

SPECIAL ARTICLE

End-of-Life Care and the Effects of Bereavement on Family Caregivers of Persons with Dementia

Richard Schulz, Ph.D., Aaron B. Mendelsohn, Ph.D., William E. Haley, Ph.D., Diane Mahoney, Ph.D., Rebecca S. Allen, Ph.D., Song Zhang, M.S., Larry Thompson, Ph.D., and Steven H. Belle, Ph.D., for the Resources for Enhancing Alzheimer's Caregiver Health (REACH) Investigators

ABSTRACT

BACKGROUND

From the Departments of Psychiatry (R.S.) and Epidemiology (A.B.M., S.Z., S.H.B.), the Institute on Aging (R.S.), and the University Center for Social and Urban Research (R.S.), University of Pittsburgh, Pittsburgh; the Department of Gerontology, University of South Florida, Tampa (W.E.H.); the Hebrew Rehabilitation Center for Aged, Boston (D.M.); the Department of Psychology, University of Alabama at Tuscaloosa (R.S.A.); and the Veterans Affairs Palo Alto Health Care System, Stanford University, Stanford, Calif. (L.T.). Address reprint requests to Dr. Schulz at the University of Pittsburgh School of Medicine, 121 University Pl., 6th Fl., Pittsburgh, PA 15260, or at schulz@pitt.edu.

Although family caregiving has been intensively studied in the past decade, little attention has been paid to the impact of end-of-life care on caregivers who are family members of persons with dementia or to the caregivers' responses to the death of the patient.

METHODS

Using standardized assessment instruments and structured questions, we assessed the type and intensity of care provided by 217 family caregivers to persons with dementia during the year before the patient's death and assessed the caregivers' responses to the death.

RESULTS

Half the caregivers reported spending at least 46 hours per week assisting patients with activities of daily living and instrumental activities of daily living. More than half the caregivers reported that they felt they were "on duty" 24 hours a day, that the patient had frequent pain, and that they had had to end or reduce employment owing to the demands of caregiving. Caregivers exhibited high levels of depressive symptoms while providing care to the relative with dementia, but they showed remarkable resilience after the death. Within three months of the death, caregivers had clinically significant declines in the level of depressive symptoms, and within one year the levels of symptoms were substantially lower than levels reported while they were acting as caregivers. Seventy-two percent of caregivers reported that the death was a relief to them, and more than 90 percent reported belief that it was a relief to the patient.

CONCLUSIONS

End-of-life care for patients with dementia was extremely demanding of family caregivers. Intervention and support services were needed most before the patient's death. When death was preceded by a protracted and stressful period of caregiving, caregivers reported considerable relief at the death itself.

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MORE THAN 6 MILLION ADULTS IN the United States provide long-term, unpaid care to disabled elderly persons in their families.¹ This service saves the health care system billions of dollars annually,² but it comes at the price of high levels of distress among family caregivers, an increased risk for caregivers of psychiatric and physical disease, and increased mortality.^{3,4} Caregivers of a family member with dementia face particularly stressful demands owing to the length of the period of care, the behavioral problems associated with dementia, and the extreme impairment of patients with end-stage dementia.⁵ Family caregiving has been intensively studied in the past decade, but with the exception of a few studies,⁶ little attention has been paid to the impact on caregivers of providing end-of-life care to a family member with dementia. Furthermore, researchers rarely follow the caregiver through the death of the patient in order to assess the effects of bereavement.⁷ Since the deaths of most persons in the United States are preceded by chronic disease, disability, and family involvement in caregiving, it is important to assess responses to bereavement when end-of-life care is provided up to the patient's death.⁸

The two main goals of our study were to describe the caregiving experience of a large cohort of family members who provided in-home care to persons with dementia during the year before the patients' deaths and to characterize the nature of in-home caregivers' short- and long-term responses to bereavement. Given that there are more than 2 million people with dementia in the United States and that most of them are cared for at home by family members, these findings provide a foundation for developing health care policy on end-of-life care and on the effects of bereavement on family caregivers.

METHODS

STUDY SAMPLE

The caregivers included in our study were enrolled in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study, a multisite trial that tested the feasibility of numerous psychosocial interventions and their impact on the health and well-being of caregivers of persons with Alzheimer's disease.⁹ Data for 1222 pairs of caregivers and recipients were collected in the years from 1996 to 2000 at six sites in the United States — Boston; Birmingham, Alabama; Memphis, Tennessee; Miami; Philadelphia; and Palo Alto, California. The eligibil-

ity criteria and recruitment methods used in the REACH study as well as a full list of the investigators have been described elsewhere.⁹ The research protocol was approved by the institutional review boards of all participating sites. Written informed consent was obtained from all caregivers enrolled in the study.

