease represents a progressive deteriorative function over the course of the illness, apparently burden may not. From a theoretical view,

it appears that burden truly lies in the eye of the beholder. The data suggest that while Alzheimer's patients do demonstrate decreased functional abilities over time, caregiver's perceptions of the meaning of these losses do not bear a one to one relationship with an increase in burden.

This recognition of the multidimensional nature of the stressors associated with caregiving, the mediating factors and caregivers' resources increases the knowledge base concerning caregiver burden and the situational demand associated with caring for a relative suffering from Alzheimer's disease.

Limitations, Implications, and

Directions for Future Research

There are several limitations in this study that make efforts to apply or generalize the findings problematic. First, since subjects were not randomly selected, it is possible that this sample may have had certain characteristics that skewed the participants' responses to the selected measures. Second, given the correlational nature of the design, it is not possible to infer causality from the obtained findings. Third, the lack of minority subjects in the present sample suggests that generalization of these findings to any other particular racial/ethnic group would be faulty and unwise. Any efforts to generalize these findings should consider the characteristics of the present sample, e.g., highly educated caucasian midwestern caregivers. Fourth, the extent to which these findings are specific to the setting employed (University Hospital) is not clear. Additionally the impact of the measures on the caregivers should be considered. For example, a response set bias may have been evidenced on the CSE and CPPE in that some subjects may have over estimated their own efficacy and underestimated the patient's efficacy to impress upon the health care research assistant their parent's/spouse's need for treatment. In this regard the need for replication of these findings, in differing settings, certainly would enhance their generalizability.

The use of the Brief Symptom Inventory (BSI) subscales of Hostility and Anxiety as measures of negative affect (NA) is in need of additional inquiry. Given the cited literature the bridge from the BSI subscales to NA seems sound, but in need of further empirical analysis. The psychometric nature of the BSI subscales may also be an issue. The BSI skew response set found in this study may have hindered better interpretation of associated statistical information such as correlation coefficients that can be substantially affected by skewness. It should be noted that the published norms of the BSI also show this characteristic. In fact, the caregiver sample in the current study demonstrates less positive skew than norms reported on a same age cohort group (Hale, Cochran, & Hedgepeth, 1984).

Also, in recruiting caregivers only clinical rosters were used. As such, the sample had a disproportionate number of caregivers who were either very active or aware in regard to their parent's/spouse's condition. Schulz et al. (1990) discussed the lack of representation of caregivers in the middle of the burden distribution when using only clinical rosters in recruitment. The recruitment bias in this sample might explain the absence of the social support total score as a significant predictor of burden. Perhaps caregivers struggling with different stages of disease are in need of more/different levels of social support. Lastly, exploration

of other salient indicators might improve prediction of caregiver burden.

In contrast with these limitations this study offers an important advantage. A theoretical model of distress was used with constructs that are well grounded in the caregiver burden literature. As such, a number of variables were examined that have been associated with caregiving individually but have received relatively little research as a model of burden. For example, negative affect (enduring attributional trait) is of prime importance to coping with stress (Watson, Clark, 1984; Watson, 1988). Unfortunately, dispositional affect has received only a modicum of interest in caregiver research (Gallagher et al., 1989). Expressed emotion, although an important concept in research on psychiatric care recipients, stress, and coping have received little attention in Alzheimer's disease research. In addition, although social support, cognitive impairment and efficacy have received relatively more attention in caregiver research, few studies have examined these variables simultaneously, to determine either their relative importance or synergistic effects.

In terms of future research, it may be crucial to begin to study the relationship of self-efficacy variables to caregiver burden from a longitudinal design. For example, what happens to perceptions of efficacy in caregiving over time? Does caregiver burden increase if self-efficacy beliefs diminish during the course of the disease? Is the negative affect in

caregiver burden an enduring trait as speculated? Such longitudinal research is needed to fully address what specific intervention may be needed during the time span spent caring for an impaired relative.

