1998

Spirituality of Caregiver Wives of Dementia Patients

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SPIRITUALITY OF CAREGIVER WIVES OF DEMENTIA PATIENTS

By

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A THESIS

Submitted to
Grand Valley State University
in partial fulfillment of the requirements for the
degree of

MASTER OF SCIENCE IN NURSING

Kirkhof School of Nursing

1998

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ABSTRACT

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The spiritual perspectives of 30 caregiver wives of dementia patients and 30 noncaregiver wives were compared using a convenience sample in the Midwest. Spiritual perspective includes behaviors such as praying privately, mentioning spiritual matters to others, and seeking spiritual guidance as well as beliefs such as forgiveness, the belief that spiritual views influence their life, and feeling close to God or a higher power during prayer or worship. The Spiritual Perspective Scale was used to measure spiritual perspective in participants. Scores on the Spiritual Perspective Scale were analyzed for the two groups using the *t* test for individual variables. Individual tool items were analyzed using the Mann - Whitney U test. The spiritual perspectives of the two groups were not significantly different from each other for either total scores on the Spiritual Perspective Scale or answers on individual items within the tool. The results of this study indicated that both groups were found to have similar levels of spiritual perspective with no difference found with the additional burden of caregiving among caregiver wives.

Acknowledgments

I would like to thank my thesis advisor, Dr. Katherine Kim, for her enthusiastic guidance and patience through the process of producing this thesis. I wish her all the best in her upcoming retirement. I would also like to thank the rest of my thesis committee for their time and effort in helping me complete this project. Lastly, thank you to my family for their gift of time to me to work on my thesis and degree. My mother-in-law was especially helpful in collecting data for me when I was frustrated with the slow process of data collection.

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CHAPTER 1

INTRODUCTION

The U.S. elderly population numbered 33.2 million in 1994. The number of elderly increased by 2.1 million or 7% since 1990. In 1993, 28% of elderly assessed their health as fair or poor (American Association of Retired Persons [AARP], 1995). The growth of the elderly population group brought with it the increase in persons with chronic health problems. The majority of those requiring care assistance received it at home (Kinney & Stephens, 1989). The care demands and the care these elderly require has increased in difficulty and duration in recent years. Caregivers have sacrificed increasing amounts of personal time including lifestyle changes for the caregiver providing primary care (Neundorfer, 1991a). The caregiver burden included concerns with the health of the care-receiver, household finances, and meeting the physical demands of caregiving (Cantor, 1983). Dementia victims have become especially burdensome to their caregivers due to the progressive loss of cognitive functions as well as physical functions associated with the disease (Kaye & Robinson, 1994).

The burden of caregiving often placed stress on the caregiver. Evans (1994) stated that caregiving involved not only the task of doing, but also the task of coping. Caregiver health declined as the caregiving tasks demanded more time (Given et al., 1988). Caregivers who are closely related to the care-receiver reported more strain than those not as closely related (Cantor, 1983). Spouses are reported to be at highest risk for caregiver burden (Jackson & Cleary, 1995). Care-receivers with cognitive and behavioral problems were found to be more stressful to care for in a study by Kinney and Stephens (1989). Baillie, Norbeck, and Barnes (1988) found that caregivers who were caring for a mentally impaired elder, who had been caring for an extended time, and who had low social support were at high risk for psychological distress or depression. Neundorfer (1991b) also found that caregiver stress leads to depression as well as anxiety. A decline in health associated with caregiving was found (Bull, 1990).

Research has shown that the caregiver's interpretation of the stress rather than the caregiving tasks determined the effect of the caregiving stress on the caregiver (Kinney & Stephens, 1989). Stress reduction may be achieved by focusing on the factors that cause the perception of stress according to Lazarus and Folkman (1984).

Lazarus and Folkman's stress and coping model (1984) suggested that the stress appraisal could be mediated by social and personal resources such as existential beliefs and positive beliefs. An increased spiritual perspective has been shown to be one such mediator in achieving a sense of positive well-being through reframing the situation and providing a coping resource (Robinson & Kaye, 1994).

Spiritual perspective was defined by Reed (1991) in terms of a sense of relatedness to a dimension greater than the self without devaluing the individual, and included such behaviors as prayer, meditation, forgiveness, and church attendance. The terms spiritual perspective and spirituality are used interchangeably by Reed. Supportant strategies, such as prayer or putting trust in God, were found to be one of the most effective coping strategies (Halstead & Fernsler, 1994). Spiritual perspective may assist the caregiver in reframing the situation and thereby affect coping through cognitive reappraisal (Lazarus & Folkman, 1984). This study sought to affirm the previous research by Kaye and Robinson (1994) which showed greater spiritual perspective and use of spiritual activities as a coping resource among caregiver wives when compared to non-caregiver wives.

Purpose

Caregivers cope with many stressors of caregiving which may have included financial concerns, physical and emotional strain, social isolation, and facing death issues. A summary of findings of research on caregivers listed 25 different burden issues faced by caregivers (Jackson & Cleary, 1995). The stress of caregiving has been shown to lead to negative effects on the caregiver such as depression, anxiety, and a decline in physical health. Caregiving for a chronically ill person may last several years. The permanent nature of the care-receivers illness requires long term coping strategies. Increased

spiritual perspective has been shown to be an effective coping resource in achieving greater well-being in grieving (Reed, 1987). Wives of dementia victims described a spiritual perspective as an important resource in caregiving (Kaye & Robinson, 1994). The purpose of this study was to determine whether caregiver wives of elderly men used spiritual perspective at a higher level compared to non-caregiver wives of elderly men. This study sought to replicate the Kaye and Robinson research.

