Dementia caregivers: Educational intervention and coping styles

Joan Dolores Ladderbush

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DEMENTIA CAREGIVERS:
EDUCATIONAL INTERVENTION AND COPING STYLES

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
Joan D. Ladderbush
June 1994
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Approved by:

Kelly R. Norton, Chair
Department of Psychology

Joanna S. Worthley,
Department of Psychology

Gloria A. Cowan,
Department of Psychology

J. Franklin Randolph,
Loma Linda University

Date 5-31-94
Caregivers of older adults who suffer from dementia experience stressors that contribute to negative psychological, social, and health consequences. Caregivers of dementia patients who were referred to a community-based comprehensive assessment program for demented and/or chronically ill older adults by physicians or community agencies were studied. Caregivers of demented and nondemented patients who attended a complete assessment were compared to a group of caregivers of demented and nondemented patients who chose not to attend. During the comprehensive assessment, caregivers were educated as to their ill family member's disease, its progression, how to care for the patient, medications, possible side effects, community services, and financial resources available. The findings indicated that the assessment program was effective as an educational resource for both caregivers of dementia and non-dementia patients. The analyses also revealed a significant, positive relationship between caregiver education and problem-focused and growth oriented coping. In addition, members of the treatment group were found to be more intrinsically religious and to feel less resentment toward their elderly relative, and the situation, than the comparison group.
ACKNOWLEDGEMENTS

To my committee members Dr. Gloria A. Cowan and Dr. Joanna S. Worthley for their thoughtful review and comments, and to Dr. J. Franklin Randolph for allowing me the opportunity of an externship at the Center for Aging and Health, where he explained the interworkings of the Comprehensive Functional Assessment. My grateful acknowledgements to my committee chair, Dr. Kelly R. Morton, whose guidance and invaluable assistance enabled me to complete this research.

My sincere appreciation to my husband, Richard, for his support and patience, and for always being there.

I also wish to acknowledge the Associated Students, Incorporated, for support of my research through an ASI award, which made this project possible.
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INTRODUCTION

Caregivers of older adults who suffer from dementia experience stressors that contribute to negative psychological, social, and health consequences (George & Gwyther, 1986; Haley, Levine, Brown, Berry, & Hughes, 1987). Because dementia is a degenerative disease process which produces severe intellectual impairment in older adults, caregiving for dementia patients is often extremely taxing and exhausting (Pratt, Schmall, Wright, & Cleland, 1985). The caregiver often faces career interruptions, financial drain, social isolation, lack of time for self, family or friends, as well as heavy physical labor while caregiving.

However, it is clear that there are marked individual differences in the degree to which caregivers experience depression and other negative outcomes (Haley & Pardo, 1989). Many studies concerning caregivers of dementia patients report that objective measures of patient impairment show little relationship to the adjustment of the caregiver (George & Gwyther, 1986; Haley, Levine, Brown, & Bartolucci, 1987; Pagel, Becker, & Coppel, 1985; Zarit, Todd, & Zarit, 1986). The caregivers' subjective interpretation of caregiving tasks as stressful appears to have a stronger impact on caregiver well-being than the actual tasks themselves (Haley, Brown, & Levine, 1987). According to Shultz and Williamson (1991), social support seems to be more important than the care recipient's level
of impairment in predicting caregiver burden and the health consequences of perceived stress. The more caregivers perceive that social support is available, the less depression they report. The results of Shultz and Williamson's (1991) two-year longitudinal study of caregiver's depression suggest that women, but not men, perceive a significant decrease in social support over time. Women more than men reported that members of their support network either do not help as expected, withdraw from the caregiver or patient, or actually make matters worse. In addition, personality characteristics of the caregiver, care recipient, or both contribute to the individual differences in caregiver strain (Hooker, Monahan, Shifrin, & Hutchison, 1992).

Two hypotheses about the relationship between the severity of patients' dementia and caregiver outcome have been suggested by Townsend, Noelk, Deimling, and Bass (1989). The first is a wear and tear hypothesis which states that some caregivers become progressively overwhelmed with stressors as the patient's symptoms steadily worsen. Since caregiving of dementia patients has been likened to exposure to multiple long term stressors, it appears reasonable that caregivers' physical and psychological stamina is depleted over time (Shultz & Williamson, 1991). According to Fitting, Rabins, Lucas, and Eastham (1986), however, increasing severity of the care recipient's illness
is only associated with higher perceived burden in younger wives and older husbands. The younger female caregivers appeared more lonely and resentful of their plight. It may be that their many other responsibilities have made adjustment to the caregiver role more difficult. Older male caregivers may have felt powerless to change the situation and, therefore, were in varying states of despair due to lack of control of the situation and unpredictability of the disease.

A second hypothesis is that the caregiver either stabilizes or improves in functioning over time, despite the patient's progressive worsening. In this adaptation hypothesis, the caregiver learns to adapt with experience, even though the patient's symptoms and problems increase. On the other hand, Pruchno and Resch (1989) suggest that caregiver burden does not follow a linear trajectory along with patient impairment, but peaks in the middle phases of dementia when behavior disturbances are most problematic.

There are other factors that contribute to caregiver burden, such as caregivers' poorer physical health, lesser degree of emotional investment in the caregiving role, and greater degree of spouse impairment. These factors, however, predicted burden in wives, but not in husbands. Caregiver burden is experienced by both young and old, male and female, but in varying degrees of severity and due to many different causes.
Alzheimer’s Disease and Other Dementias

Alzheimer’s disease (AD) appears to be the most frequent cause of dementia for which there is no known cause or cure (Mace & Rabins, 1981). Although the definitive diagnosis of Alzheimer’s disease depends on evidence of excess plaques and tangles at autopsy or brain biopsy, a variety of clinical tests and techniques now make it possible for health care professionals to identify probable AD with confidence (Drachman, Friedland, Larson, & Williams, 1991). Once dementia is established, the differential diagnosis includes about 20 causes, but only a few are common. Some of the dementias (perhaps 15%) are reversible, and nearly all are favorably influenced by optimal medical care. The early symptoms of Alzheimer’s disease are memory loss, confusion, and disorientation. Although the disease symptoms may not necessarily increase over time, the patient’s behaviors do change (Haley & Pardo, 1989; Zarit, Todd, & Zarit, 1986). Patient behaviors may become disruptive and dangerous, and may include wandering, paranoid accusations, and restlessness. The patient may also lose the ability to manage activities of daily living, such as bathing, dressing, and toileting. Late in the illness the patient becomes physically handicapped as well as intellectually impaired, and requires constant care.

Multi-infarct dementia is a second common cause of dementia in older adults (Mace & Rabins, 1981). The
condition is irreversible, but reducing risk factors for stroke can somewhat stabilize the condition (Drachman, Friedland, Larson, & Williams, 1991). Multi-infarct dementia generally progresses in a step-like manner, rather than gradually as in Alzheimer’s disease. This progression is caused by repeated strokes that destroy small areas of the brain. The strokes may be small enough so that the patient or caregiver is not aware of them. The patient may suddenly appear worse, and then remain stable for a period of time. After a time lapse, another stroke occurs and the sequence is repeated, leaving the patient in yet another worsened stage.

Dementia progresses in severity, and unless the patient dies from some other disease, this decline in basic functioning will finally lead to a severe end stage in which the patient is bedridden, unable to chew solid food, and incontinent. Death eventually follows from a combination of deterioration and the complications of this bedridden state. Caregiver Characteristics

The most consistent finding in caregiving research is that the majority of family caregivers are women. Stone, Cafferata, and Sangl (1987) reported that 72% of their sample of 2,089 caregivers were women, with adult daughters comprising 29% of all caregivers. The average age of the caregivers was 57.3 years.

Horowitz (1985) reports that caregiving continues to be
primarily the role of daughters and daughters-in-law when there is no available spouse. Sons tend to take on the role as primary caregiver only in the absence of an available female sibling; however, the caregiving behavior of daughters-in-law often compensates for that of sons. In addition, women caregivers offer significantly higher levels of over-all assistance, such as attending to the personal hygiene needs of the care recipient, as well as engaging in household tasks and meal preparation. It has been suggested that women perform these tasks as extensions of the nurturant activities and behaviors performed as mothers and wives (Miller & Cafasso, 1992). Men, on the other hand, are more likely to receive help with tasks, especially with housework, laundry, and cooking (Pruchno & Resch, 1989).