There were 265 in-home caregivers whose care recipients (referred to hereafter as patients) died in the course of the study. Of those caregivers, 43 (16.2 percent) were excluded, because they dropped out of the study after the death of the patient and before the next scheduled follow-up appointment. An additional five caregivers were excluded from the analysis because the date of the patient's death was missing. The characteristics of the remaining 217 caregivers included in our analysis were similar to those of the 48 caregivers who were excluded, in regard to demographic variables, clinical measures, and scores on the Center for Epidemiologic Studies Depression Scale (CES-D) obtained before the patient's death. The proportion of caregivers who characterized their race as white was higher among those who were included in our study than among those who were excluded (65.9 percent vs. 50.0 percent, $P=0.05$).

COLLECTION OF DATA

Standardized survey instruments and several open-ended questions were administered by trained and certified interviewers before the study participants were randomly assigned to either the treatment group or the control group. At all six sites of the REACH study, the treatment phase lasted approximately six months. In addition to the base-line assessment, participating caregivers were assessed at 6, 12, and 18 months. If the patient either was placed in a long-term care facility or died during the 18-month course of the study, the assessment was modified by eliminating items that were no longer relevant to the caregiver's situation and by adding other items related to either the placement or bereavement. Data for our report were based on assessments performed before and closest to the patient's death and on all assessments performed after the death. Assessments before the death were performed from 4 days to 65 weeks (median, 15 weeks) beforehand. Because the deaths occurred throughout the 18-month study period, the number of follow-up assessments of bereaved caregivers varied. The median time until the caregiver's first follow-up visit after the patient's death was 15 weeks.

In addition to the standard sociodemographic data, caregivers were asked to provide information on the amount of assistance they gave to the patient. These data were collected with the use of standardized functional assessment instruments for activities of daily living (bathing, dressing, eating, getting out of a bed or chair, grooming, and using the toilet)¹⁰ and instrumental activities of daily living (using the telephone, shopping, preparing meals, housekeeping, doing laundry, traveling by car or bus, administering medications, and handling finances)¹¹; other data collected included the number of hours per day that caregivers felt they were “on duty,” had to be in the same room as the patient, and had to be at home to supervise the care of the patient. To assess caregivers’ subjective evaluations of levels of distress due to caregiving, caregivers were asked to evaluate how burdened, depressed, or both they felt. Burden was assessed on the basis of items from the Revised Memory and Behavior Problems Checklist,¹² which is used to characterize memory and behavior in patients with dementia (range, 0 to 96, with higher values indicating greater burden). Depressive symptoms were assessed both at base line and in follow-up visits with the use of the CES-D (range, 0 to 60, with higher values indicating more depressive symptoms).¹³

We also collected data on caregivers’ receipt of prescribed medication for symptoms of depression and anxiety by transcribing information from medication containers, which were provided by the caregivers. After the patient’s death, caregivers were asked a series of questions about the amount of time the patient had felt pain before death, the extent to which death was a relief to the patient and to the caregiver, and the extent to which they had been prepared for the patient’s death. Caregivers were also asked about their use of and need for bereavement-related services (e.g., counseling, support groups, medication, and physicians’ services).

Because the assignment of caregivers to the treatment group (those provided with psychosocial and behavioral interventions designed to alleviate the burden on the caregiver) or to the control group had no effect on the outcomes examined in our study, for our analysis we combined in-home caregivers in the intervention group and those in the control group into a single group.

STATISTICAL ANALYSIS

Descriptive statistics are reported in order to characterize the experience of caregiving. McNemar’s test

was used to determine whether there was a change in the level of depression and in the use of anti-anxiety medication after the death of the patient. Changes in the CES-D scores before and after the death were assessed with the use of a Wilcoxon matched-pairs signed-rank test. We also examined levels of depressive symptoms among caregivers who had cared for a patient who was institutionalized during the study period (180 of 1222 caregivers). The analysis was designed to assess whether caregivers’ depressive symptoms improved after they were relieved of the burden of in-home care. To help interpret our data on bereavement, we compared the changes in levels of caregivers’ depressive symptoms after the patient’s institutionalization among the 180 caregivers who cared for a patient who was institutionalized with changes in the levels of depressive symptoms among the 217 caregivers after the patient’s death.

