Published in final edited form as:

Aging Ment Health. 2008 January ; 12(1): 100–107. doi:10.1080/13607860801936631.

The effect of spousal caregiving and bereavement on depressive symptoms

D. H. TAYLOR JR.^{1,2}, M. KUCHIBHATLA^{3,4}, T. ØSTBYE^{3,5}, B. L. PLASSMAN⁶, and E. C. CLIPP^{3,5,7,8}

¹Duke University Center for Health Policy, Durham, NC

²Duke University, Terry Sanford Institute of Public Policy, Durham, NC

³Center for the Study of Aging and Human Development, Duke University Medical Center, Durham, NC,

⁴Department of Biostatistics and Bioinformatics, Duke University Medical Center, Durham, NC

⁵Department of Medicine, Duke University Medical Center, Durham, NC

⁶Department of Psychiatry, Duke University Medical Center, Durham, NC,

⁷School of Nursing, Duke University Medical Center, Durham, NC

⁸Geriatric Research Education and Clinical Center, Durham Veterans Affairs Medical Center, Durham, NC, US

Abstract

The objective of the study was to determine whether spousal caregiving and bereavement increases caregiver depressive symptoms. We followed 1,967 community-dwelling elderly couples from the 1993 Health and Retirement Study (HRS) until 2002 (five bi-annual surveys) or death. Depressive symptoms were measured by the Center for Epidemiological Studies-Depression (CESD) scale. Adjusted depressive symptoms were higher for females for three of the four caregiving arrangements tested (as were unadjusted baseline levels). Depressive symptoms were lowest when neither spouse received caregiving (adjusted CESD of 2.97 for males; 3.44 for females, $p < 0.001$). They were highest when females provided care to their husband with assistance from another caregiver, (4.01) compared to (3.37; $p < 0.001$) when males so cared for their wife. A gender by caregiving arrangements interaction was not significant ($p = 0.13$), showing no differential effect of caregiving on CESD by gender. Depressive symptoms peaked for bereaved spouses within three months of spousal death (4.67; $p < 0.001$) but declined steadily to 2.75 ($p < 0.001$) more than 15 months after death. Depressive symptoms initially increased for the community spouse after institutionalization of the care recipient, but later declined. We conclude that caregiving increases depressive symptoms in the caregiver, but does not have a differential effect by gender. Increases in depressive symptoms following bereavement are short-term.

Introduction

Unpaid informal care provided by family members is the centerpiece of long-term care in the US. Among older married couples, a spouse typically provides assistance in completing Basic and Instrumental Activities of Daily Living (ADL and IADL) to their spouse, at least

initially (North Carolina Family Caregiver Support Program, 2005; Schulz & Martire, 2004). Spouses providing care to their partners is the second most common informal caregiving arrangement in the US, with 41% of all informal long-term care provided in this manner (adult children caring for parents is the most common, 42% of the cases) (Georgetown University Center on an Aging Society, 2005). Spousal care likely is preferred by care recipients and can be viewed as fulfillment of marriage vows; on the other hand, there is empirical evidence of numerous negative effects of caregiving on the caregiving spouse (Schulz & Beach, 1999; Schulz & Martire, 2004). In a nation that relies on informal caregiving as the US does, it is important to understand the negative effects of caregiving and to determine whether any harm is permanent or subsides after the death and/or institutionalization of the spouse receiving care.

Spousal caregiving leads to increased depression in the caregiver in a variety of contexts and across methods used to identify cases, with females, generally, and wives in particular, appearing to be more adversely affected than males (Barusch & Spaid, 1989; Beach et al., 2000; Burton et al., 2003; Cantor, 1983; Clipp & George, 1990; Dura, Haywood-Niler, & Kiecolt-Glaser, 1990; Fitting et al., 1986; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; George & Gwyther, 1986; Gilleard et al., 1984; Miller, 1987; Prigerson et al., 1997; Pruchno & Potashnik, 1989; Stommel, Given, & Given, 1990; Wright, Clipp, & George, 1993). Gender differences in depression hold across a variety of reasons for caregiving (Deimling & Bass, 1986; Tennstedt, Cafferata, & Sullivan, 1992) with dementia caregivers typically having much higher rates (above 80% is common) (Drinka & Smith, 1983; George & Gwyther, 1986; Rabins, Mace, & Lucas, 1982) than those caring for stroke or heart disease patients (11–37%) (Gallagher et al., 1989; Schulz, Tompkins, & Rau, 1988; Wade, Legh-Smith, & Hewer, 1986; Young & Kahana, 1989).

