Involvement in Caregiving and Adjustment to Death of a Spouse
Findings From the Caregiver Health Effects Study

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More than 2 million persons die in the United States each year. The large majority of these deaths occur among older persons who have 1 or more disabling conditions that compromise their ability to function independently prior to death. As a result, a typical death is preceded by an extended period of time during which family members provide care to their disabled relative.1,2 Although researchers have repeatedly documented the psychiatric and physical health effects of family caregiving,3,4 caregivers are rarely followed up long enough to assess the effect of the death of the disabled relative on the caregiver.5 Similarly, bereavement researchers rarely explore the extent to which family members were involved in care prior to the death of their relative as a factor affecting bereavement outcomes. To better understand the role of caregiving in adjustment to bereavement, we examine predeath to postdeath changes in both self-report and objective health outcomes among elderly persons providing varying levels of care prior to their spouse’s death.

Context Most deaths in the United States occur among older persons who have 1 or more disabling conditions. As a result, many deaths are preceded by an extended period during which family members provide care to their disabled relative.

Objective To better understand the effect of bereavement on family caregivers by examining predeath vs postdeath changes in self-reported and objective health outcomes among elderly persons providing varying levels of care prior to their spouse’s death.

Design and Setting Prospective, population-based cohort study conducted in 4 US communities between 1993 and 1998.

Participants One hundred twenty-nine individuals aged 66 to 96 years whose spouse died during an average 4-year follow-up. Individuals were classified as noncaregivers (n=40), caregivers who reported no strain (n=37), or strained caregivers (n=52).

Main Outcome Measures Changes in depression symptoms (assessed by the 10-item Center for Epidemiological Studies–Depression [CES-D] scale), antidepressant medication use, 6 health risk behaviors, and weight among the 3 groups of participants.

Results Controlling for age, sex, race, education, prevalent cardiovascular disease at baseline, and interval between predeath and postdeath assessments, CES-D scores remained high but did not change among strained caregivers (9.44 vs 9.19; P=.76), while these scores increased for both noncaregivers (4.74 vs 8.25; F1,116=14.33; P<.001) and nonstrained caregivers (4.94 vs 7.13; F1,116=4.35; P=.04). Noncaregivers were significantly more likely to be using nontricyclic antidepressant medications following the death than the nonstrained caregiver group (odds ratio [OR], 12.85; 95% confidence interval [CI], 1.02-162.13; P=.05). The strained caregiver group experienced significant improvement in health risk behaviors following the death of their spouse (1.47 vs 0.66 behaviors; F1,116=20.23; P<.001), while the noncaregiver and nonstrained caregiver groups showed little change (0.27 vs 0.27 [P=.99] and 0.46 vs 0.27 [P=.39] behaviors, respectively). Noncaregivers experienced significant weight loss following the death of their spouse (149.1 vs 145.3 lb [67.1 vs 65.4 kg]; F1,116=8.12; P=.005), while the strained and nonstrained caregiving groups did not show significant weight change (156.2 vs 155.2 lb [70.3 vs 69.8 kg] [P=.41] and 156.2 vs 154.0 lb [70.3 vs 69.3 kg] [P=.12], respectively).

Conclusions These data indicate that the impact of losing one’s spouse among older persons varies as a function of the caregiving experiences that precede the death. Among individuals who are already strained prior to the death of their spouse, the death itself does not increase their level of distress. Instead, they show reductions in health risk behaviors. Among noncaregivers, losing one’s spouse results in increased depression and weight loss.

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comes including depression symptoms, antidepressant medication use, health risk behaviors, and weight among husbands and wives providing varying levels of care to their spouse prior to death. These outcomes were selected because of their known association with caregiving and/or bereavement.

Although bereavement in the elderly is generally associated with increased depression and weight loss, opposing hypotheses have been proposed to predict the effects of bereavement in the context of caregiving: exposure to the chronic stresses of caregiving depletes the emotional and social resources of caregivers and thus makes them more vulnerable to negative outcomes when their spouses die; alternatively, the loss of a disabled spouse may lead to an improvement in mental and physical health outcomes because of the reduced caregiving burden. Studies addressing these hypotheses are inconclusive because of a lack of appropriate comparison groups, or a focus on select subgroups such as caregivers of patients with the human immunodeficiency virus. In addition, published studies are often based on retrospective accounts of caregiving involvement.

