

# Caregiving as a Risk Factor for Mortality

## The Caregiver Health Effects Study

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ONE OF SOCIETY'S GREAT ASSETS is the many family members who provide care to ill or disabled relatives. By some estimates, more than 15 million adults currently provide care to relatives,<sup>1,2</sup> saving the formal health care system billions of dollars annually. The majority of caregivers are middle-aged adult children and older spouses who care for a parent or spouse with functional limitations. Although family caregivers perform an important service for society and their relatives, they do so at considerable cost to themselves. There is strong consensus that caring for an elderly individual with disability is burdensome and stressful to many family members,<sup>3,4</sup> and contributes to psychiatric morbidity in the form of increased depression. Researchers have also suggested that the combination of loss, prolonged distress, physical demands of caregiving, and biological vulnerabilities of older caregivers may compromise their physiological functioning and increase their risk for health problems.<sup>4,5</sup> Some support for this hypothesis is found in studies showing that caregivers are less likely to engage in preventive health behaviors,<sup>6</sup> decrements in immunity measures compared with controls,<sup>5,7,8</sup> exhibit greater cardiovascular reactivity,<sup>9</sup> and experience slow wound healing.<sup>10</sup> Some caregivers are at increased risk for serious illness.<sup>5,11</sup> Overall, these studies show that a subgroup of caregivers is at risk for negative health outcomes. They are characterized as hav-

**Context** There is strong consensus that caring for an elderly individual with disability is burdensome and stressful to many family members and contributes to psychiatric morbidity. Researchers have also suggested that the combination of loss, prolonged distress, the physical demands of caregiving, and biological vulnerabilities of older caregivers may compromise their physiological functioning and increase their risk for physical health problems, leading to increased mortality.

**Objective** To examine the relationship between caregiving demands among older spousal caregivers and 4-year all-cause mortality, controlling for sociodemographic factors, prevalent clinical disease, and subclinical disease at baseline.

**Design** Prospective population-based cohort study, from 1993 through 1998 with an average of 4.5 years of follow-up.

**Setting** Four US communities.

**Participants** A total of 392 caregivers and 427 noncaregivers aged 66 to 96 years who were living with their spouses.

**Main Outcome Measure** Four-year mortality, based on level of caregiving: (1) spouse not disabled; (2) spouse disabled and not helping; (3) spouse disabled and helping with no strain reported; or (4) spouse disabled and helping with mental or emotional strain reported.

**Results** After 4 years of follow-up, 103 participants (12.6%) died. After adjusting for sociodemographic factors, prevalent disease, and subclinical cardiovascular disease, participants who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than noncaregiving controls (relative risk [RR], 1.63; 95% confidence interval [CI], 1.00-2.65). Participants who were providing care but not experiencing strain (RR, 1.08; 95% CI, 0.61-1.90) and those with a disabled spouse who were not providing care (RR, 1.37; 95% CI, 0.73-2.58) did not have elevated adjusted mortality rates relative to the noncaregiving controls.

**Conclusions** Our study suggests that being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers. Caregivers who report strain associated with caregiving are more likely to die than noncaregiving controls.

JAMA. 1999;282:2215-2219

www.jama.com

ing high levels of caregiving demands, experiencing chronic stress associated with caregiving, and being physiologically compromised. By extension, they may also be at risk for increased mortality, although researchers have not been able to test this hypothesis because study samples have been too small and follow-up periods have been too brief.

The Caregiver Health Effects Study (CHES), an ancillary study of the Cardiovascular Health Study (CHS), a large population-based study of the elderly,

affords an opportunity to test the relationship between caregiving and mortality because of the relatively large sample size (approximately 400 spousal caregivers and 400 matched con-

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trols), the availability of large numbers of objective prevalent disease measures as well as subclinical disease indicators, and a relatively long follow-up period of 4 years. Consistent with other studies that have examined

health outcomes among caregivers, we also explored the association between caregiving and mortality in subgroups of caregivers who are physiologically compromised and are exposed to varying levels of caregiving strain.