CHAPTER 2

CONCEPTUAL FRAMEWORK AND LITERATURE REVIEW

Conceptual Framework

Lazarus and Folkman (1984) conceptualized stress as transaction based, focusing on stress related processes of cognitive appraisal and coping. Cognitive appraisal is understood to have been "the process of categorizing an encounter with respect to its significance to the person's well - being" (p. 31). They viewed coping as a dynamic, reciprocal, and bi-directional relationship between the person and their environment mediated by person factors, situational factors, primary appraisal, and secondary appraisals.

Coping is defined by Lazarus and Folkman (1984) as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). The definition of stress emphasizes "the relationship between the person and the environment, which takes into account characteristics of the person on one hand, and the nature of the environmental event on the other" (p. 21). Whether an event is judged as stressful as well as to what degree the event is stressful hinges on cognitive appraisal.

Cognitive appraisal seeks to reflect the individualism of each person and event. Each person is different in their background, personal coping skills, and personal factors. Each event is different in its situational factors such as novelty and social support. Thus, each person reacts differently to an event. The cognitive appraisal may also be changed through manipulation of the personal and situational factors. In other words, coping can be improved and new coping skills can be learned.

Secondary appraisal is the exercise of evaluating coping options. It is the process of evaluating coping options for their effectiveness, outcomes, and consequences. Reappraisal can occur during this process. Reappraisal is a change in the original appraisal based on new information either from the person or the environment. It is through this

process that the perceived level of stress of the caregiving situation can be changed. For example, the person may decide things aren't as bad as previously thought, or the situation was not important enough to worry about. The condition of the care-receiver will not have changed but the perceived stress can be reduced through intervention from the person or the environment. Person factors that may reduce the perceived stress may be such things as increased knowledge or increased use of existential beliefs. Existential beliefs, such as faith in God, are beliefs that "enable people to create meaning out of life, even out of damaging experiences, and to maintain hope" (Lazarus & Folkman, 1984, p. 77).

Coping resources such as positive beliefs may also be included in the secondary appraisal phase. Positive beliefs may include a belief in justice or in God that serve as a basis for hope. Hope can be encouraged by the belief that outcomes are controllable and that positive outcomes are possible. Positive beliefs can help put a good light on experiences.

In summary, a spiritual perspective can affect perceived stress through use of the person factor of existential beliefs and through the coping resource of positive beliefs. Together or separately these two factors can influence the cognitive appraisal of the care situation initially. An increased spiritual perspective can decrease the perceived stress during the caregiving situation through cognitive reappraisal.

This study sought to assess the spiritual perspectives of caregiver wives of elderly dementia patients. Higher levels of spiritual perspective in caregiver wives when compared to noncaregiver wives would indicate it as an important resource in decreasing the stress perceived by these caregivers.

Review of Literature

The current literature was reviewed for research on the characteristics of caregivers, effects of caregiving, spiritual perspective, and coping as it related to the use of spiritual perspective.

Caregivers Characteristics

Given et al. (1988) surveyed 87 caregivers. They found the mean caregiver age was 57 years and the mean age of the care-receiver was 73 years of age. The caregivers had been caring for their relatives for approximately 6.5 years. Seventy-five percent of the caregivers were female, and 77% were Caucasian. The sample was well educated but 68% earned less than $25,000. Family members spent, on average, 15 hours a day on caregiving activities, and performed these activities with little help. There was a mean of 1.6 persons assisting them in caregiving. Hypertension, heart disease, stroke, arthritis, Alzheimer's disease, and diabetes were the most common health problems of the care-receivers. Most of the care-receivers had some degree of memory impairment. Half were continent. Caregiver health was found to decline as the caregiver's reaction to the caregiving became more negative. Caregiver health also declined as the caregiving tasks took up more of their daily schedules. This study may be limited by its predominantly Caucasian sample. No percentages were given for the number of care-receivers having physical versus cognitive diagnoses. However, the study does point out the intense burden of caregiving on the caregiver's time and health. A summary of literature in 1995 by Jackson and Leary described the typical spousal caregiver as a 68 year old white woman with a high school education who has been caring for her impaired husband for an average of 6 to 7 years, with an average household income of $19,000 or more.

A study by Jones (1994) compared household activities of 28 caregiver women caring for men with either physical and mental impairments or physical impairments alone. The average caregiver was 52 years old, white, and had been caring for the care-receiver for 3.35 years. The average household income was $24,500. Averaging 83 years of age, the care-receiver was typically housebound, suffering from 3 limitations of activities of daily living, and 6 limitations of instrumental activities of daily living. The majority of the care-receivers were widowed (75%). The remaining care-receivers were married (17.9%) or other marital status (7.1%). Those caring for care-receivers who were physically and

cognitively impaired were less likely to work outside the home, and more likely to perform heavy housework, do paperwork, and pray. Prayer was reported to have been used by 50% of those caregivers caring for those with cognitive impairments while prayer was used by 14.3% by those caring for elders with physical impairments only. The average number of hours reported spent in prayer by all caregivers in the study was 12 hours per week.

Affects of Caregiving

Caregiver burden may be affected by characteristics of the caregiver and the care-receiver. Bull (1990) found that caregivers who were over 65 years of age suffered more of a decline in health than younger caregivers. Montgomery, Gonyea, and Hooyman (1985) found that younger caregivers with lower incomes reported more subjective burden of caregiving than older caregivers. This may be due to the younger caregivers having demands of family and jobs in addition to the caregiving tasks. McCarty's study of daughters caring for a parent with Alzheimer's disease found frustration with the demands of balancing job, family, and caregiving. Many daughters were trying to "do it all" but were finding everyone involved feeling neglected to some degree. The daughters were having difficulty finding community resources to help them cope and keep their parent at home as long as possible. The daughters were also finding it difficult to decide when it was time to turn from home care to institutional care (McCarty, 1996).