The Caregiver Health Effects Study (CHES), an ancillary study of the Cardiovascular Health Study (CHS), a large population-based study of elderly persons, affords a unique opportunity to examine the effects of bereavement in the context of caregiving. It has a relatively large sample size (approximately 400 spousal caregivers and 400 matched controls) and measures of quality of life and physical and psychological health outcomes. In this article we examine prospectively the effects of spousal death on depression symptoms, antidepressant medication use, health risk behaviors, and weight as a function of level of involvement in caregiving prior to death. We examine bereavement effects among noncaregivers, caregivers who report no strain associated with caregiving, and caregivers who report strain.

**METHODS**

**Study Population**

The sample for this ancillary study (CHES) 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, a total of 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, Pennsylvania. Potential participants were identified from a random sample stratified by age group (65-74, 75-84, ≥85 years) from the Health Care Financing Administration Medicare Enrollment lists. Exclusion criteria included being wheelchair bound in the home, unable to participate in the examination at the field centers, or undergoing active treatment for cancer. Additional information regarding sampling and recruitment for the CHS has been published previously. A supplemental cohort of 687 African American men and women aged 65 years or older was recruited prior to the fourth wave of CHS data collection using the same sampling methods.

The CHES ancillary study was initiated following the fourth wave of CHS data collection (1992-1993) with the goal of recruiting approximately 400 caregivers and 400 noncaregiver controls matched for age and sex. Probable caregivers were defined as individuals whose spouse had difficulty with at least 1 activity of daily living (ADL) or instrumental activity of daily living (IADL) “due to physical or health problems or problems with confusion.” The noncaregiving group included individuals whose spouse did not have any difficulty with ADLs or IADLs. A total of 819 individuals (caregivers: n = 392; noncaregivers: n = 427) distributed evenly across the 4 recruitment sites were enrolled into the CHES study. Beginning in 1993, CHES participants completed 3 annual, in-person, structured interviews with a trained interviewer. A fourth wave of data was collected 2 years after the third wave. For this study, individuals who reported being widowed at wave 2, 3, or 4 were included in the analysis (N = 129). The CHES participants who had died prior to wave 4 (n = 103) were not included in these analyses. Additional analyses revealed that the deceased participants had significantly higher levels of prevalent cardiovascular disease at CHES baseline, were older, and were more likely to be male. These variables are included as covariates in the analyses.

**Measures**

**Sociodemographic Variables.** Four sociodemographic variables were included in the analyses as covariates: (1) mean (SD) age at the time of entry into the CHES study (80.07 [4.9] years); (2) race (90% white, 10% nonwhite [mostly African American]); (3) education, coded as the highest grade of school ever completed (23% had not completed high school, 32% graduated from high school, 12% had attended some type of vocational or trade school, and 33% had attended college); and (4) sex (74% female, 26% male).

**Baseline Prevalent Cardiovascular Disease.** To adjust for physical health status at the time of entry into the CHES study, a simple count of the number of 6 prevalent cardiovascular diseases—myocardial infarction, angina pectoris, congestive heart failure, intermittent claudication, stroke, and transient ischemic attack—was included as a covariate in the analyses. Presence of each of the cardiovascular diseases was determined through varying combinations of medical record confirmation, electrocardiogram results, physician validation, medication use, and/or history of medical procedures related to the disease end points (eg, revascularization procedure, lower extremity bypass/angioplasty).

**Prebereavement Caregiving Status.** Caregiving status in the wave prior to the spouse’s death was established...
on the basis of 3 indicators: (1) the level of spousal disability; (2) the extent to which participants helped the spouse with tasks related to the disability; and (3) the level of strain associated with this helping behavior. First, participants were asked whether their spouse had difficulty with 6 ADL tasks (eg, eating, dressing) and 6 IADL tasks (eg, housework, shopping) “due to physical or health problems or problems with confusion.” If the participant reported that the spouse had difficulty with a task, the participant was then asked a yes or no question: “Do you help your spouse with this task?” This question was followed by 2 questions about strain associated with helping: “How much of a mental or emotional strain [“physical strain” in the second question] is it on you to either provide the help directly, or to arrange for help to be provided for this activity?” Response options for the questions about strain were “no strain,” “some strain,” and “a lot of strain.”