The assumption that men and women will respond to the caregiver role differently is based upon cultural stereotypes. Traditionally, women have been the caregivers in their families; however, Lowenthal (1975) suggests that middle-aged women undergo a role shift away from caregiving and may resent a return to the full-time caregiver role. Moreover, Zarit, Todd, and Zarit (1986) report that female caregivers exhibit significantly higher levels of stress than their male counterparts.

Male caregivers, on the other hand, typically provide transportation and help the older person with home repairs and financial management. Men may enjoy the role of
caregiver because it is a new experience, and a means of expressing their nurturing feelings. Schultz and Williamson (1991) report, however, that although male caregivers exhibit normative levels of depressive symptomatology at the outset of caregiving, they become significantly more depressed over time. Therefore, over time, the degree of burden experienced by men and women may level out.

According to Stone, et al. (1987), two important sources of caregiver stress are competing familial obligations and work conflict. The presence of children under the age of 18 in the households of one-fifth of the overall caregiver population is a major source of competing demands on the caregiver. Work conflict appears to be more of a problem for women, as working daughters are expected to quit their jobs or rearrange their work schedules more frequently than sons in order to provide the necessary care.

Caregiver Burden

According to Haley and Pardo (1989), as dementia progresses in severity, caregiver stressors do not necessarily increase at a steady pace. Rather, care demands shift over a period of time. Initially, the patient may require assistance with shopping, transportation, and finances. In many families, dementia is undetected for several years. The patient’s confusing and uncharacteristic behavior is viewed as rejection by some families instead of symptoms of disease (Chenoweth & Spencer, 1986). In
addition, unclear diagnosis and inadequate explanations about the disease to family members by physicians leaves the primary caregiver without knowledge of what to expect or how to care for the patient. Some families deny the consequences of dementia, resent the primary caregiver's concern, and family conflict often occurs.

In the middle phase of dementia, constant supervision may be necessary due to the patient's disruptive and dangerous behavior. At this time the caregiver must also deal with personal care of the patient, such as bathing, dressing, and feeding. The late phase brings heavy nursing care duties for the caregiver, although the disruptive behavioral problems may decrease. Several researchers have found that the behavioral problems of mid-stage dementia are more distressing than the final stage when the patient may be bedridden and incontinent (Haley, Brown, & Levine, 1987; Kinney & Stephens, 1989). As the patient's death nears, coping with this death becomes a final stressful experience. Not only must the caregiver cope with the loss of their loved-one, but many caregivers reflect on the guilt of having wished for the death in order to decrease the pain of both patient and caregiver.

In a comparison study of different types of patient impairment, Birkel and Jones (1989) examined caregiving burden. In one group, care recipients suffered significant dementia in combination with severe physical disability and
illness. The other group were equally physically disabled, but were cognitively unimpaired. Birkel and Jones (1989) found several implications that an elderly care receiver's mental status is a critical determinant of the size and composition of the caregiver's social support network. Generally, people tend to avoid older adults with obvious mental impairment. Because of the social stigma related to mental illness and aging, the lack of available trained help, the difficulty of caring for dementia patients, and the constant care required, caregivers of dementia patients are denied many rewards and needed support in their caregiving endeavors. Therefore, caregivers of dementia patients accept heavier burdens of caregiving than those who care for physically impaired, but lucid, older adults.

Caregiver Stressors

Kinney and Stephens (1989) investigated the role of daily caregiving stressors (hassles) and small caregiving satisfactions (uplifts) in the well-being of 60 family caregivers. Although hassles are thought to exert a weak threat individually, an accumulation of these stressors over time can have a significant impact on health. On the other hand, uplifts are considered to be a buffer for the consequences of these hassles. The researchers examined four types of hassles and uplifts, those associated with care recipients' behaviors, care recipients' cognitive status, level of activities of daily living assistance, and
the practical aspects of caregiving.

Findings from this study indicate that the caregivers examined suffered high levels of distress, and that both events appraised as hassles and those appraised as uplifts were related to caregiver well-being. In addition, the degree of the caregivers' distress could be predicted from events occurring in their caregiving routines. However, the relationships were stronger for hassles than for uplifts. Caregivers reporting more behavioral and cognitive hassles experienced greater distress in social and psychological functioning, while activities of daily living hassles and those associated with the practical aspects of caregiving were unrelated to either of these outcomes. In addition, the results of the Kinney and Stephen's study indicate the importance of assessing individuals' appraisals of events. Many of the same events were interpreted by some respondents as hassles, and by other respondents as uplifts, indicating that coping styles may differ according to how the event is appraised.

According to Haley, Brown, and Levine (1987), although caregivers often find activities of daily living tasks irritating, these tasks are more predictable and controllable than are behavioral and cognitive hassles. Furthermore, Kinney and Stephens (1989) suggest that behavioral and cognitive limitations may be a symbolic and constant reminder of a family member's changing personality.
and intellectual capability. Caregivers who are caring for
individuals who are still socially responsive, but
behaviorally inappropriate, find the care recipient’s
behavioral and cognitive problems the most irritating. In
general, caregivers’ characteristics, such as age, sex,
duration of the caregiving relationship, amount of time
spent assisting the care recipient, and relationship between
caregiver and care recipient, are stronger predictors of
uplifts. On the other hand, care recipient characteristics
are stronger predictors of hassles. These characteristics
include age, cognitive confusion, degree of physical
limitations, inappropriate behavior, and social withdrawal.

Patient Institutionalization

The most consistent predictor of nursing home placement
of dementia patients appears to be caregiver stress
(Townsend, 1990). Many caregivers place their relative in a
nursing home in an attempt to reduce their own burden, even
though there is evidence to suggest that caregiver stress
often continues after institutionalization (George &
Gwyther, 1984; Pratt, Schmall, Wright, & Cleland, 1985).
Moss and Kurland (1979) found that family members often
maintain extensive contact with the mentally impaired
nursing home resident. In addition, the family members
often continued assisting with caregiving activities, such
as grooming, walking, and doing laundry service for their
relative.
Stephens, Kinney, and Ogrocki (1991) examined differences in stressors and well-being for caregivers who care for a relative with dementia at home and those who had placed their relative in a nursing home. The caregivers who had institutionalized their relative had been the primary caregiver to the patient prior to institutionalization. In this way, the researchers were able to observe the persistence of caregiving stress after institutionalization. The researchers hypothesized that caregivers who institutionalized their relative would continue to experience distress because the stressors associated with the nursing home setting replace the stressors of day-to-day responsibility for the patient's direct care. The patient's cognitive functioning prompted stress and anxiety for the caregiver more often than hassles related to nursing home care. Significant differences emerged, however, for social functioning. In-home caregivers reported significantly more disruptions in their family networks and more restriction on their social activities than the nursing home caregivers. In addition, an important source of stress for both groups of caregivers appeared to be the failure to receive emotional and tangible support from family members and friends.

Although it appears that the confusion and disorientation of the dementia patient produces stress for the caregiver whether care is provided at home or in a
nursing home, there are many instances when patient institutionalization is not only advisable, but necessary. Chenoweth and Spencer (1986) report that almost 75% of caregivers of institutionalized relatives surveyed placed their relative in a nursing home because 24-hour care was too difficult, or that having to watch their relative every minute of every day was intolerable. In addition, some caregivers sustained injuries during physical care of the patient, and others had heart attacks, ulcers, or prolonged illnesses resulting from exhaustion. Most caregivers who received a physician’s recommendation of patient institutionalization because of the patient’s deterioration welcomed it as one they could act upon with less guilt. **Coping Strategies**

Approaches to coping have been investigated by various researchers, and some have emphasized general coping traits, styles, or dispositions. These researchers assume that an individual will utilize the same type of coping in most stressful situations. However, since many psychological traits, including coping styles, show very limited generality, they are poor predictors of behavior in any given situation (Cohen & Lazarus, 1973; Mischel, 1968).

In contrast to trait-oriented approaches, Lazarus and his colleagues developed a transactional theory of psychological stress and coping (Lazarus, 1966; 1981; Lazarus & DeLongis, 1983; Lazarus & Folkman, 1984a; 1984b).
According to this theory, two processes, cognitive appraisal and coping, are identified as critical mediators of stressful events and their immediate and long-range outcomes.

Cognitive appraisal relates to an evaluation of a particular encounter with the environment, and whether it is relevant to a person's well-being. There is both primary and secondary appraisal, with primary appraisal involving the evaluation of the potential of harm or benefit to commitments, values, goals, or self-esteem. In secondary appraisal, various coping options are evaluated, such as altering the situation, accepting it, seeking more information, or controlling impulsive actions.

