

Original Contribution

Family Caregiving and All-Cause Mortality: Findings from a Population-based Propensity-matched Analysis

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Previous studies have provided conflicting evidence on whether being a family caregiver is associated with increased or decreased risk for all-cause mortality. This study examined whether 3,503 family caregivers enrolled in the national Reasons for Geographic and Racial Differences in Stroke (REGARDS) Study showed differences in all-cause mortality from 2003 to 2012 compared with a propensity-matched sample of noncaregivers. Caregivers were individually matched with 3,503 noncaregivers by using a propensity score matching procedure based on 15 demographic, health history, and health behavior covariates. During an average 6-year follow-up period, 264 (7.5%) of the caregivers died, which was significantly fewer than the 315 (9.0%) matched noncaregivers who died during the same period. A proportional hazards model indicated that caregivers had an 18% reduced rate of death compared with noncaregivers (hazard ratio = 0.823, 95% confidence interval: 0.699, 0.969). Subgroup analyses by race, sex, caregiving relationship, and caregiving strain failed to identify any subgroups with increased rates of death compared with matched noncaregivers. Public policy and discourse should recognize that providing care to a family member with a chronic illness or disability is not associated with increased risk of death in most cases, but may instead be associated with modest survival benefits for the caregivers.

caregiving; cohort studies; mortality; propensity scores

Abbreviations: CHES, Caregiver Health Effects Study; REGARDS, Reasons for Geographic and Racial Differences in Stroke.

The increasing number of older adults, rising prevalence of many chronic diseases, and greater emphasis on noninstitutional care are requiring a greater number of individuals to serve as informal caregivers of family members with chronic illnesses or disabilities (1). These family caregivers often endure substantial life changes and chronic stressors that several studies suggest are linked to deleterious health effects (2-5), including increased risk of death (6, 7). A widely cited landmark study of spouse caregivers, the Caregiver Health Effects Study (CHES), found that those who were providing care to a disabled spouse and who reported some strain associated with that care had a 63% elevated risk of death compared with noncaregiving spouses (6). Increased rates of death have also been reported for the spouses of partners who have recently been hospitalized (7). Along with findings from many studies that suggest caregivers have poorer mental and physical health

status than noncaregivers (3), caregiving has been widely portrayed as a serious public health problem in the professional literature (8, 9) and as a threat to survival in the popular media (e.g., "the most devoted family caretakers are at risk of dying first themselves" (10, p. 70)).

Despite these common conclusions that caregiving presents a health risk that could extend to increased risk of death, several other recent studies have provided opposing evidence and suggested that caregiving may actually be associated with preserved health over time and reduced risk of death. Married participants from the Health and Retirement Study providing 14 or more hours of care per week to their spouses who had problems with activities of daily living or instrumental activities of daily living were found to have reduced rates of death compared with spouses who provided no such care (11). An analysis of Northern Ireland census data found that individuals

Matching Factor	Caregivers, % (<i>n</i> = 3,503)	All Noncaregivers, % (<i>n</i> = 24,863)	<i>P</i> Value	Propensity-matched Noncaregivers, % (<i>n</i> = 3,503)	P Value
Female sex	63.35	54.51	<0.0001	62.40	0.4145
African American race	43.11	40.22	0.0011	43.48	0.7539
Age, years	63.58 (8.93) ^a	65.44 (9.44) ^a	<0.0001	63.27 (9.04) ^a	0.1408
Region			<0.0001		0.9561
Stroke belt ^b	38.00	34.36		37.91	
Stroke buckle ^c	21.64	21.02		21.44	
Rest of United States	40.37	44.62		40.65	
Education			0.0023		0.9806
Less than high school	10.85	12.27		10.85	
High school graduate	24.32	26.08		24.26	
Some college	28.49	26.54		28.92	
College graduate	36.34	35.11		35.97	
Income			0.0395		0.4703
<\$20,000	16.56	17.85		15.16	
\$20,000-\$34,000	25.18	23.98		24.64	
\$35,000-\$74,000	31.40	29.80		32.40	
≥\$75,000	15.19	16.29		15.56	
Refused to specify	11.60	12.08		12.25	
Marital status			<0.0001		0.7161
Married	66.69	58.30		67.49	
Divorced	12.96	14.61		12.96	
Single/never married	5.57	5.20		5.71	
Widowed	12.48	19.59		11.39	
Separated/refused to specify	2.31	2.30		2.46	
				Ti	able continues