**Table 1.** Participant Characteristics and Descriptions of Variables\*

Characteristics	No. (%) of Caregivers
Age, mean (SD), y	79.6 (5.0)
Range (median), y	66.2-95.7 (79.0)
Sex	
Women	420 (51.3)
Men	399 (48.7)
Race	
White	737 (90.0)
Other	82 (10.0)
Education, mean (SD), y	14.6 (4.6)
Range (median), y	1-21 (14.0)
Stressful life events, mean (SD)	0.8 (0.9)
Physical health status	
Prevalent disease, overall	222 (27.1)
Myocardial infarction	83 (10.1)
Angina pectoris	176 (21.5)
Congestive heart failure	47 (5.7)
Intermittent claudication	23 (2.8)
Stroke	30 (3.7)
Transient ischemic attack	25 (3.1)
Subclinical disease, overall	336 (41.0%)
Rose questionnaire for claudication	11/802 (1.4)
Rose questionnaire for angina	27/804 (3.4)
Ratio of ankle to arm blood pressure	
Right and left ankle to arm blood pressure indicating atherosclerotic obstruction to blood flow in the legs; measured in clinic, $\leq 0.90$	86/778 (11.1)
Major ECG abnormality	261/774 (33.7)
Measured during baseline ECG, any of the following: ventricular conduction defects, major Q/Qs wave abnormalities, left ventricular hypertrophy, isolated major ST-T-wave abnormalities, atrial fibrillation, or first-degree atrioventricular block	
Carotid stenosis	353/782 (45.1)
Measured during baseline carotid ultrasound for left or right: carotid stenosis $>25$ th percentile	
No prevalent or subclinical disease	261 (31.9) (referent)
Caregiving status, categorical/dummy	
Spouse not disabled	427 (52.1) (referent)
Not helping disabled spouse	75 (9.2)
Reports that spouse has at least 1 ADL/IADL difficulty, but does not provide help to spouse	
Helping disabled spouse (no caregiving strain)†	138 (16.8)
Reports that spouse has at least 1 ADL/IADL difficulty, provides help, but reports no physical or emotional strain	
Helping disabled spouse (caregiving strain)‡	179 (21.9)
Reports that spouse has at least 1 ADL/IADL difficulty, provides help, reports physical or emotional strain	

\*Total number of subjects is 819 unless otherwise noted. All data are presented as number (percentage) unless otherwise indicated. ECG indicates electrocardiogram; ADL, activities of daily living; and IADL, instrumental activity of daily living.

†This represents 43.5% of those providing care.

‡This represents 56.5% of those providing care.

## METHODS

### Study Population

The sample for this ancillary study was drawn from the CHS, a prospective, observational study designed to determine the risk factors for and consequences of cardiovascular disease in older adults. Beginning in 1989, 5201 men and women aged 65 years or older were recruited in 4 US communities: Forsyth County, North Carolina; Washington County, Maryland; Sacramento County, California; and Allegheny County (Pittsburgh), Pennsylvania. Potential participants were identified from a random sample stratified by age group (65-74, 75-84,  $\geq 85$  years) from the Health Care Financing Administration Medicare Enrollment Lists. All persons thus identified and age-eligible household members who were planning to reside in the community for at least 3 years were eligible to participate. Exclusion criteria included being confined to a wheelchair in the home, being unable to participate in the examination at the field centers, or undergoing cancer treatment. Additional sampling and recruitment information has been published previously.<sup>12,13</sup> A supplemental cohort of 685 black men and women aged 65 years or older was recruited prior to the fourth wave of CHS data collection using the same sampling methods. These participants were from all of the CHS communities, except Washington County.

The CHES ancillary study was initiated before the fourth wave of CHS data collection with the goal to recruit approximately 400 caregivers and 400 noncaregiver controls matched for age and sex. Caregivers were defined as individuals whose spouse had difficulty with at least 1 activity of daily living or instrumental activity of daily living "due to physical or health problems or problems with confusion." The noncaregiving group included individuals whose spouse did not have any difficulty with activities of daily living or instrumental activities of daily living. A total of 819 persons (392 caregivers, 427 noncaregivers) distributed evenly across the 4 recruitment sites were enrolled into the CHES study.

