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**PERCEIVED CAREGIVER BURDEN AS A FUNCTION
OF DIFFERENTIAL COPING STRATEGIES**

**A Thesis
Presented to the
Faculty of
California State University,
San Bernardino**

**In Partial Fulfillment
of the Requirements for the Degree
Master of Arts
in
Psychology**

**by
Kevin Scott Olin**

June 1994

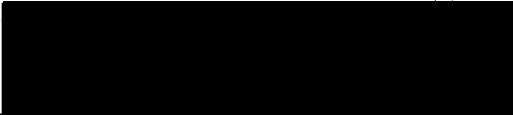
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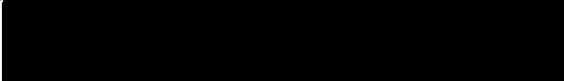
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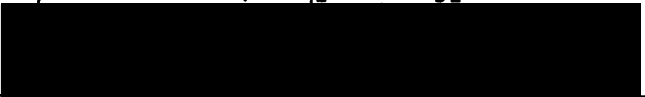
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ABSTRACT

The literature on Alzheimer's disease shows that caring for an Alzheimer's patient places a substantial burden on caregivers and severely taxes their psychological and material resources. The present investigation examines the effect of caregivers' strategies (emotion focused vs. problem-focused) on their experienced burden. The study sample was 32 family caregivers of Alzheimer's disease patients; the majority were white females between the ages of 60-69. All subjects were drawn from such sources as the Alzheimer's Disease and Related Disorders Association (ADRDA) and caregiver support groups. Caregivers completed a Demographic sheet, a Multidimensional Caregiver Burden Inventory (CBI, Novak & Guest, 1989) which measures the impact of burden on caregivers; and a Ways of Coping Checklist (WCCL, Vitaliano, Maiuro, & Russo, 1987; Carr, Maiuro, & Becker, 1985), which assesses coping strategies by caregivers. The findings indicate that problem-focused coping seems to be effective in alleviating overall caregiver burden. Contrary to our expectations, we did not find that combined coping strategies lowered the burden. Implications for the study are found in greater acceptance through a realistic appraisal of Alzheimer's disease, which helps caregivers adopt coping strategies that buffer stress and enhance feelings of competence.

ACKNOWLEDGEMENTS

I would like to thank all of my thesis committee members, especially my chairperson, Joanna Worthley. My committee members were all very supportive and put forth a great deal of effort in guiding me and helping me through the thesis process.

DEDICATION

I would like to dedicate my thesis to my grandmother, who has had Alzheimer's Disease for five years and is in the most advanced stage of the disease. She is currently living in a nursing home specifically for Alzheimer's patients, where she requires one hundred percent, full-time care.

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INTRODUCTION

Background: Alzheimer's Disease

Alzheimer's disease is expected to be the worst public health problem of the next century (Champagne & Stachow, 1986). Already there are at least one and a half million victims in the United States (Clark & Hager, 1979) and Alzheimer's accounts for at least 50-60% of all dementias (Pratt, Schmall, & Wright, 1986). It is the fourth leading cause of death among the aged population (Nathan, 1986). Although there are various theories regarding the cause of Alzheimer's disease, there is currently no known cure (Gwyther, 1982).

Alzheimer identified this disease in 1907 in a post-mortem examination of the brain of a 55 year old female dementia victim. What looked like twisted pieces of yarn were deteriorated nerve cells called tangles and plaques (Nathan, 1986). These tangles and plaques are found in the cerebral cortex, the outer gray covering of the brain, which is associated with higher mental functions such as memory and learning (Nathan, 1986). It appears these tangles and plaques disrupt the flow of information to the brain. Dementia progresses as these formations increase.

Alzheimer's disease is one type of dementia, a global term for any neurological disorder in which the major symptoms include the deterioration of mental functioning (Rybash, Roodin, & Santrock, 1991). In identifying

dementias, it is important to distinguish between Alzheimer's disease, memory losses due to depression, and normal memory loss. Several researchers have developed models which help in distinguishing among these various memory problems.

For example, according to Grober and Buschke (1987), cited by Birren and Schaie (1990), memory problems can be the result of apparent memory deficits or genuine memory deficits. Apparent memory deficits are memory problems due to the use of ineffective encoding and retrieval strategies. This type of memory deficit can be overcome by showing individuals how to process information effectively or by giving individuals effective retrieval aids. Genuine memory deficits are memory problems that are still apparent even after individuals have carried out effective encoding and retrieval activities. According to Grober and Buschke (1987), genuine memory deficit would be more likely experienced by individuals suffering from irreversible forms of dementia such as Alzheimer's disease. On the other hand, normal elderly and depressives would be more likely to experience apparent memory deficits.

Among the dementias there are many overlapping symptoms, thus Alzheimer's disease is difficult to diagnose and there is no single clinical test to identify it. Moreover, before diagnosis of the disease is made, other possibilities need to be excluded; that is, all other diagnoses are ruled out until nothing else remains that could explain symptoms. Factors which can produce dementia-like symptoms include depression, adverse drug

reactions, metabolic changes, nutritional deficiencies, head injuries and stroke (Rybash, Roodin & Santrock, 1991). According to Heston and White (1983), cited in Birren and Schaie (1990), the only way to make a positive diagnosis of Alzheimer's disease is at autopsy. During an autopsy, the brain tissue is observed and analyzed to determine the presence and location of excessive plaques, tangles, and related cell loss (Rybash, Roodin, & Santrock, 1991).

Alzheimer's disease is devastating and places a heavy burden on caregivers, severely taxing their psychological and material resources (Quayhagen & Quayhagen, 1988). However, some of the current literature suggests that there are differences in caregivers' stress and coping styles. These differences may mean that some caregivers are more successful in coping with the caregiving role than others. Specifically, there appear to be differences in caregivers' helping strategies which affect their ability to care for the Alzheimer's patient.

