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Mortality Associated with Caregiving, General Stress, and Caregiving-Related Stress in Elderly Women: Results of Caregiver-Study of Osteoporotic Fractures (SOF)

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Abstract

OBJECTIVES—Studies of the effects of caregiving on mortality have inconsistent results, and none have adjusted for perceived stress. This study investigated the separate and combined effects of caregiver status and high stress on mortality risk over 8 years among elderly women.

DESIGN—Prospective cohort study conducted in four U.S. communities followed from 1999–2001 (baseline) to December 31, 2007.

SETTING—Home-based interviews.

PARTICIPANTS—375 caregiver and 694 non-caregiver participants from the Caregiver-Study of Osteoporotic Fractures (Caregiver-SOF) who participated in the baseline Caregiver-SOF interview.

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Author Contributions:

Lisa Fredman: Conceptualized the hypotheses and study design, took a lead role in the data analyses, interpretation of results and preparation of the manuscript; and designed the Caregiver-SOF study on which these analyses were performed (including obtaining funding for this study).

Jane Cauley: acquisition of subjects and data; administrative support; critical review of the manuscript.

Marc Hochberg: Involved in collection of data from subjects enrolled in the Baltimore Clinical Center and the critical review of the manuscript.

Kristine Ensrud: acquisition of subjects and data, interpretation of data; critical review of manuscript.

Gheorghe Doros: designing and performing statistical analyses; interpretation of data; and critical review of manuscript.

Sponsor's Role

The sponsors had no direct role in the conduct of the study; the collection, management, analyses and interpretation of the data; or the preparation or approval of the manuscript.

MEASUREMENTS—Caregiver status was based on SOF respondents' self-report of performing 1 instrumental or basic ADLs for a relative or friend with impairments. Two measures of stress: Perceived Stress Scale, and stress related to caregiving tasks. All-cause mortality was the outcome.

RESULTS—Caregivers were more stressed than non-caregivers; 19.7% of caregivers and 27.4% of non-caregivers died. Mortality was lower in caregivers than non-caregivers (adjusted hazards ratio, HR = 0.74, 95% confidence interval, 0.56–0.89). High-stress respondents had increased mortality risk compared to low-stress respondents over the first three years of followup (adjusted HR = 1.81, 1.16–2.82), but not in later years. Likewise, high-stress caregivers and non-caregivers had elevated mortality risk compared to low-stress non-caregivers. Low-stress caregivers, however, had significantly lower mortality than did non-caregivers, whether perceived stress or caregiving-related stress was measured (adjusted HRs = 0.67 and 0.57). Similar results were observed in analyses comparing spouse caregivers to married non-caregivers.

CONCLUSION—Short-term effects of stress, not caregiving per se, may increase the risk of health decline in older caregivers.

Keywords

caregiving; mortality; perceived stress

INTRODUCTION

Caregiving is considered a chronic stressor due to persistent and often physically-demanding caregiving tasks, and the emotional toll of caring for a loved one with a debilitating illness. Caregivers consistently report more stress than non-caregivers¹. Chronic stress is associated with adverse health outcomes such as high blood pressure^{2, 3}, poorer immune status^{4, 5}, and mortality^{6, 7}. Results of studies of caregiving and mortality^{8–12} or disease incidence¹³ are inconsistent, however. Some studies have found higher rates of mortality^{8, 9} and coronary heart disease (CHD)¹³ in older caregivers for a spouse (i.e., spouse caregivers) than married non-caregivers. A census-based study of all residents of Northern Ireland, however, found that older caregivers had lower mortality rates than non-caregivers¹¹. Furthermore, other studies observed elevated rates of mortality^{8, 10, 12, 13}, CHD¹³ and incident disability¹⁰ only among subgroups of white respondents¹⁰, strained spouse caregivers⁸, and respondents who provided less than 14 hours of care per week to their spouse¹² or more than 9 hours of care per week to non-spouse relatives¹³. Thus, evidence for higher mortality among caregivers comes mostly from comparisons of spouse caregivers to married non-caregivers^{8, 9}, and may partly reflect study design characteristics.

