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Journal

American Journal of Geriatric Psychiatry, 22(5)

ISSN

1064-7481

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Publication Date

2014-05-01

DOI

10.1016/j.jagp.2012.08.010

Peer reviewed



Published in final edited form as:

Am J Geriatr Psychiatry. 2014 May ; 22(5): 481–488. doi:10.1016/j.jagp.2012.08.010.

Depressive Symptoms among Dementia Caregivers: The Role of Mediating Factors

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Abstract

Objectives—To compare depressive symptoms between caregivers to persons with dementia and other illnesses, and determine whether caregiver role captivity and care recipient disruptive behaviors mediate this association.

Design—Prospective cohort study of older women in four U.S. communities followed from 1999 to 2009.

Setting—Home-based interviews.

Participants—345 caregiving participants from the Caregiver-Study of Osteoporotic Fractures.

Measurements—Caregiver status based on self-report of performing one or more instrumental or basic activities of daily living for care recipient. Depressive symptoms measured using the 20-item Center for Epidemiologic Studies Depression Scale. Scores of 16 or greater represented high depressive symptoms. Caregiver role captivity and care recipient problematic behaviors measured using validated instruments.

Results—Approximately one-third of the caregivers cared for a person with dementia. High depressive symptoms were more common among dementia caregivers (22.8% vs. 11.2%, $p < 0.001$), (unadjusted odds ratio [OR] 2.12, 95% CI 1.20-3.74). This association was completely mediated by caregiver role captivity and care recipient problematic behaviors. In adjusted results, high depressive symptoms was associated with middle and highest tertiles of role captivity

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Conflicts of Interest

The authors report no conflicts of interest.

An abstract of this work was presented at the Gerontological Society of America annual meeting in Boston, MA, November 2011.

(adjusted odds ratios [AOR] 5.01, 95% CI 2.31-11.05 and 9.41, 95% CI 3.95-22.40 for the middle and highest tertiles, respectively) and care recipient problematic behaviors (AOR 2.52 95% CI 1.02-6.19 and 5.26, 95% CI 2.00-13.8 for each tertile, respectively).

Conclusions—Older caregivers to persons with dementia are at increased risk of high depressive symptoms. Targeting problematic behaviors among dementia patients and addressing aspects of dementia care that result in role captivity may ameliorate caregiver depression.

Keywords

caregiver burden; dementia; depression

INTRODUCTION

In the U.S., the majority of care to elders with long-term functional dependence is provided by informal caregivers, and close to one-third of households have a person serving as an informal caregiver.¹ Although many persons derive substantial benefits from caregiving,² the persistent physical and emotional demands can act as chronic stressors, placing caregivers at increased risk of adverse physical and psychological outcomes including stress, depression and anxiety.^{3, 4}

Dementia is the most common illness requiring informal caregiving,¹ a need likely to increase as the prevalence of dementia increases.⁵ Compared to caring for persons with other illnesses, dementia caregiving is particularly demanding due to the duration of illness, the degree of functional dependence and the prevalence of behavioral disturbances.⁶ For example, compared to other caregivers, those who care for a person with dementia spend more time providing care, have less time for leisure and family, report greater physical and emotional strain and feel more trapped in their role as caregiver (i.e., role captivity).^{6, 7} The concept of role captivity has been described as the unwilling assumption of the caregiver role, and is separate from the difficulty of the caregiving tasks required. It is particularly relevant to caregivers of persons with dementia, and has been shown to decrease when such care recipients are placed in long-term care facilities.⁸ Role captivity also predicts depressive symptoms among dementia caregivers.^{9, 10}

The prevalence of depression among caregivers to persons with dementia is estimated to range between 30% to 40%,^{11, 12} with symptoms increasing prior to the care recipient's death.¹³ Greater psychological distress has been reported by caregivers to persons with dementia compared to those with other illnesses.^{14, 15} However, few studies have directly compared depressive symptoms between dementia and non-dementia caregivers. Behavioral disturbances in care recipients have been shown to be independent predictors of depression among caregivers.^{11, 16} However, it is not clear whether caregiving demands or psychological stresses related to dementia care mediate caregiver depressive symptoms. We hypothesized that caregivers to persons with dementia would have greater depressive symptoms than other caregivers and that this association would be mediated by the care recipient's behavioral disturbance and caregiver role captivity.