Even though diagnosis of Alzheimer's disease is difficult, it does exhibit a predictable, progressive decline in psychological, physiological, and social functioning. Six stages of cognitive decline are described by the Functional Assessment Staging System developed by Reisberg, Ferris, and Franssen (1985). According to Rybash and his collaborators (1991), caregivers have distinct responsibilities in each of these stages.

RELEVANT LITERATURE REVIEW

Stages of Alzheimer's, Caregiver Responsibilities, and Levels of Burden

Alzheimer's disease is progressive and irreversible, though specific symptomatology varies by patient. Common characteristics include forgetfulness, confusion, and motor and language impairments. The illness begins subtly and the typical age range at onset is between sixty to seventy-five years of age, although Alzheimer's has been diagnosed as early as the middle twenties (Gruetzner, 1988). The earliest symptoms are usually memory lapses about recent events that the person tries to disguise. As these impairments become more difficult to cope with, the individual starts to withdraw, becomes less sociable, and more apathetic and depressed. This early stage lasts approximately 2 to 4 years (Reisberg & Ferris, 1982; Mace, 1984). In this first stage, the caregiver does not have specific responsibilities per se; however, he or she has to deal with the realization that their relative may be experiencing permanent, irreversible cognitive decline.

During the second stage, mild cognitive decline, the Alzheimer's patient experiences more than one of the following: (a) becomes lost when traveling to an unfamiliar location, (b) co-workers indicate awareness of poor performance, (c) word and name-finding deficits increase, (d) reading comprehension declines, (e) patient persistently loses objects, and (f) patient has difficulty concentrating for a long period of time. Denial is prevalent.

Typically, patients deny that they have a disease, both to themselves, and to family members. The caregiver in this stage may have to keep reminding the patient where they have placed familiar objects and frequently needs to tell them the names of individuals they know very well (Nathan, 1986).

The third stage, moderate cognitive decline, is characterized by a decrease in knowledge of current and recent events, an inability to remember personal history, difficulty with simple arithmetic (such as an inability to balance a checkbook), and a decreased ability to function on a daily basis. For example, the patient can not find their way home or leaves the stove on or the water running. The victim may deny their deficits and feel angry and upset over losses. They may continue to attempt these tasks but withdraw from more and more activities as their failures and confusion increase. These patients are able to recognize familiar persons, to travel to familiar locations, and are oriented to time and place (Gruetzner, 1988).

Caregivers at this stage may have to track down patients who become lost when traveling and constantly must remind the patient of the identity of intimate others. Also, caregivers have to help the patient with their daily routines, such as hygiene, choosing clothes, and preparing meals.

Additionally, a caregiver may have to spend more time than previously finding objects the patient has misplaced. Caregivers also have to deal with the anxiety and denial that accompanies this stage.

Dependency deepens during the fourth stage, moderately severe cognitive decline, when the patient cannot survive without assistance (Pratt, Schmall & Wright, 1986). Cognitive decline is similar to the previous stage; however, it's much more noticeable. Caregivers' responsibilities are likewise similar but involve much closer monitoring and serious interruptions of caregivers' work and personal life.

Severe cognitive decline during the fifth stage involves deficits which completely impair daily functioning. Individuals at this stage forget names of significant others and are unaware of all recent events and their surroundings. Such individuals are usually incontinent and are unable to cope with basic daily tasks (Nathan, 1986). This stage places extreme demands on caregivers. Assistance with the most simple tasks of feeding and toileting are demeaning to the patient and time-consuming; however, they are made even more difficult by the victim's reactions to this assistance. The patient may become violent and make it almost impossible for the caregiver to accomplish these activities without stress (Nathan, 1986). In addition, the diurnal rhythm of the patient is frequently disturbed in such a way that the Alzheimer's victim reverses day and night, with the worst behavioral symptoms appearing in the evening. This is referred to as "sundowning." Sundowning may disrupt caregivers' sleep and lead to exhaustion and illness (Nathan, 1986). Victims are now able to recall only their own name, and are only occasionally able to distinguish familiar from unfamiliar persons.

During this stage, caregivers may feel a lack of appreciation when the victim cannot recognize them or their efforts (Gruetzner, 1988). Personality and emotional changes such as delusions, obsessions, anxiety, agitation, and previously nonexistent violent outbursts further complicate the caregiver's tasks.

The final stage of Alzheimer's is called very severe cognitive decline. All verbal abilities and psychomotor skills are lost and the victim requires assistance to do everything. The patient becomes bedridden and eventually dies (Nathan, 1986).

Stage progression generally lasts from 1 to 10 years, as the duration within any one stage is highly variable. The responsibility of the caregiver is incrementally greater with each stage until the patient becomes totally dependent on the caregiver for daily survival. Each stage of cognitive decline results in more responsibilities for the caregiver, more anger, guilt and grief, and an overall increase in caregiver burden.

Caregiver Reactions to Alzheimer's

Caregivers typically react to the early stages by covering up for the victim to avoid embarrassment. This denial delays the recognition, diagnosis and intervention that this overwhelming disease requires. Usually a caregiver needs an extreme crisis situation to force them to confront the severity of the situation. For example, a fire from a forgotten iron, an

inappropriate scene in a restaurant when the victim eats with their hands or undresses in public may be the necessary "last straw" (Nathan, 1986).

Caregivers frequently express hope that the diagnosis is a mistake and that the patient will recover; however, such denial is generally unproductive and may aggravate adjustment problems (Champagne-Shibbal & Stachow-Lipinska, 1986).