These study design characteristics include restricting the sample to spouse caregivers and married non-caregivers^{8, 9, 12}. Elderly adults who are married have a large health advantage¹⁴, and caregivers for a spouse report more psychological distress than caregivers for other relatives¹. Thus, researchers may be comparing the most stressed caregivers to the healthiest non-caregivers. In addition, none of these studies included a measure of general stress, thereby precluding the ability to distinguish the independent and combined effects of caregiving and stress on mortality.

The theoretical framework for this study was the caregiving and stress process model¹⁵. This model proposes that the relationship between caregiving and health outcomes is influenced by the context of caregiving, caregiving-related stressors, secondary stressors and mediators of stress; these factors may build upon each other, making the caregiver more susceptible to health decline. This study investigated the association between caregiving and mortality over 8 years in a sample of elderly women, and further, examined the roles of

general- and caregiving-related stress on this relationship. We included measures of general perceived stress, as well as stress resulting from caregiving tasks, and measures of health (i.e., co-morbidities, BMI and ADL and IADL limitations) that are risk factors for mortality in older adults.

We hypothesized that overall, there would be little difference in mortality rates between caregivers and non-caregivers, after adjusting for confounders. Moreover, both caregivers and non-caregivers with high perceived stress levels would have higher mortality rates than non-caregivers with low perceived stress levels.

METHODS

Sample

The participants in these analyses were enrolled in the Study of Osteoporotic Fractures (SOF) ¹⁶. The SOF sample included 9,704 women who were at least 65 years old and were recruited between 1986 and 1988 from population-based listings in four areas of the United States: Baltimore County, MD; Minneapolis, MN; Portland, OR; and the Monongahela Valley, PA. Women were excluded if they could not walk without help or had a history of bilateral hip replacement. Although African-American women were initially excluded because of their low incidence of hip fracture, 662 elderly African-American women with similar characteristics were enrolled in 1996–97. Approximately every two years, SOF participants have a comprehensive clinical evaluation. Participants in Caregiver-SOF included members of the original and African-American SOF cohorts who participated in the 6th biennial examination that took place from 1997–99.

Caregiver-SOF subsample

The Caregiver-SOF sample was identified in two phases, described elsewhere ¹⁷. The first phase consisted of administering a caregiver screening questionnaire to 5,952 SOF participants who had their 6th biennial examination at their home or a SOF clinic and were not cognitively impaired, or living in long-term care facilities. The second phase began in 1999, and consisted of re-administering the screening questionnaire by telephone to all caregivers and a subset of non-caregivers who had been identified by the initial screening questionnaire. The questionnaire asked SOF participants if they currently helped a relative or friend with each of seven instrumental activities of daily living (ADL) tasks (IADLs; use the telephone, get to places out of walking distance, shop, prepare meals, manage medications, manage finances, do heavy housework) ¹⁸ and seven basic ADL tasks (walk across a room, groom, transfer from bed to chair, eat, dress, bathe, use the toilet) ¹⁹ because that person was physically, cognitively, or mentally unable to do that task independently. These measures have excellent validity ^{18, 19}. Participants were categorized as caregivers if they helped one or more persons with at least one task, and as non-caregivers if they did not help anyone with these tasks.

In the telephone re-evaluation phase, respondents who were currently caregiving were invited to participate in Caregiver-SOF. Respondents who had stopped caregiving (n=493) were excluded. After each caregiver agreed to participate, we randomly selected a group of 1–5 SOF participants who had been identified as non-caregivers by the screening questionnaire, and who matched the caregiver on SOF site, age, race, and zip code. The first one or two non-caregivers from each group who agreed to participate were included in the sample, resulting in 375 caregivers and 694 non-caregivers.

Data collection

Within two weeks of the telephone re-evaluation, a face-to-face interview was conducted with the respondent at her home (i.e., Caregiver-SOF baseline interview). Followup contacts included quarterly post-cards and biennial exams for SOF¹⁶ and two annual Caregiver-SOF interviews. This study was approved by the Institutional Review Boards at each SOF site and at the Boston University Medical Center. All participants provided written informed consent.

Independent variables

Caregiving status—Respondents were classified as caregivers or non-caregivers based on whether they assisted someone with any IADL/ADL tasks, as described above, at the Caregiver-SOF baseline interview.