Mixed models¹⁴ were used to analyze caregivers’ scores on the CES-D as a function of the time since the death of the patient, with adjustment for potential confounders. We used a compound symmetric covariance pattern to account for the correlation among the observations for the same participant.¹⁵ Before fitting the models, we generated plots to assess the functional form of the relation between the CES-D scores and the time since the death. The plots indicated that the relation was not linear; for this reason we used a piecewise linear-function approach¹⁶ for the time variable. This method permitted the slopes to change across intervals but to remain constant within intervals. Four intervals were created — less than 13 weeks, 13 to 39 weeks, 39 to 65 weeks, and more than 65 weeks after the death of the patient.

RESULTS

DESCRIPTION OF THE CAREGIVING EXPERIENCE AND END-OF-LIFE CARE

At the time of enrollment, the mean (\pm SD) age of the caregivers was 65.0 ± 13.3 years; 84.3 percent were women, and the group was evenly divided between spouses (49.8 percent) and nonspouses (50.2 percent, primarily children) of the persons they cared for (Table 1). The mean age of the patients was 81.0 ± 7.6 years. The majority of them were men (53.9 percent). The average score of patients on the Mini-Mental State Examination¹⁷ was 10.9 ± 7.2 , which indicated moderate-to-severe cognitive impairment. The characteristics of our sample of care-

givers were similar to those of a national sample of family caregivers of persons with severe dementia who were living at home.²

The number of years of caregiving ranged from less than 1 year to 40 years. The median number of years of caregiving at enrollment in the study was three (Table 2). Half the caregivers reported spending at least 11 hours per week helping patients with activities of daily living and at least 35 hours per week helping with instrumental activities of daily living. More than half (59.0 percent) of caregivers reported feeling they were on duty 24 hours a day owing to the responsibilities of caregiving. The median score for the burden on the caregivers, according to the Revised Memory and Behavior Problems Checklist, was 12 (of a possible score of 96). This score is equivalent to being either extremely bothered by three problems in the behavior of the patient (e.g., memory problems, behavior dangerous to self, aggression, and misplacing objects) or moderately bothered by six problems in behavior.

Of 56 caregivers who were employed outside the home, 27 (48.2 percent) had to reduce their work hours because of the demands of caregiving. Of the full cohort of 217 caregivers, 39 (18.0 percent) stopped working in order to provide care.

The most common formal health care services used before the patient's death were physicians' services; 57.6 percent of caregivers and 64.4 percent of the patients visited a physician in the month preceding the last assessment before the patient's death. Nearly half (45.6 percent) of the caregivers used the services of a home health aide. Caregivers also received help from informal sources—56 percent received help from other family members.

CAREGIVERS' RESPONSES TO THE DEATH OF THE PATIENT

Over 90 percent of the caregivers indicated that they believed either somewhat or very much that death came as a relief to the patient, and 72.0 percent reported that it was somewhat or very much a relief to themselves. Most caregivers (68.5 percent) stated that they had been prepared for the patient's death. When asked if the patient had felt pain at the last assessment before death, 62.6 percent of caregivers reported that the patient had been in pain "often" or "all of the time."

Of 215 caregivers for whom data were available, 21.4 percent reported having used bereavement-related services after the patient's death, and 14.4 percent reported having needed such services.

Table 1. Characteristics of 217 Pairs of Bereaved Caregivers and Deceased Patients.*

Characteristic	Caregivers	Patients
Age — yr	65.0±13.3	81.0±7.6
Race or ethnic group — no. (%)		
White	143 (65.9)	143 (65.9)
Black	44 (20.3)	45 (20.7)
Hispanic	30 (13.8)	29 (13.4)
Sex — no. (%)		
Female	183 (84.3)	100 (46.1)
Male	34 (15.7)	117 (53.9)
Education — no. (%)†		
Less than high-school graduation	52 (24.0)	94 (45.4)
High-school graduation	63 (29.0)	45 (21.7)
More than high-school graduation	102 (47.0)	68 (32.9)
Income — no. (%)‡		
<\$20,000	88 (41.9)	—
\$20,000–\$39,999	76 (36.2)	—
≥\$40,000	46 (21.9)	—
Relationship to patient — no. (%)		
Spouse	108 (49.8)	—
Nonspouse	109 (50.2)	—
Location of patient at death — no. (%)§		
Home	—	66 (32.2)
Hospital	—	83 (40.5)
Institution	—	56 (27.3)
Score on Mini-Mental State Examination¶	—	10.9±7.2

* Plus-minus values are means ±SD.

† Data on education were available for 207 patients.

‡ Data on income were available for 210 caregivers.

§ Data on the location of death were available for 205 patients.