## Evaluation

Sociodemographic and physical health status indicators were collected as part of the CHS assessment protocol, while caregiving status was assessed during the CHES interview. TABLE 1 provides a description of the variables included in these analyses, as well as descriptive statistics. All CHS data reported were collected during the fourth wave of the study at approximately the same time as the initial CHES interview was conducted. Physical health status was measured as the presence of various prevalent clinical disease and subclinical disease indicators strongly associated with mortality in the elderly. Three mutually exclusive categories of physical health status were created: (1) prevalent disease, participants who entered the CHES study with at least 1 of 6 prevalent disease indicators present (Table 1); (2) subclinical disease, participants with no prevalent disease, but with at least 1 of 5 subclinical indicators of prevalent disease present (Table 1); and (3) no prevalent or subclinical disease. Caregiving status was determined by first asking participants whether their spouse had difficulty with 6 activity of daily living and 6 instrumental activity of daily living tasks. For each task with which their spouses had difficulty, respondents were asked a simple yes or no question: "Do you help your spouse with this task?" They were also asked, "How much of a mental or emotional strain is it on you to either provide the help directly, or to arrange for help to be provided for this activity?" (There was a separate item asking about physical strain). Response options to the strain questions were "no strain," "some strain," and "a lot of strain." Based on this battery of questions, 4 mutually exclusive categories of caregiving status were created: (1) spouse not disabled (control subjects), (2) spouse disabled but not helping, (3) spouse disabled and helping but with no reports of caregiving strain, and (4) spouse disabled and helping and reports of caregiving strain (Table 1). This categorization was intended to capture increasing levels of caregiving demands.

Study participants were followed up for an average of 4.5 years (range, 3.4-5.5 years). Confirmation of deaths was conducted through reviews of obituaries, medical records, death certificates, and the Health Care Financing Administration health care utilization database for hospitalizations. As a result, there was 100% follow-up ascertainment of mortality status.

## Analytic Methods

The major focus of the analyses was the relationship between caregiving status and 4-year mortality, after controlling for other known demographic and physical health status predictors. Caregiving status and the other covariates were assessed at CHES baseline, and Cox regression was used to model their effects on mortality. Survival time was the number of years between the baseline interview and the last interview or death. Table 1 presents information for all variables used in the analysis, including coding schemes and descriptive statistics. TABLE 2 presents results from the Cox regression model and shows both adjusted and unadjusted relative risk (RR) ratios (from a Cox model with only that variable as a predictor). Caregiving status effects were tested by entering 3 dummy vari-

ables (with respondents whose spouses had no disability serving as control subjects, which also serves as the referent category), while physical health status effects were tested with 2 dummy variables (with no prevalent or subclinical disease as the reference category). All variables were entered on a single step.

Data were missing on several subclinical disease indicators (eg, 45 participants did not have electrocardiogram data). To preserve sample size and to be cautious, we treated participants with missing data as not having that particular subclinical disease.

To test the proportional hazards assumption of the Cox model, interactions between caregiving status and physical health status and survival time were computed and allowed to enter a model with all covariates. Neither term was significant, thus the assumption appeared to be met for these predictors.

## RESULTS

Table 1 reports descriptive statistics for all variables. In terms of sociodemographic variables, participants ranged in age from 66 to 96 years at baseline, with a mean age of approximately 80 years; 51% were women and 49% were men. Among those participants with

**Table 2.** Association of Sociodemographic Variables, Baseline Physical Health Status, and Baseline Caregiving Status With 4-Year Mortality\*

Variables	Unadjusted Relative Risk (95% CI)	Adjusted Relative Risk (95% CI)
Sociodemographic factors		
Age	1.11 (1.07-1.15)†	1.10 (1.06-1.14)†
Sex	2.39 (1.58-3.62)†	1.88 (1.23-2.88)‡
Race	1.14 (0.61-2.13)	2.00 (1.03-3.89)§
Education, y	0.99 (0.95-1.03)	1.00 (0.96-1.05)
Stressful life events	0.93 (0.75-1.15)	0.83 (0.67-1.03)
Baseline physical health status		
Prevalent disease	4.55 (2.52-8.24)†	3.30 (1.79-6.08)†
Subclinical disease (no prevalent disease)	2.21 (1.20-4.08)§	1.84 (0.99-3.42)
Baseline caregiving status		
Not helping disabled spouse¶	1.84 (0.99-3.45)	1.37 (0.73-2.58)
Helping disabled spouse (no caregiving strain)¶	1.40 (0.81-2.42)	1.08 (0.61-1.90)
Helping disabled spouse (caregiving strain)¶	1.75 (1.10-2.80)§	1.63 (1.00-2.65)§

\*Total number of subjects is 819. Total number of deaths is 103 (12.6%). CI indicates confidence interval.