General stress was measured by the Perceived Stress Scale²⁰. This 14-item scale reflects the amount of stress experienced in the past week, with responses ranging from 0 to 56. It has excellent psychometric properties (coefficient alpha ranged from 0.84–0.86 in different samples)²⁰. For analyses comparing “high” and “low stress” respondents, we categorized respondents according to whether their scale score was 20 or greater. This was the cutpoint for the top quartile of the distribution among non-caregivers in our sample, which was intended to minimize potential bias by caregiving-related stress.

Caregiving-related stress—Caregivers reported whether each IADL/ADL task they performed for their care recipient was emotionally and/or physically stressful. Those who reported that one or more tasks were stressful were categorized as “high caregiving-related stress”; others were categorized as “low caregiving-related stress.”

Caregiving characteristics—Dichotomous variables indicated whether caregivers cared for a spouse versus another relative or friend, lived with the care recipient, length of time caregiving, if the care recipient had dementia or a stroke, and had scheduled time away from caregiving.

Outcome

All-cause mortality as of December 31, 2007, was documented through death certificates obtained at each SOF site. Survival time was measured as the number of days from the respondent’s Caregiver-SOF baseline interview to the date of death, date of last contact, or December 31, 2007, whichever came first.

Covariables

Sociodemographic variables were self-reported at the Caregiver-SOF baseline interview, and included age, race (White or Black), highest education level, and marital status (married versus other). Social contact was assessed by frequency of visits with family and friends: responses were collapsed into contact on a weekly to daily basis versus less frequently.

Health status at the Caregiver-SOF baseline interview was assessed by several variables. Limitations in IADLs and ADLs for caregivers and non-caregivers were based on the respondent’s self-reported ability to independently perform each of the IADLs and ADLs listed above. Separate variables were constructed for the total number of IADL (0–7) and ADL (0–7) limitations.

Respondents reported whether a physician or health professional had told her that she had hypertension, heart disease, diabetes, or cancer. These conditions were chosen because of their association with mortality in elderly adults. Body mass index (kg/meter²) was based on

the respondent's height, measured at her baseline SOF visit, and weight, measured at the baseline Caregiver-SOF visit.

Analyses

Bivariate analyses comparing caregivers and non-caregivers were performed using t-tests or ANOVAs for continuous variables and chi-square tests for categorical variables. Hypotheses were tested using Cox proportional hazards models. We calculated the crude and adjusted hazards ratios (HR) and 95% confidence intervals (CI). Individual covariables were evaluated as potential confounders in multivariable analyses if their addition to a model containing only the caregiver variable altered the association with mortality by 10% or more. All potential confounders were included in the initial proportional hazards model. Variables that were not statistically significant ($p=0.10$) were eliminated one at a time, as long as their exclusion did not substantially change the beta coefficient for the caregiver variable.

We created indicator variables for testing the independent and combined effects of caregiving and stress. For these analyses, low-stress non-caregivers formed the referent group, and indicator variables represented high-stress non-caregivers, low-stress caregivers, and high-stress caregivers. For variables on caregiving characteristics that were included in multivariable models, non-caregivers were coded as being unexposed.

The proportional hazards assumption was tested by a Kolmogorov-type supremum test based on 1,000 simulations and incorporated in the ASSESS statement of PROC PHREG²¹. We found no evidence that the proportional hazards assumption did not hold for the caregiving variables in these data. Preliminary analyses showed that high perceived stress had a smaller association with 8-year mortality than with mortality over shorter followup periods. Therefore, we modeled two time-dependent terms to separate the early and late effects of stress on mortality. We defined "early" as the effect of stress on mortality within the first three years of followup, and "late" as its effect on mortality beyond three years. Three years was chosen because this cutpoint resulted in a model with the best goodness-of-fit according to the Akaike Information Criterion (AIC).

All analyses were performed using PC-SAS²².

