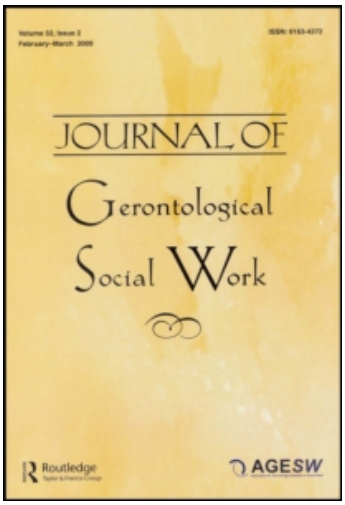

Journal of Gerontological Social Work
Publication details, including instructions for authors and subscription information:
http://www.informaworld.com/smpp/title~content=t792304007

Caregiver's Spirituality and Its Influence on Maintaining the Elderly and Disabled in a Home Environment

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Online Publication Date: 14 August 2008

To cite this Article Choi, Gil, Tirrito, Terry and Mills, Frances(2008)'Caregiver's Spirituality and Its Influence on Maintaining the Elderly and Disabled in a Home Environment',Journal of Gerontological Social Work,51:3,247 — 259
To link to this Article: DOI: 10.1080/01634370802039528
URL: http://dx.doi.org/10.1080/01634370802039528

Caregiver's Spirituality and Its Influence on Maintaining the Elderly and Disabled in a Home Environment

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ABSTRACT. This study examined the role that faith-based organizations play for caregivers in maintaining the elderly and disabled in their homes. The study explored if persons who use religious beliefs and practices cope with caregiver stress better than those who do not use religious beliefs and practices. The study also explored the role of religious coping as a factor affecting decisions to institutionalize, and the role that faith-based practices and organizations play in helping caregivers maintain the elderly and disabled in their homes.

KEYWORDS. Elderly, older adults, spirituality, religiosity, religious coping, caregiving, caregiver burden, caregiver stress, faith–based organizations, congregations, disabled persons

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Journal of Gerontological Social Work, Vol. 51(3–4) 2008
Available online at http://jgsw.haworthpress.com

doi:10.1080/01634370802039528

INTRODUCTION

According to recent census data, the fastest growing sector of the population over the next two decades will be older adults (U.S. Census Bureau, 2001). Koenig and Lawson (2004) reported that in 2000, there were eight times more people in the 65–74 age group, 16 times more people in the 75–84 age group, and 34 times more people over 85 than there were in 1900, and maintained that this trend will continue. As the aging population increases dramatically in the next two decades, the need for services to support and maintain optimal quality of life will also increase for this population. Advances in medicine and technology now allow people to live longer, but often with disabilities that require ongoing care (Koenig & Lawson, 2004).

The need for caregiving is expected to increase along the same trajectory, as an aging population will result in numbers of people whose health prevents them from caring for themselves (Canadian Study of Health and Aging Working Group, 2002 & Navalie-Waliser et al., 2001). According to Koenig (1994), family members provide 85% of all caregiving to ill or disabled older adults and are at risk themselves for deteriorating health and social relationships. Some of the conditions of older adults that necessitate caregiving include Alzheimer's Disease (AD), and chronic illnesses such as diabetes, mental retardation, and frailty. The number of people with these conditions will only increase. For example, Morano and King (2005) stated that, by the year 2010, the number of people diagnosed with AD is expected to grow from 4 million to more than 10 million. With this expected growth, it is important for social work research to develop an understanding of how caregivers navigate the strain of caregiving and to identify factors that may impact caregiver decision making.

Religion and spirituality's positive effects have been identified as contributing to a caregiver's sense of well-being and coping (Berg-Weger, Rubio, & Tebb, 2001). Religiosity and spirituality have been found to help mediate the perception of and reaction to caregiving stress (Morano & King, 2005). Few research studies have focused on the impact of religiosity and spirituality on caregiver decisions that involve placing loved ones in institutional care. Finding out how spirituality and religiosity impact caregiving decisions can provide important knowledge to social workers for the development of caregiving interventions. It has implications for the care recipient, the caregiver, and for faith-based organizations as well.

After a brief literature review, this study uses adaptations of the stress and appraisal models of Pearlin, Mullan, Semple, and Skaff, (1990) and

Chang (1998) to examine the effects of religion and spirituality and religious coping on caregiver decision-making.