Of particular interest in understanding the impact of caregiving on American society is determining whether caregiver depression remains elevated after the death of one's spouse (bereavement) or whether it resolves and can therefore be considered temporary (Aneshensel, Botticello, & Yamamoto-Mitani, 2004; Bodnar & Kiecolt-Glaser, 1994; Carr et al., 2001; Collins et al., 1994; Schulz et al., 2003). Some work has identified improvement in caregiver depression after bereavement, on average (Schulz et al., 2003) or among a subset of caregivers (women and those reporting greater strain prior to bereavement) (Aneshensel, Botticello, & Yamamoto-Mitani, 2004). Other work has suggested that caregiver depression does not change substantially after bereavement (Bodnar & Kiecolt-Glaser, 1994), even if care had been provided for more than six months (Carr et al., 2001). Of similar interest is the effect of spousal institutionalization on caregiver depression. Institutionalization has been found to result in increased stress during the transitional period but, overall, to have effects on depressive symptoms that are similar to bereavement (Aneshensel, Pearlin, & Mullan, 1995). Other work has found that accounting for site of death (institution versus community) did not alter the shape of the relationship between time since bereavement and depression among caregivers (Schultz et al. 2003) and that site of death did not differ significantly across different trajectories of depressive symptoms of caregivers following bereavement (Aneshensel, Botticello, & Yamamoto-Mitani, 2004).

Our study focuses on whether there are gender differences in how spousal caregiving influences caregiver depressive symptoms, and whether bereavement or admission of the care recipient to a nursing home influences this. The study offers several important advantages. First, we are able to determine whether the effects of caregiving differ by gender, while many studies focus on wives caring for husbands. Second, our database is representative of the elderly population as a whole, meaning that we are able to estimate the effects of caregiving on depressive symptoms in comparison to depressive symptoms of couples who are not providing any care. Third, the reasons for caregiving in our study are

varied, just as is the case in the population, while many prior studies have studied caregiving for a particular condition only. Finally, our sample is longitudinal with assessment of depressive symptoms for the surviving spouse continued upon bereavement and institutionalization of the care recipient spouse, allowing for an assessment of caregiving across the various phases of the caregiving career (Aneshensel, Pearlin, & Mullan, 1995).

Methods

Selection and description of participants

A total of 1,967 spousal couples were identified from the population representative sample of the Health and Retirement Study (HRS) in which: (1) both spouses responded to the 1993 baseline interview; and (2) at least one member of the spousal dyad reported one or more instrumental or basic activity of daily living limitations on one or more surveys (five surveys were used: 1993, 1995, 1998, 2000 and 2002). That is, all couples had at least one member who had some disability, but all couples did not report caregiving. All respondents to the baseline HRS lived in the community at the first survey, but moves to nursing homes and deaths were tracked and surviving spouses continued to be interviewed. The HRS sample was not chosen with respect to caregiving or need for caregiving, but was designed to be representative of community-dwelling persons age 70 and older and their spouses, regardless of age.

Conceptual model

We use the classic model offered by Aneshensel and colleagues to guide our empirical analyses (Aneshensel et al., 1995). This model conceives of caregiving as an ‘unexpected’ career with distinct phases that entail different sources and amounts of stress that lead to negative caregiver outcomes (Pearlin et al., 1981, 1990). A key aspect of this model is the notion that the distinct stages of the caregiver career (acquisition, enactment and disengagement of the caregiving role) have different effects on caregiver outcomes, in our case, depressive symptoms. All phases of the career are observed in this study since many spousal dyads are not involved in caregiving, others initiate caregiving during the study, many continue providing care, while others can be said to disengage and begin the readjustment process given the death of the care-recipient spouse (bereavement). The database used for this study was not selected for caregiving, which increases the representativeness of the study, but limits the measures of caregiving available to operationalize the stress process that operates within distinct phases of the caregiving career. For example, we directly measure objective primary stressors, such as caregiving arrangements, but are unable to measure subjective stressors, such as role overload, though these concepts are believed to be at work in explaining the effect of caregiving on the depressive symptoms of the caregiver. The longitudinal nature of our data are key to allowing us to test for gender differences during the role enactment phase (measured by caregiving arrangements in the community and institutionalization) and to document any changes in depressive symptoms that are related to the transition from the role enactment to the role disengagement phase (bereavement).