 Table 1.
 Baseline Characteristics of Caregivers and Noncaregivers From the REGARDS Study Before and After Propensity-based Matching, 2003–2007

who reported family caregiving responsibilities had lower 4year death rates than noncaregivers (12). Fredman et al. (13) reported that older American women who engaged in informal caregiving activities had lower 8-year death rates than a corresponding sample of noncaregiving women, and that higher levels of physical performance (e.g., walking speed, strength measures) were maintained over a 2-year period among the caregivers who provided a high level of assistance with activities of daily living or instrumental activities of daily living (14).

Several factors might partially explain the findings of preserved health and lower rates of death among some caregiving samples. These factors form the core of the "healthy caregiver hypothesis" (14) and include both possible selection processes and potential psychological and social benefits of caregiving. Selection factors concern who takes on informal caregiving responsibilities when a family member becomes seriously ill or disabled. One population-based study found that healthier individuals were more likely to take on and endure in family caregiving roles over time (15). Health and resource factors might be especially important in the selection of nonspouse caregivers. Other investigators have noted the potential positive aspects of caregiving (16, 17), including possible health and longevity benefits for individuals who become more active themselves when volunteering or providing help and support to others (18–20).

One topic that is rarely addressed is whether the mortality effects of caregiving are similar across different subgroups of caregivers. Caregivers are an incredibly diverse group consisting of many relationship subtypes (e.g., spouses, adult children, and others) who handle different types of care recipient problems. Caregivers may or may not live with their care recipients and may perceive different levels of caregiving strain. Existing studies of the caregiving-mortality association in the United States have not only led to conflicting findings, but have also been limited to spouse caregivers (6, 7, 11) or female caregivers (13). Population-based studies of caregivers and matched non-caregiving controls that include larger numbers of minority participants and more diverse and representative relationship subtypes are needed to further inform this important area of investigation.

A promising analytical approach for examining potential causal variables that cannot be subjected to random assignment is through the use of propensity scores that can be obtained

Table 1. Continued

Matching Factor	Caregivers, % (<i>n</i> = 3,503)	All Noncaregivers, % (n = 24,863)	<i>P</i> Value	Propensity-matched Noncaregivers, % (n=3,503)	<i>P</i> Value
Have medical insurance	91.12	93.82	<0.0001	91.29	0.8002
Smoking			<0.0001		0.8283
Current	15.84	13.98		15.50	
Former	35.66	40.65		36.31	
Never	48.50	45.37		48.19	
Current alcohol use			0.0077		0.4910
Heavy	3.48	4.11		3.85	
Moderate	31.83	33.77		32.66	
None	64.69	62.12		63.49	
Six-item cognitive screener ^d			<0.0001		0.7174
0-4 correct	6.56	9.42		7.51	
5 correct	21.30	21.64		20.92	
6 correct	72.14	68.94		71.57	
Self-rated health			0.2947		0.7099
Excellent	15.42	16.34		14.53	
Very good	30.17	30.87		30.75	
Good	36.05	34.65		35.48	
Fair	15.19	14.71		16.07	
Poor	3.17	3.43		3.17	
Have hypertension	57.44	57.88	0.6210	56.32	0.3468
Have diabetes	21.32	22.40	0.1510	21.50	0.8613
Have cardiovascular disease	18.53	23.12	<0.0001	18.58	0.9510

^a Reported as mean (standard deviation).

^b The stroke belt included the portions of North Carolina, South Carolina, and Georgia not included in the stroke buckle, plus all of Alabama, Mississippi, Tennessee, Arkansas, and Louisiana.

^c The stroke buckle included a coastal plain region of North Carolina, South Carolina, and Georgia.