Coping is defined as "cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984b). This definition is process oriented in that it focuses on what the person actually thinks or does in a specific stressful encounter and how this changes over the unfolding of the encounter. In addition, coping is influenced by the person's appraisal of the actual demands in the encounter and resources for managing them, and therefore, is viewed as contextual. Lastly, there is no consideration of good or bad coping strategies, but only a person's efforts to manage the situation, no matter how successful the efforts are.
Lazarus and Folkman (1984b) distinguished between the process of coping and outcome. The person's judgment of the extent to which the encounter was resolved successfully is referred to as the immediate outcome. If a person feels that the demands of the encounter were managed as well as could be expected, an outcome can be evaluated favorably even though there has not been a resolution of the problem causing the distress. On the other hand, if the resolution is inconsistent with other values and goals, an outcome can be judged unfavorably even though the problem causing distress may have been resolved.

How caregivers cope with specific self-identified caregiving stressors was examined by Stephens, Kinney, Norris, Ritchie and Grotz (1988). The researchers investigated the relations between coping strategies and caregiver's positive and negative affect in an attempt to test the general hypothesis that some forms of coping are more adaptive than others. Caregivers recalled a recent situation in caregiving that they appraised as stressful, and their coping styles for that event were measured. Caregivers were then measured for network disruption and social activity restriction associated with caregiving. According to Stephens, et al. (1988), the results indicated that escape avoidance coping is a prominent strategy. Caregivers who engaged in escape-avoidance coping to a greater degree tended to experience more dysphoria and
conflict with their families and friends. The caregivers who coped by redefining an event to derive inspiration or personal growth experienced greater positive affect.

According to Lazarus and Folkman (1980), there are two major types of coping. First, problem-focused efforts are those directed toward altering the problem causing the distress. Second, emotion-focused coping refers to regulating stressful emotions, and responses to the problem. Folkman, Lazarus, Dunkel-Schetter, DeLongis, and Gruen (1986) examined the functional relations among cognitive appraisal and coping processes and their short-term outcomes within stressful encounters. In this study, a within person comparison across five stressful encounters was conducted. This approach allowed investigation of shifts away from typical appraisal and styles. The researchers found that subjects used more problem-focused forms of coping in encounters they appraised as changeable. On the other hand, in situations where the subjects saw few if any options for affecting the outcome, they used more emotion-focused forms of coping.

In contrast, Pruchno and Resch (1989) found that caregiving spouses of patients with Alzheimer’s disease used multiple coping strategies, with the majority of coping efforts being emotion-focused rather than problem-focused. Since Alzheimer’s disease is chronic, long-term, and uncontrollable, emotion-focused strategies that concentrate
efforts on minimizing distress appeared to be the coping strategy most often chosen.

Prucho and Kleban (1993) considered relationships between adult children and their institutionalized parents and the stresses of caregiving. Research has documented that after parents are institutionalized, relationships between parents and their children remain strong (Cohn & Jay, 1988; Moss & Kurland, 1979). Therefore, the emotional strain experienced by children of institutionalized parents is comparable to that of those living in the community (Brody, 1977). Contrary to findings reported by other researchers (Haley, Levine, Brown, Berry, & Hughes, 1987; Pratt, Schmall, Wright, & Cleland, 1985) the results of Pruchno and Kleban's (1993) study indicated that emotion-focused coping strategies mediate the relationship between stressors and mental health, whereas problem-focused strategies do not. Although higher levels of stressors were associated with more frequent use of problem-solving strategies, problem-solving strategies were not associated with positive mental health. In addition, it appears that realistic appraisal and acceptance of a very difficult situation are healthy coping strategies.

Nevertheless, several studies have reported that problem-focused coping is associated with higher life satisfaction and lower levels of burden in caregivers, whereas emotion-focused coping is not (Haley, Levine, Brown,
Berry, & Hughes, 1987; Wright, Lund, Pratt, & Caserta, 1987). Pratt, Schmall, Wright, and Cleland (1985) found that problem-solving and reframing were coping strategies which were correlated with lower levels of burden, even more so than the presence of a confidante or social network.

One problem that arises in the study of coping is the question of whether coping strategies affect mental health, or whether the caregiver’s mental health determines the coping style used in a stressful event. The issue of causality might be addressed by examining specific stressors rather than generalized burden, and the style of coping which is most beneficial for each particular stressor. Caregiving of the elderly patient with dementia offers a unique opportunity to study coping strategies in a specific experience of stress.

Religious Coping

Research suggests that religion can be a part of the coping process, a contributor to coping, and a product of coping with life crises and stresses (Maton, 1989; Hathaway & Pargament, 1991). According to Pargament, Ensing, Falgout, and Olsen (1990), beliefs in a just, benevolent God, the experience of God as a supportive partner in coping, involvement in religious rituals, and the search for support through religion are associated with more positive coping efforts. Furthermore, an intrinsic religious orientation, or living one’s life in faith, provides a
framework for the individual to turn to religion more easily in times of crisis.

Park, Cohen, and Herb (1990) suggest that having and using an intrinsic religious belief system in times of life stress might provide meaning, a sense of mastery, and, consequently, a higher self-esteem. In addition, an intrinsic orientation might reduce the perceived threat of loss associated with experienced negative events, and enhance an individual's evaluation of coping resources. Therefore, religious beliefs might serve as a life stress buffer by influencing the reliance on specific coping strategies.

Comprehensive Functional Assessment

Comprehensive functional assessment provides detailed evaluation of the older person's functional, medical, and cognitive abilities, as well as social functioning. Interdisciplinary teams composed of physicians, social workers, nurses, and other health professionals can sometimes evaluate and manage frail, elderly persons more effectively than can individual practitioners. Comprehensive Geriatric Evaluation and Management (GEM) programs have been shown to significantly decrease mortality in the elderly, improve functional ability and morale, and provide outpatient health care in place of inpatient care (Boult, Boult, Murphy, Ebbitt, Luptak, & Kane, 1994). Therefore, emergency room use and institutionalization are
decreased and result in lower health care costs. Effective GEM programs identify the elderly persons most likely to benefit, deliver therapeutic interventions rather than simple recommendations, and extend the interval in which GEM services are provided through a one to four month case management program.

According to Brown, Potter, and Foster (1990), one important aspect of social functioning relevant to dementia patients is the emotional cost, or the burden, experienced by the caregiver. Although studies have attempted to relieve caregiver burden through long-term care services, such interventions have not lessened the caregiver's degree of dysphoria or anxiety (Mohide, Pringle, Streiner, Gilbert, Muir, & Tew, 1990). Fitting, et al. (1986) have noted that the caregivers may suffer a demoralized state rather than a major depression, in that the caregivers are unable to change the outcome of their relatives' condition. It may be that the caregiver's coping style, along with practical assistance, alleviates caregiver burden.

The major goals of comprehensive functional assessments are to improve functional status, promote independence, and to prevent premature institutional placement. Brown, et al. (1990) state that it is the family's perception of burden in providing care for their elder, rather than the older person's disabilities, that instigates premature placement. Therefore, assessment of caregivers' subjective burden is as
important to measure as older persons' disabilities.

Furthermore, caregiver burden is increased due to lack of control over the situation. One source of control is knowledge of the disease, its progression, and how to care for the dementia patient. Other areas of caregiver education include information about medication and/or side effects, community and financial resources available for the impaired elderly, and methods of dealing with the caregiver's feelings of inadequacy, guilt, anger, and depression. According to Kahan, Kemp, Staples, and Brummel-Smith (1985), educating caregivers about their older relative's problems serves to reduce caregiver burden. By knowing what to expect, and facing a more predictable situation and accepting the prognosis given by the team, better coping styles may be adopted by the caregiver.

The Present Investigation

The present investigation examined the dementia/disease education of the caregivers by comparing those who received the comprehensive functional assessment with those who did not. In addition, the coping styles used by the caregivers were examined as a function of the educational intervention. Intrinsic religiosity that offers meaning to life, and positive reasons for the caregiving role, was included as a coping strategy in relation to burden and resentment. It was hypothesized that the comprehensive functional assessment helps to improve coping styles and, therefore,
lessen the caregivers' perceived burden in dementia caregiving by increasing the caregivers' knowledge, skills, and abilities regarding caregiving. Therefore, the present investigation tested the following specific hypotheses:

1. Higher caregiver education scores will relate positively to problem-focused, seeks social support, and growth oriented coping strategies, and negatively to wishful thinking, and self-blame coping strategies.

2. An intrinsic religious orientation that involves a true commitment to the caregiver's faith, and a search for the meaning of events in terms of this faith, will:
   a. relate positively to problem-focused coping, seeks social support, and growth oriented coping strategies.
   b. relate negatively to caregiver strain and burden.
   c. relate negatively to resentment.