Throughout the course of the disease, caregivers may experience depression, isolation, and physical deterioration (Cantor, 1983). Continual care of an Alzheimer's patient, without relief, can leave caregivers feeling emotionally and physically exhausted. Isolation adds to the problem since the demands of 24 hour care prevent them from maintaining support and outside interests. Thus, it is not unusual for caregivers to become physically ill and to develop stress-related disorders. As a result of the bizarre characteristics of the disease, friends and extended family drift away. This adds to the caregiver's loneliness and depression (Lezak, 1978).

The Caregiver Role: An Overview of the Demographics of Caregivers

According to the National Long Term Care Survey (LTCS) conducted by Stone, Cafferata and Sangl (1987), cited in Birren and Schaie (1990), there are approximately 2.2 million caregivers in the United States. Approximately 70% are "primary" caregivers. About 21% of the caregivers are aged 85 or older. Thirty to 40% of caregivers are spouses, and 30-40% are adult

children, 80% of whom were female. Another study, by Martin, Ko, and Bengston in 1987, cited in Birren and Schaie (1990), found that 18% of caregivers are spouses, 38% are adult children, 3% are adult grandchildren, additionally, 4% of the caregivers are siblings, 6% are nieces or nephews and the other 31% are men and women caregivers assisting a relative of their spouse.

The Caregiver Role: Coping Styles and Burden

Coping Strategies for Caregivers. Research suggests that in coping with the Alzheimer's patient, caregivers use two basic strategies: problem-focused and emotion-focused coping (Folkman & Lazarus, 1980). Specifically, problem-focused coping refers to the effort aimed at managing or altering the stress-inducing problem, and involves seeking out information to learn more about the disease (Folkman & Lazarus, 1980). It appears from the literature that male caregivers tend to use more problem-focused coping strategies than female caregivers. An example of a problem focused strategy is participation in an educational program which has a positive impact on the coping abilities of primary caregivers of patients with Alzheimer's disease (Quayhagen & Quayhagen, 1989).

Another problem-focused coping strategy is seeking spiritual growth. A study by Pratt, Schmall, Wright, and Cleland (1985) found that spiritual growth was correlated with lower levels of burden experienced by caregivers.

According to Olson, McCubbin, Bonds, Larsen, Muyen, and Wilson (1985), cited in Pratt et al. (1985), spiritual growth may be useful in dealing with chronic problems or conditions by contributing to self-esteem.

Spiritual growth involves changing or growing as a person in a positive way. Examples of spiritual growth outcomes for caregivers are, "I came out of the experience better than when I went in" and "I changed something about myself so I could deal with the situation better" (Vitaliano, Maiuro, Russo & Becker, 1987).

On the other hand, emotion-focused coping strategies are directed toward regulating the caregiver's emotional response to the problem. Examples include wishful thinking, denial, and self-blame. However, acceptance may also be an outcome of emotion-focused coping (Folkman & Lazarus, 1980).

Wishful thinkers fantasize that they can change some aspect of the situation (Pruchno & Resch, 1989). Examples of wishful thinking experienced by caregivers include: "Hoped a miracle would happen," "Wished I was a stronger person--more optimistic and forceful," "Wish I could change what happened or the way I felt" (Vitaliano, Maiuro, Russo & Becker, 1987). According to Pruchno and Resch (1989), greater use of these fantasizing strategies yielded poorer mental health--more depression and anxiety--because these fantasizing strategies mentally remove the caregiver from the

demands of the Alzheimer's patient, and directs responsibility for the crisis to the self.

According to Sistler (1989), acceptance, another emotion-focused strategy, focuses attention on the stressor and/or on one's psychological reactions to the stressor, such as "changed something" or "accepted my feelings." Pruchno and Resch (1989) found that use of these strategies resulted in lower depression, higher positive affect, and less negative symptomatology. It seems that realistic appraisal and acceptance of this very difficult situation is healthy and enables the caregiver to accommodate their own needs as well as those of their spouse.

Lastly, in some instances, emotion-focused and problem-focused coping appear to overlap. This is demonstrated in seeking social support. Specifically, seeking social support involves seeking information about the disease (problem-focused) and seeking communal support for one's emotional burdens (emotion-focused). Such social support is found with Alzheimer's support groups, and through family or friends (Gonyea, 1989). Research suggests that social support may protect an individual from some of the negative aspects of life stressors (Pilisuk & Froland, 1978; Katz, 1981; Lieberman & Borman, 1979).

According to Gonyea (1989), during the past two decades there has been an increase in the number of self-help or mutual aid groups in our society. For example, the Alzheimer's Disease and Related Disorders

Association (ADRDA) has established a nationwide network for families with Alzheimer's disease patients. One of ADRDA's outreach efforts involves caregiver support groups. Currently, there is only limited research assessing the impacts of support group participation on caregivers. Gonyea's (1989) examination of Alzheimer's disease support groups included a meta-analysis of 47 groups and dealt with their structure, format, and perceived benefits. Gonyea's review suggests that overall, members benefitted from their support group experience. In general, the support group was perceived as most helpful in providing information about Alzheimer's disease, health and social services, and in offering families social or peer support. This study also found, however, that such groups were not as successful in addressing caregivers' emotional needs, exploring how Alzheimer's disease affects the whole family system, or in strengthening family relationships and caregiver skills.

Research on Coping Strategies. In an interesting study examining problem-focused and emotion-focused coping strategies, Pruchno and Resch (1989) found that successfully coping with an Alzheimer's patient requires both managing the day-to-day demands, (problem-focused strategies) and monitoring the emotional distress experienced by the caregiver (emotion-focused strategies). Thus, a combination of the coping strategies may enable the caregiver to meet the demands of the patient and the need for self-

protection; this research suggests that both strategies are needed to promote positive mental health and alleviate stress (Mechanic, 1978).