^d The 6-item screener of global cognitive status described by Callaham et al. (29).

from large observational data sets (21–23). In this approach, individuals who are exposed to a treatment (or a risk factor) are compared with a selected comparison group of untreated individuals, such that both groups are balanced on a wide range of potential confounding factors. Large, population-based, observational studies that assess caregiving status as 1 of a range of contextual variables provide a unique opportunity to implement this approach and to examine the health effects of caregiving after controlling for many confounding variables. However, to our knowledge, no previous study of the caregiving-mortality association has compared caregivers with a matched sample of noncaregivers by using an empirical, propensity score matching procedure.

In this study, family caregivers were identified from a large national epidemiologic study and confirmed to differ from noncaregivers on a range of demographic, medical history, and health behavior variables. A logistic regression, propensitymatching algorithm was used to individually match and balance caregiving and noncaregiving subgroups, and survival analysis methods were then used to examine subsequent allcause mortality rates. We also conducted supplemental analyses to examine whether the mortality effects of caregiving were comparable across races and sexes, between caregivers of parents versus spouses, and among those with different levels of self-reported caregiving strain to see if different patterns would emerge among subgroups that might partly explain the previous contradictory findings.

MATERIALS AND METHODS

Participants

Participants in the REGARDS Study were randomly sampled from a commercially available nationwide list. The design, enrollment, and interviewing procedures for the REGARDS Study have been previously described in detail elsewhere (24–27). Briefly, exclusion criteria included age of less than 45 years, race other than African American or white, previous diagnosis of cancer requiring chemotherapy, residence in a nursing home, or being on a waiting list for a nursing home. African Americans and residents from the southern "stroke belt" region of the United States were oversampled on the basis of the stratified random sampling design that was used in the REGARDS Study. All procedures were reviewed and approved by the institutional review boards of each participating institution. Enrollment occurred from 2003 through 2007. Of the 30,239 enrolled participants, 1,873 (6.2%) had missing data on mortality status or at least 1 of the 15 propensity-matching covariates, leaving 28,366 participants with complete data for the present analyses.

Procedures and measures

Trained interviewers contacted potential participants, established eligibility, obtained verbal informed consent, and administered a computer-assisted telephone interview. Data were obtained on the variables that are described in the following sections.

Demographic variables. Age was calculated on the basis of the number of days between the participant's date of birth and the baseline interview date. Sex and race (African American vs. white) were dichotomous variables based on self-report. Region was analyzed on the basis of the stratified sampling categories that were used (stroke belt, "stroke buckle," "nonbelt"). The stroke buckle included a coastal plain region of North Carolina, South Carolina, and Georgia. The stroke belt included the remainder of these 3 states plus all of Alabama, Mississippi, Tennessee, Arkansas, and Louisiana. The nonbelt region included the other 40 contiguous states. Marital status, educational level, and annual income were coded as categorical variables as indicated in Table 1. Insurance coverage was a dichotomous indicator of whether the participant reported having any type of medical insurance.

Health behaviors. Responses to interview questions concerning smoking were coded as indicated in Table 1. Alcohol use categories of none, moderate drinking, or heavy drinking were based on sex-specific guidelines for alcohol use within the past week (28).

Cognitive function. The 6-item screener of global cognitive status (29) was administered during telephone interviews that began in December 2003. This measure was obtained from the baseline interview for 24,448 participants and from the first available semiannual follow-up interview for the remaining 5,167 participants who were enrolled before this procedure was added to the baseline interview protocol. The number of correct responses (ranging from 0 to 6) was included as a categorical variable in the propensity-matching procedure.

Health and disease history. Participants provided an overall description of their self-rated health (excellent, very good, good, fair, or poor). Participants were also asked a number of health history questions. Participants who reported that they had been told by a doctor or health professional that they had high blood pressure or hypertension or who were taking medications for high blood pressure were coded as having a history of hypertension. Participants were coded as having a history of diabetes if they reported being told by a doctor or health professional that they had diabetes or "high blood sugar" or were taking medications specifically for diabetes. A history of cardiovascular disease was coded, as in a previous analysis (26), for any participants who reported a history of myocardial infarction, stroke, transient ischemic events, carotid endarterectomy, coronary intervention, repair of aortic aneurism, or peripheral arterial intervention.