METHODS

Participants

The study sample came from the Caregiver-SOF sample, an ancillary study to the Study of Osteoporotic Fractures (SOF).¹⁷ SOF is a prospective cohort study of risk factors for fractures and falls among women. SOF included 9,704 women aged 65 and older recruited between 1986 and 1988 from population-based listings in four areas of the United States: Baltimore, Maryland; Minneapolis, Minnesota; Portland, Oregon; and the Monongahela Valley, Pennsylvania.¹⁸ Women were excluded if they were unable to walk without help or had a history of bilateral hip replacement. African-American women were initially excluded because of their low incidence of hip fracture. In 1996, a cohort of 662 African-American women age 65 years and older was added. All SOF participants underwent a comprehensive clinical examination approximately every 2 years after the baseline examination.

The Caregiver-SOF sample included members of the original and the African-American SOF cohorts who participated in the 6th biennial examination which took place between 1997 and 1999. The study sample was identified in two phases, described in detail elsewhere.¹⁷ The first phase consisted of administering a caregiver screening questionnaire to community-dwelling participants who had their 6th biennial examination and were not cognitively impaired. The second phase began in 1999, and consisted of re-administering the screening questionnaire by telephone to all participants who had been identified by the initial screening questionnaire as caregivers and to a subset of participants who had been identified as non-caregivers. Participants were classified as caregivers if they were currently helping a relative or friend with one or more of seven basic activities of daily living (ADLs; i.e., walking, grooming, moving from bed to chair, eating, dressing, bathing, and toileting) or seven instrumental ADL tasks (IADLs; i.e., using the telephone, getting to places out of walking distance, shopping, preparing meals, and managing medications and money) because that person was unable to perform the task independently due to cognitive, physical, or psychological impairments. Participants were categorized as non-caregivers if they did not help anyone with these tasks. SOF participants who were identified as caregivers at the initial screening, but as non-caregivers at the second screening were excluded; those who were identified as non-caregivers at the initial screening but as caregivers at the second screening were classified as caregivers. For each caregiver who agreed to participate, 1 or 2 non-caregivers were recruited, matched on SOF site, age, race, and zip code. The resulting Caregiver-SOF baseline sample consisted of 1069 participants, of whom 375 were caregivers and 694 were non-caregivers. The institutional review boards at each SOF site and at Boston University Medical Center approved this study. All participants provided written informed consent.

Data collection and analytic sample

Between 1999 and 2009, five face-to-face interviews were conducted with Caregiver-SOF participants in their homes. The first 3 interviews took place between 1999 and 2004 at approximately annual intervals, and the last two were conducted between 2006 and 2009, at approximately 18-month intervals. At each interview, caregiver status was re-assessed for all participants. This allowed us to document caregivers who continued caregiving or stopped

over the study interval, as well as non-caregivers who had started caregiving for someone since the previous interview.

Participants contributed between zero and four intervals to the sample for the current study, which was defined as the period between two consecutive interviews in the Caregiver-SOF study. This analytic sample was developed by combining all intervals into a single longitudinal dataset. All analysis was done at the interval level and information from interviews at both the start and the end of interval was used to define the participant's caregiving status during any given interval.