Variable definition

Dependent variable—Depressive symptoms were measured using a modified CESD scale (range 0–9, higher values indicate more depressive symptoms) and was measured for all sample members, during each biannual interview.

Explanatory variables

Caregiving arrangements—Each sample member was considered a potential caregiver for his or her spouse. At each wave, information was collected on the care received (if any) and whether the spouse provided any care. All participants were asked if they received assistance with I/ADLs. Activities of daily living included walking across a room, dressing, bathing/ showering, eating, getting in and out of bed and using the toilet. Instrumental activities of daily living included hot meal preparation, grocery shopping, making a telephone call, taking medications and managing money. Instrumental activities of daily living were measured identically for both spouses and the survey identified providers of care other than the spouse. Using this information, we constructed a 4-level caregiving-arrangement variable for each sample member, indicating whether or not an individual provided care to their spouse and whether others provided care. The four mutually exclusive categories were: (1) no care was given by a spouse or anyone else; (2) no care was given by a spouse, but care was provided to an individual by someone else (the potential caregiving spouse was alive); (3) care was provided by a spouse and someone else; and (4) care was provided by the spouse only. The caregiving arrangement variable was entered as a time-varying covariate and is the key explanatory variable that identifies the effect of the caregiving arrangements used by a couple on the actual or potential caregiving spouse's depressive symptoms.

Other explanatory variables

Other explanatory variables included characteristics of the actual or potential caregiving spouse: gender, age, race (white versus non-white), and years of education; and the following time-varying covariates: self-rated health (range: 1 = excellent to 5 = poor); cognition (range: 0–20; higher numbers representing better cognition) as measured by the HRS cognitive screening instrument; number of physician visits in the preceding year; and total number of I/ADL limitations (range: 0–11) that the potential or actual caregiving spouse had difficulty in completing.

To determine whether depressive symptoms remained unchanged after the death of the spouse receiving care, we included a variable to represent time since death (spouse living; died within 0–3 months of the survey measurement; died within 4–15 months; and died more than 15 months prior to survey measurement). Date of death was obtained from the National Death Index, which has been linked to the HRS. We also included a variable that signified the number of biannual interviews since the individual entered a nursing home (e.g. first, second, etc.). Finally, we included a time trend variable equal to one in 1993 and five in 2002 to capture any temporal trend in depressive symptoms.

Statistical analyses

Descriptive statistics for the sample were summarized using percentages for categorical variables and means and standard deviations for continuous variables. *T*-tests were used to compare means of continuous variables by gender. We used mixed models (PROC MIXED in SAS) (Laird & Ware, 1982) to determine the effect of caregiving arrangements and selected characteristics of both members of a couple on depressive symptoms of the actual or potential caregiving spouse as measured by the CESD. The outcome variable, CESD, was a time-varying variable measured at each of five surveys. PROC MIXED utilizes all of the data that are available across survey waves to estimate models and is designed to produce robust estimates under the assumption that incomplete data are missing at random (Little & Rubin, 1987). In our analyses, there are two sources of attrition, death and other types of missing information including item non-response of variables and loss-to-follow-up. Of the 19,670 observations used across the waves from the total sample, we dropped 3971 and

2963 observations that are due to deaths and other reasons, respectively, from the mixed models.

In order to highlight whether the relationship between caregiving and CESD differed by gender we displayed our results as adjusted mean CESD values, allowing for a separate estimate for females and males for each level of the caregiving arrangements variable, controlling for all other explanatory variables. We analyzed differences in least square means within the mixed procedure to compare adjusted mean CESD by gender for each level of the caregiving arrangements variable, as well as to highlight other comparisons. Further, we estimated a mixed model that included a gender by caregiving arrangements interaction term as an alternative way to test whether caregiving had a different effect on depressive symptoms for males versus females. Analyses were conducted using SAS version 9.1 (SAS Institute Inc., 2004).