LITERATURE REVIEW

Caregiver burden and caregiver strain are terms that refer to the numerous negative outcomes of providing care to or for another person (Hunt, 2003). Negative outcomes of caregiving may include social isolation, disruption of leisure/employment time, depression and anxiety, physical symptoms/illnesses, and emotional instabilities (Berg-Weger, Rubio, & Tebb, 2001; Dillworth-Anderson, Williams, & Gibson, 2002).

There is evidence in the caregiving literature that high levels of caregiver burden are related to premature institutionalization of the care recipient. The gerontological literature indicates that stress, strain, and negative responses to caregiving are well recognized as issues that influence a caregiver's decision to institutionalize a family member in a long-term care facility. Gaugler, Kane, Kane, Clay, and Newcomer (2005) maintained that the institutional process is a complex one. According to them, the emotional, psychological, and physical tolls associated with caregiving, subjective appraisals of stress by caregiver, and a sense of being trapped are associated with institutionalization because primary caregivers view institutionalization as a relief. They also maintain that, as caregiving requires more physical assistance, institutionalization is further expedited. In other words, the desire to institutionalize is greatest when caregivers experience high levels of stress and when the caregiving is physically burdensome. Aneshensel, Pearlin, and Schuler (1993) also noted that increased levels of caregiving strain are associated with institutionalization.

In recent years, researchers have increasingly directed their attention to the relationship between caregiver's religious involvement and its effects on caregiving. Some studies indicate that family members who practice religious beliefs to cope with the task of providing care exhibit less caregiving strain and more positive psychological well-being than others who do not (Fingerman, Gallagher-Thompson, Lovett, & Rose, 1996; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). Koenig (1994) noted that indexes of religious coping have been associated with lower rates of depression. Williams and Dilworth-Anderson (2002) reported that caregivers who have more cohesive networks of informal support, such as those provided by religious congregations, are less likely to use formal supports to provide care.

Crowther, Parker, Achenbaum, Larimore, and Koenig (2002) suggested that the concept of positive spirituality should be a factor in Rowe and Kahn's model of successful aging. Rowe and Kahn's model defines successful aging as avoidance of disease and disability, maintenance of physical and cognitive functioning, and engagement in social activities. However, Crowther et al. stated that spirituality has positive effects on wellness, and asserted that this opens doors of opportunity for groups who have become reluctant recipients of traditional interventions.

Religious involvement has been linked positively to physical and mental health as well as to longevity (Koenig, 2004). Kraus (2002) pointed out the positive relationship between religion and optimism, and identified a substantial number of studies between optimism and physical health. Kraus stated that people who are optimistic tend to cope more effectively with stressful life events and concluded that spiritual support is related to health. Due to the stress-buffering role of religious involvement, caregivers have a lower incidence of depression (Morano & King, 2005). Caregiver depression is known as a factor associated with earlier admission of a loved one to a nursing home. Chang (1998) reported that caregivers who use religious or spiritual beliefs to cope have a better relationship with their care recipients, a factor associated with lower levels of depression.

Little is known about how religion or spirituality helps caregivers in making decisions that affect their loved ones, such as the decision to institutionalize or the decision to keep at home. Finding out how spirituality and religion impact caregivers' decisions can provide important knowledge for social work in the development of caregiving interventions. It has implications for caregivers, care recipients, and for faith-based organizations as well.

Faith-based organizations can fill the gap for social services that public agencies are unable to provide to older adults. Faith communities provide numerous advantages for older adults and their caregivers. Hale and Bennett (2003) stated that faith-based organizations and relationships that develop as a result of involvement provide a natural means to foster and support caregiving. They emphasize that faith-based communities have regular contact with the people who need them and are likely to reflect the traditions and values of the community residents, thus lending a sense of familiarity and comfort when seeking help and support. Barker (2002) noted the strengths of these relationships, stating that they possibly play a key role through social interaction that will reduce anxieties and stave off institutionalization.

This analysis was designed to assess the influence of religiosity and spirituality on caregiver decision-making, specifically the decision to provide care for a loved one at home, rather than to institutionalize.