A common finding in the coping literature suggests that the caregiver's mental health status has an effect on their level of stress as a caregiver. Specifically, caregivers who viewed their own mental health status more negatively had a greater sense of perceived burden than those caregivers who viewed their mental health more positively (Killen, 1990). Additionally, Morris and Britton (1989), cited in Killen (1990) stated that the impact of caregiving depends on a range of other factors, such as level of effective support received from other family members and friends, and the caregiver's feeling of control over their situation, as well as their relationship to the patient, and the residential location of the patient (cited in Killen, 1990).

Caregiver Burden. Burden is defined as the degree to which the caregiver perceives the caregiving situation as having negative effects on his or her life in terms of emotional, physical, social, and economic status (Montgomery, Gonyea & Hooyman, 1985). Generally, researchers have found that caring for an Alzheimer's patient places a substantial amount of strain on caregivers. As mentioned earlier, one source of caregiver burden is social isolation due to the constant demands of caregiving; another source of burden is financial: the high cost involved in caring for the Alzheimer's patient and

the likelihood of career interruption are just two examples of financial burden (Montgomery, Gonyea, & Hooyman, 1985).

Burden is a construct with several different components, including emotional costs, feelings of embarrassment, role strain, and a deterioration in physical health (Zarit & Zarit, 1986). Much of the recent research on caregivers of dementia sufferers has followed the distinction made by Grad and Sainsbury (1965) between objective and subjective burden. Objective burden refers to the actual changes in the caregiver's life, such as having less time, the physical burden of care, changes in daily routine, and changes in employment and health (Gatz, Bengston, & Blum, 1990). Examples of objective burden are the daily demands of bathing and feeding the patient. Subjective burden refers to feelings of distress, operationalized as the impact of caregiving on different areas of the caregiver's life, including stress and strain, negative effects on morale, anxiety, and depression (Morris, Woods, Davies & Morris, 1991).

Purpose and Rationale for the Study

As mentioned earlier, there has been limited research assessing the coping styles of caregivers to show how these styles relate to their perception of objective and subjective burden. With increased longevity, the incidence of Alzheimer's is expected to rise during the next century, placing more individuals in the caregiver role. One result of this is increased attention to

the caregiving role. The purpose of the present study is to gain a better understanding of caregivers' coping styles in order to show how coping strategies relate to levels of perceived burden. A further application of the study is the development of proposals for interventions in caregiver activities.

As discussed above, problem-focused coping involves trying to manage or change the problem that is causing the stress (an instrumental approach); however, it does not focus on dealing with the caregiver's emotional response to the problem, which is a major focus of emotion-focused coping. Also, problem-focused coping is meant to help the caregiver cope with the objective burden of caregiving. Once again, objective burden refers to the actual changes in the caregiver's life due to the constant demands of patient care; it includes such activities as feeding, grooming, bathing, and toileting. Thus, the problem-focused coper would make a plan to carry out these activities, or would try harder, or would find some solution, or change something in order to help cope with the situation better. Such problem-focused coping may indirectly result in reduction of caregiver stress, depression, and anxiety, all aspects of subjective burden. Additionally, much of the research suggests that engaging in problem-focused coping has a positive impact on caregiver coping abilities and results in a lower level of overall burden. Accordingly, it is first hypothesized that caregivers who score high on the problem-focused coping scale will indicate low levels of objective burden, low levels of subjective burden, as well as low levels of overall burden.

In contrast with problem-focused coping, emotion-focused coping is geared toward regulating the caregiver's emotional response to the problem (an expressive approach). Examples include wishful thinking, denial, self-blame, but also, acceptance. There appears to be a direct relationship between emotion-focused coping and subjective burden. Subjective burden refers to feelings of distress as a result of the impact of caregiving in several areas of the caregiver's life. Emotion-focused coping by definition helps focus on the caregiver's emotional reactions to the disease; however, it neglects issues related to dealing with and accomplishing the daily demands of caregiving (objective burden). Some research (e.g., Killen, 1990; Sistler, 1989) suggests that an emotion-focused coping approach for this particular type of disease seems to be less effective in reducing overall burden compared to a problem-focused coping approach. Also, it is important to note that on the Ways of Coping Checklist (WCCL), the majority of the items on the emotion-focused scale consist of wishful thinking, self-blame and denial, and research suggests that strategies which mentally remove the caregiver from the caregiving role are ineffective in reducing burden. Therefore, secondly, it is hypothesized that caregivers who score high on the emotion-focused scale will indicate low levels of subjective burden, while their perceived objective burden and overall burden will remain high.

Finally, in line with some of the literature (e.g., Mechanic, 1978; Pruchno & Resch, 1989), we suggest that combination coping, which involves

the use of both problem-focused and emotion-focused coping would allow the caregiver to manage their own lives more effectively while dealing with the daily demands of caring for an Alzheimer's patient. As a result, thirdly, it is hypothesized that caregivers who score high on the combination scale will indicate low levels of both objective and subjective burden, as well as low overall burden.

To summarize, three hypotheses were proposed in this study:

1. Caregivers who score high on the problem-focused coping scale will indicate low levels of objective burden, subjective burden, and overall burden.
2. Caregivers who score high on the emotion-focused coping scale will indicate low levels of subjective burden, while their perceived objective burden and overall burden will remain high.
3. Caregivers who score high on the combination coping scale will indicate low levels of objective burden, subjective burden, and overall burden.

METHOD

Subjects

The sample included 32 caregivers of Alzheimer's disease patients. Given the greater numbers of female caregivers, it was impossible to obtain an equal number of male and female caregivers, though there was an attempt to include as many male caregivers as possible. All subjects were drawn from San Bernardino County and Riverside County in Southern California. The caregiver subjects were recruited from such sources as the Alzheimer's Disease Research Center, the Alzheimer's Disease and Related Disorders Association (ADRDA) and support groups for caregivers of Alzheimer's patients.