Caregiving status. Toward the end of the baseline interview, each participant was asked, "Are you currently providing care on an on-going basis to a family member with a chronic illness or disability? This would include any kind of help such as watching your family member, dressing or bathing this person, arranging care, or providing transportation." Respondents who answered affirmatively were categorized as caregivers and were subsequently asked whether they lived with the care recipient, their relationship with the care recipient (e.g., spouse, child), the amount of perceived mental or emotional strain associated with that care (none, some, a lot), and the number of hours per week they provided such care. A cutpoint of 14 hours per week was used for the subgroup analyses, consistent with the approach used by Brown et al. (11).

All-cause mortality. Preliminary dates of death were typically obtained from proxy reports when participants could not be reached for routine semiannual follow-up interviews. A death certificate was then obtained from the participants' families or state departments of health, and dates of death were verified by using the death certificates or the National Death Index (30, 31). Analyses were based on the deaths that occurred through April 1, 2012.

Statistical analysis

Descriptive χ^2 tests were used to compare caregivers and noncaregivers on all covariates except for age, for which an independent-groups Student's t test was used. The dichotomous caregiving status variable (yes or no) was then regressed on the 15 covariates in Table 1 by using a standard binary logistic regression analysis. The propensity scores from this analysis represented the predicted probability of being a caregiver based each participant's covariate values. Each caregiver was then individually matched with a noncaregiving participant on this propensity score by using a modified "greedy" matching algorithm without replacement (32). Matches were accomplished by first completing all matches that could be made at the fifth decimal place (i.e., propensity score differences < 0.00001), then the fourth decimal place, and so on, until all caregivers were matched. In cases of tied propensity score differences, the matching noncaregiver was selected randomly from the pool of tied cases. The mean absolute value of the propensity score differences was 0.00003, and the largest absolute difference was 0.00768.

The descriptive comparisons between the caregivers and the propensity-matched noncaregivers were repeated on the covariates to confirm the balance between these 2 groups. A Cox proportional hazards survival analysis was then conducted for the propensity-matched caregivers and noncaregivers. This analysis was based on the number of days elapsed between the baseline interview and the date of death for the deceased cases (median, 1,463 days) or the date of the last semiannual follow-up interview for the living cases (median, 2,277 days). The overall median length of follow-up time was 6.1 years (2,226 days).

The caregiving subgroup analyses were conducted by repeating the logistic regression, propensity matching, group balance confirming, and proportional hazards survival analysis sequence of steps each time for each subgroup examined separately. In many of these subgroup analyses, only 14 balancing covariates were used in the logistic regression propensity score calculation because both the caregivers and matched noncaregivers were restricted to just 1 class on a remaining demographic variable. For example, in the analysis of spouse caregivers, only married noncaregivers were available for potential matching, and marital status was, therefore, not included as a predictor variable in the logistic regression analysis that calculated the propensity score. Likewise, female caregivers were matched with female noncaregivers only. Similar adjustments were made for men and for race-specific caregiving subgroup analyses.

RESULTS

Propensity matching

Table 1 summarizes the descriptive comparisons between the 3,503 caregivers and the noncaregivers in the REGARDS Study. Prior to matching, caregivers differed significantly from noncaregivers on 12 of the 15 covariates. Caregivers were younger, on average, and more likely to be women, African American, and married. Caregivers were less likely to have health insurance and to report a history of cardiovascular disease. Subtle but statistically significant differences were also observed for education, income, smoking status, and alcohol use. After propensity matching, the 3,503 caregivers did not differ significantly from their 3,503 matched noncaregivers on any of the 15 covariates, confirming the success of the binary logistic regression and greedy matching procedure for identifying balanced groups of caregivers and matched noncaregivers for further analysis.

Mortality effects across all caregivers

Figure 1 displays the descriptive survival curves for the 3,503 caregivers, for all of the 24,863 noncaregivers, and for the 3,503 propensity-matched noncaregivers. Of the 3,503 caregivers, 264 (7.5%) died during the follow-up period, whereas 2,782 of the 24,863 noncaregivers (11.2%) died during this same period. After propensity matching, 315 of the 3,503 matched noncaregivers were deceased (9.0%), which was a significantly greater proportion than the 7.5% of caregivers according to a simple χ^2 test (*P* = 0.0269). The Cox proportional hazards analysis revealed that caregivers died at approximately an 18% lower rate than their individually matched noncaregivers over this 6-year period (hazard ratio = 0.823, 95% confidence interval: 0.699, 0.969; *P* = 0.0196).