The current analyses were restricted to participants who completed at least two consecutive interviews (n=1027, 3332 intervals), and were caregivers at the beginning of an interval (n=407, 887 intervals). Of these, we focused on intervals in which the caregiver either continued caregiving or ceased caregiving due to the care recipient's death (n=345, 718 intervals). We excluded intervals in which caregiving ceased for the following reasons: the care recipient was placed in a nursing home or other long-term care facility, the care recipient recovered, the caregiver was unable to continue caregiving, or other reasons (n=62, 169 intervals) due to sample size considerations. One interval was excluded due to missing data on the caregiver's depressive symptoms. Of the remaining 717 intervals, 180 were those in which caregiving ceased due to the care recipient's death (n=179 respondents), and 537 were those in which caregiving continued (n=282 respondents). These analyses included a total of 345 respondents due to some respondents contributing intervals in both categories.

Measures

Care recipients with dementia—The caregivers' self-report of the main reason for caregiving was ascertained at the beginning of each interval and characterized for this analysis as dementia vs. other illness. Other illnesses were further categorized as neurological disease, frailty, multiple ailments, ocular disease or other.

Depressive Symptoms—Depressive symptoms were measured at the beginning of each interval using the 20-item version of the Center for Epidemiologic Studies Depression Scale (CES-D).¹⁹ Possible scores range from 0-60. The presence of high depressive symptoms (versus low) was defined as a score of 16 or greater. This cut point is conventionally used and has good sensitivity and specificity for a major depressive disorder diagnosis.²⁰

Care recipient nearing end of life—At each interval, a variable was constructed to denote whether the care recipient was at the end of life, based on information from the subsequent interview noting that the care recipient had died.

Caregiver and care recipient characteristics—Caregiver and care recipient characteristics were obtained at the beginning of each interval. Caregiver sociodemographic measures included: age in years; race (white vs. non-white); highest level of education (college vs. less than college); and relationship to the care recipient (spouse vs. other). Health status variables included whether the caregiver required assistance in at least one ADL or IADL task,^{21, 22} and her self-report of ever having been diagnosed with two or more of five chronic medical conditions (heart disease, hypertension, stroke, diabetes, and

arthritis). Measures of caregiver burden included whether others helped with care (yes vs. no), whether the caregiver had time away from caregiving (yes vs. no), and whether she was satisfied with family life (very satisfied vs. somewhat satisfied, somewhat dissatisfied, or very dissatisfied). Caregiver role captivity was assessed using a three item scale inquiring about the degree to which caregivers wish they were free to live a life of their own, feel trapped by their care recipient's illness or wish they could run away (range 0-9, higher scores indicate greater role captivity).²³ This scale was divided into tertiles for ease of presentation and interpretation of results. Scores were grouped as follows: the lowest tertile contained scores 0-1, the middle tertile 2-3 and the upper tertile scores greater than 3.

Care recipient characteristics included age in years and the number of ADL tasks requiring assistance. The number of problematic behaviors exhibited by the care recipient was captured using a 19 item scale measuring the caregivers' report of the frequency of specific behaviors (i.e., agitation, irritability, suspicion, incontinence etc.), and ranges 0-42, higher scores indicate more problematic behaviors or greater frequency.²³ This scale was divided into tertiles for ease of presentation and interpretation of results. Scores were grouped as follows: the lowest tertile contained scores less than 15, the middle tertile 15-18 and the upper tertile scores greater than 18.

Analysis

Means for continuous variables and proportions for categorical variables were calculated at the interval level for caregiver and care recipient characteristics. Logistic regression models were conducted at the interval level to examine the association between caring for a person with dementia, with the outcome of high depressive symptoms. Robust standard error estimates^{24, 25} were used to adjust for clustering at the individual level and fixed effects were used to account for SOF site and interval. Potential confounders were identified through bivariate logistic regression analysis of each covariate with high depressive symptoms: those covariates associated at the level of $p < 0.10$ were included in the multivariable models.

We followed Baron and Kenny's approach²⁶ to evaluate whether caregiver role captivity and problematic behaviors mediated the relationship between caregiving to a person with dementia and high depressive symptoms. First, we evaluated whether each potential mediator was independently associated ($p < 0.05$) with caring for a person with dementia, and with high depressive symptoms, respectively. Next, we tested the association between caring for a person with dementia and high depressive symptoms. Subsequent analyses added the potential mediators to this baseline model. All statistical analyses were performed using STATA SE version 10.0 (STATA Corporation, College Station, TX).