RESULTS

Sample characteristics are presented in Table 1. The sample included 375 caregivers and 694 non-caregivers. All respondents were women, 88 percent were white, and the mean age was 81.3 years (range = 69–95, standard deviation = 3.7). Approximately half of the caregivers were taking care of a spouse or living with the care recipient; 28% cared for a relative or friend with dementia. On average, they had been caregiving for 6.8 years (standard deviation = 9.9, ranging from less than 1 to 53 years). Caregivers were slightly but significantly younger than non-caregivers because our matching protocol required a caregiver to enroll before identifying and inviting non-caregivers to participate (for details, see Fredman et al, 2004¹⁷). Caregivers also had fewer IADL and ADL limitations, and were more stressed than non-caregivers.

Caregivers who had high stress were significantly more likely to be younger, married, and to have less social support than other respondents (Table 1). These caregivers also were more likely to care for a spouse or a person with dementia, live with the care recipient, and have less time away from caregiving. The high-stress non-caregivers were more likely to be black and have more ADL and IADL limitations.

A total of 74 caregivers (19.7%) and 190 non-caregivers (27.4%) died, while 9.5% of caregivers and 10.4% of non-caregivers requested to be terminated from the study. The mortality rate was lower in caregivers than non-caregivers, when adjusted for sociodemographic and health variables (adjusted HR = 0.74, 95% CI = 0.56–0.89) (Table 2). Respondents with high perceived stress at baseline were 1.8 times more likely to die over the first three years of followup (adjusted HR = 1.81, 95% CI = 1.16–2.82), but did not have higher mortality rates after three years of followup.

Combination of caregiving status and stress on mortality

Both caregivers and non-caregivers with high perceived stress at baseline had elevated mortality rates during the first three years of followup compared to low-stress non-caregivers. The adjusted hazards ratios ranged from 1.44 (0.77–2.69) for high-stress caregivers to 1.69 (1.01–2.81) for high-stress non-caregivers (Table 3). High stress was not associated with mortality beyond three years. However, caregivers who had low perceived stress or who reported that caregiving tasks were not stressful had significantly lower mortality rates than non-caregivers: adjusted hazards ratios were 0.67 and 0.57, respectively.

Exploratory analyses comparing the 178 spouse caregivers to the 183 married non-caregivers showed similar trends (results not shown). High-stress spouse caregivers were 1.74 times more likely to die over the first three years than married non-caregivers, while mortality rates were lower among spouse caregivers with low perceived stress or who were not stressed by caregiving tasks (adjusted HRs = 0.78 and 0.83, respectively). These associations were not statistically significant, however, probably because of small numbers.

DISCUSSION

This study found that elderly women caregivers had a lower adjusted risk of mortality over eight years than did non-caregivers. This result appeared to be due to caregivers who had low levels of general stress or caregiving-related stress: low-stress caregivers had 33% lower risk of mortality than did low-stress non-caregivers, and caregivers who were not stressed by caregiving tasks had a 43% lower mortality risk than all non-caregivers. By contrast, respondents with high stress had significantly higher mortality rates over the first three years of followup, regardless of caregiver status. These results supported our hypothesis that higher stress, rather than caregiving per se, is associated with increased rates of mortality. Furthermore, the effect of high stress on mortality was stronger among spouse caregivers than all caregivers combined (adjusted HR = 1.74 versus 1.44), supporting the assertion that comparing spouse caregivers to married non-caregivers may overestimate the adverse health effects of caregiving.

Our results confirm previous studies that found associations between chronic stress and increased mortality^{6, 7} and are consistent with studies that did not find higher mortality rates among caregivers versus non-caregivers^{10, 11, 13}. They are partially consistent with the Caregiver Health Effects Study (CHES), which found higher mortality rates among strained spouse caregivers⁸. The CHES study found no difference in mortality rates between caregivers who were not stressed by caregiving activities and non-caregivers, but caregivers who were stressed by these tasks had a 60% increased mortality risk over a 4-year period. In our sample, high perceived stress was associated with an 81% increased risk of mortality over a three-year period, and with a two-fold greater risk among spouse caregivers compared to married non-caregivers over the same period. Our results may have differed from studies that found elevated rates of mortality and CHD incidence^{8, 9, 13} in that our sample included only older women who were followed for more years and was not restricted to married couples.