Results

Among the 1,967 married couples in the analysis sample in 1993, females were younger (72.8 years; SD 6.81 versus 76.4 years; SD 5.77) and slightly more educated than males (Table I). Over the study period, 9–14% of husbands provided some care to their wives, while 16–22% of wives provided some care to their husbands. Approximately one-in-ten respondents were non-white. Death was a significant source of attrition over the nine-year study period, with 32.2% of females ($n=633$) and 51.2% ($n=1,007$) of males dying prior to the final survey. Females were more likely to provide care to their husbands than vice-versa, in all waves. Mean values of the primary outcome CESD and other time-varying covariates are shown for surviving individuals at each wave, stratified by gender. Unadjusted baseline depressive symptoms were significantly higher for women (mean CESD 2.04) compared to men (1.61; $p<0.001$).

An individual whose spouse received care had higher depressive symptoms than one who did not, regardless of the arrangement used to provide such care. The lowest level of depressive symptoms was observed among persons whose spouse received no care from anyone (CESD 3.20—Table II, reference group). The highest level was found when a spouse provided care to a husband or wife with assistance from another caregiver (3.69; $p<0.001$) and each of the other two arrangements (care provided by the spouse only: CESD 3.35, and care provided by someone other than the spouse only: CESD 3.46; $p<0.001$ for both comparisons) resulted in depressive symptoms that were significantly higher for the actual or potential caregiver spouse than the reference arrangement. This basic pattern generally held true whether the actual or potential caregiver was a male or a female, except that depressive symptoms for males were not significantly elevated when the husband was the sole provider of care for his wife.

Depressive symptoms were higher among women compared to men for three out of four caregiving arrangements tested. When no care was provided to the spouse, depressive symptoms for females (3.44) were significantly higher than the level observed for men under the same arrangement (2.97; $p<0.001$). When a female was the only provider of care to her husband, depressive symptoms were also elevated compared to the case where the husband was the sole provider of care to his wife (3.65 versus 3.06; $p<0.001$). When a female provided care to her husband in conjunction with someone else, depressive symptoms were also higher than for a husband who was likewise caring for his wife (4.01 versus 3.37; $p<0.001$). In an alternative specification, we did not find that the effect of caregiving on caregiver depressive symptoms differed by gender; a coefficient testing for an overall gender by caregiving arrangements interaction was not statistically significant ($p=0.13$, not shown). We conducted a sensitivity analysis whereby we dropped the couples that

could be termed ‘simultaneous caregivers’ because both members of the spousal dyad were caring for the other at a given survey ($n=210$ subjects for a total of 254 observations across all the waves). This sensitivity analysis had no effect on our results and is therefore not shown.

Upon bereavement, the level of depressive symptoms of the surviving spouse initially rises substantially and then steadily declines to a level that is similar to what was observed prior to the death of the spouse. The increase in depressive symptoms prior to death of 2.53 to 4.67 when the CESD is measured by an HRS survey within three months of death is highly significant ($p<0.001$), as is each of the subsequent transitions shown (from 4.67 to 3.75; $p<0.001$) and 3.75 to 2.75 ($p<0.001$) more than 15 months after bereavement. Thus, more than 15 months after bereavement, depressive symptoms of the surviving spouse were still significantly elevated compared to pre-death levels (2.75 versus 2.53; $p = 0.03$), but the levels had fallen substantially since the immediate bereavement period.

Following nursing home admission of one’s spouse, the depressive symptoms of the spouse remaining in the community increase significantly (3.11 to 3.78; $p<0.001$). Depressive symptoms declined significantly from the first survey after institutionalization to the second (3.78 to 3.67; $p<0.02$), but did not change significantly thereafter, nor were they significantly different from the pre-institutionalization period.

Discussion

Over the study period, from 9–14% of husbands provided some care to their wives, and 16–22% of wives did so for husbands. We confirmed that providing care increases depressive symptoms, even after adjusting for other factors. Adjusted depressive symptoms were higher for women compared to men in three of the four caregiving arrangements, but they were also higher at baseline and in subsequent waves in unadjusted form. We did not find evidence that caregiving increases depressive symptoms more for female than for male caregivers when tested by an interaction of gender and caregiving. Instead, caregiving appears to have a similar effect on elevating depressive symptoms for both genders.

We found statistically significant differences between adjusted depressive symptoms across caregiver arrangements (with no caregiving as the reference group), but the clinical significance of the differences identified was negligible. In only one of the six caregiving groups (gender by arrangements) was the mean adjusted depressive symptoms greater than 4 (out of 9) and in that case it was only 4.01, when females provided care for their husbands with the assistance of another caregiver. Thus, no group was found to have extremely elevated levels of depressive symptoms, on average. However, we investigated the distribution of depressive symptoms across the four caregiving groups and found that the 90th percentile of depressive symptoms at baseline was 4, 7, 6 and 4 out of 9 when looking at the groups in the order they are shown in Table II. In addition, the range of depressive symptoms was 0–9 for the first two caregiving arrangements, and 0–8 for the last two. Thus, only a small subset of caregivers have very high levels of depressive symptoms. Determining methods of identifying such at risk caregivers on a population basis is an important public health priority.