Those caregivers who were more closely related to the care-receiver, such as spouses and children, have been found to suffer the greater strain of caregiving compared to other relatives, friends , or neighbors (Cantor, 1983). Kinney and Stephens (1989) survey of 60 family caregivers of Alzheimer patients, using a relatively new tool developed by the authors, found that those care-receivers who had cognitive problems, such as confusion, and behavioral problems, such as wandering off, were more stressful to care for than those with physical problems. The results of the study could not discern whether the caregivers were distressed because they found the caregiving difficult or if the caregivers were

distressed already and then found the caregiving difficult because of their distress. The tool had not been verified by other researchers. The final stressful event of caregiving may be when the care-receiver's eventual death becomes apparent (Haley & Pardo, 1989).

On the other hand, Neundorfer's study (1991b) of 60 spouse caregivers of persons with dementia found that neither the care-receivers problems nor the caregiver's appraisal of their coping options was a significant predictor of caregiver's health outcomes. Caregivers in this study had been caring for their spouse an average of 2.9 years, considerably less than some of the other studies, which may account for the lack of health problems found. She did find that the caregiver's appraisal of the level of stress they were experiencing was a significant predictor of depression and anxiety, thus confirming Lazarus and Folkman's cognitive model. Most of the care-receivers in this sample were dependent in activities of daily living (ADL) activities. Coping was measured with Lazarus and Folkman's Ways of Coping Checklist which has been well validated.

A study by Robinson (1989) of 78 wife caregivers of memory impaired husbands revealed that all felt depressive symptoms "some or a little of the time." Social support had a negligible effect on caregiver depression ($r = -.06$). Depression rates were less in those who were happy with their marriage one year before the onset of their husband's illness. Robinson also found that caregivers had a negative attitude toward asking for help. Caregiver health was found to be the best predictor of depression in this study.

Depressive symptomatology and strain of caregivers of impaired older adults were unaffected by the intervention of home health care nursing in a study of 100 caregivers by Schwarz and Blixen (1997). Strain and depressive symptomatology was significantly higher for those caring for cognitively impaired persons.

It could be concluded from the above studies that caregiver burden leads to declining health, increased stress, and depression. Schulz et al. (1995) review of research on caregiving revealed elevated levels of depressive symptoms among caregivers.

Psychiatric morbidity in caregivers was linked to patient problem behaviors, income, self-rated health, perceived stress, and life satisfaction. Physical morbidity in caregivers was more likely to occur if patient problem behaviors and cognitive impairment were present. Physical morbidity in caregivers was also more likely to lead to caregiver depression, anxiety, and less perception of less social support.

Caregiving is stressful and frequently coupled with negative effects on the caregiver. One source that may decrease the perceived stress and its effects is spirituality.

Spiritual Perspective

A study of caregiver wives of dementia victims by Robinson and Kaye (1994) found that caregiver wives had a stronger spiritual perspective than noncaregiver wives. Their hypothesis that spiritual perspective would decrease levels of depression was rejected. The relationship was in the predicted direction, but was not statistically significant. The hypothesis that a positive relationship would exist between spiritual perspective and social support was also found to be in the predicted direction but was rejected because the results were not statistically significant.

Kaye and Robinson's report (1994) on the same study looked at only at spiritual perspective. They found that spiritual perspective scores using the Spiritual Perspective Scale (SPS) between caregiver wives and noncaregiver wives were not statistically different. However, caregivers scored higher than noncaregiver wives and terminally ill patients in a study by Reed (1987) using the same tool. Kaye and Robinson's study (1994) found 77% of caregiver wives mentioned spiritual matters at least once a week, 88% read spiritually related material once a week, 94% engaged in private prayer once a day. Caregiver wives engaged in private prayer, shared the joys and problems of living according to their spiritual belief, and sought spiritual guidance in making decisions more often than noncaregiver wives. More of the caregiver wives (94%) agreed that forgiveness is an important part of spirituality compared to noncaregiver wives (86%). Fifteen (88%) of the caregiver wives indicated spirituality is especially important because

it answers many questions about the meaning of life and 94% indicated that their spiritual views have had an influence on their lives. Of the noncaregivers, 78% agreed or strongly agreed that spirituality was especially important. Kaye and Robinson recommended further research on spirituality in caregivers as well as the use of church members as a resource. Weaknesses of the two studies by Kaye and Robinson include their use of the Spiritual Perspective Scale which has limited reliability and validity, study sample limited to one geographic area in the southern U.S., and a small sample size of only 17 wives in each group. Combined, these weaknesses make it difficult to reach statistically significant conclusions and to generalize the results to the caregiver population.

Reed (1987), who later developed the Spiritual Perspective Scale, studied terminally ill adults using her Religious Perspective Scale (RPS). She found significantly greater religiousness among the terminally ill group as compared to a healthy group. Reed found women to have higher scores on the RPS than men.

Forbes (1994) study of 17 elderly, community dwelling care recipients and their primary caregivers using open ended questions found an "abundance" of health related prayer. Forbes found that caregiver's spiritual well-being was higher in those caregivers who perceived a high spiritual well-being in the care-receiver. She also stated that the caregiver's spiritual well being level was likely to be the same as the care-receiver's, whether high or low.

Spiritual Perspective and Coping

Coping strategies of long term cancer survivors were studied by Halstead and Fernsler (1994) using the revised Jalowiec Coping Scale. Almost half of the 59 subjects described changes in coping since their cancer diagnoses. One of the reported changes was spirituality. Supportant strategies for coping such as "prayed or put trust in God" were found to be one of the most effective in coping, and the item "prayed or put trust in God" was rated by the subjects as the most often used and very helpful coping strategy

(67.8%). Saudia et al. (1991) also found prayer to be perceived as a helpful coping mechanism in their study of patients awaiting cardiac surgery.