Of the 32 caregivers, 20 (62%) were spousal caregivers, 9 (28%) were adult child caregivers, and the remaining 3 (approximately 10%) were siblings of the Alzheimer's patient. The respondents were primarily female (26/32 = 81.3%) and white (29/32 = 90.6%). The remainder of the respondents were a composite of blacks (1/32 = 3.1%), Hispanics (1/32 = 3.1%), and Native Americans (1/32 = 3.1%). The majority of the respondents were between 60 and 69 years of age, and the ages ranged from 40 to 89 years. Most (75%) of the caregivers were married, while 6.3% were single, 9.4% were divorced, and 9.4% widowed. Also, the majority of the sample was retired (75%), while approximately 20% were homemakers and the remainder were working, full-

time or part-time. About 3% of the sample had not completed high school, 25% had completed high school, 43.8% had some college, 9.4% had a college degree, 12.5% had done some post graduate work, and 6.3% had an advanced degree. The annual family income ranged from \$10,000 per year to more than \$75,000, with a mean of \$37,500.

Measures

A set of three questionnaires was used in this study:

1. The Caregiver Burden Inventory (CBI),
2. A demographic sheet, and
3. The Ways of Coping Checklist (WCCL).

The Caregiver Burden Inventory. The CBI, developed by Novak and Guest (1989) is a multidimensional measure of caregiver burden (see Appendix A). The measure includes 24 items and is divided into five subscales. The score on each item ranges from 0 (not at all descriptive) to 4 (very descriptive). The internal consistency of this multidimensional measure is good. For example, subscales A and B had Alpha values of .85 and subscales C, D, and E had Alpha values of .86, .73, and .77, respectively.

A. Time-Dependence Burden. This subscale consists of five questions (1-5) and describes the burden due to restrictions on the caregiver's time. All of these five questions are related to the measure of objective burden.

B. Developmental Burden. This subscale consists of five questions (6-10) and describes the caregivers' feelings of being "off time" in their development compared to their peers. All of these five questions are related to the measure of subjective burden.

C. Physical Burden. This subscale consists of four questions (11-14) and assesses the caregivers' feelings of chronic fatigue and damage to physical health. These four questions are related to the measure of objective burden.

D. Social Burden. This subscale consists of five questions (15-19) and describes caregivers' feelings of role conflict. For example, they may have to limit the time and energy that they invest in relationships or in their jobs. The questions on this subscale are related to the measure of objective burden.

E. Emotional Burden. This last subscale consists of five questions (20-24) assessing the caregiver's negative feelings toward the patient related to the patient's bizarre behavior. These questions are related to the measure of subjective burden.

The Demographic Sheet. The demographic sheet (Appendix B) contains 8 questions concerning the subject's background, including age, sex, ethnicity, education, and family income.

The Ways of Coping Checklist. This measure was adapted from Folkman and Lazarus (1980) and revised by Vitaliano, Russo, Carr, Maiuro,

and Becker (1985). It contains 42 items on a Likert-type scale, assesses coping strategies used by caregivers (see Appendix C). Each item is rated on a four point scale from zero (does not apply and/or not used) to three (used a great deal). The Ways of Coping Checklist uses five scales to determine caregiver coping strategies: (a) problem-focused, (b) seeking social support (combination scale), (c) wishful thinking, (d) avoidance, and (e) self-blame. The wishful thinking, avoidance, and self-blame scales were combined into an emotion-focused scale. The problem-focused scale includes questions 1 through 15 with a score range of 0-45. The combination scale includes questions 16 through 21 with a score range of 0-18. The emotion-focused scale includes questions 22 through 42, with a score range of 0-63. This measure has good internal consistency, with a Cronbach's Alpha of .82. Additionally, according to Vitaliano, Maiuro, and Russo (1987), this revised scale has "respectable construct and criterion-related validity" (p.21); however, no specific numbers were given in their review. Construct validity was assessed by examining the relationships of coping to the source of the stressor, appraisal, and distress.

Criterion-related validity was determined by examining the degree to which the original versus revised coping scales related to membership in a support group. Specifically, membership in this group reflects distress and/or illness behavior, thus it is a valid behavioral criterion for coping strategies (Vitaliano, Maiuro, and Russo, 1987).

Procedure

Caregivers who attended support groups were asked to participate in this study on a voluntary basis. They were presented with a packet explaining the purpose of the study. The same packet was mailed out to other caregivers in the area, identified by a support group leader. Those participants who agreed to participate were asked to sign an informed consent form (see Appendix D). The packet contained The Caregiver Burden Inventory, The Ways of Coping Checklist, and a Demographic Data Sheet. Upon completion of the questionnaires, the caregivers were given a debriefing statement (see Appendix E), explaining the nature and the purpose of this research, giving instructions for obtaining results of the study, and providing contact persons and telephone numbers for questions or concerns regarding their participation in the study. All of the participants were treated in accordance with all ethical and legal APA standards.

Scoring and Analysis

The CBI Scores. Subjects' scores on each subscale of The Caregiver Burden Inventory (CBI) range from 0 to 20, except for Subscale C (the physical burden) which contains 4 items instead of 5. Thus the score range for Subscale C is 0-16. Subscale C score was adjusted by multiplying the score by 1.25. Separate scores were obtained for these 5 subscales. As mentioned earlier, the focus of this study was on subjective, objective, and

overall burden. The subjective burden score was constructed by adding the scores from subscale B and subscale E. Scores for subjective burden range from 0-40. The objective burden score was obtained by adding the scores from subscales A, C, and D. Scores for objective burden range from 0-60. The overall burden score was obtained by adding all the scores from the 5 subscales; the overall burden score range is 0-100.