Bereavement initially sharply increased depressive symptoms, but the increase is relatively short-term as adjusted levels returned to near pre-death levels within 15 months after bereavement. This suggests that harm due to caregiving in the form of increased depressive symptoms does not appear to be long lasting, though levels remain slightly elevated as compared to pre-bereavement levels. The time path of resolution of depressive symptoms and bereavement is consistent with that found by Schultz (Schulz et al., 2003) and others,

but we have identified this relationship with a nationally representative sample of elderly couples only (no adult child caregivers), including a group of couples not involved in caregiving. The literature on the effect of bereavement on caregiver depressive symptoms is mixed. Some work has identified improvements in depressive symptoms after bereavement, on average (Aneshensel, Botticello, & Yamamoto-Mitani, 2004; Bodnar & Kiecolt-Glaser, 1994; Carr et al., 2001; Collins et al., 1994; Schulz et al., 2003) or among sub-groups (one-fifth to one-fourth) of caregivers (Aneshensel, Botticello, & Yamamoto-Mitani, 2004; Collins et al., 1994). We tested for interactions in this relationship by gender, but did not find an interaction with gender that past work has identified (Collins et al., 1994). We also did not find interactions between death of the spouse and caregiving arrangements.

The placement of one's spouse in a nursing home was associated with an increase in depressive symptoms at the first and second survey waves after placement. By the third wave post-placement, depressive symptoms did not differ from those prior to placement of the spouse. In one sense, our results concur with the findings of Schultz et al. (2003) that, while depression did consistently decline after the death of the care recipient, placement of the same in a nursing home did not appreciably change depressive symptoms of the caregiving spouse.

Our study sample is nationally representative and was not drawn specifically in order to study caregiving, allowing us to look at the effect of caregiving on depressive symptoms from a public health perspective that considers all elderly couples, and not simply focus on those already engaged in caregiving. This is a major strength of this study. However, there is a trade-off between specificity of measures related to caregiving and the representativeness of the sample used in a study. In our data we could not precisely measure hours of caregiving per day or tasks completed. Other limitations included not having the exact date of nursing home entry (as we did with death). We could identify between which biannual waves a person was institutionalized, but this imprecision in measurement means that our results on nursing home placement should be viewed with more caution than our findings on bereavement. The time-varying nature of our analysis does allow us to observe couples moving from no-caregiving to a caregiving arrangement but likely does not precisely control for stage of illness causing the need for caregiving, which is a limitation. We did control for the level of I/ADL limitations and cognition of the care recipient spouse, but these are not perfect controls of need for care.

From a public policy standpoint, our study provides mixed results. On the negative side, much of the burden of caregiving still falls to the spouse when an elderly person needs care and is married. On the positive side, the increase in depressive symptoms associated with caregiving, while statistically significant, does not rise above levels that are thought to signify clinical depression. However, a sub-set of caregivers is likely to suffer a great deal of psychological distress due to caregiving and we currently do not have a good means of identifying such caregivers. The aging of American society will increase the prevalence of caregiving and the number of persons so engaged, with the potential for many of them to experience negative psychological consequences. Placement of a spouse in a nursing home does not appear to provide a clear benefit to community-dwelling spouses in terms of reduced depressive symptoms. In the future, continuing to assess the impact of caregiving in representative samples will be key for understanding the costs and benefits of depending so heavily on informal care and in developing interventions that may ameliorate the distress that is suffered by caregivers.

Acknowledgments

We gratefully acknowledge that this study was funded by a grant from the National Institute of Nursing Research, grant number 1RO1-NR008763.