¶ Data were available for 209 patients. Scores on the Mini-Mental State Examination range from 0 to 30, with higher scores indicating higher cognitive function.

Among those who reported needing assistance, the most common types of assistance were support groups for the family (65.5 percent of caregivers) and individual counseling (53.3 percent).

At the last assessment before the patient's death (median interval, 15 weeks), the mean CES-D score was 15.8±11.7 (median, 13), and 42.9 percent of the caregivers had scores above 15. At the time of the patient's death, the mean CES-D score spiked to 22 (Fig. 1), but within 15 weeks the scores had declined to a level similar to prebereavement levels (mean, 16.2±12.3; median, 14). Scores for depression at the 1-year anniversary of the death (44 to 60 weeks after the death) among the 53 caregivers for whom data were available declined further, to a mean of 11.5±9.4 (median, 9; $P=0.03$ by the Wilcoxon signed-rank test, as compared with scores before the death), and less than one third of caregivers (30.2 percent) had scores above the level considered to indicate a risk of clinical depression.

Table 2. Levels of In-Home Care Provided to 217 Patients with Dementia.

Variable	Median (Interquartile Range)
Years of caregiving	3 (2–5)
Help with ADLs and IADLs*	
No. of ADLs	4 (3–5)
No. of IADLs	7 (6–8)
Hours per wk helping with ADLs†	11 (3–24)
Hours per wk helping with IADLs	35 (21–56)
Hours per day “on duty”	24 (14–24)
Hours per day must be in room‡	23 (21–24)
Hours per day must be at home	24 (23–24)
Burden on caregiver according to RMBPC§	12 (5–21)
	Number (Percent)
Effect on working caregivers	
Had to reduce hours worked¶	27 (48.2)
Had to stop working	39 (18.0)
Patient institutionalized during study	57 (26.3)

* Caregivers were asked about the need to help with the six activities of daily living (ADLs) and the eight instrumental activities of daily living (IADLs).

† Data were available for 214 caregiver–recipient pairs.

‡ Data were available for 216 caregiver–recipient pairs.

§ Scores on the Revised Memory and Behavior Problems Checklist (RMBPC) range from 0 to 96, with higher values indicating greater burden.

¶ Data were available for 56 working caregivers.

To help us interpret these findings, we examined changes in scores for depression among the 180 caregivers before and after the patients they cared for were institutionalized. At the last assessment of the caregivers before placement of the patient (median interval, 17 weeks) and the first assessment after placement (median interval, 12 weeks), the mean scores for depression were 17.1 ± 11.9 (median, 15) and 18.1 ± 13.0 (median, 15), respectively. These values were slightly higher than the values for caregivers of patients who died. One year after placement, scores for depression remained high and were significantly higher among caregivers of patients who had been institutionalized than among those of patients who had died (mean, 16.2 vs. 11.5; median, 14 vs. 9; $P=0.02$ by the Wilcoxon signed-rank test).

Before the death of the patient, 16.6 percent of caregivers reported receiving antidepressant medication, and 19.4 percent reported receiving anxiolytic drugs. After the death, 21 percent of caregivers reported receiving antidepressant medication, and 18 percent reported receiving anxiolytic drugs. These data represent a net increase of 9 caregivers

receiving antidepressant medication (11 reported starting medication and 2 reported stopping it; $P=0.01$, by the McNemar test) and a net decrease of 2 caregivers receiving anxiolytic drugs (13 reported starting medication and 15 reported stopping it, P not significant).

CHANGES IN CES-D SCORES OF CAREGIVERS AFTER THE PATIENT'S DEATH

Estimates of the slopes of the lines in the model relating CES-D scores to the time after the patient's death showed that the scores declined significantly in the 13 weeks immediately after the death (0.61 point per week, $P<0.001$) (Fig. 1). After those 13 weeks and through the total of 65 weeks after the death, CES-D scores continued to decline, but the slopes of the lines did not differ significantly from zero. The CES-D scores reached a plateau at 65 weeks after the death of the patient.

To control for potential confounders of caregivers' depression after the patient's death, we reran the model to include the relationship between caregiver and patient, the amount of time the caregiver spent helping the patient to perform activities of daily living and instrumental activities of daily living, burden as measured by the Revised Memory and Behavior Problems Checklist, whether the patient was institutionalized before death, whether the caregiver received antidepressant or anxiolytic medication (entered into the model as time-dependent covariates to reflect receipt of medication as reported at interviews with the caregiver after the death), the depression score before the death, the study site, and the random assignment to the treatment or control group. Because the addition of these covariates did not change the results in any substantive way, we report only the results of the first iteration of the model.