Based on the above questions, 3 mutually exclusive caregiving categories were created. A “noncaregiver” category (n=40) included people who reported that their spouse had no difficulty with any of the ADL or IADL tasks (n=34), as well as individuals who reported that their spouse had difficulty with at least 1 of the ADL or IADL tasks but did not provide any caregiving assistance to their spouse (n=6). Given the small sample size of the latter group and the fact that they were not providing any caregiving assistance, we combined these 2 groups into one. A “caregiver-no strain” category (n=37) included people who reported that (1) their spouse had difficulty with at least 1 ADL or IADL task; (2) they helped the spouse with at least 1 of these tasks; and (3) they reported no physical or emotional strain associated with that helping. This categorization is intended to reflect increasing levels of caregiving demands,16 which was expected to moderate the effects of bereavement.

Depression Symptoms. Depression symptoms were assessed using the 10-item version of the Center for Epidemiological Studies-Depression (CES-D) scale. The 10-item version of the CES-D has been found to be highly correlated with the full 20-item version (r=0.96) and to have little or no loss in sensitivity, specificity, or internal reliability.17 Participants respond on a 0 to 3 scale (“rarely or none of the time” to “most of the time”) to statements such as “I felt depressed” using the preceding week as a time frame. The sum of the 10 items was used as a measure of depression symptoms. A score of 8 or higher is viewed as placing the individual at risk for clinical depression.

Antidepressant Medication Use. The CHS protocol requires participants to bring all prescription medications to the yearly clinic visit. The medications are then recorded and categorized using a computerized classification algorithm. For the purposes of this analysis, we examined the proportion of individuals taking tricyclic and nontricyclic antidepressant medications.

Health Risk Behaviors. Participants were asked 6 yes or no questions about the following health risk behaviors: (1) missing at least 1 physician appointment in the last 6 months; (2) not having enough time to go to the physician; (3) not having enough time to exercise; (4) forgetting to take medication; (5) not getting enough rest in general; and (6) not being able to slow down and get enough rest when sick. A simple count of “yes” answers to these questions was used as a measure of health risk behaviors for analysis.

Weight. As part of an annual CHS clinic examination, participants were weighed by a laboratory technician using a standardized balance-beam scale. Participants were weighed wearing underwear and an examination sweat suit, but no shoes. The weight of the examination suit was subtracted when calculating the weight. Weight was recorded to the nearest 0.5 lb and was rounded down.

Data Analytic Strategy
All spousal deaths that occurred after baseline and before wave 4 were included. Data collected at the interview immediately preceding the spouse’s death were used as prebereavement measures, and data collected during the interview immediately following the death were used as postbereavement measures. Since the time between prebereavement and postbereavement measures and the spouse’s death varied across participants, 2 time interval variables, based on dates of the spouse’s death and interview dates, were calculated: (1) time between the collection of prebereavement measures and the death (time before bereavement), and (2) time between the death and the collection of postbereavement measures (time since bereavement). Since the amount of time before and since spousal death may be related to depression symptoms, antidepressant medication use, health risk behaviors, and weight, these time interval variables were used as covariates in the primary analysis.

The primary analytic strategy used was a 3 × 2 repeated measures analysis of covariance with 1 between-subjects factor and 1 within-subjects factor. Prebereavement caregiving status (noncaregiver, caregiver-no strain, caregiver-strain) was the between-subjects factor, and time point (before and after spouse’s death) was the within-subjects factor. The major focus of the analysis was on simple effect tests of time (ie, the death of the spouse) within the 3 caregiving status groups. The 4 demographic variables (age, sex, race, and education), the number of prevalent cardiovascular diseases, and the 2 time interval variables (time before and since bereavement) were used as covariates. The time intervals between predeath and postdeath data collection in relation to time of death varied somewhat as a function of the type of outcome: for depression symptoms, predeath data were col-
lected within 1 year of the death for most respondents (88%), as were postdeath data (85%). Antidepressant medication use was assessed within 1 year before the death in 91% of the sample, and within 1 year following the death in 94% of the sample. The corresponding figures for the health risk behavior data were 67% (within 1 year predeath) and 68% (postdeath), and 93% (within 1 year predeath) and 93% (postdeath) for participant weight. Time intervals varied slightly because of the different assessment schedules used by CHS and CHES.