3. Caregivers who receive the comprehensive functional assessment intervention will have higher education scores than those who do not.

4. Caregiver education and problem-focused coping scores will be lower for caregivers of institutionalized patients than non-institutionalized patients.

5. Although no hypothesis was proposed, the study explores gender and age effects regarding dementia/disease education and burden.
METHOD

Subjects

Caregivers of older adults who participated in a Comprehensive Geriatric Evaluation and Management (GEM) program over the last three to six years were included in the present study. These subjects had agreed to further research participation in a longitudinal investigation being conducted by Dr. Frank Randolph of Loma Linda University and Dr. Kelly Morton. All elderly patients had been referred for GEM by a physician, community agency, or family member. The subject population included 137 of the caregivers of patients who attended the assessment and 41 of the caregivers of patients who chose not to attend for various reasons.

The caregivers whose family members received the Comprehensive Functional Assessment had also participated in a family conference provided by the assessment center. During the assessment, and at the time of the family conference, caregivers were educated as to the patient’s disease, its progression, how to care for the patient, medications and side effects, nutritional needs of the patient, financial and community resources available, and applicable legal issues. In addition, the caregivers were given relevant brochures and course materials, and were advised to read The 36-Hour Day: A Family Guide to Coping for Persons with Alzheimer’s Disease, Related Dementing
Illnesses, and Memory Loss in Later Life (Mace & Rabins, 1981), to increase their problem solving skills relating to patient care. Finally, the caregivers, community agencies if appropriate, and the patient’s physician were mailed a complete written report of the findings, along with recommendations for care.

Materials

Demographics and Caregiver Education. Demographic data and measurements of caregiver burden derived from the Time 2 interview was included in the present study. The Time 2 measurement occurred over the past year and included the patient’s and caregiver’s gender, relationship, patient diagnosis, and duration of caregiving. The caregiver’s age was requested in the present survey. The caregiver was also asked whether the patient is institutionalized and, if so, for how long.

In order to ascertain that the treatment group of caregivers did receive and assimilate the educational information presented at the Comprehensive Functional Assessment, the caregivers were given a detailed list of topics which may have been discussed, and asked to circle all of the topics about which they believe themselves to be well informed. A greater number of topics noted by the subject indicate more caregiver education retained from the family conference. Although the comparison caregiver group did not attend the Comprehensive Functional Assessment, this
question measured their perceived level of caregiver education. A 5-point scale elicited responses of (0) I understand nothing about this, (1) Have very little understanding, (2) Have some understanding, (3) Have quite a bit of understanding, (4) I understand completely.

Resentment. Respondents were asked to report on the extent to which they feel resentful of other relatives who are not helping the elderly patient, extent of resentment toward the patient, and toward the health care system. The statement, "I feel resentful toward other relatives who could but do not do things for our family member," elicited one of the following responses: (1) strongly agree, (2) agree, (3) neither agree nor disagree, (4) disagree, (5) strongly disagree. In addition, resentment toward the patient was measured with similar responses to the statement: "I feel resentful toward my elderly relative for putting me in this situation." A third statement, "I feel resentful toward the health care system for not being more helpful," was measured on the same 5-point scale. The caregiver's responses were scored so that a total lower score across the three items indicate more resentment and discontent (see Appendix A). During analysis the scores were reversed to facilitate ease of interpretation; a total higher score across the three items indicates more resentment and discontent.

Coping. Coping strategies were assessed with the Ways
of Coping Checklist, a 31-item scale based on that developed by Folkman and Lazarus (1985; see Appendix B). Vitaliano, Russo, Carr, Maiuro, and Becknew (1985) examined four psychometric properties of this revised scale, including the reproducibility of the factor structure of the original scales, the internal consistency reliabilities and intercorrelations of the original and revised subscales, the construct and concurrent validity of the subscales, and their relationships to demographic factors. The researchers found that the revised scales were consistently more reliable and shared substantially less variance than the original subscales. In addition, the scale was chosen because of its previous use with caregiver samples.

Respondents were asked to indicate how often during the past month each strategy was used in dealing with the stresses of caregiving. A 4-point scale was used to record responses of (0) not used, (1) used somewhat, (2) used quite a bit, and (3) used a great deal. The subscales of the checklist include the following:

Problem-focused describes deliberate problem-solving efforts to alter the situation (e.g., "Got professional help and did what they recommended").

Self-blame describes blaming self for own part in cause of the problem (e.g., "Wished I was a stronger person -- more optimistic and forceful").

Wishful thinking describes an effort to escape the
situation by daydreaming or wishing it would go away (e.g., "Hoped a miracle would happen").

*Seeks social support* describes efforts to seek emotional support (e.g., "Talked to someone about how I was feeling").

*Growth oriented* describes efforts to create positive meaning by focusing on personal growth (e.g., "Changed or grew as a person in some way").

*Religious Coping.* Religiosity, as a buffer against negative life events and an influence on specific coping strategies, was measured with the Intrinsic and Extrinsic Scales: Revised (Gorsuch & McPherson, 1989; see Appendix C). The scales are based on Allport's (1959) theory that people with an intrinsic religious orientation are truly committed to their faith for its own sake, while those with an extrinsic religious orientation are committed for reasons external to the faith itself. The researchers found that the 14-item revised scales have reliabilities equal to or better than those of the original Age-Universal intrinsic and extrinsic religiosity scales.

A 5-point response format was used including: (1) strongly agree, (2) mostly agree, (3) neither agree nor disagree, (4) disagree, (5) strongly disagree. An example of the items included on the intrinsic scale is: "It is important to me to spend time in private thought and prayer." The extrinsic scale includes items such as, "I go
to church mainly because I enjoy seeing people I know there." A lower score indicated an intrinsic religious orientation. During analyses the scores were reversed to facilitate ease of interpretation; a higher score indicated an intrinsic religious orientation.

Procedure

The surveys were mailed to the caregivers who agreed to participate in future research during the Time 2 measurement. A self-addressed, stamped envelope was enclosed with the survey to facilitate the return of the completed survey. The mailing also included a letter explaining that the caregiver's feedback is valuable to the project and will allow us to make recommendations to physicians and other service providers so that the care of older adults is improved. This letter served as the informed consent and included the statement that participation was completely voluntary, and all information received would be kept strictly confidential (see Appendix D). In addition, caregivers were given the option of omitting any questions that they did not care to answer. Approximately 1-2 weeks after the initial mailing, a reminder was sent to ensure that the survey had not been disregarded due to an oversight, and included a replacement survey in case one was needed (see Appendix E). Finally, a debriefing statement was mailed thanking the participant, explaining the study, reiterating confidentiality, and
providing the telephone numbers of both Dr. Frank Randolph and Dr. Kelly Morton, should the caregiver have any further questions or concerns (see Appendix F). A debriefing statement was also included as a conclusion to the survey (see Appendix G).

Out of 137 surveys mailed to caregivers who had attended the GEM and agreed to further research participation, 12 were returned because of address change and 46 surveys were received. Thus, there was a 37% response rate in the GEM group. Out of 41 surveys mailed to the comparison group of caregivers, 2 were returned because of address change and 22 surveys were received. Thus, there was a 56% response rate in the comparison group.

Scoring Procedures

Ways of Coping. The scale was scored by summing specific items to create subscale scores. Specifically, the problem-focused subscale was created by summing items 1, 2, 3, 5, 6, 8, 9, 10, 11, 12, 13, 15, and 17. The growth oriented subscale was created by summing items 4, 7, and 14. The seeks social support subscale was created by summing items 16, 17, and 18. The self-blame subscale was created by summing items 19, 20, and 21. The wishful thinking subscale was created by summing items 22, 23, 24, 25, 26, 27, 28, 29, 30 and 31. High scores on the subscales indicate more of that type of coping.

Resentment. The scale was scored by summing across the
3 items; resentment toward other relatives, resentment toward the elderly patient, and resentment toward the health care system. A lower total score of the 3 items indicates more resentment, anger, and discontent. During analysis the scores were reversed to facilitate ease of interpretation; a higher total score of the 3 items indicates more resentment, anger, and discontent.

**Intrinsic and Extrinsic Religiosity.** The scale was scored by summing across the 14 items to arrive at a total score for both intrinsic and extrinsic religiosity. Specifically, the intrinsic religious items are 1, 3 (item 3 is reversed scored) 4, 5, 7, 10 (item 10 is reversed scored), 12, and 14 (item 14 is reversed scored). The extrinsic religious items are 2, 6, 8, 9, 11, and 13. Lower scores on the scale indicate a more intrinsic religious orientation. During analysis the scores were reversed to facilitate ease of interpretation; higher scores on the scale indicate a more intrinsic religious orientation.