Conceptual Model

Pearlin et al. (1990) offered a conceptual model of caregiving and the stress process. They maintained that caregiver stress is not a unitary occurrence but a mix of circumstances, experiences, responses, and resources that vary considerably among caregivers, and that consequently vary in their impact on caregiver health and behavior. Their model is based on background and context, such as socioeconomic status, caregiving history, family and network composition, and program availability; primary stress indicators, such as cognitive status, problematic behavior of care recipient, and overload and relational deprivation of caregiver; secondary role strains, such as family conflict, economic problems, and constriction of family life; secondary intrapsychic strains, such as self-esteem, mastery, loss of self, role captivity, competence, and gain; outcomes, such as depression, anxiety, irascibility, cognitive disturbance, physical health, and yielding of role; and mediators, include coping and social support. They noted that there are caregivers who find some inner enrichment and growth, even as they contend with mounting burdens while other caregivers do not. According to Pearlin et al., mediators include coping and social support.

Chang (1998) provided a conceptual view of religious coping. Chang noted an indirect influence of religious and spiritual coping on caregiver distress. Chang reported that caregivers who use religion and spirituality to cope with caregiving have a better relationship with care recipients and have lower levels of depression. This study examined the social service needs of the caregiver and proposed the following hypotheses.

H1: Persons who use religious practices cope with caregiving stress better than those who do not.

H2: Religious support received from congregations affects decisions to institutionalize.

METHOD

Sample

A random sample of 941 long-term care participants was obtained to test the research hypotheses. Participants were caregivers of continuing long term care recipients of the South Carolina Department of Health and

Human Services. Those who chose to participate in the study completed the anonymous questionnaire that took about 30 minutes. After the surveys were entered into SPSS and cleaned for missing data, a total *N* of 232 was obtained.

Measures

Demographic variables. Morano and King (2005) stated that variables such as caregiver's gender, age, income, and years of education are frequently reported in the caregiving literature. Race, employment status, marital status, relationship to care recipient, place of caregiving, number of hours of caregiving, and length of caregiving were also variables of interest with regard to the caregivers in this study. The care recipient's gender, age, and cognitive status were also variables of interest in this study.

Care burden stressor variables. Care burden stress (Pearlin, et al., 1990) was measured on three subscales: *role overload* was measured with three items; *role captivity* was measured with three items; and six stressors associated with the consequences of long term caregiving and overall care burden were measured with one item. The instrument shows high internal consistency with a Cronbach's coefficient alpha of 0.88 for role overload, 0.84 for role captivity, and 0.81 for stressors associated with the consequences of long term caregiving.

Quality of life variables. The overall quality of life was measured on a single item taken from the McGill Quality of Life Questionnaire (Cohen, 1997). Internal consistency was examined and found to be good with a Chronbach's alpha of 0.83 for the total scale.

Social life. Caregiver's social life (Clipp & George, 1993) was measured on 4 items. It showed a high internal consistency of 0.85. Questions were answered on a scale where 1 = *very dissatisfied*, 2 = *dissatisfied*, 3 = *satisfied*, and 4 = *very satisfied.*

Depression. Depression was measured by the CES-D Scale (Radloff, 1977). The instrument consists of 20 items measuring a broad range of manifestations of depression and has excellent internal consistency with Cronbach's coefficient alpha of 0.90.

Religious/spiritual coping. The role of religious and spiritual coping with caregiving was measured using a single item (Chang, 1998). It measures to what extent religious or spiritual beliefs help caregivers handle the whole experience of caregiving.

Data Analysis. Analyses were conducted using SPSS. Independent sample *t*-tests were conducted to assess differences between gender and differences between race on role overload, role captivity, and other stressors; on quality of life; on social life; on depression; and on whether religious and spiritual beliefs helped to cope with caregiving. A one-way ANOVA was conducted to assess differences in role overload, role captivity, other stressors, and overall care burden among different education and household income categories of caregivers. Correlation coefficients among study variables in the two groups, gender and race, were compared.