RESULTS

Caregiver characteristics

Caregiver characteristics at the interval level are presented in Table 1. The average age was 82 years, most were white (90%) and 40% were college educated. ADL or IADL limitations were present in 48% of the sample, 46% had at least two medical conditions and 47% were

spouses of the care recipient. Half (52%) received help from others with caregiving, 77% had time away from caregiving and 67% were satisfied with family life.

Caregivers to persons with dementia were significantly more likely than other caregivers to be the care recipient's spouse (64% vs. 40%) and to have at least two medical comorbidities (56% vs. 41%). Dementia caregivers were more likely to feel trapped by their caregiving responsibilities (role captivity scale score 2.4 vs. 1.4).

Care recipient characteristics

Care recipient characteristics at the interval level are presented in Table 1. The average age was 83 years. Care recipients with dementia were significantly older than other care recipients (86 vs. 81 years), had significantly higher scores on the problematic behavior scale (22.3 vs. 16.9), and more ADL needs (2.0 vs. 1.5). Care recipients with dementia also were more likely to be near the end of life than those without dementia (31% vs. 23%).

Of the 717 assessments, 206 (28.7%) were for care for a person with dementia. The 511 intervals representing care for persons with other illnesses included 30% for multiple ailments, 23% for frailty, 17% for neurological diseases including stroke, Parkinson's disease or other neurological ailments, and 6% for ocular diseases. The remaining 24.1% were for a variety of other illnesses, none of which accounted for more than 4% of the sample.

Care recipient dementia status and caregiver depressive symptoms

Caregivers to persons with dementia were more likely than other caregivers to have high depressive symptoms (22.8% vs. 11.2%, $p < 0.001$, $\chi^2 = 16.1$, $df=1$). This was true for those who cared for recipients at the end of life (29.7% vs. 14.7%, $p = 0.02$, $\chi^2 = 5.83$, $df=1$) as well as those whose care recipient was not at the end of life (19.7% vs. 10.1%, $p = 0.003$, $\chi^2=8.69$, $df=1$). The association between care recipient dementia status and caregiver depressive symptoms did not remain significant in adjusted analysis (Table 2).

Factors associated with caregiver depressive symptoms and mediators

Caregivers to persons with dementia were twice as likely to experience high depressive symptoms, even after adjusting for whether the care recipient was at the end of life (Table 2). However, this association was completely mediated by caregiver role captivity and care recipient problematic behaviors. Across the four assessments, Cronbach's coefficient alpha ranged from 0.79-0.91 for the role captivity scale and from 0.74-0.81 for the problematic behaviors scale.

In the fully adjusted logistic regression model, caregiving to a person with dementia was no longer associated with high depressive symptoms, while the upper tertiles of caregiver role captivity as well as care recipient problematic behaviors remained independent predictors (Table 2). In addition, greater caregiver functional limitation was associated with high depressive symptoms while satisfaction with family life was protective. A more parsimonious model did not significantly alter these findings.

Evidence of mediation was supported by caregiver role captivity (OR 1.21, 95% CI 1.10-1.34, $p < 0.0001$, Wald Chi2 14.82, 1df) and care recipient problematic behaviors (OR 1.23, 95% CI 1.16-1.29, $p < 0.001$, Wald Chi2 55.31, 1df) being associated with dementia care recipient status in unadjusted logistic regression. Caregiver role captivity (OR 1.43, 95% CI 1.29-1.57, $p < 0.0001$, Wald Chi2 49.7, 1df) and care recipient problematic behaviors (OR 1.16, 95% CI 1.10-1.22, $p < 0.001$, Wald Chi2 31.87, 1df) were also associated with high caregiver depressive symptoms in unadjusted logistic regression.