**Caregiver Education.** The scale was scored by summing across all of the items to arrive at a total score. Higher scores on the scale indicate that the respondent is well-informed and highly educated concerning caregiving.

**Caregiver Burden.** The objective burden scores derived from the Robinson Caregiver Strain Index (Robinson, 1983) are presently on file. The scale was scored by summing across all of the items to arrive at a total score. Higher
scores on the scale indicate more caregiver burden.
This study generated information concerning the relations among measures of dementia/disease education, coping styles, intrinsic religiosity, burden, and resentment. The following general plan of analysis was employed. First, descriptive statistics of caregiver and patient characteristics were calculated to form different independent variable groups (i.e., treatment or comparison, age, gender, dementia, and institutionalization status of the patient). Second, Pearson product-moment correlations were computed to observe the relationships among the dependent variables. Third, MANOVA’s were employed to determine group differences between dementia/disease education, coping styles, intrinsic religiosity, resentment, and burden. Fourth, to investigate specific caregiver burden and educational intervention predictions, a series of stepwise multiple regressions were employed.

Characteristics of the Caregivers and Patients

The respondents included 68 caregivers; 46 (67%) from the Geriatric Evaluation and Management (GEM) group and 22 (32%) from the comparison group. However, six caregivers were omitted from further analysis because of incomplete questionnaires; therefore, the total sample included 62 caregivers. The caregivers ranged in age from 31 to 87 years, with a mean age of 60.6 years (SD=13.0). Fifty-two (84%) of the caregivers were female and 10 (16%) were male.
Forty-one (66%) of the caregivers were caring for an elder in the community, whereas 21 (34%) were caring for an institutionalized elder. Forty-seven (76%) of the caregivers were caring for patients who suffered from some type of dementia, while 15 (24%) were caring for a lucid, but elderly relative. Caregiver treatment status, age, sex, institutional status of the patient, and dementia status of the patient were the independent variables for the group difference comparisons.

Intercorrelations of the Dependent Variables

Dependent variable means and standard deviations for the total sample are presented in Table 1. Pearson product-moment correlations were computed to determine the relationships between coping styles (problem-focused, growth oriented, seeking social support, blames-self, and wishful thinking) dementia/disease education, intrinsic religiosity, resentment (patient, relatives, and the health care system), and caregiver burden. All correlation matrices are in Tables 2-4. Only correlations significant at the p<.05 level are described.
Table 1

Descriptive Statistics for the Dependent Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burden</td>
<td>61</td>
<td>8.26</td>
<td>3.55</td>
<td>0 - 13</td>
</tr>
<tr>
<td>Education</td>
<td>62</td>
<td>35.29</td>
<td>10.45</td>
<td>12 - 68</td>
</tr>
<tr>
<td>Blames-Self</td>
<td>58</td>
<td>1.38</td>
<td>1.36</td>
<td>0 - 6</td>
</tr>
<tr>
<td>Growth Oriented</td>
<td>57</td>
<td>5.00</td>
<td>2.71</td>
<td>0 - 9</td>
</tr>
<tr>
<td>Intrinsic Religion</td>
<td>58</td>
<td>18.72</td>
<td>6.24</td>
<td>8 - 32</td>
</tr>
<tr>
<td>Problem-Focused</td>
<td>58</td>
<td>19.71</td>
<td>8.06</td>
<td>0 - 33</td>
</tr>
<tr>
<td>Overall Resentment</td>
<td>62</td>
<td>9.60</td>
<td>2.84</td>
<td>3 - 15</td>
</tr>
<tr>
<td>Resent Health Care</td>
<td>62</td>
<td>2.82</td>
<td>1.36</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Resent Patient</td>
<td>62</td>
<td>3.94</td>
<td>1.21</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Resent Relative</td>
<td>62</td>
<td>2.84</td>
<td>1.34</td>
<td>1 - 5</td>
</tr>
<tr>
<td>Seeks Social Support</td>
<td>58</td>
<td>4.52</td>
<td>2.56</td>
<td>0 - 9</td>
</tr>
<tr>
<td>Wishful Thinking</td>
<td>58</td>
<td>11.21</td>
<td>7.08</td>
<td>0 - 27</td>
</tr>
</tbody>
</table>
Table 2 indicates the correlations between the coping measures: coping styles, religiosity, and education scores. Caregiver education was positively correlated with problem-focused coping and growth oriented coping. Thus, hypothesis 1 concerning caregiving education and coping was only partially supported as education was unrelated to seeking social support, wishful thinking, or blames-self coping.

Intrinsic religiosity was positively correlated with growth oriented and blames-self coping. Hypothesis 2 was also partially supported as growth oriented coping was related to intrinsic religiosity but unrelated to problem-focused and seeking social support coping. In particular, the relationship between blames-self and religiosity was unexpected.
Table 2

Intercorrelations Between Caregiver Education, Intrinsic Religiosity, and Coping Variables

<table>
<thead>
<tr>
<th>Coping Variable</th>
<th>Education</th>
<th>Intrinsic Religiosity</th>
</tr>
</thead>
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<tr>
<td>Problem-Focused</td>
<td>.36**</td>
<td>.07</td>
</tr>
<tr>
<td></td>
<td>(n=58)</td>
<td>(n=56)</td>
</tr>
<tr>
<td>Growth Oriented</td>
<td>.30*</td>
<td>.32*</td>
</tr>
<tr>
<td></td>
<td>(n=57)</td>
<td>(n=56)</td>
</tr>
<tr>
<td>Seeks Social Support</td>
<td>.07</td>
<td>.21</td>
</tr>
<tr>
<td></td>
<td>(n=58)</td>
<td>(n=56)</td>
</tr>
<tr>
<td>Blames-Self</td>
<td>.03</td>
<td>.28*</td>
</tr>
<tr>
<td></td>
<td>(n=58)</td>
<td>(n=56)</td>
</tr>
<tr>
<td>Wishful Thinking</td>
<td>-.25</td>
<td>-.09</td>
</tr>
<tr>
<td></td>
<td>(n=58)</td>
<td>(n=56)</td>
</tr>
</tbody>
</table>

*p<.05  **p<.01
Table 3 indicates the correlations between the stress and coping variables. Resentment of the elderly patient and overall resentment were both negatively correlated with caregiver education. Resentment towards the elderly patient, relatives, the health care system, and overall resentment were positively correlated with wishful thinking coping. Burden was positively correlated with both wishful thinking coping and blames-self coping. The sub-hypotheses concerning the relationships between intrinsic religiosity and the stress variables of burden and resentment were not supported.
<table>
<thead>
<tr>
<th></th>
<th>Burden</th>
<th>Patient Resent</th>
<th>Relative Care Resent</th>
<th>Health Care Resent</th>
<th>Overall Resent</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>(.02)</td>
<td>(.33*)</td>
<td>(.24)</td>
<td>(.16)</td>
<td>(.33*)</td>
</tr>
<tr>
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<td>(n=62)</td>
<td>(n=62)</td>
<td>(n=62)</td>
<td>(n=62)</td>
</tr>
<tr>
<td>Education</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>(.17)</td>
<td>(.21)</td>
<td>(.08)</td>
<td>(.14)</td>
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<tr>
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<td>(n=58)</td>
<td>(n=58)</td>
<td>(n=58)</td>
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<tr>
<td>Intrinsic Religion</td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-.10</td>
<td>-.02</td>
<td>.15</td>
<td>.04</td>
<td>.09</td>
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<tr>
<td></td>
<td>(n=57)</td>
<td>(n=58)</td>
<td>(n=58)</td>
<td>(n=58)</td>
<td>(n=58)</td>
</tr>
<tr>
<td>Problem-Focused</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>-.02</td>
<td>-.04</td>
<td>-.17</td>
<td>.11</td>
<td>-.11</td>
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<tr>
<td></td>
<td>(n=56)</td>
<td>(n=57)</td>
<td>(n=57)</td>
<td>(n=57)</td>
<td>(n=57)</td>
</tr>
<tr>
<td>Growth Oriented</td>
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<td></td>
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<td></td>
</tr>
<tr>
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<td>-.02</td>
<td>-.03</td>
<td>-.19</td>
<td>-.11</td>
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<tr>
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<td>(n=58)</td>
<td>(n=58)</td>
<td>(n=58)</td>
<td>(n=58)</td>
</tr>
<tr>
<td>Seeks Social Support</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>.32*</td>
<td>.20</td>
<td>.11</td>
<td>.19</td>
<td>.23</td>
</tr>
<tr>
<td></td>
<td>(n=57)</td>
<td>(n=58)</td>
<td>(n=58)</td>
<td>(n=58)</td>
<td>(n=58)</td>
</tr>
<tr>
<td>Blames-Self</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>.40**</td>
<td>.33*</td>
<td>.33*</td>
<td>.28*</td>
<td>.45***</td>
</tr>
<tr>
<td></td>
<td>(n=57)</td>
<td>(n=58)</td>
<td>(n=58)</td>
<td>(n=58)</td>
<td>(n=58)</td>
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<tr>
<td>Wishful Thinking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p<.05  **p<.01  ***p<.001
Caregiver Group Differences