Hemodialysis patients adjustment to long term treatment and their religious faith were studied by O'Brien (1982). Those persons who never attended church were found to have the greatest degree of alienation. Seventy three percent of the patients held the opinion that religious or ethical belief were to some degree associated with acceptance of their disease and its total treatment regimen. The perception of the importance of religious faith in adjusting to their illness had either changed from a negative to positive attitude or had notably increased in the degree of importance perceived during the previous three years for 26.6% of the subjects.

Sodestrom and Martinson (1987) studied spiritual coping strategies in 25 hospitalized cancer patients. The most frequently used spiritual coping strategies reported were personal prayer, asking others to pray for them, use of religious television, radio, music and objects. Patients read the Bible on average six hours a week. Those who attended church regularly used more spiritual resource people and activities than those who did not attend church regularly. Those patients aware of their poor prognosis also used a greater number of spiritual activities than those unaware of their prognosis. The majority (66%) of patients reported increase in awareness and practice of their spiritual beliefs since diagnosis.

In summary, caregiving has been found to be a stressful experience with physical and psychological tolls on the caregiver. Caregiving is a chronic stressor as evidenced by the number of years the caregivers in the studies had been engaged in the caregiving. The use of spirituality in the coping process has been reported to be an important and effective coping strategy for caregivers. This study sought to determine whether the caregiver wives in this sample also reported spiritual perspective to be used at a higher level than their noncaregiver wives counterparts as in previous research studies. If the caregiver

wives use spiritual perspective at a higher level than noncaregiver wives it may be seen as an important resource in the caregiving process.

Research Question

Do caregiver wives of elderly men with dementia use spiritual perspective at a higher level than noncaregiver wives ?

Definition of Terms

Caregiver wife: an individual who provides personalized services in activities of daily living to ameliorate a health problem, improve the quality of life, and/or meet care needs of her husband which he is unable to provide for himself (Forbes, 1994).

Care receiver: a husband who receives personalized services in activities of daily living to ameliorate a health problem, improve the quality of life, and/or meet care needs he is unable to provide for himself (Forbes, 1994).

Dementia: a condition characterized by change in cognitive skills due to changes in the brain and marked by the loss of thinking and functional abilities which is organically based and is not responsive to known treatments or interventions (Rozema, 1996).

Elderly: a person of more than 50 years of age.

Noncaregiver wife: an individual who does not provide any personalized services to ameliorate a health problem, improve the quality of life, or meet care needs of her husband which he is unable to provide for himself (Forbes, 1994).

Spirituality: personal views and behaviors that express a sense of relatedness to a transcendent dimension or to something greater than the self and do not devalue the individual. Spirituality may include behaviors such as prayer, meditation, forgiveness, church attendance and reading of spiritual literature such as books or the Bible (Reed, 1991).

Spiritual perspective: a term interchangeable with spirituality.

CHAPTER 3

METHOD

Research Design

The research design is descriptive correlational. The problem studied was not amenable to experimental design and manipulation. The correlational design was amenable to the population being studied since introducing the stressor of caregiving for a spouse was impossible.

The advantage of this design was the ability to obtain an adequate sample for data analysis. The use of subjects who were willing to participate in the study was advantageous to obtaining data but may have had negative effects on data through personal bias. The subjects may have volunteered for the study because of personal interest in the study topic. This personal bias could have inflated or deflated the spirituality scores. Those caregiver wives who are not interested in spirituality or who are atheists or agnostics might have chosen not to participate. It is hoped that the use of comparison groups will have negated the effects of personal bias as results were based on group differences instead of caregiver wives' scores only. The collection of data from one geographical area could be another disadvantage. The results could not be generalized to the U. S. population. The other disadvantage of this geographic area in particular is the high prevalence of conservative churches, schools, and morals. This religious orientation could have resulted in higher spirituality scores than might be found in other geographic areas. It is hoped the comparison of this research confirms results of previous research done in the Southern United States.

The use of women subjects only was an advantage in that it made the sample more homogenous but could have been a disadvantage in limiting generalizability. Limiting the sample to caregiver wives of dementia patients instead of all caregivers was done to make the sample homogenous. Caregivers of dementia patients were specifically chosen as they were known to be the group of caregivers with the highest known levels of perceived

stress. The use of this sample was similar to the sample used by Kaye and Robinson (1994), enabling comparison to previous research by Kaye and Robinson.

The use of community organizations and support groups to solicit study participants could have proved a disadvantage if the subjects in these groups use spirituality differently than those caregiver wives who did not use community resources. The relationship between community resource use and spirituality was not covered in this study.

The study was done using comparison groups solicited from area community agencies and support groups. There were exceptions to this with 2 caregiver participants coming from other geographical areas in the U. S. through contacts with other participants. Caregiver wives of dementia patients were compared with non-caregiver wives. Both groups were from the same geographical area and age group. The instrument was administered by mail to both groups one time only without interventions.

Sample and Setting

The sample was a convenience sample solicited from community agencies and support groups in a Midwestern city. Both groups were married women who were of age 50 years and older and who had at least one family member living no further than 45 minutes driving distance. Exceptions were made in the age and distance criteria to include more participants for a more thorough data analysis. The caregiver wives were the primary caregiver for a husband with a diagnosis of irreversible dementia. The non-caregiver wives did not provide any caregiving activities to their husbands.

The procedure for sampling was to solicit participation through staff at area agencies and members of local support groups. Those who agreed to participate were given or mailed the tool, along with a demographic questionnaire and informed consent form.

Sample size was planned to be 30 participants for each comparison group for a total of 60 participants. This was larger than the sample size used in the Kaye and

Robinson study being replicated. The sample size was felt to be minimally adequate for statistical analysis and comparison of results to previous research.

Instrument

The instruments used were the Spiritual Perspective Scale, designed by Dr. Pamela Reed, and a demographic data form.