Mortality and caregiving subgroups

The sample of 3,503 caregivers included many different subgroups identified by race, sex, caregiving relationship, perceived caregiving strain, and amount of caregiving involvement. Table 2 summarizes the results of the subgroup analyses that were conducted. In each analysis, specific caregivers were individually matched with qualified potential noncaregiving controls by using a new logistic regression and propensity score matching procedure. In all cases, the propensity matching procedure was effective for balancing the caregiver and noncaregiver groups on the relevant covariates. All P values were greater than 0.12, and 170 of the 174 possible covariate comparisons resulted in P values greater than 0.20.



Figure 1. Survival curves for caregivers (black line, n = 3,503), propensity-matched noncaregivers (gray line, n = 3,503), and all noncaregivers (dotted line, n = 24,863) from the REGARDS Study over the 8 years of follow-up after enrollment, 2004–2012.

3

4

Follow-up, years

5

6

7

8

2

The results of the Cox proportional hazards models identified 1 subgroup of caregivers with a significantly lower death rate. Adult child caregivers who were providing care to a parent were found to have a significantly lower rate of death compared to their propensity-matched noncaregivers (P = 0.0064). In addition, trends that approached conventional levels of statistical significance were observed for white caregivers (P =(0.0791), female caregivers (P = 0.0703), and caregivers who provided 14 or more hours of care per week (P = 0.0752). The hazard ratio for each of these subgroups was similar to the hazard ratio for all caregivers, but the hazard ratios for the subgroups were no longer statistically significant at the P <0.05 level because of reduced sample sizes and power. No subgroup of caregivers showed a trend for increased risk of death compared with propensity-matched noncaregivers. The strained spouse caregiving subgroup, which included spouses who reported either moderate or high caregiving strain, was similar to the spouse caregivers found to have an elevated rate of death in the CHES (6).

DISCUSSION

0.84

0.80

0

The present findings contribute important new information concerning the paradox of whether informal family caregiving

Caregiver Group	No.	Caregivers, % died	Propensity-matched Noncaregivers, % died	HR	95% Cl
All	3,503	7.5	9.0	0.823*	0.699, 0.969
White	1,993	7.0	8.4	0.818	0.654, 1.024
African American	1,510	8.2	9.2	0.884	0.694, 1.127
Women	2,219	4.9	6.0	0.792	0.615, 1.020
Men	1,284	12.1	14.3	0.841	0.679, 1.041
Spouse	786	11.1	12.3	0.872	0.653, 1.165
Adult child	1,197	3.0	5.2	0.565**	0.375, 0.852
No-strain	1,163	8.9	10.3	0.858	0.660, 1.115
Moderate-strain	1,748	6.3	7.4	0.831	0.644, 1.071
High-strain	578	8.1	8.0	1.022	0.681, 1.535
Strained spouse	537	9.3	9.9	0.944	0.642, 1.390
≥14 hours of care per week	1,588	7.3	9.1	0.801	0.628, 1.023
<14 hours of care per week	1,915	7.7	7.7	0.992	0.789, 1.245

 Table 2.
 Survival Rates of All Caregivers and Caregiving Subgroups Compared With Propensity-matched

 Noncaregivers in the REGARDS Study, 2004–2012

Abbreviations: CI, confidence interval; HR, hazard ratio.

* *P* < 0.05; ***P* < 0.01.

responsibilities are associated with higher or lower rates of death, as suggested by multiple conflicting previous studies (6, 7, 11–13). Our findings are consistent with the studies suggesting lower rates of death among caregivers, (11-13) in that the self-identified family caregivers from the REGARDS Study, as an overall group, experienced lower all-cause mortality rates than the empirically matched sample of noncaregivers from the same epidemiologic sample. The propensity matching procedure resulted in sufficiently balanced caregiving and noncaregiving comparison groups across key demographic, health history, and health behavior variables. The present study used a more diverse and inclusive sample of caregivers than have previous studies of the caregivingmortality association in the US population, and it is the first such study to demonstrate caregiving-mortality effects by using a propensity score matching procedure. As indicated in Figure 1, an even stronger protective effect for caregiving was found when the caregivers were compared directly with all noncaregivers before propensity-based matching.