† $P < .001$ .

‡ $P < .01$ .

§ $P < .05$ .

||Reference category is no subclinical or prevalent disease.

¶Reference category is no spouse disability (ie, control subjects).

disabled spouses, about 81% were providing care and about 56% of those reported caregiver strain. There was substantial variability on most of the prevalent disease and subclinical disease indicators. In terms of prevalent disease, there were particularly high levels of angina pectoris (21.5%), while the most frequent subclinical disease indicators were carotid stenosis (45.1%) and major electrocardiogram abnormalities (33.7%). Slightly more than 27% of the sample had at least 1 prevalent disease at CHES baseline, while an additional 41% had at least 1 subclinical disease. Thirty-two percent had neither. The distribution of prevalent and subclinical disease across the 4 caregiving groups was roughly equal with the exception of 1 group. Individuals with a disabled spouse who were not providing care had higher rates of prevalent disease compared with the other 3 caregiving groups (40.0% vs 24.6%, 27.5%, and 27.4% for the control group, help with no strain, and help with strain groups, respectively;  $\chi^2_6$ , 13.8,  $P < .032$ ).

After 4 years of follow-up, 103 deaths (12.6%) occurred among the total sample. Death occurred in 40 (9.4%) of

the 427 participants whose spouses were not disabled at baseline, in 13 (17.3%) of the 75 subjects whose spouses were disabled but who were not providing help, in 19 (13.8%) of the 138 subjects who were providing care but were not strained, and in 31 (17.3%) of the 179 who were providing care and reported caregiver strain ( $\chi^2_3$ , 9.38;  $P < .025$ ). As would be expected, there was a strong linear trend ( $\chi^2_1$ , 31.59;  $P < .001$ ) in mortality rates for physical health status: no prevalent or subclinical disease (14/261 [5.4%]); subclinical (no prevalent) disease (39/336 [11.6%]); and prevalent disease (50/222 [22.5%]).

Table 2 shows that after adjusting for sociodemographic factors (ie, age, sex, race, education, and stressful life events) and physical health status (ie, prevalent disease and subclinical disease), participants who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than those whose spouse was not disabled (RR, 1.63; 95% confidence interval [CI], 1.00-2.65). Note that the other 2 groups with disabled spouses did not have significantly higher adjusted mortality risks. The higher unadjusted mor-

tality rate among the group whose spouses were disabled but did not help appeared to be explained by their higher rates of prevalent disease. In addition, participants who were older, male, black, or had at least 1 prevalent disease had higher 4-year mortality rates.

To further explore the caregiving status-mortality link and to test predictions derived from a diathesis-stress model, we examined mortality rates within each combination of caregiving status and disease status. We were particularly interested in whether the associations between levels of caregiving and mortality were stronger among those who were already physically compromised. We constructed 11 dummy variables that captured membership in the disease (3 levels) by caregiving (4 levels) cells (participant with no disease and whose spouse was not disabled served as the referent category). These were entered as predictors in a Cox regression model that also controlled for sociodemographic variables. Results from the Cox regression, as well as crude death rates across cells, are presented in TABLE 3. Note that, compared with the control group, there were elevated mortality rates for all participants in the prevalent disease group, regardless of caregiving status. Although the highest percentage of mortality (32.7%) and the highest relative RR (7.25; 95% CI, 2.61-20.14) were observed for the prevalent disease-strained caregiver group, this analysis does not allow us to conclude that the combination of prevalent disease and caregiver strain is differentially associated with mortality. A more definitive test of the diathesis-stress hypothesis will require a larger number of observations.