A MANOVA was computed to determine differences between GEM and the comparison group on the dependent variables of education, problem-focused coping, intrinsic religiosity, resentment, and burden, $F(5,23) = 4.46, p<.01$. Post hoc ANOVA's were calculated; the group means for each dependent variable are presented in Table 4. This analysis revealed that the GEM group had significantly higher caregiver education scores than the comparison group, $F(1,53) = 11.94, p<.01$. The GEM group had significantly higher intrinsic religiosity scores than the comparison group, $F(1,53) = 7.82, p<.01$. The GEM group had significantly lower overall resentment scores than the comparison group, $F(1,53) = 4.25, p<.05$ (see Table 4). Thus, hypothesis 3 concerning caregiver education was supported.

A MANOVA was computed to determine differences between caregivers caring for institutionalized patients versus those caring for non-institutionalized patients. The multivariate test was not significant, $F(5,22) = 1.74, p>.05$. Thus, hypothesis 4 was not supported. Institutionalization status groups were not significantly different on caregiver education, problem-focused coping, intrinsic religiosity, or resentment.

Caregiver age and gender differences were explored for burden and education scores. Age categories were as follows: young adult (31 to 50 years), and older adult (51
years and older). A MANOVA was computed to determine differences between age and gender groups for burden and caregiver education, $F(2,16) = 6.99, p<.01$. Post hoc ANOVA's indicated a main effect for age group. Older caregivers had significantly higher burden scores ($M = 10.6$) than younger caregivers ($M = 7.0$), $F(1,35) = 6.41, p<.05$. There were no significant gender differences or interactions for either burden or caregiver education scores.

A MANOVA was computed to determine differences between caregivers caring for dementia patients and those caring for lucid, but elderly adults. The multivariate test was not significant, $F(2,25) = 2.71, p>.05$. Therefore, dementia status groups were not significantly different on either burden scores or caregiver education scores.
Table 4
Group Means for GEM Group and Comparison Group

<table>
<thead>
<tr>
<th></th>
<th>GEM Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>38.8**</td>
<td>29.3</td>
</tr>
<tr>
<td>Intrinsic Religiosity</td>
<td>52.6**</td>
<td>48.0</td>
</tr>
<tr>
<td>Problem-focused Coping</td>
<td>20.6</td>
<td>17.5</td>
</tr>
<tr>
<td>Resentment</td>
<td>4.8</td>
<td>6.3*</td>
</tr>
<tr>
<td>Burden</td>
<td>8.7</td>
<td>7.4</td>
</tr>
</tbody>
</table>

* p<.05  **p<.01
A 2-way ANOVA was computed to determine differences between the GEM comparison groups by the dementia and non-dementia patient groups for dementia/disease education scores. A main effect was found for the treatment group. The GEM group had significantly higher dementia/disease education scores regardless of patient's dementia status, $F(3,51) = 12.80, p<.01$.

**Stress Prediction With Coping Variables**

A stepwise multiple regression was performed with caregiver education as the dependent variable. The analysis was employed to determine whether or not dementia/disease education could be predicted from problem-focused coping, seeking social support, growth oriented coping, intrinsic religiosity, and resentment. Table 5 presents the variables which were included and excluded from the regression equation according to the criteria of .05 to enter and .1 for removal from the regression equation. An examination of these statistics indicates that problem-focused coping and overall resentment scores entered the analysis, accounting for 25% of the variance in education scores. The Multiple $R$ was significantly different from zero, $F(2,53) = 8.80, p<.001$. Intrinsic religiosity, seeking social support, and growth oriented coping were removed from the equation because the .05 limits were not obtained.
Table 5
Multiple Regression Predicting Dementia/Disease Education Scores

<table>
<thead>
<tr>
<th>Variables Predicting Education</th>
<th>B</th>
<th>SE B</th>
<th>Beta</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem-Focused</td>
<td>.51</td>
<td>.16</td>
<td>.38</td>
<td>3.19**</td>
</tr>
<tr>
<td>Overall Resentment</td>
<td>-1.32</td>
<td>.46</td>
<td>-.34</td>
<td>-2.86**</td>
</tr>
<tr>
<td>(Constant)</td>
<td>12.55</td>
<td>5.69</td>
<td></td>
<td>2.20*</td>
</tr>
</tbody>
</table>

Multiple R: .50**
R Square: .25
Adjusted R Square: .22
Std Error: 9.42

*p<.05     **p<.01
A stepwise multiple regression was performed with burden as the dependent variable. The analysis was employed to determine whether or not burden could be predicted from dementia/disease education, intrinsic religiosity, resentment, blames-self coping, or wishful thinking coping. Table 6 presents the variables which were included and excluded from the regression equation according to the criteria of .05 to enter and .1 for removal from the regression equation. An examination of these statistics indicates that wishful thinking coping and intrinsic religiosity scores entered the analysis, accounting for 24% of the variance in burden scores. The Multiple R was significantly different from zero, $F(2,52) = 8.27$, $p < .001$. Resentment, education, and blames-self coping were removed from the equation because the .05 limits were not obtained.
Table 6

Multiple Regression Predicting Caregiver Burden Scores

<table>
<thead>
<tr>
<th>Variable</th>
<th>( B )</th>
<th>( SE_B )</th>
<th>Beta</th>
<th>( t )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wishful Thinking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping</td>
<td>.29</td>
<td>.06</td>
<td>.43</td>
<td>3.54***</td>
</tr>
<tr>
<td>Intrinsic Religiosity</td>
<td>.17</td>
<td>.07</td>
<td>.29</td>
<td>2.31*</td>
</tr>
<tr>
<td>(Constant)</td>
<td>9.12</td>
<td>1.53</td>
<td></td>
<td>5.94***</td>
</tr>
</tbody>
</table>

Multiple R: .50***  
R Square: .24  
Adjusted R Square: .21  
Std Error: 3.25

*\( p<.05 \)  **\( p<.01 \)  ***\( p<.001 \)
A stepwise multiple regression was performed with intrinsic religiosity as the dependent variable. The analysis was employed to determine whether or not intrinsic religiosity could be predicted from problem-focused coping, seeking social support, growth oriented coping, burden, or resentment. Table 7 presents the variables which were included and excluded from the regression equation according to the .05 to enter and .1 for removal from the regression equation. An examination of these statistics indicates that growth oriented coping and burden scores entered the analysis, accounting for 16% of the variance in intrinsic religiosity scores. The Multiple $R$ was significantly different from zero, $F(2,52) = 4.89$, $p<.05$. Problem-focused coping, seeking social support, and resentment were removed from the equation because the .05 limits were not obtained.
Table 7
Multiple Regression Predicting Intrinsic Religiosity Scores

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE</th>
<th>Beta</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Growth Oriented Coping</td>
<td>.75</td>
<td>.30</td>
<td>.32</td>
<td>2.49*</td>
</tr>
<tr>
<td>Burden</td>
<td>.47</td>
<td>.22</td>
<td>.28</td>
<td>2.17*</td>
</tr>
<tr>
<td>(Constant)</td>
<td>26.73</td>
<td>2.58</td>
<td></td>
<td>10.35***</td>
</tr>
</tbody>
</table>

Multiple R   .40*
R Square     .16
Adjusted R Square   .13
Std Error     5.75

*p<.05    **p<.01    ***p<.001
ILL: 5372838  Borrower: WEL  ReqDate: 19980921  NeedBefore: 19981021
Status: SHIPPED  RecDate:  RenewalReq:
OCLC: 33140486  Source: OCLCILL  DueDate: 19981027  NewDueDate:
Lender: *CSB
CALLNO: 
AUTHOR: Ladderbush, Joan Dolores.
TITLE: Dementia caregivers: educational intervention and coping styles
VERIFIED: OCLC
PATRON: LOMBARDO/2740  DEPT:CHEE  STATUS:STA
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BORROWING NOTES: *OBEGROUP**  BLC GROUP**
AFFILIATION: NELINET ILL CODE, OBERLIN GROUP, BOSTON LIBRARY CONSORTIUM
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LENDING RESTRICTIONS:
LENDING NOTES: PLEASE RETURN PAPERWORK WITH BOOK. THANK YOU!!
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DISCUSSION

The present study investigated the effect of relationships between dementia/disease education and coping styles, intrinsic religiosity, burden, and resentment. It was hypothesized that higher caregiver education scores would relate positively to problem-focused, seeking social support, and growth oriented coping strategies, and negatively to wishful thinking, and blames-self coping strategies. Our results indicate that both problem-focused and growth oriented coping are related to higher caregiver education, partially supporting our first hypothesis.