DISCUSSION

In this community-dwelling cohort of older female caregivers, one in five caregivers for persons with dementia had high depressive symptoms. Caregivers to a person with dementia were more than twice as likely as other caregivers to have high depressive symptoms, an association completely mediated by greater caregiver role captivity and care recipient problematic behaviors. These results supported our hypothesis about the relationship between caregiving to a person with dementia and high depressive symptoms.

This study compared depressive symptoms between caregivers to persons with dementia vs. other illnesses. Large studies of community dwelling caregivers of persons with dementia have documented rates of depression ranging from 32-39%,^{11, 12} with symptoms increasing prior to care recipient death.¹³ Only 23% of respondents in our study reported high depressive symptoms, with symptoms increasing prior to the care recipient's death for both dementia and non-dementia caregivers. Few studies have directly compared caregivers to dementia with other caregivers, although dementia caregivers have been found to have greater depression than those who provide care to persons with Parkinson's disease.¹⁵

We hypothesized that caregivers to persons with dementia would have higher levels of role captivity, and indeed this was the case, even though they were no less likely than other caregivers to have time away from caregiving or to receive help from others with care. In addition, the relationship between role captivity and caregiver depressive symptoms held after adjustment for care recipient functional limitations. These findings imply that role captivity is not simply a reflection of the physical care required of the caregiver, but that it captures the emotional component of providing that care. The feeling of being trapped by caregiving fully mediated the association between dementia caregiving and high depressive symptoms, suggesting that the emotional toll of caring for a relative or friend with dementia is particularly high and likely to influence the caregiver's emotional health. Aspects of dementia likely to contribute to role captivity among caregivers include the need for monitoring of behaviors due to cognitive impairment, and the fact that dementia is a relentlessly progressive illness without cure.

Problematic behaviors such as agitation, wandering or aggression are known to be a prominent concern of dementia caregivers,²⁷ and in this cohort, dementia caregivers reported a greater frequency of these behaviors than non-dementia caregivers. Prior work has noted an association between problematic behaviors and depressive symptoms among dementia caregivers,^{11, 16} but without comparison to other caregivers. Our results suggest that such behaviors represent a key link between dementia caregiving and caregiver

depression. Problematic behaviors have been described as a primary stressor due to the vigilance required in preventing the care recipient from harming self or others.²⁸ Other possible reasons why problematic behaviors may be strongly linked to caregiver depression include the fact that they are difficult to treat, either with behavioral or pharmacologic methods, and are often felt to be embarrassing, which may contribute to caregivers' feeling of social isolation.^{29, 30}

Among caregivers of persons with dementia, prior work demonstrates that health behaviors, particularly physical activity,³¹ and activity restriction³² partially mediate the relationship between neuroticism and depressive symptoms. Based on these findings, it is possible that the effect of the mediators in our study (role captivity and problematic behaviors) may be partially related to activity restriction although we did not evaluate this.

Our results should be interpreted in light of certain limitations. First, our sample was composed predominantly of white women, and our results may not be generalizable to caregivers who are younger, minority, or male, although most caregivers in the United States are elderly women; therefore, these results apply to the majority of caregivers. Second, although we used a well validated measure of depressive symptoms, we were unable to determine whether participants met criteria for major or minor depression. Third, while we have information on whether a care recipient died during an interval, we do not have the exact date of death for all participants who died and are therefore unable to quantify time from caregiver assessment to care recipient death. Lastly, measures of role captivity and problematic behaviors were developed in a cohort of dementia caregivers, thus their validity in other caregiver populations is less well established.

In summary, our findings document that caregivers to persons with dementia were twice as likely as other caregivers to have high levels of depressive symptoms. In addition, this increased risk of high depressive symptoms appeared to be explained by feelings of caregiver role captivity and by care recipient problematic behaviors. However, caregivers who were satisfied with family life were at lower risk of high depressive symptoms. Reviews of the effectiveness of interventions to decrease caregiver psychological distress have been mixed, especially for dementia caregivers.^{33, 34} However, recent work focusing on the role of caregiver psychological strengths such as self-efficacy have shown promise in decreasing depressive symptoms among dementia caregivers.^{35, 36} Our findings may provide information useful in testing future such interventions aimed at decreasing depression among those caring for persons with dementia.