References

- Aneshensel, CA.; Pearlin, LI.; Mullan, JT.; Zarit, SH.; Whitlach, CJ. Profiles in caregiving: The unexpected career. Academic Press; San Diego: 1995.
- Aneshensel C, Botticello AL, Yamamoto-Mitani N. When caregiving ends: The course of depressive symptoms after bereavement. *Journal of Health & Social Behavior*. 2004; 45:422–440. [PubMed: 15869114]
- Barusch AS, Spaid WM. Gender differences in caregiving: Why do wives report greater burden? *Gerontologist*. 1989; 29:667–676. [PubMed: 2513266]
- Beach SR, Schulz R, Yee JL, Jackson S. Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the caregiver health effects study. *Psychology & Aging*. 2000; 15:259–271. [PubMed: 10879581]
- Burton LC, Zdaniuk B, Schulz R, Jackson S, Hirsch C. Transitions in spousal caregiving. *Gerontologist*. 2003; 43:230–241. [PubMed: 12677080]
- Bodnar JC, Kiecolt-Glaser JK. Caregiver depression after bereavement: Chronic stress isn't over when it's over. *Psychology and Aging*. 1994; 9:372–380. [PubMed: 7999322]
- Cantor MH. Strain among caregivers: A study of experience in the United States. *Gerontologist*. 1983; 23:597–604. [PubMed: 6662373]
- Carr D, House JS, Wortman C, Nesse R, Kessler RC. Psychological adjustment to sudden and anticipated spousal loss among older widowed persons. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 2001; 56B(4):S237–S248.
- Clipp EC, George LK. Psychotropic drug use among caregivers of patients with dementia. *Journal of the American Geriatric Society*. 1990; 38:227–235.
- Collins C, Stommel M, Wang S, Given CW. Caregiving transitions: Changes in depression among family caregivers of relatives with dementia. *Nursing Research*. 1994; 43:220–225. [PubMed: 8047426]
- Deimling GT, Bass DM. Symptoms of mental impairment among elderly adults and their effects on family caregivers. *Journal of Gerontology*. 1986; 41:778–784. [PubMed: 3772056]
- Drinka T, Smith J. Depression in caregivers of demented patients. *Gerontologist*. 1983; 23(Special issue):115.
- Dura JR, Haywood-Niler E, Kiecolt-Glaser JK. Spousal caregivers of persons with Alzheimer's and Parkinson's disease dementia: A preliminary comparison. *Gerontologist*. 1990; 30:332–336. [PubMed: 2354791]
- Fitting M, Rabins P, Lucas MJ, Eastham J. Caregivers for dementia patients: A comparison of husbands and wives. *Gerontologist*. 1986; 26:248–252. [PubMed: 3721231]
- Gallagher D, Rose J, Rivera P, Lovett S, Thompson LW. Prevalence of depression in family caregivers. *Gerontologist*. 1989; 29:449–456. [PubMed: 2521102]
- Gallagher, D.; Wabretz, A.; Lovett, S.; Del Maestro, S.; Rose, J. Depression and other negative affects in family caregivers. In: Light, E.; Lebowitz, B., editors. *Alzheimer's disease treatment and family stress: Directions for research*. National Institute of Mental Health; Washington, DC: 1989. p. 218-223.
- George LK, Gwyther LP. Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *Gerontologist*. 1986; 26:253–259. [PubMed: 3721232]
- Georgetown University Center on an Aging Society. [Retrieved November 3, 2005] A decade of informal caregiving. 2005. from: <http://ihcrp.georgetown.edu/agingsociety/pdfs/caregivers1-E.pdf>
- Gilleard CJ, et al. Emotional distress amongst the supporters of the elderly mentally infirm. *British Journal of Psychiatry*. 1984; 145:172–177. [PubMed: 6466915]
- Laird NM, Ware JH. Random-effects models for longitudinal data. *Biometrics*. 1982; 38:963–974. [PubMed: 7168798]