This study suggests that in addition to caregiver and care recipient demographics, caregiver vulnerability, perceptions and resources are jointly important in predicting subsequent burden. Leading researchers have begun to argue that research on burden should focus not on whether burden exists, but rather on those factors that make some caregivers more vulnerable to distress than others (Zarit, 1989; Schulz et al., 1990). It is hoped that this small current study will be useful in identifying factors relevant to caregiver burden.

These findings have a number of implications for interventions with Alzheimer's disease caregivers, if the findings concerning caregiver efficacy and negative affect patterns are substantiated as risk factors for subsequent caregiver burden. Screening programs can be developed to identify those caregivers most at risk.

Specific interventions to reduce hostility and anxiety (through stress management or skill training) and increase feelings of efficacy in caregiving may be most helpful and provide a logical link between caregiver intervention studies and caregiver burden research. For example, although numerous caregiver intervention programs exist, none includes "efficacy enhancement" as a management tool, and yet this research

points to the need for just such an intervention. As researchers continue to uncover the complexities of the demands and needs of caregivers, specialized interventions targeting specific needs and diverse treatment spanning a variety of elements are essential. Clearly, the results of this present study suggest that burden is a complicated phenomenon that will require a multivariate approach to research and treatment alike.

APPENDICES

Appendix A

Control Sheet

ID#_____

Patient's Name _____ Patient's Age _____ Sex_____

Patient's Education Level_____

Patient's Living Arrangement:

1. Lives Alone   2. Lives with spouse   3. Lives with
relative

4. Lives with non-relative

How many living children does the patient have ? _____

Patient's type of residence:

1. single family home   2. apartment   3. assisted living
4. AFC   5. nursing home   4. other

What distance are you from the patient ?

1. less than 10 miles   2. 10 - 25 miles   3. 25 or more miles

CAREGIVER INFORMATION

Your Name _____   Age_____ Sex_____

What is your highest level of education?
1. Less than high school   2. High school graduate
3. Some college   3. College degree
4. Graduate school   4. Doctoral degree

Satisfaction with relationship:

1. How close were you to the patient in the past ?

        1   2   3   4   5
Very Close   Close   Somewhat   Distant   Very Distant

2.   How close are you to the patient now ?

```
     1            2           3          4            5
Very Close      Close    Somewhat   Distant   Very Distant
```

3.   How strong would you rate you religious commitment ?

```
     1            2           3          4            5
Very Strong     Strong   Somewhat   Weak     Very Weak
```

4.   How much is your religious faith helping you cope with the
      patient's illness ?

```
      1           2           3           4            5
Very helpful   Helpful   Somewhat   Very little   Not at all
```

Appendix B

SPS

Instructions

In answering the following set of questions, think about your current relationships with friends, family members, co-workers, community members, and so on. Please indicate to what extent you agree that each statement describes your current relationships with other people. Use the following scales to give your opinion. So, for example, if you feel a statement is very true of your current relationships, you would indicate "strongly agree." If you feel a statement clearly does not describe your relationships, you would respond "strongly disagree."