Acknowledgments

Sources of Funding: This work was supported by the National Institute on Aging at the National Institutes of Health (K23 AG034967 to JLG). The Study of Osteoporotic Fractures is supported by the National Institute on Aging at the National Institutes of Health (AG05407, AR35582, AG05394, AR35584, AR35583, R01 AG005407, R01 AG027576-22, R01 AG005394-22A1, and R01 AG027574-22A1). Additional funding support comes from R01 AG18037 for the Caregiver-SOF study and R01 AG028144 for LF and CM and R01 AG028556, and R21 AT002959 for LF.

REFERENCES

1. National Alliance for Caregiving. Caregiving in the US 2009. www.caregiving.org

Am J Geriatr Psychiatry. Author manuscript; available in PMC 2015 May 01.

2. Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. *Int J Geriatr Psychiatry* Feb. 2002; 17(2):184–188.
3. Schulz R, Newsom J, Mittelmark M, et al. Health effects of caregiving: the caregiver health effects study: an ancillary study of the Cardiovascular Health Study. *Ann Behav Med*. 1997; 19(2):110–116. [PubMed: 9603685]
4. Pinquart M, Sorensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging*. 2003; 18(2):250–267. [PubMed: 12825775]
5. Brodaty H, Breteler MM, Dekosky ST, et al. The world of dementia beyond 2020. *J Am Geriatr Soc*. 2011; 59(5):923–927. [PubMed: 21488846]
6. Ory MG, Hoffman RR 3rd, Yee JL, et al. Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *Gerontologist*. 1999; 39(2):177–185. [PubMed: 10224714]
7. Bertrand RM, Fredman L, Saczynski J. Are all caregivers created equal? Stress in caregivers to adults with and without dementia. *J Aging Health*. 2006; 18(4):534–551. [PubMed: 16835388]
8. Aneshensel CS, Pearlin LI, Schuler RH. Stress, role captivity, and the cessation of caregiving. *J Health Soc Behav*. 1993; 34(1):54–70. [PubMed: 8463635]
9. Alspaugh ME, Stephens MA, Townsend AL, et al. Longitudinal patterns of risk for depression in dementia caregivers: objective and subjective primary stress as predictors. *Psychol Aging*. 1999; 14(1):34–43. [PubMed: 10224630]
10. Pioli MF. Global and caregiving mastery as moderators in the caregiving stress process. *Aging Ment Health*. 2010; 14(5):603–612. [PubMed: 20480415]
11. Covinsky KE, Newcomer R, Fox P, et al. Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. *J Gen Intern Med*. 2003; 18(12):1006–1014. [PubMed: 14687259]
12. Harwood DG, Barker WW, Cantillon M, et al. Depressive symptomatology in first-degree family caregivers of Alzheimer disease patients: a cross-ethnic comparison. *Alzheimer Dis Assoc Disord*. 1998; 12(4):340–346. [PubMed: 9876963]
13. Schulz R, Mendelsohn AB, Haley WE, et al. End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *N Engl J Med*. 2003; 349(20):1936–1942. [PubMed: 14614169]
14. Leinonen E, Korpiamall L, Pulkkinen LM, et al. The comparison of burden between caregiving spouses of depressive and demented patients. *Int J Geriatr Psychiatry*. 2001; 16(4):387–393. [PubMed: 11333426]
15. Hooker K, Monahan DJ, Bowman SR, et al. Personality counts for a lot: predictors of mental and physical health of spouse caregivers in two disease groups. *J Gerontol B Psychol Sci Soc Sci*. 1998; 53(2):P73–85. [PubMed: 9520924]
16. Schulz R, Williamson GM. A 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychol Aging*. 1991; 6(4):569–578. [PubMed: 1777145]
17. Fredman L, Tennstedt S, Smyth KA, et al. Pragmatic and internal validity issues in sampling in caregiver studies: a comparison of population-based, registry-based, and ancillary studies. *J Aging Health*. 2004; 16(2):175–203. [PubMed: 15030662]
18. Cummings SR, Black DM, Nevitt MC, et al. Appendicular bone density and age predict hip fracture in women. The Study of Osteoporotic Fractures Research Group. *JAMA*. 1990; 263(5):665–668. [PubMed: 2404146]
19. Radloff L. The CES-D scale: a self-report depression scale for research in the general population. *Appl Psychol Meas*. 1977; 1(3):385–401.
20. Weissman MM, Sholomskas D, Pottenger M, et al. Assessing depressive symptoms in five psychiatric populations: a validation study. *Am J Epidemiol*. 1977; 106(3):203–214. [PubMed: 900119]
21. Katz S, Ford AB, Moskowitz RW, et al. Studies of Illness in the Aged. The Index of Adl: A Standardized Measure of Biological and Psychosocial Function. *JAMA*. 1963; 185:914–919. [PubMed: 14044222]
22. Multidimensional Functional Assessment. the OARS Methodology. NC Duke University Center for the Study of Aging and Human Development; Durham: 1978.