- Little, RJA.; Rubin, DA. Statistical analysis with missing data. John Wiley and Sons; New York: 1987.
- Miller B. Gender and control among spouses of the cognitively impaired: A research note. *Gerontologist*. 1987; 27:447–453. [PubMed: 3623142]
- North Carolina Family Caregiver Support Program. Family caregivers in North Carolina: what do we know? What are we doing to help?. Department of Health and Human Services, Division of Aging and Adult Services; Raleigh: 2005.
- Pearlin LI, Lieberman MA, Menaghan E, Mullan JT. The stress process. *Journal of Health and Social Behavior*. 1981; 22:337–356. [PubMed: 7320473]
- Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*. 1990; 30:583–594. [PubMed: 2276631]
- Prigerson HG, Bierhals AJ, Kasl SV, Reynolds CF 3rd, Shear MK, Day N, Beery LC, Newsom JT, Jacobs S. Traumatic grief as a risk factor for mental and physical morbidity. *American Journal of Psychiatry*. 1997; 154:616–623. [PubMed: 9137115]
- Pruchno RA, Potashnik SL. Caregiving spouses: Physical and mental health in perspective. *Journal of the American Geriatrics Society*. 1989; 37:697–705. [PubMed: 2754154]
- Rabins PV, Mace NL, Lucas MJ. The impact of dementia on the family. *Journal of the American Medical Association*. 1982; 248:333–335. [PubMed: 7087127]
- SAS Institute Inc.. Version 9.1. SAS Institute Inc; Cary, NC: 2004.
- Schulz R, Beach SR. Caregiving as a risk factor for mortality. *Journal of the American Medical Association*. 1999; 282:2215–2219. [PubMed: 10605972]
- Schulz R, Martire LN. Family caregiving of person with dementia: Prevalence, health effects and support strategies. *American Journal of Geriatric Psychiatry*. 2004; 12:240–249. [PubMed: 15126224]
- Schulz R, Mendelsohn AB, Haley WE, Mahoney D, Allen RS, Zhang S, Thompson L, Belle SH, for the Resources for Enhancing Alzheimer's Caregiver Health (REACH) Investigator. End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine*. 2003; 349:1936–1942. [PubMed: 14614169]
- Schulz R, Tompkins CA, Rau MT. A longitudinal study of the psychosocial impact of stroke on primary support persons. *Psychology and Aging*. 1988; 3:131–141. [PubMed: 3268251]
- Stommel M, Given CW, Given B. Depression as an overriding variable explaining caregiver burden. *Journal of Aging & Health*. 1990; 2:81–102.
- Tennstedt S, Cafferata GL, Sullivan L. Depression among caregivers of impaired elders. *Journal of Aging & Health*. 1992; 4:58–76. [PubMed: 10116446]
- Wade DT, Legh-Smith J, Hower RL. Effects of living with and looking after survivors of a stroke. *British Medical Journal*. 1986; 293:418–420. [PubMed: 3091140]
- Wright LK, Clipp EC, George LK. Health consequences of caregiver stress. *Medicine, Exercise, Nutrition, and Health*. 1993; 2:181–195.
- Young RF, Kahana E. Specifying caregiver outcomes: Gender and relationship aspects of caregiving strain. *Gerontologist*. 1989; 29:660–666. [PubMed: 2689296]

Table I

Sample characteristics of community-dwelling elderly couples, 1993–2002.

Variables	Female		Male		<i>p</i> -value
	<i>n</i>	Mean (SD)/(%)	<i>n</i>	Mean (SD)/(%)	
CESD [*] (SD)					
1993	1816	2.04 (2.24)	1658	1.61 (1.93)	<0.0001
1995	1618	1.99 (2.23)	1414	1.58 (1.95)	<0.0001
1998	1419	2.54 (2.25)	1134	2.04 (1.98)	<0.0001
2000	1231	2.59 (2.28)	926	2.09 (2.05)	<0.0001
2002	1065	2.57 (2.26)	720	2.11 (2.12)	<0.0001
Give care to spouse (%)					
1993	1967	21.6	1967	13.3	<0.0001
1995	1745	15.9	1843	13.8	<0.0001
1998	1462	17.7	1679	12.6	<0.0001
2000	1203	16.4	1509	11.4	<0.0001
2002	956	16.6	1327	8.6	<0.0001
Age at baseline (SD)	1967	72.75 (6.81)	1967	76.35 (5.77)	<0.0001
Race (% non-white)		9.9		9.7	
Education (in years) (SD)		11.33 (3.28)		10.83 (3.98)	<0.0001
Self-rated health [‡] (SD)					
1993	1966	2.97 (1.17)	1967	3.09 (1.18)	0.0014
1995	1780	3.02 (1.15)	1688	3.07 (1.16)	0.2026
1998	1589	3.21 (1.15)	1391	3.28 (1.14)	0.0961
2000	1410	3.11 (1.09)	1130	3.2 (1.13)	0.0402
2002	1226	3.19 (1.10)	886	3.2 (1.12)	0.8379
Cognition [‡] (SD)					
1993	1816	13.04 (3.17)	1658	12.06 (3.10)	<0.0001
1995	1615	13.13 (3.14)	1414	12.10 (2.91)	<0.0001
1998	1419	12.87 (3.20)	1135	12.08 (2.92)	<0.0001
2000	1231	12.87 (3.08)	928	11.85 (2.85)	<0.0001
2002	1065	12.40 (3.20)	720	11.40 (3.08)	<0.0001
I/ADL limitations [§] (SD)					
1993	1967	0.95 (1.96)	1967	1.06 (2.07)	0.0871
1995	1849	1.21 (2.31)	1755	1.47 (2.33)	0.0008
1998	1682	1.46 (2.60)	1467	1.62 (2.48)	0.0785
2000	1512	1.45 (2.60)	1206	1.70 (2.51)	0.0115
2002	1334	1.62 (2.84)	960	1.80 (2.77)	0.1304
Doctor visits, <i>n</i> (SD)					
1993	1945	4.7 (5.46)	1944	4.89 (6.03)	0.3031
1995	1728	9.27 (9.06)	1647	9.34 (9.51)	0.8267
1998	1508	10.37 (9.55)	1322	10.44 (9.81)	0.8477
2000	1400	12.27 (18.91)	1130	12.48 (18.77)	0.7806