RESULTS

Descriptive Characteristics of Sample and Study Variables

The final sample consisted of 232 caregivers with notable gender differences. Approximately 19% were men and 81% were women. On average, participants were 57.4 years of age (*SD* = 11.9). Approximately 49.8% of the caregivers who took this survey were White and 49.3% of the caregivers were Black. Educational attainment by respondents reflected that 83% had a high school education or greater, 39% worked full or part-time, and the remaining 61% were retired or unemployed due to health or caregiving duties. Approximately 66% of participants reported that they had an income under $25,000, and over half (59.4%) were married. Over half of the caregivers (63%) reported their own home as the place most frequently used to provide care and, on average, the number of hours a day spent providing care by the caregiver was 17.5 (*SD* = 8.9). Caregivers reported that they had cared for the care recipient on average 9.4 years (*SD* = 9.5). The length of time for caregiving ranged from 9 months to 60 years. Gender of the care recipients was reported as 41% men and 59% women. The average age of the care recipient was 65.5 (*SD* = 20.7), and 53% of survey respondents reported that the care recipient was cognitively impaired. See Table 1.

The results of the *t*-test indicate that there was no statistically significant difference in role overload, role captivity, and other stressors based on gender ($p > .05$). However, female caregivers showed slightly higher stress levels in each of the three domains. Data analysis indicated that African American caregivers and White caregivers showed a significant difference in role overload ($t = 2.31$, $df = 201$, $p \leq .05$) and in other stressors associated with the consequences of long-term caregiving ($t = 2.94$, $df = 200$,

TABLE 1. Characteristics of community long-term care participants

Variable	Total (N = 232)		African American (n = 106, 46.5%)		Native American (n = 2, .9%)		White (n = 105, 46.1%)	
	M	SD	M	SD	M	SD	M	SD
Caregiver age	57.4	11.9	54.4	11.3	63.5	5	60.2	12.2
Care recipient age	65.4	20.9	67.2	19.9	50	12.7	64.8	20.7
Caregiver gender:								
Female	169		88		2		79	
Male	43		17		0		26	
Education								
Between high school and some college	2.8	1.2					2.6	1.2
Some college			3	1.3	3	1.4		
Income								
$15,000–$24,999	3	1.3			3	1.4		
Slightly below $15,000–$24,999			2.7	1.3				
Slightly above $15,000–$24,999	3.3	1.3					3.3	1.3
Hours/day caregiving	17.6	8.9	17.6	8.6	NA		17.1	9.3
Length of care	9.3	9.5	7.7	7.6	NA		10.9	11.1
Cognitive impairment of care recipient								
Yes	103		51		2		50	
No	89		45		0		44	

$p \leq .01$). It is apparent that White caregivers were more significantly stressed by role overload and other stressors than were African American caregivers. However, no significant difference was found in role captivity between African American caregivers and white caregivers ($p > .05$).

No significant difference in the subjective quality of life was found based on gender ($t = 0.072$, $p > .05$) and race ($t = 1.00$, $p > .05$) even though female and African American caregivers rated slightly higher than male caregivers.

T-tests revealed no significant difference in all domains of social life based on gender ($p > .05$). However, a significant difference between White caregivers and African American caregivers is apparent. African American caregivers are more satisfied with contacts with friends and relatives ($t = 3.20$, $df = 211$, $p = .002$), worship attendance and involvement in voluntary organizations and clubs ($t = 3.50$, $df = 208$, $p = .001$), amount of time spent on recreation and hobbies ($t = 3.32$, $df = 208$, $p = .001$), and time

spent relaxing (t = 3.77, df = 211, p = .000) than are White caregivers. Data analysis indicated that African American caregivers were more social than White caregivers under the same circumstances of caregiving.

Independent samples t-test showed that there was no statistically significant difference in depression between men and women (t = 1.216, df = 163, $p > .05$). Even though female caregivers (M = 18.90, SD = 12.75) were more depressed than men (M = 15.97, SD = 10.78), the difference was not significant. White caregivers (M = 20.71, SD = 13.61) were significantly more depressed than were African American caregivers (M = 15.99, SD = 10.50, t = 2.448, df = 160, p = .015).

H1: Persons who use religious practices cope with caregiving stress better than those who do not.

Religious and spiritual coping was negatively correlated with role overload (r = –0.153, $p \leq .05$), role captivity (r = –0.169, $p \leq .05$), other stressors (r = –.198, $p \leq .05$), caring role preoccupation (r = –0.203, $p \leq .01$), and depression (r = –0.205, $p \leq .01$). Data analysis indicated that caregivers who used religious and spiritual coping were able to lower care burden stresses, thus resulting in lower depression. See Table 2.