RESULTS
Descriptive Statistics
The table reports sociodemographic variables; prevalent cardiovascular disease; and prebereavement and postbereavement depression symptoms, health risk behavior scores, and weight by prebereavement caregiving status. Depression Symptoms. The analysis yielded a significant main effect for prebereavement caregiving status (F_{2,110}=6.33, P = .002) due to the fact that the caregiver-strain group had higher levels of depression symptoms than the noncaregiver and caregiver-no strain groups. The main effect for time was not significant. Most relevant to the central research question, a significant caregiving status by time interaction was found (F_{2,116}=4.78, P = .01). Adjusted means for prebereavement and postbereavement depression symptoms by group are plotted in Figure 1A. They reveal significant increases in depression symptoms for the noncaregiver group (4.74 vs 8.25; F_{1,116}=14.33, P < .001; mean difference score=3.52 [95% confidence interval (CI), 1.68-5.36]), and, to a lesser extent, the caregiver-no strain group (4.94 vs 7.13; F_{1,110}=4.35, P = .04; mean difference score=2.19 [95% CI, 0.11-4.27]) but not for the caregiver-strain group, which remained essentially unchanged (9.44 vs 9.19; P = .76).

Another way to interpret the interaction is to note that significant prebereavement differences in depression symptoms between the caregiver-strain group and the other groups became nonsignificant by the postbereavement measurement point. The only significant covariate effect was a main effect for race.
that the caregiver-strain group exhibited higher levels of health risk behaviors than the other groups. The main effect for time was not significant. As was the case for depression symptoms, the data revealed a significant prebereavement caregiving status by time interaction ($F_{2,118}=4.85$, $P=.009$). The prebereavement and postbereavement adjusted means for the caregiving status groups are plotted in Figure 1B. They reveal a significant drop in health risk behaviors for the caregiver-strain group following the death of the spouse (1.47 vs 0.66; $F_{1,118}=20.23$, $P<.001$; mean difference score = −0.80 [95% CI, −1.16 to −0.45]), while the noncaregiver and caregiver-no strain groups showed relatively little change (0.27 vs 0.27 [P = .99]; 0.46 vs. 0.27 [P = .39], respectively). Similar to the depression symptom results, significant prebereavement differences in health risk behaviors between the caregiver-strain group and the other groups became nonsignificant following the death of the spouse. In terms of the covariates, there were significant main effects for time prior to ($P=.05$) and since bereavement ($P=.02$) that showed that health risk behaviors increased the closer the respondent was to the spouse’s death. There was also a significant sex by time interaction ($P=.04$), due to the fact that women exhibited more health risk behaviors prior to the deaths of their spouses, while there was no postbereavement sex difference.

**Participant Weight.** The analysis yielded nonsignificant main effects for both prebereavement caregiving status and time. In addition, the caregiving status by time interaction was not significant. However, the simple effect tests of time within the caregiving status groups revealed different patterns. There was significant weight loss for the noncaregiver group following the death of the spouse (149.1 vs 145.3; $F_{1,101}=8.12$, $P=.005$; mean difference score = −3.8 [95% CI, −6.4 to −1.1]), but not for the caregiver-no strain group (156.2 vs 154.0 [$P=.12$]) or the caregiver-strain group (156.2 vs 155.2 [$P=.41$]). The only significant covariate effect showed that men weighed significantly more than women ($P<.001$) both before and after the spouse’s death.