Problem-focused coping, growth oriented coping, and seeking social support are all coping strategies that benefit an individual's well-being. On the other hand, blames-self coping and wishful thinking are coping styles that are usually ineffective coping strategies, and consequently detrimental to an individual's well-being and, in fact, blames-self and wishful thinking coping do relate positively to the caregiver's burden.

In addition, caregivers who reported more intrinsic religiosity employed growth oriented coping strategies more than those who did not, partially supporting the second hypothesis. However, intrinsically religious caregivers also use blames-self coping strategies. Until recently, the religious dimension of coping has received only limited attention. Pargament, Olsen, Reilly, Falgout, Ensing, and
Van Haitsma (1992) have noted that religion can contribute to the coping process and be a product of coping. The results of this study indicate that intrinsic religiosity is associated with growth oriented coping strategies, which in turn may provide meaning to the caregiving role and contribute to the coping process. Self-blame in these same caregivers may produce a feeling of control over the difficult event which also contributed to the coping process.

Although caregiver education does not appear to affect burden, the results suggest that caregivers who perceive that they are more educated are less likely to feel resentment of their situation, or toward the elder they are caring for. However, two coping strategies appear to increase burden: wishful thinking and blames-self coping. Caregivers who employ wishful thinking coping strategies are also more resentful toward the elderly patient, other relatives, and the health care system, than those who do not.

The findings from this study support the hypothesis that the Comprehensive Functional Assessment process is effective as an educational resource for caregivers of elderly adults. Since dementia/disease education may increase a caregiver’s control over the situation, it is unclear why increased knowledge did not affect burden for participants. One possible explanation is that burden was
measured objectively rather than subjectively in the original longitudinal study. Thus, the actual stressors continue to exist in the caregivers' lives even though they cope better after they understand the causes of the stressors.

To understand the effects of an educational intervention on caregiver burden one would have to investigate the multidimensional sources of their distress. The sources may include caregiver vulnerability, familial resources, and care recipient functioning (Vitaliano, Russo, Young, Teri, & Maiuro, 1991). Research has reported that caregivers at risk for distress were characterized not only by their coping strategies, but by their attributional style, relationship with care recipient, levels of formal and informal support (Morris, Morris, & Britton, 1988), and motives for caregiving (Cicirelli, 1993). Even though the GEM group did not differ in objective burden from the comparison group it appears that they do harbor less overall resentment toward their situation and employ more successful coping strategies.

It is interesting to note that subjects who attended the GEM with their older relative had a more intrinsic religious orientation than those who did not attend. According to Park, Cohen, and Herb (1990), religious beliefs may serve as a life stress buffer by influencing the reliance on coping strategies that are beneficial to the
individual. The comparison group may be a self-selected group of individuals who were coping poorly and were not able to seek out resources and educational interventions.

Although 36% of the sample was caring for an institutionalized patient, there was no indication of any differences in caregiver education, coping styles, or burden between the institutionalized and community dwelling groups. However, comments from some caregivers revealed dissatisfaction with the care provided by nursing facilities, such as staff interactions, which may increase objective burden. Other stressors, such as guilt for not caring for their relative themselves, and the degree of cognitive impairment demonstrated by the institutionalized elder relative may affect subjective burden. On the other hand, according to Stephens, et al. (1991), the patients’ memory loss and their problematic/asocial behaviors are strong predictors of caregivers’ well-being, whether the patient is cared for at home or in a nursing facility. It is evident from these data that caregiver objective burden persists even after patient institutionalization.

The GEM is concerned with preventing premature placement of dementia patients because living in the community allows the patient to maintain functions longer. Placement should not be undertaken to reduce caregiver burden as research indicates that burden remains even after the patient is institutionalized. There may be instances
when placement is necessary due to a caregiver’s unavailability, poor health, or a physician’s suspicion of elder abuse.

Older caregivers appear to suffer more burden than younger caregivers. Seemingly, the older caregivers may have less financial resources, poorer health, and fewer social supports. It is also more likely that the patient is the caregiver’s spouse and the caregiver is experiencing a loss of an intimate partner and, consequently, is bereaved.

There were no gender or dementia status group differences. However, this may be explained by the low number of males and non-dementia group respondents in the sample. Future studies need to address the difficulty of obtaining appropriate comparison groups in general.

Multiple regression analyses were carried out to identify predictors of dementia/disease education, caregiver burden, and intrinsic religiosity. The educational intervention scores were predicted by problem-focused coping and less overall resentment. When caregivers are given the tools to cope with their specific caregiving situation, they feel less anger and resentment toward the patient, their family, and the health care system.

Wishful thinking coping is not an effective coping style and, thus, use of such strategy is predictive of burden. As noted previously, religiosity not only affects coping with stress, but is at times a product of stress.
For example, increases in faith sometimes occur after periods of loneliness or emotional problems (Pargament, et al., 1992). Thus, religiosity explains an additional proportion of the variance in caregivers' burden scores as the individuals may begin to seek meaning when faced with the decline and death of a loved one. This process is further illuminated by the prediction of intrinsic religiosity by growth oriented coping. The caregivers looking for meaning in the caregiving situation may be intrinsically religious to begin with, or may turn to religion to find that meaning when experiencing extreme stress and loss. These processes help them cope with their difficult situations.

The implications of this study for Comprehensive Functional Assessment are many. It appears that caregiving education is helpful in increasing a caregiver's problem-focused coping and may, therefore, promote more efficient management of the caregiving situation. This instrumental coping activity may in turn allow the caregiver the time and energy to seek meaning and understanding concerning illness, aging, and death. Thus, the Comprehensive Functional Assessment process may allow the team physician to address the problems of dementia caregivers that contribute to their sense of burden. Caregiving education can reduce caregiver vulnerability through skills training, which increases coping strategies and enhances self-esteem. We know that
empathic understanding provided by caregiver support groups increases the caregiver’s sense of self-worth, and contributes to a feeling of acceptance. Attending the GEM with their elder relative is, in itself, a source of social support for the caregiver.

A limitation of our study is small sample size. Longitudinal investigation is difficult in dementia caregiving research because of the high mortality rates of both patients and caregivers. In addition, the motivation to attend a GEM program is unclear. It may be that the GEM group members are more concerned with the welfare of their elder relative than the comparison group. Even though dementia caregivers ultimately experience the same levels of objective burden, the intervention can help the caregiver process to proceed in a less negative way.

Future research is necessary to further identify methods of inducing beneficial coping strategies in caregivers of dementia patients. In this way, caregivers may attain relief from stress and burden that they may experience, and may grow as individuals in the process.
Caregiver Wellness Survey

Please answer the following questions. The survey applies to you as a caregiver, whether or not you are still active in the caregiving role. There are no right or wrong answers and all information you provide will be kept strictly confidential. Your participation is completely voluntary and you may omit any questions that you do not feel like answering. Thank you so much for any help that you can provide.

1. Age of caregiver? ______

2. How long has the patient been in an institution?
   a. They are not in an institution.
   b. They are in an institution and have been for ___ months ___ years.