Spiritual Perspective Scale

The Spiritual Perspective Scale (SPS) was developed by Dr. Pamela Reed and is used to measure spiritual beliefs and behaviors (see Appendix A). The SPS has 10 items that measure participants' perspective of the extent to which certain spiritual views are held and spiritually related interactions are utilized. The instrument has been tested on adults of all ages and states of health. Permission to use the SPS was obtained from Dr. Reed (see Appendix B).

The SPS uses Likert-like questions ranging from 1 to 6. A score of 1 equals "not at all" or "strongly disagree". A score of 6 equals "about once a day" for spiritual activities or "strongly agree" for beliefs. Total scores could range from 10 to 60.

Reliability coefficient for internal consistency in the Kaye and Robinson study (1994) was consistently above .90 using Cronbach's alpha. Reliability for the present study was examined using data from this study. Reliability using Cronbach's alpha was found to be .95. Validity was demonstrated through previous research by Reed (1987) where scores related as expected to the variables of age, sex, and years of education. Individuals who indicated no religious affiliation had significantly lower scores than those with religious affiliation (Reed, 1987).

Demographic Data Form

A demographic data form was designed for this study by this researcher (see Appendix C). Questions were designed to collect pertinent data for analysis as well as comparison to the previous study by Kaye and Robinson (1994). There are thirteen questions on the

data form. The questions relate to demographics of age, income, race, health, marriage longevity, dementia diagnosis, and caretaking needs and tasks.

Procedures

Prior to data collection, approval from the Human Research Review Committee of Grand Valley State University was obtained (see Appendix D). Additional approval was obtained as needed from community groups.

Recruiting of these participants was done through area support groups and community groups as well as senior centers. The SPS was given or mailed out to prospective participants. Included in the mailing was a cover letter, informed consent form, a demographic data questionnaire, and the SPS instrument. The cover letter included information on voluntary participation, freedom of withdrawal, confidentiality and use of research results (see Appendix E). Participants were given a stamped return envelope to return the forms. Confidentiality was explained in the cover letter. Questionnaires were identified by numbers only on returned forms.

CHAPTER 4

RESULTS

Data Analysis Plan

The demographic data were compared between the two groups for homogeneity. The data of age, years of school, years of marriage, and driving distance of the nearest family member are ratio level measurements that were analyzed using the *t*-test for independent samples. The data of financial abilities, race, and religion are nominal measurements that were analyzed using the chi-square test.

The SPS items are at the ordinal level, but the total score is considered at the interval level. SPS total scores of two groups were used to test the research question. SPS mean total scores of the two groups was compared using the *t* test. Individual items on the SPS were compared between the two groups using the Mann-Whitney *U* test.

Characteristics of Subjects

The two groups were compared according to the demographic questions. (see Table 1). The mean age of 59 years of the noncaregivers was younger than that of 69 years of the caregiver group, and the difference was found to be significant ($p < .05$). The mean age of the husbands in the noncaregiver group was 62.4, while the mean age of the husbands in the caregiver group was 70.7. This difference in ages was significant ($p < .05$). The noncaregiver group had slightly more education, with a mean of 15.7 years. The caregiver group had a mean of 12.8 years of education. The difference was significant ($p < .05$). The caregiver group had been married a mean of 41 years compared to a mean of 35 years on the noncaregiver group, but these differences were not significant when analyzed ($p > .05$). There was not a significant difference in the driving distance of the nearest relative lived ($t(57) = 1.61$, $p > .05$). The caregiver wives had a relative living a mean of 13 minutes away compared to 41 minutes in the noncaregiver wives group.

Table 1

Comparison of Demographic Characteristics of Age, Education, Years of Marriage, and Driving Distance of Caregiver and Noncaregiver Wives

Characteristics	Caregiver (n = 30)	Noncaregiver (n = 30)	t	p
Age (in years)				
Mean	69.3	59.9		
SD	7.5	8.6	4.46	.000
Range	53 - 80	46 - 79		
Age of husband (in years)				
Mean	70.7	62.4		
SD	7.9	9.0	3.79	.000
Range	52 - 80	47 - 80		
Education (in years)				
Mean	12.8	15.7		
SD	2.0	3.6	3.77	.000
Range	8 - 19	9 - 25		
Years of marriage (in years)				
Mean	41.2	35.7		
SD	12.6	8.6	1.96	.055
Range	16 - 59	18 - 52		
Driving distance to nearest relative (in hours)				
Mean	0.23	0.76		
SD	0.23	1.8	1.61	.119
Range	0.6 - 1.25	0.6 - 8.0		

There was no significant difference between the groups concerning race, financial ability, or religion, ($p > .05$). (see Table 2). Both groups were predominantly white, able to pay bills with some left over, and Protestant.

Table 2

Comparison of Demographic Characteristics of Race, Financial Situation, and Religion of Caregiver and Noncaregiver Wives

Characteristic	Caregiver		Noncaregiver	
	n	%	n	%
Race [a]				
White	28	93.3	30	100.0
African-American	1	3.3	0	0
Asian	1	3.3	0	0
Financial situation [b]				
Able to pay bills with some left over	20	66.7	23	76.7
Able to pay bills with little left over	10	33.3	7	23.3
Not able to pay all of the bills	0	0	0	0
Religion [c]				
Protestant	24	80.0	25	83.3
Catholic	5	16.7	4	4.0
Other	1	3.3	0	0
None	0	0	1	3.3

[a] $X^2 = 2.08$, df = 2, p = .35

[b] $X^2 = 0.74$, df = 1, p = .39

[c] Fisher's Exact test, two tail = 1.00

The caregiver wives had been caring for their husbands with dementia from 10 months to 15 years with a mean of 2.5 years. Table 3 shows the activities of daily living (ADL's)

assisted by the caregiver wives. Of the husbands, 56.7% required assist with bathing, 76.7% with dressing, 50% with toileting, 23% with eating, and 56.7% with transfers. Table 4 shows the independent activities of daily living assisted by the caregiver wives. Of the husbands, 66.7% required assist with using the phone, 83.3% with traveling, 76.7% with shopping, 80.0% with preparing meals, 70% with heavy housekeeping, 73.3% with taking medications, and 86.7% with managing money.