23. Pearlin LI, Mullan JT, Semple SJ, et al. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist*. 1990; 30(5):583–594. [PubMed: 2276631]
24. Huber, P. The behavior of maximum likelihood estimates under nonstandard conditions; Paper presented at: Proceedings of the Fifth Berkeley Symposium on Mathematical Statistics and Probability; Berkeley, CA. 1967.
25. White H. A heteroskedasticity-consistent covariance matrix estimator and a direct test for heteroskedasticity. *Econometrica*. 1980; 48:817–830.
26. Baron RM, Kenny DA. The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *J Pers Soc Psychol*. 1986; 51(6): 1173–1182. [PubMed: 3806354]
27. Schulz R, O'Brien AT, Bookwala J, et al. Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist*. 1995; 35(6):771–791. [PubMed: 8557205]
28. Pruchno RA, Resch NL. Aberrant behaviors and Alzheimer's disease: mental health effects on spouse caregivers. *J Gerontol*. 1989; 44(5):S177–182. [PubMed: 2768777]
29. Treloar A, Crugel M, Prasanna A, et al. Ethical dilemmas: should antipsychotics ever be prescribed for people with dementia? *Br J Psychiatry*. 2010; 197(2):88–90. [PubMed: 20679257]
30. Cohen-Mansfield J. Nonpharmacologic interventions for inappropriate behaviors in dementia: a review, summary, and critique. *Am J Geriatr Psychiatry*. 2001; 9(4):361–381. [PubMed: 11739063]
31. Gallant MP, Connell CM. Neuroticism and depressive symptoms among spouse caregivers: do health behaviors mediate this relationship? *Psychol Aging*. 2003; 18(3):587–592. [PubMed: 14518817]
32. Mausbach BT, Patterson TL, Grant I. Is depression in Alzheimer's caregivers really due to activity restriction? A preliminary mediational test of the Activity Restriction Model. *J Behav Ther Exp Psychiatry*. 2008; 39(4):459–466. [PubMed: 18294613]
33. Brodaty H, Green A, Koschera A. Meta-analysis of psychosocial interventions for caregivers of people with dementia. *J Am Geriatr Soc*. 2003; 51(5):657–664. [PubMed: 12752841]
34. Thompson CA, Spilsbury K, Hall J, et al. Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatr*. 2007; 7:18. [PubMed: 17662119]
35. Au A, Lai MK, Lau KM, et al. Social support and well-being in dementia family caregivers: the mediating role of self-efficacy. *Aging Ment Health*. 2009; 13(5):761–768. [PubMed: 19882415]
36. Romero-Moreno R, Losada A, Mausbach BT, et al. Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process. *Aging Ment Health*. 2011; 15(2):221–231. [PubMed: 20924819]