Our results fit a “Healthy Caregiver” effect, suggestive of the “Healthy Worker Effect.” The Healthy Worker Effect is a bias that leads to underestimating the health effects of harmful, work-related exposures so that the exposures appear to have smaller effects, or no effect on health outcomes²³. This bias results from selection processes whereby healthier persons are more likely than comparison subjects to become employed and remain employed, and from not measuring health outcomes from the time employment began²³. Indeed, previous studies found that healthier older adults were more likely to become caregivers and to remain as caregivers²⁴. We found that caregivers were physically healthier than non-caregivers at baseline, and low-stress caregivers reported the fewest ADL and IADL limitations. Our results may not reflect a bias as much as an explanation for the relationships among caregiving, stress, and mortality. Although we could not adjust for health status at the commencement of caregiving, adjustment for several measures of baseline health reduced the protective effect of caregiving. This adjustment addressed one aspect of the Healthy Worker Effect, although residual confounding may have remained from unmeasured health variables. Further, our analyses separated the putative exposure, stress, from a marker of the exposure, caregiver status.

Our results also may reflect physical and psychological benefits of caregiving. Caregiving tasks may have kept respondents physically active, leading to a reduced risk of mortality²⁵,²⁶. Caregivers also may have had stronger feelings of purpose than non-caregivers: elderly adults who feel more useful have lower mortality rates²⁷. Additionally, satisfaction from caregiving experiences, especially among the low-stress caregivers, may have benefited health.

Alternatively, lower mortality among low-stress caregivers may have resulted from minimal caregiving involvement. Compared to high-stress caregivers, low-stress caregivers were less likely to care for a spouse, performed fewer caregiving tasks and reported more social contact. Thus, they may not have been the main caregiver, thereby incurring less stress from caregiving.

Our findings may have reflected the advanced age of the sample (mean age = 81 years). Women who survived to this age and could perform caregiving activities may have had exceptionally hearty constitutions. Nonetheless, similar results have been found in younger samples.^{10, 11, 13}

This study had several limitations. Caregiver-SOF was comprised of older women, who were mainly white. The results may not be generalizable to caregivers who are younger, minority, or male. However, most caregivers in the United States are elderly women, therefore these results apply to the majority of caregivers. This study assessed only all-cause mortality, and lacked sufficient power to conduct cause-specific analyses. In addition, caregiver status and stress were measured only at baseline, and we did not include length of time the respondent had been caregiving at baseline. Measuring caregiver status and intensity of caregiving at multiple timepoints could distinguish the relationships between continuation versus cessation of caregiving on mortality.

Nonetheless, this study had many strengths. The design allowed analyses of the separate effects of caregiving and stress on mortality. The Caregiver-SOF sample is a community-based sample of elderly women. All caregivers and non-caregivers came from the same source population, thereby reducing potential biases that may result from recruiting caregivers from patient registries and non-caregivers from other sources. The inclusion criteria required that caregivers were currently performing at least one IADL/ADL task for the care recipient, ensuring that all caregivers were actively involved in caregiving activities

at baseline. These criteria resulted in a heterogeneous sample, thus increasing the generalizability of results to a wide variety of older women caregivers.

In conclusion, this study found that stress, rather than being a caregiver, increased mortality risk in elderly women. Moreover, caregivers who were not stressed had a lower mortality risk than non-caregivers. Because these results are based on a sample of elderly women, additional studies are needed to corroborate them. Future studies should include measures of general stress, health status, and physical activity to disentangle the effects of caregiving from stress, and to adjust for caregivers' potential health advantage. Caregiver stress constitutes a growing public health concern. There are an estimated 44 million informal caregivers in the United States, and this figure is expected to rise²⁸. This study underscores the importance of determining caregivers' level of stress and recommendations to reduce it. Examples include interventions designed specifically for caregivers²⁹ or generic stress-reduction programs, such as mindfulness-based stress reduction,³⁰ that teach techniques to reduce stress in everyday life and therefore are adaptable to evolving caregiving situations. Such interventions may improve caregivers' psychological status, as well as their physical health and ability to provide optimal care for their care recipient.