Table 3

Activities of Daily Living (ADL) Assistance Provided by Caregiver Wives

Activity	Care receiver needed assistance		Care receiver did not need assistance	
	n	%	n	%
Bathing	17	56.7	13	43.3
Dressing	23	76.7	7	23.3
Toileting	15	50.0	14	46.7
Feeding self	7	23.3	23	76.7
Transferring to chair or walking	17	56.7	13	43.3

In summary, the two groups were not significantly different with respect to all characteristics examined with exception of age and education. The caregivers and their husbands were older compared to the noncaregiver group. The noncaregivers had more education than the caregiver group.

Table 4

Independent Activities of Daily Living (IADL) Assistance Provided by Caregiver Wives

Activity	Care receiver needed assistance		Care receiver did not need assistance	
	n	%	n	%
Using telephone [a]	20	66.7	9	30.0
Traveling [a]	25	83.3	4	13.3
Shopping [a]	23	76.7	6	20.0
Meal planning / cooking [b]	24	80.0	4	13.3
Heavy housework [b]	21	70.0	7	23.3
Taking medicines correctly [b]	22	73.3	6	20.0
Managing money, buying needs, writing checks, paying bills [a]	26	86.7	3	10.0

[a] One case missing
[b] Two cases missing

Research Question Findings

The research question of "Do caregiver wives of elderly men with dementia use spiritual perspective at a higher level than noncaregiver wives?" was answered in the following analysis. The caregiver wives and noncaregiver wives were compared according to their total score on the Spiritual Perspective Scale (SPS). The groups were also compared by their answers to each of the 10 questions on the SPS. Total scores on the SPS could range from 10 to 60. The caregiver group scores ranged from 31 to 60, with a mean of 54.6. (see Table 5). Scores from the noncaregiver group ranged from 21 to 60,

with a mean of 54.8. There was no significant difference between the groups scores with respect to total SPS scores (t (57) = 0.10, p > .05). The research question was not supported.

Table 5

Comparison of Spiritual Perspective Scale Scores of Caregiver and Noncaregiver Wives

	Caregiver (n = 29)	Noncaregiver (n = 30)	t	p
M	54.6	54.8		
SD	6.13	8.08		
Range	31 - 60	21 - 60	0.924	.640

Mann-Whitney U tests of the individual questions on the SPS showed no significant difference in rankings of each items on the SPS between the caregiver and noncaregiver groups. Table 6 shows the analysis of the responses to the individual questions.

In summary, the findings did show the caregivers were engaged in providing assistance with many ADL's and IADL's to their husbands with dementia. However, they did not show a significant difference in their use of spiritual perspective along with the burden of caregiving from their noncaregiver counterparts. An increase in the use of spiritual perspective among caregivers would have been seen if it were a strong source of coping with caregiver burden. It was not seen amongst the participants in this study.

Table 6

Comparison of SPS Item Mean Ranks of Caregivers and Noncaregivers

Item	Caregiver mean rank	Noncaregiver mean rank	"U"	Z	p
1	34.1	26.9	342.5	-1.72	.08
2	29.5	31.5	419.5	-0.48	.63
3	30.7	30.2	442.5	-0.13	.89
4	30.0	30.9	436.0	-0.37	.71
5	30.3	30.6	446.5	-0.07	.94
6	28.5	31.4	390.5	-0.76	.45
7	29.2	30.7	412.0	-0.48	.65
8	31.4	28.6	394.5	-0.71	.47
9	28.7	31.1	402.0	-0.63	.53
10	28.1	31.8	381.0	-0.98	.32

CHAPTER 5

DISCUSSION

Discussion

The research question in this study " Do caregiver wives of elderly men with dementia use spiritual perspective at a higher level than noncaregiver wives?" was not supported. The results of the study did not confirm the assertions by Lazarus and Folkman (1984) in their conceptual framework. They theorized that stress, such as that in caregiving, would be reduced by increased use of person factors such as existential beliefs.

The sample was comparable in demographics to previous studies by Robinson and Kaye (1994) with the exception of religious denomination. Their studies reported a population that was almost half Protestant and half Catholic compared to the predominantly Protestant sample in this study.

This study sought to replicate the previous study by Kaye and Robinson (1994). Their study did not find a significant difference between caregiver and noncaregiver groups scores on the SPS, but did find scores in the predicted direction. This study found neither a significant difference in SPS scores nor SPS scores tending in the predicted direction.

The Kaye and Robinson group used a smaller study group of 17 caregivers and 23 noncaregivers. The small size of their study groups may have affected the statistical results of their study. They limited their caregivers to those caring for husbands with Alzheimer's dementia whereas this study included husbands with any kind of dementia. The Kaye and Robinson study was done with husbands in the early stages of the disease. Information about types of caregiving tasks provided by the caregiver wives is not given in the Kaye and Robinson study so a more accurate comparison between their study and this study is not possible. There may have been differences in the level of care provided between the two groups, thus affecting the stress and coping of the caregivers in the Kaye

and Robinson study. Research would have to be done to determine if there is a difference in stress and coping between those caring for Alzheimer husbands and those caring for husbands with other types of dementia. The Kaye and Robinson study was done in the Southeastern United States compared to this study being done in the Midwest. The demographics between these groups were comparable but there may be some regional differences not appearing in either study.