**Follow-up Analysis** We conducted follow-up analyses to help clarify the significant interaction effects for depression symptoms and health risk behaviors, with a focus on the caregiver-strain group. We compared changes in depression symptoms and health risk behaviors in the bereaved caregiver strain group with sex- and age-matched nonbereaved-strained caregivers over an equivalent period of time (ie, they reported caregiving strain 2 years in a row). In these analyses, levels of spousal need were assessed by a count of the number of spousal ADL and IADL difficulties reported, and levels of strain were assessed by a count of spousal ADL or IADL difficulties for which they reported experiencing emotional or physical strain at the first measurement point. The analyses included age, sex, race, education, and number of prevalent cardiovascular diseases at baseline as covariates. (Time before and since bereavement could not be included as covariates, and thus adjusted means for the bereaved caregiver-strain group differ slightly from those reported above.) Results for depression symptoms are shown in **FIGURE 2A**. In contrast to the bereaved group, continuing strained caregiver depression symptom scores increased significantly over time (6.75 vs 8.86; $t_{53}=-2.78$, $P=.007$), although continuing strained caregivers had significantly lower depression symptom scores at the first measurement point (6.75 vs 9.45; $t_{53}=-2.42$, $P=.02$) when compared with the prebereavement level of depression symptoms of bereaved caregivers. The latter finding is consistent with the fact that both initial level of spousal need for ADL and IADL assistance ($4.67 vs 6.49$; $t_{100}=-2.74$, $P=.007$) and initial level of strain ($3.59 vs 5.59$; $t_{100}=-2.09$, $P=.04$) among continuing caregivers was significantly lower than prebereavement levels for the bereaved group. Thus, continuing caregivers were at earlier
stages in the caregiving career (ie, their spouses were less disabled).

A parallel analysis of health risk behaviors, summarized in Figure 2B, showed that while the bereaved group evidenced a significant decline in such behaviors postbereavement (1.55 vs 0.68; $t_{10}=4.39, P<.001$), the continuing strained caregivers had similar levels at the 2 time points, although health risk behaviors in this group also declined slightly (1.13 vs 0.92 [$P = .27$]).

**COMMENT**

Consistent with earlier research, our study showed that caregivers who report caregiving strain have higher levels of depression symptoms and have worse health practices than noncaregivers or caregivers who report no strain. This study is the first to clearly show that they are at earlier stages of the caregiving career. These findings should be viewed in the context of other data we have reported showing that strained caregivers have an increased risk of mortality. Thus, the most vulnerable caregivers may not be represented in bereaved samples because they do not outlive their spouse.

A number of mechanisms may contribute to the absence of negative or generally positive outcomes observed among strained caregivers. First, the death of the spouse often brings with it an end to the decedent's prior suffering as well as an end to demanding caregiving tasks. Second, the fact that death in many cases occurs predictably after a period of disability and decline enables the caregiver to grieve prior to the death, as well as prepare for the death and its aftermath. Third, the need for caregiving is likely to mobilize a familial support system that would already be in place when the death occurs. The combined effect of these multiple mechanisms may be to attenuate the impact of the loss and promote adaptive functioning after the death of the spouse.

In contrast to strained caregivers, widowed noncaregivers had increased depression symptoms and antidepressant medication use, significant weight loss, but no change in health risk behaviors. The negative effects of bereavement for this group may be the result of the relatively unpredictable nature of their spouse’s death and the greater disruption of the social environment associated with these deaths. Caregivers who report no strain occupy a middle ground between noncaregivers and strained caregivers. They exhibit smaller, though still significant, increases in depression symptoms and no change in antidepressant medication use, health risk behaviors, or weight. This may be expected given the low levels of stress prior to death and the possibility that they have some opportunity to prepare for their spouse’s death.

The scientific study of the effects of caregiving and bereavement have emerged as 2 important but distinct areas of inquiry. One goal of this study is to show that bereavement should be viewed in the context of the caregiving experiences that preceded death, and that caregivers should be followed through the bereavement experience. Inasmuch as end-of-life experiences for many family members will increasingly entail elements of caregiving, it is essential that these experiences be studied together. These findings have a number of clinical implications. Clinicians should explore the caregiving experience of the surviving spouse and tailor their interventions accordingly. Bereaved strained caregivers with significant depression symptoms should receive treatment with medication and/or psychosocial intervention. Bereaved noncaregivers should also be monitored for medication use and significant weight loss, which may place them at risk for significant health decline. In addition, knowing that depression levels of strained caregivers persist through the bereavement experience suggests they may be candidates for the prevention of bereavement depression. Providing indicated medication or counseling prior to the death of their disabled spouse may help shorten the period of distress after bereavement.
REFERENCES


If a man will begin with certainties, he shall end in doubts; but if he will be content to begin with doubts he shall end in certainties.

—Francis Bacon (1561-1626)