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Table 1

Sample characteristics, according to baseline caregiver status combined with the top quartile of Perceived Stress Scale scores among 1069 Caregiver-SOF respondents

Variable	Non-caregiver: low stress (n=502)	Non-caregiver: high stress (n=192)	Caregiver: low stress (n=226)	Caregiver: high stress (n=149)	p-value
Mean age (std)	81.6 (3.7)	81.2 (3.9)	81.3 (3.5)	80.5 (3.7)	0.02
% Black	10.4	15.1	12.0	12.1	0.34
% married	25.7	28.1	51.3	61.7	<0.001
% college +	52.2	46.4	61.1	51.7	0.02
% daily social contact	35.1	33.3	40.9	20.8	<0.001
ADL limitations : mean (std)	0.4 (0.8)	0.8 (1.1)	0.3 (0.5)	0.5 (0.7)	<0.001
IADL limitations: mean (std)	0.8 (1.2)	1.2 (1.6)	0.3 (0.7)	0.5 (0.8)	<0.001
Medical conditions: mean (std)	1.7 (1.1)	2.0 (1.2)	1.6 (1.1)	2.0 (1.2)	<0.001
BMI: mean (std)	27.2 (5.1)	27.6 (5.7)	27.0 (4.7)	27.4 (5.7)	0.62
Perceived Stress Scale: mean (std)	12.1 (4.7)	24.0 (4.3)	12.5 (4.9)	25.0 (4.3)	<0.001
% caregiver to spouse			40.7	57.7	<0.01
% lives with care recipient			45.1	58.4	0.01
% care recipient has dementia			20.8	36.9	<0.001
% caregiving 5 years			43.4	43.6	0.96
% no scheduled time away from caregiving			19.5	27.5	0.07
# ADLs caregiver helps with			1.4 (1.6)	1.6 (1.9)	0.27
# IADLs caregiver helps with			3.6 (2.0)	4.3 (2.0)	0.003

Table 2

Caregiver status and 8-year mortality rate among 1069 Caregiver-SOF respondents

Variables	% Died	Mortality rate per 1000 person-years	Unadjusted HR (95% CI)	Adjusted HR (95% CI)
Non-caregiver (n=694)	27.4	46.4	1.00	1.00
Caregiver (n=375)	19.7	29.8	0.62 (0.47–0.81)	0.74 (0.56–0.89)
High vs. low perceived stress:				
Early effect (years 1–3)				1.81 (1.16– 2.82)
Late effect (> 3 years)				0.96 (0.69– 1.33)
Age (in years)				1.09 (1.05–1.12)
Race: black vs. white				0.59 (0.35–1.00)
# IADL limitations				1.32 (1.20–1.44)
1 or more medical conditions				1.35 (1.02–1.79)
BMI (kg/meters ²) ^a				0.98 (0.95–1.00)

^a = HR is for a 1-unit increase in BMI

HR= Hazards ratio

CI = Confidence Interval

Table 3

Combination of caregiver status and stress level on 8-year mortality rate among 1069 Caregiver-SOF respondents

Variables	% Died	Mortality rate per 1000 person-years	Unadjusted HR (95% CI)	Adjusted HR* (95% CI)
A. General perceived stress				
Non-caregiver: low stress (n=502)	26.9	44.9	1.00	1.00
Non-caregiver: high stress (n=192)	28.7	50.5	1.13 (0.83–1.55)	
Early effect (years 1–3)				1.69 (1.01 2.81)
Late effect (> 3 years)				0.87 (0.57 1.32)
Caregiver: low stress (n=226)	16.8	25.2	0.54 (0.38–0.77)	0.67 (0.46 0.94)
Caregiver: high stress (n=149)	24.2	36.7	0.79 (0.54–1.14)	
Early effect (years 1–3)				1.44 (0.77 2.69)
Late effect (> 3 years)				0.76 (0.48 1.21)
B. Caregiving-related stress				
Non-caregiver (n=694)	27.4	46.4	1.00	1.00
Caregiver: caregiving tasks not stressful (n=219)	14.6	21.3	0.44(0.30–0.64)	0.57 (0.38–0.84)
Caregiver: caregiving tasks physically and/or emotionally stressful (n=156)	26.9	42.6	0.89(0.64–1.25)	1.00 (0.71–1.41)

* Adjusted for age, race, BMI, # IADL limitations and presence of medical conditions.

HR= Hazards ratio

CI = Confidence Interval