Variables	Female		Male		p-value
	n	Mean (SD)/(%)	n	Mean (SD)/(%)	
2002	1210	14.24 (27.57)	882	15.45 (38.14)	0.3997
Death (% from baseline that died by end of study)		32.2		51.2	

* 0–9; higher values reflect more depressive symptoms.

[†] Range: 1 = excellent, to 5 = poor.

[‡] Range: 0–20; higher values reflect better cognition.

[§] Range: 0–11, reflecting the number of activities for which the person needs help. Higher scores indicate more disability.

Table II

The effect of caregiving, bereavement and institutionalization on CESD of potential and actual caregiver spouses.

Variables*	Adjusted mean CESD (SE)	p-value
Caregiving arrangements		
No care given by spouse or otherwise	3.20 (0.20)	Ref
No care given by spouse, but provided by someone else	3.46 (0.22)	0.016
Care provided by spouse and someone else	3.69 (0.21)	<0.001
Care provided by spouse only	3.35 (0.21)	<0.001
Gender by caregiving arrangements interaction		
<i>Male</i>		
No care given by spouse or otherwise	2.97 (0.20)	Ref
No care given by spouse, but provided by someone else	3.38 (0.24)	<0.001
Care provided by spouse and someone else	3.37 (0.22)	<0.001
Care provided by spouse only	3.06 (0.21)	0.26
<i>Female</i>		
No care given by spouse or otherwise	3.44 (0.20)	Ref
No care given by spouse, but provided by someone else	3.53 (0.24)	<0.001
Care provided by spouse and someone else	4.01 (0.22)	<0.001
Care provided by spouse only	3.65 (0.21)	<0.001
Time (in months) since the death of the care recipient [‡]		
0 months (pre-death/no death of a care recipient)	2.53 (0.17)	Ref
0–3 months	4.67 (0.44)	<0.001
3–15 months	3.75 (0.22)	<0.001
>15 months	2.75 (0.19)	0.03
Time (wave) since the nursing home admission of the care recipient [‡]		
0 wave (pre-nursing home admission/no nursing home admission)	3.11 (0.13)	Ref
1st wave since admission	3.78 (0.22)	<0.001
2nd wave since admission	3.67 (0.27)	0.02
3rd wave since admission	3.08 (0.36)	0.94
4th wave since admission	3.50 (0.46)	0.37
Age at baseline	0.00 (0.00)	0.92
Race		
White	3.41 (0.21)	Ref
Other	3.44 (0.20)	0.63
Cognition of spouse	−0.02 (0.01)	0.001
Activities of Daily Living of spouse	0.21 (0.01)	<0.001

p-values are for test of difference of adjusted mean across the different levels of the variables shown; ref stands for reference category.

* Model also adjusted for the following aspects of the caregiver: education, time (wave) of interview, self-reported health, cognition, ADL/ IADL limitations, and number of doctor visits of the potential or actual caregiver.

[†]Includes the death of spouses who did not receive caregiving from the spouse or otherwise. *P*-values for the following transitions are as follows: 4.67 to 3.75, *p*<0.001; 3.75 to 2.75, *p*= 0.03.

[‡]Includes institutionalization of spouses who did not receive caregiving from the spouse or otherwise.