The WCCL Scores. According to Vitaliano, Maiuro, Russo, and Becker (1987), raw scores for a particular coping scale on the Ways of Coping Checklist (WCCL) do not accurately reflect an individual's emphasis on the specific strategies. Accordingly, relative scores, which represent the percentage of efforts made on the specific strategies were used. Scoring on the WCCL begins with three raw scores for each subject. The first raw score is for the problem-focused scale (PF), the second raw score is for the emotion-focused scale (EF), and the third raw score is for the scale that measures the combination of problem-focused and emotion-focused coping. The score range for the PF scale is 0-45; for the EF scale is 0-63; and for the combination scale, 0-18. Based on these raw scores, a relative score is computed for each of the three subscales. For each subject, relative scores can be computed by first obtaining a mean score for each scale (i.e., raw score divided by the number of items). A specific relative score is computed by dividing the mean item score (MI) on each scale by the sum of the three mean item scores, then

multiplying by 100%. For example, the relative score for problem-focused coping (PF) is:

$$PF\% = \frac{\text{MI for PF}}{\text{Sum of MI Scores}} \times 100\%$$

Thus for a particular subject $PF\% + EF\% + \text{Combination}\% = 100\%$. A Pearson r correlation was used to analyze the relationship between the degree of each coping style and the level of each kind of perceived burden. In this study, a significance level of $p = .05$ was adopted to conclude statistical significance.

Results and Discussion

Table 1 shows the results of the Pearson correlation analyses which were conducted to assess the relationship between: (a) degree of emotion-focused coping and levels of objective burden, subjective burden, and overall burden; (b) degree of problem-focused coping and levels of objective burden, subjective burden, and overall burden; and (c) degree of combination coping and levels of objective burden, subjective burden, and overall burden.

Table 1

Intercorrelations Between Levels of Perceived Burden and Degree of Coping Strategy Used^a

Type of Coping Strategy	Type of Perceived Burden		
	Objective	Subjective	Overall
Emotion-focused	.48**	.56**	.55**
Problem-focused	-.35*	-.32*	-.36*
Combination	-.12	-.22	-.17

^aNumber of Subjects = 32.

* $p \leq .05$. ** $p \leq .01$.

The Relationship Between Levels of Perceived Burden and the Degree of the Use of Problem-Focused Coping Strategy

As can be seen from Table 1, as hypothesized, employing a problem-focused coping strategy allowed caregivers to significantly release their burden. This is true for all three kinds of burden: objective, $r(31) = -.35$, $p < .05$; subjective, $r(31) = -.32$, $p < .05$; and overall burden, $r(31) = -.36$, $p < .05$.

As mentioned in the Introduction, a problem-focused coping approach concentrates on managing or altering the problem causing the distress and may involve changing something about caregivers to help them better cope with the patient. This type of coping style uses a more instrumental approach, focused on managing objective burden was confirmed in this study. In addition, this finding that using a problem-focused coping strategy allows caregivers to release their burden is consistent with the findings suggested by Pratt, Schmall, Wright and Cleland (1985); Vitaliano, Cowley, Luciano, Zheng and Dunner (1992); and Quayhagen and Quayhagen (1989) which stated that greater use of problem-focused strategies had a positive impact on the caregiver's ability to cope and resulted in a lower level of burden.

The Relationship Between Levels of Perceived Burden and the Degree of the Use of Emotion-Focused Coping Strategy

As indicated in Table 1, emotion-focused coping strategy was not an effective coping strategy in reducing caregivers any kinds of perceived burdens. There was a significant positive correlation between the degree of emotion-focused strategy used in coping and each of the three kinds of burdens of our interest (i.e., subjective, objective, and overburdens).

This set of results partially supported the second hypothesis proposed in this study. Caregivers who score high on the emotion-focused coping scale did not indicate low levels of subjective burden. However, their levels of perceived objective burden and overall burden remained high.

A possible explanation for this finding is that emotion-focused coping strategies which might mentally remove the caregiver from the constant demands of caregiving were ineffective for caregivers who were dealing with patients with this particular type of irreversible, degenerative disease, even when dealing with subjective burden (Pruchno & Resch, 1989). Additionally, perhaps, because Alzheimer's is such a long term disease that these emotion-focused coping strategies which include wishful thinking, avoidance, self-blame, and denial may only be more effective in the very beginning stages of the illness. Specifically, caregivers may hope that the diagnosis is a mistake, that this is not happening to them and their loved one will soon get better; or in the early stages of the disease they might go through a period of denial.

Following Folkman and Lazarus (1984) discussions, we suggested that coping with a stressor may be situation specific, in that an individual's coping style may change as the stressor or situation changes.

The Relationship Between Levels of Perceived Burden and the Degree of the Use of Combination Coping Strategy

As can be seen from the results summarized in Table 1, employing a combination coping strategy did not significantly reduce objective burden, subjective burden, and overall burden. However, the correlation shows the expected negative relationship. This suggests that a "combined coping" strategy may need further exploration in a larger sample. According to the literature, due to the nature and characteristics of Alzheimer's disease, the combination coping style enables the caregiver to more effectively live their own lives while accommodating the needs of the patient (Pruchno & Resch, 1989; and Mechanic, 1974).

There were no statistical analyses performed on coping styles by gender due to the small number of men in the sample.

CONCLUSIONS

Most the hypotheses from this research were supported. In this study, the problem-focused coping style seemed to be the most effective in alleviating caregiver burden. By contrast, an emotion-focused approach was related to higher levels of objective, subjective, and overall burden. It seems that the realistic appraisal involved in problem-focused coping allows the acceptance of the prognosis in Alzheimer's disease, which aids caregivers in successfully coping with the patient and managing their own lives more effectively. By contrast, emotion-focused coping styles, such as denial, wishful thinking, and avoidance seem counterproductive for this particular type of long term disease which is degenerative, irreversible, and can last anywhere from one to 20 years.