H2: Religious support received from congregations affects decisions to institutionalize.

Caregiver's decision-making is positively correlated with spiritual help-seeking (r = 0.266, p = .000); church-based emotional support (r = 0.255, p = .000); church-based religious/spiritual support (r = 0.226, p = .000);

TABLE 2. Religious/spiritual coping, careburden stressors, and depression

	1	2	3	4	5	6
1. Religious/spiritual coping	—					
2. Role overload	–0.153*	—				
3. Role captivity	–0.169*	0.653**	—			
4. Stressors	–0.198*	0.660**	0.709**	—		
5. Role preoccupation	–0.203**	–0.481**	–0.417**	–0.537**	—	
6. Depression	–0.205**	0.480**	0.410**	0.487**	–0.336**	—

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

TABLE 3. Religious beliefs that impact decision-making

	1	2	3	4	5	6	7
1. Beliefs and decision	—						
2. Spiritual help-seeking	0.266**	—					
3. Church-based emotional support	0.255**	0.362**	—				
4. Church-based spiritual support	0.226**	0.385**	0.789**	—			
5. Religious practice	0.337**	0.480**	0.408**	0.448**	—		
6. Daily spiritual experience	0.351**	0.514**	0.408**	0.433**	0.514**	—	
7. Religious/spiritual coping	0.222**	0.422**	0.377**	0.331**	0.307**	0.392**	—

**$p \leq .001$.

religious practice including worship attendance, praying, reading the Bible, and watching televised programs ($r = 0.337$, $p = .000$); daily spiritual experiences ($r = 0.351$, $p = .000$); and religious/spiritual coping ($r = 0222$, $p = .000$). Data analysis indicated that religious beliefs have a significant impact on a caregiver's decision of whether to care for the loved one at home or to place the loved one in a nursing home. When a caregiver's religious beliefs are strengthened by spiritual help-seeking, emotional and spiritual/religious support provided by church, daily spiritual experiences, and active religious practices, they are likely to decide to care for their loved ones at home, rather than to place their loved ones in a nursing home. See Table 3.

DISCUSSION

This analysis assessed the extent to which religious and spiritual support of caregivers impacted the caregiver's decision to care for their loved one at home. The findings of this study indicate that caregivers who used religious and spiritual practices to cope with care burden were able to lower care burden stresses, thus resulting in lower depression. Church-based emotional support was negatively correlated with role captivity, care burden stressors, overall care burden, and depression. Church-based emotional support showed a moderating effect on depression. Accessibility to religious support services was negatively correlated with role captivity, stressors, overall care burden, and depression. Caregivers who felt that they were able to obtain help from their pastors, ministers, and people in their congregations in time of need were less stressed and less depressed.

Data analysis indicated that religious practices had a significant impact on a caregiver's decision to care for a family member at home or to place in a nursing home. When a caregiver's religious practices were strengthened by spiritual help-seeking, emotional and spiritual/religious support provided by religious congregations, daily spiritual practices, and active religious practices, they were likely to decide to care for their family member at home, rather than to place them in nursing homes.

This analysis is limited by the cross-sectional nature of the sample, geographic region, and by the higher educational status of sample participants. Use of a longitudinal research design and inclusion of a more representative sample may increase the generalizability of the study findings and the ability to infer causal effects. The findings of this study confirm the research hypothesis that faith-based organizations can have a significant impact upon long-term care services. It is clear from the study findings that programs and services provided by faith-based organizations can delay institutionalization.

It is important to share this information with faith-based organizations in supporting the need for faith-based organizations to become involved in programs and services for caregivers and older adults. Current support services should be assessed to determine the feasibility of faith-based activities for caregivers. Social workers can provide resource information to faith-based organizations that can be easily distributed in places of worship. Social workers can work with clergy to develop interventions to assist faith-based organizations in securing federal funding for programs and services for the elderly and disabled.

From the results of this study, it is clear that a caregiver's spirituality influences decision-making on caregiving. With less stress, burden, and role overload, the caregiver can maintain the elderly or disabled person in a home environment. Spiritual support from places of worship plays a significant role in the caregiver's ability to support the older adult or the person with a disability at home. The question remains, "How can we mobilize faith organizations to offer support to caregivers?"

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