3. Please circle the most appropriate comment to the following statements as they apply to you.
   a. "I feel resentful toward other relatives who could but do not do things for our family member."
      1. Strongly agree
      2. Agree
      3. Neither agree nor disagree
      4. Disagree
      5. Strongly disagree

   b. "I feel resentful toward my elderly relative for putting me in this situation."
      1. Strongly agree
      2. Agree
      3. Neither agree nor disagree
      4. Disagree
      5. Strongly Disagree

   c. "I feel resentful toward the health care system for not being more helpful."
1. Strongly Agree
2. Agree
3. Neither agree nor disagree
4. Disagree
5. Strongly Disagree

4. Please circle all of the topics that you feel well-informed about. These topics apply to the elderly family member that you are or were caring for. Choose from the following answers:

   0 = I understand nothing about this
   1 = Have very little understanding
   2 = Have some understanding
   3 = Have quite a bit of understanding
   4 = I understand completely

a. Information about the dementia process
b. What to expect as the dementia progresses
c. Information about other chronic illnesses of patient
d. medications and side effects
e. How to give physical care
f. Nutritional needs of the patient
g. How to solve problems relating to care
h. Read "The 36-Hour Day" by Mace and Rabins
i. Community resources for the impaired elderly
j. Financial resources available for the impaired elderly
k. Caregiver emotional health (dealing with feelings of depression, anger, guilt, inadequacies, etc.)
l. Community resources for caregivers
m. Home safety precautions for impaired elderly
n. Durable Power of Attorney for Health Care for the elderly
o. Role of a primary care physician
p. Written copy of the Geriatric Assessment report
q. Other (specify)
APPENDIX B

Ways of Coping Checklist

Please indicate the appropriate category which describes the extent to which you used each of these strategies in a stressful experience during the past month.

0 = Not Used  
1 = Used Somewhat  
2 = Used Quite a Bit  
3 = Used a Great Deal

___ 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.
<table>
<thead>
<tr>
<th></th>
<th>Description</th>
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<tbody>
<tr>
<td>0</td>
<td>Not Used</td>
</tr>
<tr>
<td>1</td>
<td>Used somewhat</td>
</tr>
<tr>
<td>2</td>
<td>Used Quite a Bit</td>
</tr>
<tr>
<td>3</td>
<td>Used a Great Deal</td>
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<tr>
<td>12</td>
<td>Came up with a couple of solutions to the problem.</td>
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<td>13</td>
<td>Accepted my strong feelings but didn’t let them interfere with other things too much.</td>
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<td>14</td>
<td>Changed something about myself so that I could deal with the situation better.</td>
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<tr>
<td>15</td>
<td>Stood my ground and fought for what I wanted.</td>
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<tr>
<td>16</td>
<td>Accepted sympathy and understanding from someone.</td>
</tr>
<tr>
<td>17</td>
<td>Talked to someone who could do something about the problem.</td>
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<tr>
<td>18</td>
<td>Talked to someone about how I was feeling.</td>
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<tr>
<td>19</td>
<td>Blamed yourself.</td>
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<td>20</td>
<td>Criticized or lectured yourself.</td>
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<tr>
<td>21</td>
<td>Realized you brought the problem on yourself.</td>
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<td>22</td>
<td>Hoped a miracle would happen.</td>
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<td>23</td>
<td>Wished I was a stronger person -- more optimistic and forceful.</td>
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<tr>
<td>24</td>
<td>Wished that I could change what had happened.</td>
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<tr>
<td>25</td>
<td>Wished I could change the way that I felt.</td>
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<td>26</td>
<td>Daydreamed or imagined a better time or place than the one I was in.</td>
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<td>27</td>
<td>Had fantasies or wishes about how things might turn out.</td>
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<td>28</td>
<td>Wished the situation would go away or somehow be finished.</td>
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</tbody>
</table>
0 = Not Used
1 = Used Somewhat
2 = Used Quite a Bit
3 = Used a Great Deal

_____29. Felt bad that I couldn't avoid the problem.
_____30. Kept my feelings to myself.
_____31. Kept others from knowing how bad things were.
### APPENDIX C

**Intrinsic and Extrinsic Religiosity**

For each of the following statements, tell how much you agree or disagree. **Circle one** answer for each.

Choose from these answers:

1 = I strongly agree  
2 = I mostly agree  
3 = I neither agree nor disagree  
4 = I mostly disagree  
5 = I strongly disagree

<table>
<thead>
<tr>
<th>Statement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<tbody>
<tr>
<td>1. I enjoy reading about my religion.</td>
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<td>2. I go to church because it helps me to make friends.</td>
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<td>3. It doesn't much matter what I believe so long as I am good.</td>
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<td>4. It is important to me to spend time in private thought and prayer.</td>
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<td>5. I have often had a strong sense of God's presence.</td>
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<td>6. I pray mainly to gain relief and protection.</td>
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<td>7. I try hard to live all my life according to my religious beliefs.</td>
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<td>8. What religion offers me most is comfort in times of trouble and sorrow.</td>
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<td>9. Prayer is for peace and happiness.</td>
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<td>10. Although I am religious, I don't let it affect my daily life.</td>
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<tr>
<td>11. I go to church mostly to spend time with my friends.</td>
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</table>

1 = I strongly agree  
2 = I mostly agree
3 = I neither agree nor disagree
4 = I mostly disagree
5 = I strongly disagree

12. My whole approach to life is based on my religion. 1 2 3 4 5

13. I go to church mainly because I enjoy seeing people I know there. 1 2 3 4 5

14. Although I believe in my religion, many other things are more important in life. 1 2 3 4 5
Introduction Letter and Informed Consent

March 10, 1994

Dear Caregiver:

We talked with you over the phone during the last year about the care you provided for an elderly family member. We have completed our initial project concerning caregivers and have found that we will need to know more about your understanding of problems of the elderly, and how you cope with stress in your life.

We are truly concerned about you and your elderly family member. The only way we may help is to have you tell us how you feel. In that way, we can make recommendations to physicians and community service providers so that the care of older adults and their caregivers is improved.

We understand that you are probably a very busy person, but your participation in our survey is valuable to us. You previously indicated that you would be willing to assist us in our research projects. Your participation is completely voluntary and all information will be kept strictly confidential. In addition, you may omit any questions that you do not care to answer.

We have enclosed a questionnaire which should take about twenty minutes for you to complete, and a self-addressed, stamped envelope for your convenience in returning the survey to us. If you have any questions or concerns about our project, please call Dr. Frank Randolph at (909) 796-6658, or Dr. Kelly Morton at (909) 880-5597.

Thank you for your time, and we hope to hear from you soon.

Sincerely,

J. Franklin Randolph, M.D.  
Assistant Clinical Professor of Family Medicine

Kelly R. Morton, Ph.D.  
Assistant Professor Research Associate
APPENDIX E

Reminder Letter

March 15, 1994

Dear Caregiver:

We recently mailed you a survey regarding the care you provide for an elderly family member. We appreciate the time and effort you spent in helping us to improve our care of elderly adults and their caregivers.

If, for some reason, you have not yet returned the survey, we encourage you to do so at your earliest convenience. We have included a replacement survey in the event you may need one. Only with information provided by caregivers like yourself will we be able to understand what is needed and be able to recommend care for improving the quality of life of people in your situation.

If you have already returned the survey, please accept our sincere thanks. Your participation is completely voluntary and all information will remain strictly confidential. If you have any questions or concerns about our project please call Dr. Frank Randolph at (909) 796-6658, or Dr. Kelly Morton at (909) 880-5597.

Thank you again for your time and thoughts.

Sincerely,

J. Franklin Randolph, M.D.
Assistant Clinical Professor
of Family Medicine

Kelly R. Morton, Ph.D.
Assistant Professor
Research Associate
APPENDIX F

Thank You Letter

April 15, 1994

Dear Caregiver:

You recently participated in our research project by providing information about your caregiving experience and how you cope with stress in your life. We truly believe that families of older adults can give us valuable feedback so that we may address their needs better in the future.

We believe that our project will allow us to make recommendations to physicians and other service providers in our community and in our profession so that the care of older adults is improved. We appreciate your time and your efforts, and hope that projects like ours will assist us in finding ways to help people in your situation.

If you have any questions or concerns about our project, please call Dr Frank Randolph at (909) 796-6658, or Dr. Kelly Morton at (909) 880-5597.

Thank you for participating in this very important work.

Sincerely,

J. Franklin Randolph, M.D.
Assistant Clinical Professor
of Family Medicine

Kelly R. Morton, Ph.D.
Assistant Professor
Research Associate
APPENDIX G

Debriefing

Thank you so very much for giving us your time and effort to answer these questions. The answers to this survey will be used to help improve the care of older patients and their caregivers. If you have any further comments, please provide them below:

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

Dr. Frank Randolph at 909-825-7170 or Dr. Kelly Morton at 909-880-5597 are available to discuss any questions or concerns you may have.

THANK YOU AGAIN FOR YOUR TIME AND COOPERATION.

PLEASE MAIL THIS FORM TO US IN THE ADDRESSED, STAMPED ENVELOPE PROVIDED.
REFERENCES