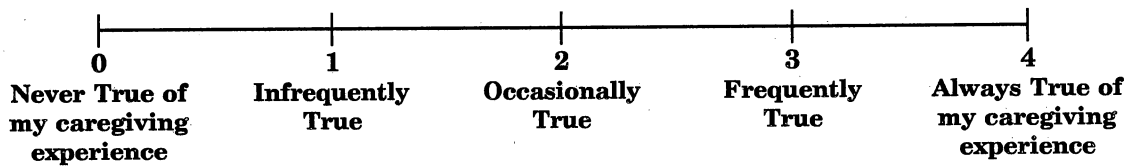
Lastly, the results from the study are limited due to the small sample size and the non-representativeness of this white, middle class, female sample. Moreover, in future studies, additional variables need investigation. For example, we need to know more about the effects of duration of the caregiving role. Perhaps caregivers use a more emotion-focused approach, going through a denial period in the beginning, and a few years later, may begin to be more problem-focused in their coping with the patient. Thus, future research might look at coping styles as the patient goes through the different stages of the disease, using a longitudinal approach. Finally, applied

research is needed to relate what is known about caregiver coping styles and related levels of burden to everyday strategies in caregiving settings, to help present and future caregivers cope with this devastating and, increasingly more common disease.

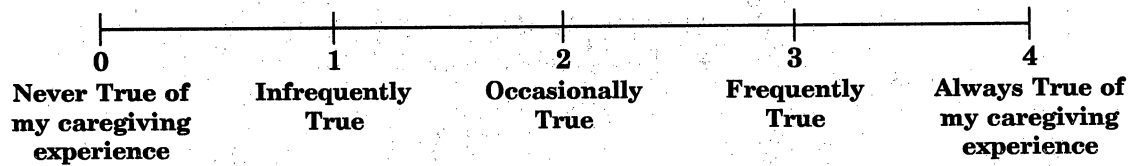
APPENDIX A
THE CAREGIVER BURDEN INVENTORY

CBI

The questions in this scale ask you about your experiences related to the role of caregiving. Every person's experience will be different, so there are no "right" or "wrong" answers. Also, even if the person you recently cared for is no longer being cared for by you, please answer the questions as you would when you were in the caregiver role. For each question, use the scale below to rate your caregiving experiences.



- ___ 1. My care receiver needs my help to perform many daily tasks.
- ___ 2. My care receiver is dependent on me.
- ___ 3. I have to watch my care receiver constantly.
- ___ 4. I have to help my care receiver with many basic functions.
- ___ 5. I don't have a minute's break from my caregiving chores.
- ___ 6. I feel that I am missing out on life.
- ___ 7. I wish I could escape from this situation.
- ___ 8. My social life has suffered.
- ___ 9. I feel emotionally drained due to caring for my care receiver.
- ___ 10. I expected that things would be different at this point in my life.
- ___ 11. I'm not getting enough sleep.



- _____ 12. My health has suffered.
- _____ 13. Caregiving has made me physically sick.
- _____ 14. I'm physically tired.
- _____ 15. I don't get along with other family members as well as I used to.
- _____ 16. My caregiving efforts aren't appreciated by others in my family.
- _____ 17. I've had problems with my marriage.
- _____ 18. I don't do as good a job at work as I used to.
- _____ 19. I feel resentful of other relatives who could but do not help.
- _____ 20. I feel embarrassed over my care receiver's behavior.
- _____ 21. I feel ashamed of my care receiver.
- _____ 22. I resent my care receiver.
- _____ 23. I feel uncomfortable when I have friends over.
- _____ 24. I feel angry about my interactions with my care receiver.

APPENDIX B
THE DEMOGRAPHIC SHEET

DEMOGRAPHIC INFORMATION

Please indicate your caregiving role by **checking** the appropriate space:

- (1) spouse caring for a spouse
- (2) adult child caring for a parent
- (3) other (please specify) _____

1. What is your sex?

- (1) Female
- (2) Male

2. How old are you?

- (0) 20 to 29 years
- (1) 30 to 39 years
- (2) 40 to 49 years
- (3) 50 to 59 years
- (4) 60 to 69 years
- (5) 70 to 79 years
- (6) 80 to 89 years
- (7) 90 years or more

3. What is your ethnic background?

- (1) Black or African American
- (2) White or Caucasian
- (3) Latino or Spanish American
- (4) Asian, Pacific Islander or Filipino
- (5) Other (describe) _____

4. What is your marital status?

- (1) Single
- (2) Married
- (3) Divorced
- (4) Widowed
- (5) Separated

5. Which of the following best describes your current employment situation?
(Check as many as apply to you).

- (1) Working full-time
- (2) Working part-time
- (3) Unemployed
- (4) Retired
- (5) Homemaker
- (6) Full-time student
- (7) Part-time student
- (8) Other (please describe) _____

6. What is your total family income for 1992?

- (1) I don't have one
- (2) Under 10,000
- (3) 10,000-15,000
- (4) 15,000-20,000
- (5) 20,000-30,000
- (6) 30,000-45,000
- (7) 45,000-75,000
- (8) above 75,000

7. What is the highest level of formal education that you completed?

- (1) Less than high school
- (2) High school
- (3) Some college
- (4) College degree
- (5) Some post graduate
- (6) Advanced degree

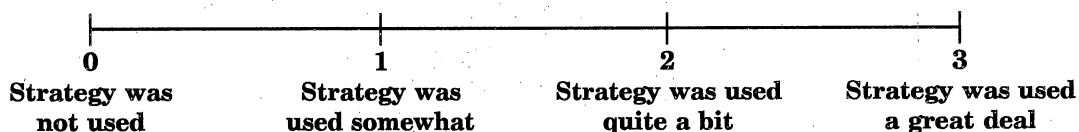
8. How often do you participate in religious activities?