The subgroup analyses typically resulted in hazard ratio point estimates that were similar to that for all caregivers. Although reduced power was available for the subgroup analyses, significant effects were observed for adult child caregivers in comparison with their respective propensity-matched noncaregiving control group. We did not find any subgroup of caregivers in the REGARDS sample that appeared to be vulnerable to increased risk of death. This includes our analyses of spouse caregivers and spouse caregivers who experience some caregiving strain. These subgroups did not show elevations in their risk of death in our sample, in contrast to the previous findings from the CHES (6). Both the CHES and the REGARDS Study assessed caregiving strain in the same manner. The highstrain caregivers in the REGARDS Study have been previously shown to have higher rates of death than the moderate- and nostrain caregivers after adjustment for demographic and other caregiving-related variables (33), but that analysis was limited to caregivers only. The present findings clarify this caregiving strain effect by showing that most caregivers report low or moderate caregiving strain, and that those caregivers do not show elevated rates of death when compared with propensity-matched samples of noncaregivers.

The present results do not rule out the possibility that some subgroups of caregivers may be vulnerable to increased risk of death. Limitations of the current analysis include a lack of information on the functional status of the care recipients and the specifics of the care being provided. We do not know, for example, how many caregivers provided assistance with activities of daily living, and some may have simply visited or "watched" their care recipients. We were also not able to distinguish caregivers of those with dementia from other subgroups. Caregivers of those with dementia typically face many unique and chronic stressors (34). These recurring stressors are associated with alterations in circulating inflammatory biomarkers (35) that have been linked to increased all-cause mortality rates (27). The finding that the hospitalization of a spouse increased the risk of death of the nonhospitalized spouse further showed that these risks of death were particularly elevated if the hospitalizations were for a disabling condition such as dementia (7). Future research should include indicators of care needs, particularly for stressful types of care involving dementia, mental health-related issues, and end-of-life situations. It may be necessary to oversample some of these specific caregiving subtypes to better define the impact of caregiving and to investigate its diverse effects.

Strengths of the REGARDS Study include a high level of participation among African Americans and the geographical

diversity of its sample. However, caution is warranted in extrapolating these findings to other ethnic groups, such as Hispanic and Asian populations, who were not included in the REGARDS Study. Gender roles and expectations in multigenerational households may confer a different mix of benefits and potential risks from the family caregiving experience.

Highly stressful caregiving situations have been the focus of considerable research and dominate media narratives about caregiving, but the caregiving experience is incredibly diverse, and the majority of caregivers appear to be willingly providing help to family members with relatively low levels of need. Only 10% of caregivers report caring for a person with dementia (1), and many caregivers of cognitively intact older adults report relatively mild caregiving demands (34). Fewer than 17% of the caregivers in the present analysis reported high levels of caregiving strain. In many cases, caregivers report receiving benefits of enhanced self-esteem, recognition, and gratitude from their care recipients (16, 17, 36). Several recent papers have reported that caregivers who report low strain or burden have better psychological well-being than noncaregivers (5, 37). Thus, when caregiving is done willingly, at manageable levels, and for individuals who are capable of expressing gratitude, it is reasonable to expect that health benefits might accrue in those situations. Previous research (18-20) shows that a variety of altruistic behaviors, including providing social support and volunteering, are associated with improved well-being and reduced morbidity and mortality. Altruism, especially within families, is likely to have evolutionary advantages, and the positive affect generated by helping others is a mechanism through which altruism might improve physical health (18).

This more balanced and diverse approach to caregiving research should not eliminate the legitimate concerns about the possible negative health effects of high-strain caregiving on caregivers' physical, psychological, and social well-being. More broadly, if highly stressful situations can be avoided or managed effectively, caregiving may actually produce some health benefits for both the care recipients and the caregivers, including reduced risk of death for those providing care. Negative public health and media portrayals of the risks of family caregiving may do a disservice by portraying caregiving as dangerous and could potentially deter family members from taking on what can be a satisfying and healthy family role. Public discussions of caregiving should more accurately balance the potential risks and gains of this universal family role.

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