There are several possible explanations for the research question not being supported in this study. There has not been a large body of research done using the Spiritual Perspective Scale. Reed, who developed the tool, has found higher use of religiousness using the Religious Perspective scale among terminally ill adults and women compared to healthy subjects (1987). It is possible the tool may not be sensitive enough to measure spiritual perspective for all groups accurately.

The high scores on the SPS by noncaregiver wives for this study may indicate a very spiritual population in the geographic area used for the study. The spiritual perspective may not change significantly in this population when under stress as it is already highly used in coping. Caregivers in this geographic region may be strengthening their coping with other person factors. The present study is limited to spiritual apects of caregivers coping behaviors. Studies would need to be done to assess the other coping mechanisms of caregivers versus noncaregivers in this geographic region to assess which coping mechanisms are used when stress is increased in a caregiver's life. There are tools with well established reliability and validity that can measure which coping mechanisms, according to Lazarus and Folkman's stress and coping conceptual framework (1984), are used by a person. Examples of such tools are the Jalowiec Coping Scale (Jalowiec, 1987) and Lazarus and Folkman's Ways of Coping Scale (Lazarus and Folkman, 1984).

Limitations

Two demographic variables that were to be included in all participants as requirements for inclusion in this study were altered slightly to increase sample size. The variable of age was to be older than 50 years. There were 3 noncaregivers younger than 50 years of age. The youngest of these participants was 47 years of age. The noncaregivers did have a lower mean age than the caregivers and this was significant in the data analysis. The husbands of noncaregivers were also found to be younger than their counterparts in the caregiver group, and this difference in means of 62.4 years of age and 70.7 years of age was also found to be significant. The other variable altered was the driving distance of the nearest relative. Participants were to have had a relative living within 45 minutes of driving distance. There were 4 noncaregivers with family living beyond the planned distance. The distances for these participants ranged from 75 minutes to 480 minutes. The mean driving distance between the two groups was not significant. The inclusive criteria of the wives' ages and driving distance was modified to increase the sample size for the purpose of data analysis of SPS scores. These changes in inclusion criteria did not affect the overall analysis of the research question. There was also a significant difference in years of education with the noncaregivers having a mean of 15.7 years of education compared to 12.8 years for the caregiver group. The fact that the noncaregiver wives were younger and better educated could have affected the results. External validity may have been affected by the use of participants in one geographic area which is predominantly white and Protestant, the small sample size, or the uniqueness of the sample. Therefore, the findings of this study may not be generalized to the larger U. S. population.

Recommendations

The recommendations for further research are bi-directional. The first recommendation would be to clarify the results of this study through further research into

the effects age and education have on spirituality. The second direction is aimed at discovering which coping mechanisms are effectively used at higher levels by caregivers.

The lack of support for spiritual perspective being used by caregivers in the study brings up questions of the SPS tool and its ability to measure spiritual perspective changes between groups. A study using a more widely used spirituality tool and the SPS would perhaps show if the SPS was effectively measuring spiritual perspective. A study using a more narrow definition of dementia diagnosis, such as documented Alzheimer's or other documented medical diagnosis of a dementia, may eliminate any variance in responses between undocumented, mild, and severe dementias. Mild dementias may not be stressful enough to require a change in coping mechanisms. Studies using the SPS in other geographic areas involving similar demographic groups would also be helpful in telling if results of this study were regional in nature. The Kaye and Robinson study was done in the Southeastern U. S. .

The stress of caregiving on the caregiver is well documented. If spirituality is not used at a higher level by caregivers when compared to noncaregivers as shown in this study, research should address which coping mechanisms are used at higher levels by caregivers. Investigation into which coping mechanisms are effective in reducing caregiver stress would be helpful. A coping mechanism used at a higher level may not be effective. The expected increase in the elderly population in the next few decades will undoubtedly bring an increase in caregivers and carereceivers. It will be beneficial to know which coping mechanisms can be recommended to these caregivers to effectively reduce their stress of caregiving before the increased numbers occur.

APPENDIX A

SPIRITUAL PERSPECTIVE SCALE

Introduction and Directions: A person's spiritual views may be an important part of their life. In general, spirituality refers to an awareness of one's inner self and a sense of connection to a higher being, nature, others, or to some purpose greater than oneself. I am interested in your response to the questions below. There are no right or wrong answers, of course. Answer each question to the best of your ability by marking an "X" in the space above that group of words which best describes you.

1. In talking with your family or friends, how often do you mention spiritual matters?

Not at all	Less than once a year	About once a year	About once a month	About once a week	About once a day

2. How often do you share with others the problems and joys of living according to your spiritual beliefs?

Not at all	Less than once a year	About once a year	About once a month	About once a week	About once a day

3. How often do you read spiritually-related material?

Not at all	Less than once a year	About once a year	About once a month	About once a week	About once a day

4. How often do you engage in private prayer or meditation?

Not at all	Less than once a year	About once a year	About once a month	About once a week	About once a day

Directions: Please indicate the degree to which you agree or disagree with the following statements by marking an "X" in the space above the words which best describe you.

5. Forgiveness is an important part of my spirituality.

Strongly Disagree	Disagree	Disagree more than agree	Agree more than disagree	Agree	Strongly Agree

6. I seek spiritual guidance in making decisions in my everyday life.

Strongly Disagree	Disagree	Disagree more than agree	Agree more than disagree	Agree	Strongly Agree

7. My spirituality is a significant part of my life.

Strongly Disagree	Disagree	Disagree more than agree	Agree more than disagree	Agree	Strongly Agree

8. I frequently feel very close to God or a "higher power" in prayer, during public worship, or at important moments in my daily life.