- (1) Never
- (2) Rarely
- (3) Occasionally
- (4) Monthly
- (5) Weekly
- (6) More than weekly

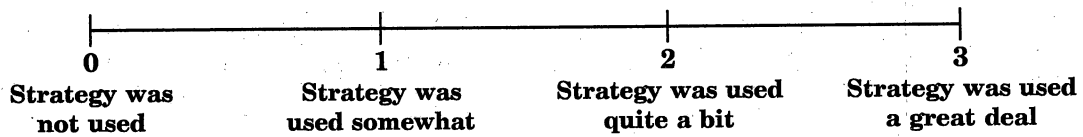
APPENDIX C
THE WAYS OF COPING CHECKLIST

WCCL

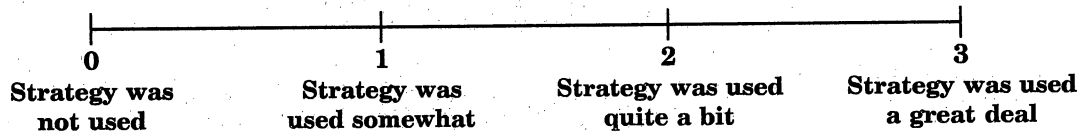
These questions relate to some of the actions taken by caregivers in providing help to Alzheimer's patients. Every person's actions will be different, so there are no "right" or "wrong" answers. Also, even if the person you recently cared for is no longer being cared for by you, please answer the questions as you would when were in the caregiver role. Please read each item, and the scale below to indicate how often the strategy was used:



- ___ 1. Bargained or compromised to get something positive from the situation.
- ___ 2. Concentrated on something good that could come out of the whole thing.
- ___ 3. Tried not to burn my bridges behind me, but left things open somewhat.
- ___ 4. Changed or grew as a person in some way.
- ___ 5. Made a plan of action and followed it.
- ___ 6. Accepted the next best thing to what I wanted.
- ___ 7. Came out of the experience better than when I went in.
- ___ 8. Tried not to act too hastily or follow my own hunch.
- ___ 9. Changed something so that things would turn out all right.
- ___ 10. Just took things one step at a time.
- ___ 11. I knew what had to be done, so I doubled my efforts and tried harder to make things work.



- ___ 12. Came up with a couple solutions to the problem.
- ___ 13. Accepted my strong feelings but didn't let them interfere with other things too much.
- ___ 14. Changed something about myself so that I could deal with the situation better.
- ___ 15. Stood my ground and fought for what I wanted.
- ___ 16. Talked to someone to find out about the situation.
- ___ 17. Accepted sympathy and understanding from someone.
- ___ 18. Got professional help and did what they recommended.
- ___ 19. Talked to someone who could do something about the problem.
- ___ 20. Asked someone I respected for advice and followed it.
- ___ 21. Talked to someone about how I was feeling.
- ___ 22. Blamed yourself.
- ___ 23. Criticized or lectured yourself.
- ___ 24. Realized you brought the problem on yourself.
- ___ 25. Hoped a miracle would happen.
- ___ 26. Wished I was a stronger person--more optimistic and more forceful.
- ___ 27. Wished that I could change what had happened.



- ___ 28. Wished I could change the way that I felt.
- ___ 29. Daydreamed or imagined a better time or place than the one I was in.
- ___ 30. Had fantasies or wishes about how things might turn out.
- ___ 31. Thought about fantastic or unreal things (like perfect revenge or finding a million dollars) that made me feel better.
- ___ 32. Wish the situation would go away or somehow be finished.
- ___ 33. Went on as if nothing had happened.
- ___ 34. Felt bad that I couldn't avoid the problem.
- ___ 35. Kept my feelings to myself.
- ___ 36. Slept more than usual.
- ___ 37. Got mad at the people or things that caused the problem.
- ___ 38. Tried to forget the whole thing.
- ___ 39. Tried to make myself feel better by eating, drinking, smoking, taking medications.
- ___ 40. Avoided being with people in general.
- ___ 41. Kept others from knowing how bad things were.
- ___ 42. Refused to believe it had happened.

APPENDIX D
INFORMED CONSENT

Dear Participant:

Hello, my name is Kevin Olin, and I am a graduate student at California State University, San Bernardino. I am currently involved in a research project with Dr. Joanna Worthley concerning men and women caregivers of Alzheimer's patients. The purpose of this research is to gain a better understanding of the caregiving role and the varied experiences of caregivers with this devastating and traumatic disease.

You will be asked to answer two questionnaires. It will take approximately 45 minutes to complete both questionnaires. Participation in this study is voluntary and you are free to withdraw from the study at any time. Your responses to these questionnaires are kept anonymous in order to ensure confidentiality. If you choose to fill it out, please do so as completely and carefully as possible. You have the right to refuse to answer any questions which make you feel uncomfortable. Any questions that you may have about this study can be answered by the researcher named below. When the study is completed (Fall 1993), results from the study can be obtained by contacting Dr. Joanna Worthley at the address given below.

Thank you for your participation!

Participant's signature

Researcher's signature

Dr. Joanna Worthley
Department of Psychology
Office # TO-11
California State University
San Bernardino, CA 92407

APPENDIX E
DEBRIEFING STATEMENT

Dear Participant:

The purpose of the research was to examine the caregiving role and the ways in which caregivers cope with Alzheimer's disease. Specifically, this study focused on caregiver coping strategies and related levels of burden. Some of the styles seem to be more effective than others in reducing levels of burden among caregivers. The goal of this research was to gain a better understanding of the effectiveness of the different coping styles in order to help present and future caregivers cope with this traumatic and devastating disease. Any questions or concerns regarding this study can be answered by contacting Dr. Joanna Worthley, department of Psychology, Office # TO-11, San Bernardino, CA, 92407, (909-880-5595). Thanks again for your participation.

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