DISCUSSION

Our study characterized the nature of family caregiving for patients with dementia at the end of life and the response of family caregivers to the death of their loved ones. Family caregivers were intensely involved in providing care to patients with dementia in the last year of the patient's life. Half the caregivers reported spending at least 46 hours per week assisting patients with activities of daily living and instrumental activities of daily living, and more than half reported that they felt they were on duty 24 hours a day. The caregivers' care was complemented

by assistance from other family members and by support from the formal health care and social-service systems in the form of help provided by home health aides and visiting nurses, homemaker services, and home delivery of prepared meals (data not shown).

Other studies have shown that disabled elderly persons wish to remain at home as long as possible and that family members want to honor this preference.¹⁸ Thus, an important policy question is how these preferences can be fulfilled at the same time as the patient's comfort is maximized and the caregiver's distress is minimized. This question has been broadly addressed in studies of caregiving that were conducted in the past decade but not with respect to the care family caregivers provide at the end of life. End-of-life care poses unique challenges in the intensity and type of the demands of this care, which are likely to be specific to the nature of the disease and to the patient's level of disability. In particular, there are special challenges in the care of patients with cognitive impairment with respect to communication, pain control, the need for extraordinary vigilance, and the complexity of coordinating the multiple formal and familial support systems needed to provide adequate care.¹⁹ More research is needed to develop interventions to maximize both the comfort of the patient and the well-being of the caregiver.

Although the death of a close relative is generally viewed as a powerful source of psychological stress, the caregivers in our study showed remarkable resilience in adapting to the death of their relatives. Within three months after the death, caregivers had significant declines in the levels of depressive symptoms, and within one year the levels of these symptoms were below the levels reported when these persons had been active caregivers. These results are underscored by the fact that only a minority of the caregivers reported using or needing bereavement-related services and that a large majority of them reported feeling relieved by the death. In contrast, caregivers whose relatives were institutionalized did not show this recovery from depressive symptoms, which suggests that relief from providing daily care alone did not account for the caregivers' recovery from bereavement.

These findings have several implications. First, they reinforce the argument that an understanding of the effects of bereavement requires close atten-

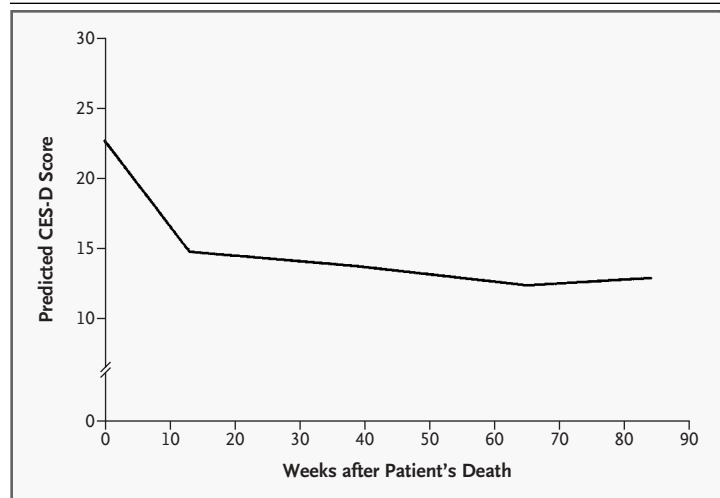


Figure 1. Changes in Levels of Depressive Symptoms According to Center for Epidemiologic Studies Depression Scale (CES-D) Scores among 217 Caregivers in the Weeks after the Patient's Death.

Before the death, the average CES-D score among caregivers was 15.8. Scores on this scale range from 0 to 60, with higher scores indicating more depressive symptoms.

tion to the context in which the death occurs.⁸ When death was preceded by a protracted and stressful period of caregiving, the negative effects on caregivers that are typically ascribed to losing a loved one may be substantially lessened, owing to the experience of caregiving. Second, the need for support after the death appears to be limited to a minority of caregivers, which suggests that highly targeted intervention strategies may be the most appropriate ones. Third, investments in resources for intervention and support may have the largest benefit when they are applied to caregivers and patients in the period of caregiving that immediately precedes the patient's death. It is possible that when caregivers know that their relatives are on a trajectory toward death and when caregivers are aware of the patient's disability and suffering, they grieve for the loss of the patient before the death. This possibility suggests that clinicians and scientists should view bereavement not only as a phenomenon that affects caregivers after the death but also as one that affects many caregivers before the death occurs.

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