## COMMENT

To our knowledge, this is the first study to show that caregiving is an independent risk factor for mortality. Controlling for sociodemographic factors and baseline prevalent and subclinical disease, our data indicate that caregivers who provide support to their spouse and report caregiving strain are 63% more likely to die within 4 years than

**Table 3.** Physical Health Status by Caregiving Status: Crude Death Rates and Adjusted Relative Risks of 4-Year Mortality\*

Disease State	Cell n	No. of Deaths	% of Crude Death Rate	Adjusted Relative Risk† (95% Confidence Interval)
No disease				
Spouse not disabled	140	5	3.6	(Referent)
Not helping disabled spouse	14	3	21.4	6.17 (1.47-25.98)‡
Helping, no strain	53	2	3.6	0.92 (0.18-4.75)
Helping, reports strain	54	4	7.4	1.71 (0.46-6.41)
Subclinical disease				
Spouse not disabled	182	19	10.4	2.62 (0.97-7.02)
Not helping disabled spouse	31	4	12.9	2.42 (0.64-9.17)
Helping, no strain	47	5	10.6	2.04 (0.58-7.13)
Helping, reports strain	76	11	14.5	3.14 (1.07-9.20)‡
Prevalent disease				
Spouse not disabled	105	16	15.2	3.43 (1.25-9.41)‡
Not helping disabled spouse	30	6	20.0	4.39 (1.33-14.52)‡
Helping, no strain	38	12	31.6	4.81 (1.63-14.16)§
Helping, reports strain	49	16	32.7	7.25 (2.61-20.14)

\*Ellipses indicate not applicable.

†From a Cox regression model including age, sex, race, education, and stressful life events. Cell dummy variables were created and tested against the no disease, spouse not disabled reference cell.

‡ $P < .05$ .

§ $P < .01$ .

|| $P < .001$ .



noncaregivers. Those with disabled spouses but providing no help and those helping a disabled spouse but reporting no strain did not have significantly higher mortality rates than noncaregivers. The analyses also revealed that, as expected, mortality rates were highest among those with prevalent disease (22.5%), followed by those with subclinical disease (11.6%), and those with no disease (5.4%). Although the number of deaths in our sample is too few to permit definitive tests of the combined effects of caregiving and biological vulnerability, the data are consistent with the notion that strained caregivers with prevalent disease may be at particular risk of mortality. Thirty-three percent of strained caregivers with prevalent disease in our sample died within the 4-year follow-up period.

These findings are consistent with other outcomes reported for this cohort showing that strained caregivers compared with age- and sex-matched noncaregiving controls have significantly higher levels of depressive symptoms, higher levels of anxiety, and lower levels of perceived health. They are also much less likely to get enough rest in

general, have time to rest when they are sick, or have time to exercise.<sup>6</sup> All of these factors, and others not assessed in this study, are possible mediators of the association between caregiving and mortality.

It is important to emphasize that the caregiver-mortality link applies only to a subset of the caregiving population. This study focuses on elderly caregiving spouses who are living with the care recipient. The literature consistently shows that caregivers who live with the care recipient experience higher levels of strain and burden.<sup>3</sup> It would be interesting to see if a caregiving-mortality link is also present for non-spousal caregivers or those not residing with the care recipient. More generally, larger sample sizes would permit a more thorough exploration of both moderators (ie, relevant subgroups) and mediators (ie, causal mechanisms) of the association between caregiving and mortality.

Primary care physicians who care for community-residing older adults may be in the best position to identify caregivers at risk. Older married couples should be evaluated as a unit, both in

terms of their health status as well as the caregiving demands that exist in the home environment. To the extent that caregiving demands are high, opportunities for restorative behaviors are limited, and the caregiver is physically compromised, an intervention that reduces caregiving demands such as the provision of respite services may be needed. Under extreme circumstances, it may be appropriate to relieve a vulnerable older person from caregiving responsibilities permanently by finding an alternative caregiver or institutionalizing the care recipient. In general, it is essential that we develop treatment approaches for older marital dyads that focus on the needs of both individuals simultaneously.

**Funding/Support:** Preparation of this article was supported in part by grants R01 MH 46015, R01 MH52247, and T32 MH19986 from the National Institute of Mental Health, grants AG13305, and AG01532 from the National Institute on Aging (), grant P50 HL65112 from the National Heart, Lung, and Blood Institute, and the Petersen Endowed Chair scholar award from Oregon State University, Corvallis. The Cardiovascular Health Study is supported by contracts N01-HC-85079 through N01-HC-85086 from the National Heart, Lung, and Blood Institute.

**Acknowledgment:** A list of the participating institutions and principal staff of the Cardiovascular Health Study was published previously (*J Am Geriatr Soc.* 1997; 45:1423-1433).

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