Strongly Disagree	Disagree	Disagree more than agree	Agree more than disagree	Agree	Strongly Agree

9. My spiritual views have had an influence upon my life.

Strongly Disagree	Disagree	Disagree more than agree	Agree more than disagree	Agree	Strongly Agree

10. My spirituality is especially important to me because it answers many questions about the meaning of life.

Strongly Disagree	Disagree	Disagree more than agree	Agree more than disagree	Agree	Strongly Agree

Do you have any views about the importance or meaning of spirituality in your life that have not been addressed by the previous questions?

_____

_____

Thank you very much for answering the questions

Permission to use obtained

APPENDIX B

College of Nursing
Associate Dean for Academic Affairs

THE UNIVERSITY OF
ARIZONA
HEALTH SCIENCES CENTER

Tucson, Arizona 85721
(602) 626-6151
FAX (602) 626-7211

February 15, 1996

Martha Preston, RN, BSN
1441 Colorado SE
Grand Rapids, MI 49507

Dear Ms. Preston:

Thank you for your interest in my work on spirituality. You are welcome to use my instrument, the **Spiritual Perspective Scale.** I ask only that you complete the Request Form and return it to me for my files. I would be happy to address any questions that arise concerning use of the SPS in your research along the way. I wish you the best in your master's thesis research.

Sincerely,

[redacted]

Pamela G. Reed, RN, PhD, FAAN
Associate Dean for Academic Affairs

encl.

cact:

APPENDIX C

DEMOGRAPHIC CAREGIVER DATA FORM

ID # _____

The following information is needed to help me with the statistical analysis of the data. This information will allow comparisons among different groups of wives.

I. What is your age? _____ (in years).

II. How old is your husband? _____ (in years)

III. How many years of school have you completed? _____ (in years).

IV. How many years have you been married to your husband? _____(in years)

V. What is your race? Are you:

1. ___ White
2. ___ Black
3. ___ Hispanic
4. ___ Native American Indian
5. ___ Asian / Pacific Islander
6. ___ Other (please specify _____)

VI. What is your financial situation? Are you:

1. ___ Able to pay bills with some left over
2. ___ Able to pay bills with little left over
3. ___ Not able to pay all of the bills

VII. What is your religion? Are you:

1. ___ Protestant
2. ___ Catholic
3. ___ Jewish
4. ___ Other (please specify _____)
5. ___ None

VIII. How far driving distance does your nearest family member live from you? (in driving minutes) _____

IX. Does your husband have diagnosis of an irreversible dementia, such as Alzheimer's?

1. ___ Yes
2. ___ No

X. If your husband has an irreversible dementia, such as Alzheimer's, are you the major provider of care to your husband?

1. ___ yes
2. ___ no

XI. If your husband has an irreversible dementia, such as Alzheimer's, what is the length of time you have been providing care for your husband? (example: 3 years and 5 months)

number of years _____ number of months _____

XII. If your husband has an irreversible dementia, such as Alzheimer's, does he need assistance with: (check <u>all</u> that apply)

1. bathing yes ___ no___
2. dressing yes ___ no___
3. toileting yes ___ no ___
4. feeding self yes ___ no ___
5. transferring to a chair or walking yes ___ no___
6. ___ does not need assistance with any of these
7. ___ does not have an irreversible dementia, such as Alzheimer's

XIII. If your husband has an irreversible dementia, such as Alzheimer's, does he need assistance with: (check all that apply)

1. answering or dialing the telephone yes ___ no ___
2. traveling (unable to drive own car or travel alone on bus or taxi) yes ___ no ___
3. shopping (if transportation is provided) yes ___ no ___
4. planning and cooking meals yes ___ no ___
5. heavy housework (cleaning floors) yes ___ no ___
6. taking the right medication at the right time yes ___ no ___
7. managing money, buying needs, writing checks, paying bills yes ___ no ___
8. ___does not need assistance with any of these
9. ___ does not have an irreversible dementia, such as Alzheimer's

APPENDIX D

GRAND VALLEY STATE UNIVERSITY
1 CAMPUS DRIVE • ALLENDALE MICHIGAN 49401-9403 • 616/895-6611

March 11, 1997

Martha Preston
1441 Colorado SE
Grand Rapids, MI 49507

Dear Martha:

Your proposed project entitled "***Spirituality Among Caregiver Wives of Dementia Patients***" has been reviewed. It has been approved as a study which is exempt from the regulations by section 46.101 of the Federal Register 46(16):8336, January 26, 1981.

Sincerely,

[redacted]

Paul Huizenga, Chair
Human Research Review Committee

APPENDIX E

Dear Participant:

I would like to ask your cooperation to take a few minutes of your time to complete the enclosed questions and send it back in the self addressed envelope. Martha Preston, a nurse completing her graduate degree in gerontological nursing at Grand Valley State University, is conducting this study.

I am studying the use of spiritual behaviors and beliefs. Spiritual behaviors include prayer, reading, and talking about spiritual things. Spiritual beliefs include believing in forgiveness and feeling close to God.

Two groups of women are being used for this study: those caring for men with a dementia, and those married to healthy husbands. The information from the wives of healthy husbands is needed for comparison.

Your participation in this study is completely voluntary. Your identity will be completely confidential. Please do not write your name on any pages.

There is no direct personal benefit to you for participating in this study. However, the results of this study will provide knowledge useful in helping others caring for persons with dementias such as Alzheimers. There are no risks involved in participating in this study. Your return of the questionnaire will be taken as your consent to participate in this study as well as to have your data included in a published paper.

If you would like a copy of the results of this study, please send a separate postcard to the researcher, Martha Preston.

If you have any questions concerning this study you may contact the researcher, Martha Preston R. N. My phone number is: (616)246-5208. If you have any questions concerning your rights as a research subject please contact Professor Paul A. Huizenga, Chair of Human Subjects Review Committee at Grand Valley State University. His phone number is (616)895-2472. Thank you for your time and participation.

Sincerely,

Martha Preston R. N.
1441 Colorado S.E.
Grand Rapids, MI 49507

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