Strongly Disagree Agree	Disagree	Agree	Strongly
1	2	3	4

1. There are people I can depend on to help if I really need it. _____

2. I feel that I do not have close personal relationships with other people. _____

3. There is no one I can turn to for guidance in times of stress. _____

4. There are people who depend on me for help. _____

5. There are people who enjoy the same social activities I do. _____

6. Other people do not view me as competent. _____

7. I feel personally responsible for the well-being of another person. _____

8. I feel part of a group of people who share my attitudes and beliefs. _____

9. I do not think other people respect my skills and abilities. _____

10. If something went wrong, no one
    would come to my assistance.   _____

11. I have close relationships that
    provide me with a sense of emotional
    security and well-being.   _____

12. There is someone I could talk to
    about important decisions in my life.   _____

13. I have relationships where my
    competence and skill are recognized.   _____

14. There is no one who shares my
    interests and concerns.   _____

15. There is no one who really relies on
    me for their well-being.   _____

16. There is a trustworthy person I could
    turn to for advice if I were having
    problems.   _____

17. I feel a strong emotional bond with
    at least one other person.   _____

18. There is no one I can depend on for
    aid if I really need it.   _____

19. There is no one I feel comfortable t
    talking about problems with.   _____

20. There are people who admire my talents
    and abilities.   _____

21. I lack a feeling of intimacy with
    another person.   _____

22. There is no one who likes to do
    the things I do.   _____

23. There are people I can count on in
    an emergency.   _____

24. No one needs me to care for them.   _____

Appendix C

CSE

Instructions: I am going ask about some areas that your spouse/parent may be experiencing problems in. Please tell me how confident you are that you can handle each area.

SCORE FOR EACH QUESTION
1= NOT AT ALL CONFIDENT   2= CONFIDENT   3=VERY CONFIDENT

1. I can help my parent/ spouse use the telephone.	1	2	3
2. I can take my parent/ spouse shopping.	1	2	3
3. I can prepare meals for my parent/spouse	1	2	3
4. I can help my parent/ spouse get house work done.	1	2	3
5. I can give my parent/ spouse their medications.	1	2	3
6 I can help my parent/ spouse handle their money.	1	2	3
7. I can bath my parent/ spouse.	1	2	3
8 I can help my parent/ spouse get dressed.	1	2	3
9. I can help my parent/spouse move from the bed to the toilet.	1	2	3
10. I can help my parent/spouse make it to the bathroom on time.	1	2	3
11. I can drive my parent/spouse to different locations.	1	2	3
12. I can feed my parent/spouse at meals.	1	2	3

13. I can help my parent/   1   2   3
spouse visit other people.

14. I can help my parent/   1   2   3
spouse remain active.

15. I can keep my parent/   1   2   3
spouse from getting sad and lonely.

Appendix D

CPPE

Instructions: I am going ask about some areas that your spouse/parent may be experiencing problems in. Please tell me <u>how confident you are that your spouse/parent can handle each area without any help.</u>

SCORE FOR EACH QUESTION
1= NOT AT ALL CONFIDENT   2= CONFIDENT   3= VERY CONFIDENT

1. My parent/spouse can use the telephone.	1	2	3
2. My parent/spouse can go shopping.	1	2	3
3. My parent/spouse can prepare his/her own meals.	1	2	3
4. My parent/spouse can get his/her housework done.	1	2	3
5. My parent/spouse can take his/her own medications.	1	2	3
6. My parent/spouse can handle his/her own money.	1	2	3
7. My parent/spouse can bath himself/herself.	1	2	3
8. My parent/spouse can get dressed independently.	1	2	3
9. My parent/spouse can move from the bed to the toilet.	1	2	3
10. My parent/spouse can make it to the bathroom on time.	1	2	3
11. My parent/spouse can arrange transportation to different locations.	1	2	3

12. My parent/spouse can feed himself/herself at meals.　　1　　2　　3

13. My parent/spouse still visits other people.　　1　　2　　3

14. My parent/spouse can remain active.　　1　　2　　3

15. My parent/spouse can prevent himself/herself getting sad and lonely.　　1　　2　　3

Appendix E

Caregiver Strain Index
Instructions: I am going to read a list of things which other
people have found to be difficult in helping out after
somebody with similar difficulties as your parent/spouse.
Would you please tell whether any of these apply to you ?

	Yes	No
1.) Sleep is disturbed (e.g., because _____ is in and out of bed or wanders around at night).	___	___
2.) It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help).	___	___
3.) It is a physical strain (e.g., because of lifting in and out of chair; effort or concentration is required).	___	___
4.) It is confining (e.g., helping restricts free time, or cannot go visiting).	___	___
5.) There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy).	___	___
6.) There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation).	___	___
7.) There have been other demands on my time (e.g, from other family members).	___	___
8.) There have been emotional adjustments (e.g., because of severe arguments).	___	___
9.) Some behavior is upsetting (e.g., because of incontinence, ____ has trouble remembering things or accuses others of taking things).	___	___
10.) It is upsetting to find ____ has changed so much from his/her former self (e.g., he/she is a different person than he/she use to be).	___	___

11.) There have been work adjustments (e.g.,   ___   ___
because of having to take time off).

12.) It is a financial strain.   ___   ___

13.) Feeling completely overwhelmed (e.g.,   ___   ___
because of worry about ____; concerns
about how well you will manage).

Appendix F

BSI Subscales Hostility and Anxiety

INSTRUCTIONS: On the attached sheet is a list of problems and complaints that people sometimes have. Please read each one carefully. After you have done so, please circle one of the numbers that best describes HOW MUCH DISCOMFORT THAT PROBLEM HAS CAUSED YOU DURING THE PAST WEEK INCLUDING TODAY. Please do not skip any items and circle only one number per item. Please feel free to ask any question.

BSI Hostility Subscale

1.) Feeling easily annoyed or irritated

0	1	2	3	4
Not at all	A little bit	Moderately	Quite a bit	Extremely

2.) Temper outbursts you cannot control

0	1	2	3	4
Not at all	A little bit	Moderately	Quite a bit	Extremely

3.) Having urges to beat, injure or harm someone

0	1	2	3	4
Not at all	A little bit	Moderately	Quite a bit	Extremely

4.) Having urges to break or smash things

0	1	2	3	4
Not at all	A little bit	Moderately	Quite a bit	Extremely

5.) Getting into Frequent Arguments

0	1	2	3	4
Not at all	A little bit	Moderately	Quite a bit	Extremely

BSI Anxiety Subscale

1.) Nervousness or shakiness inside

0	1	2	3	4
Not at all	A little bit	Moderately	Quite a bit	Extremely

2.) Suddenly scared for no reason

0	1	2	3	4
Not at all	A little bit	Moderately	Quite a bit	Extremely

3.) Feeling Fearful

0	1	2	3	4
Not at all	A little bit	Moderately	Quite a bit	Extremely

4.) Feeling Tense and Keyed up

0	1	2	3	4
Not at all	A little bit	Moderately	Quite a bit	Extremely

5.) Spells of terror and panic

0	1	2	3	4
Not at all	A little bit	Moderately	Quite a bit	Extremely

6.) Feeling so restless you couldn't sit still

0	1	2	3	4
Not at all	A little bit	Moderately	Quite a bit	Extremely

Appendix G

Informed Consent

This study will attempt to explore the caregiving relationship between you and your spouse/parent. We are interested in different factors that may be playing a role in your ability to successfully assist your spouse/parent in their daily activities. In attempting this study we hope to come to a better understanding of the resources needed to cope with the stresses associated with caring for an aging person with an illness. We will be asking you to fill out several questionnaires, these questionnaires are fairly short and will take no more than 15-25 minutes of your time. If you agree to participate we will also be using a portion of your spouse's/parent's medical evaluation, a short measure of their memory and mental ability. It should be noted that this short scale is a standard part of the clinic's medical evaluation and will not add additional time or discomfort to the patient's evaluation.

Please be assured that your participation is strictly voluntary. You may decide not to participate in or withdraw from the study at any time without fear of penalty or loss of service from the clinic. All information gain in the study will be confidential and all people agreeing to participate will be assigned an ID number to insure that all information is kept secure. You will not be identified in any reports on this study. The study's findings will be shared with participates who wish to receive the results. Any questions or needed information may be addressed to the researcher for immediate feedback. Thank you for your time.

<u>I have read the information above. I understand the meaning of the information. The researcher has satisfactorily answered my questions concerning the study. I hereby consent to participate in the study.</u>

_____

signature of participate   Date

One copy of this document will be kept together with our research records on this study. A second copy will be place in your spouse/parent's record. A third copy will be given to you to keep.

If you have any questions or concerns about your rights as a research subject, you may also contact the Office of Patient-Staff Relations, A-6028 University Hospital, Telephone 763-5456

THANK YOU

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