Caregiver and care recipient characteristics at 717 assessments from n=345 caregivers to persons with or without dementia, the Caregiver-SOF study

Table 1

Characteristic	Overall N=717 ¹	Care recipient with dementia N=206 ¹	Care recipient without dementia N=511 ¹	P value ²	Wald chi2 (df=1)
Caregiver characteristics					
Age in years, mean (SD)	82.0 (3.5)	82.4 (3.6)	81.9 (3.5)	0.19	1.73
White race, n (%)	648 (90.4)	192 (93.2)	456 (89.2)	0.27	1.21
College education, n (%)	283 (39.5)	72 (35.0)	21 (41.3)	0.28	1.17
Spouse of care recipient, n (%)	334 (46.6)	131 (63.6)	203 (39.7)	<0.001	18.39
Any ADL or IADL limitation, n (%)	343 (47.8)	107 (51.9)	236 (46.2)	0.25	1.33
2 medical comorbidities, ³ n (%)	326 (45.6)	115 (56.1)	211 (41.4)	0.01	7.54
Caregiver burden					
Others help with care, n (%)	364 (52.0)	115 (56.7)	249 (50.1)	0.20	1.62
Time away from caregiving, n(%)	549 (77.0)	155 (75.6)	394 (77.6)	0.63	0.23
Satisfied with family life, ⁴ n (%)	477 (66.5)	125 (60.7)	352 (68.9)	0.09	2.81
Captivity scale, ⁵ mean (SD)	1.69 (2.25)	2.41 (2.43)	1.39 (2.09)	<0.001	14.82
Care recipient characteristics					
Age in years, mean(SD)	82.5 (11.1)	85.8 (5.7)	81.2 (12.4)	<0.001	18.59
Problematic behaviors, ⁶ mean (SD)	18.4 (5.3)	22.3 (6.6)	16.9 (3.8)	<0.001	55.31
ADL needs, ⁷ mean (SD)	1.7 (1.8)	2.0 (1.9)	1.5 (1.7)	0.02	5.52
Near end of life, n (%)	180 (25.1)	64 (31.1)	116 (22.7)	0.01	6.65

¹ number of assessments

² logistic regression with outcome of care recipient dementia, robust standard errors used to adjust for multiple observations per person

³ hypertension, heart disease, diabetes, stroke or arthritis

⁴ very satisfied vs. somewhat satisfied, somewhat or very dissatisfied

⁵ sum of role captivity scale (range 0-9)

⁶ caregiver report of care recipient behaviors (range 0-42)

⁷ number of ADL task requiring assistance (range 0-7)

Table 2

Association between caregiving to a person with dementia and high depressive symptoms: mediation by caregiver role captivity and care recipient problematic behaviors

	Base model ¹	Adjusted for care recipient close to death	Adjusted for caregiver role captivity	Adjusted for care recipient problematic behaviors	Fully adjusted model ¹
Independent variables and mediators	AOR (95% CI) p value N=717 Wald chi2=20.3 df=7	AOR (95% CI) p value N=717 Wald chi2=22.2 df=8	AOR (95% CI) p value N=673 Wald chi2=70.8 df=9	AOR (95% CI) p value N=711 Wald chi2=50.5 df=10	AOR (95% CI) p value N=667 Wald chi2=96.5 df=17
Care recipient has dementia	2.12 (1.20-3.74) 0.01	2.05 (1.15-3.64) 0.01	1.35 (0.783-2.48) 0.34	1.15 (0.60-2.20) 0.68	0.75 (0.36-1.58) 0.45
Care recipient near end of life		1.52 (0.92-2.51) 0.01	1.64 (0.95-2.82) 0.08	1.41 (0.83-2.40) 0.21	1.60 (0.88-2.91) 0.12
Caregiver role captivity ²					
Lowest tertile			ref		ref
Middle tertile			6.73 (3.28-13.81) <0.001		5.01 (2.31-11.05) <0.001
Highest tertile			14.67 (6.67-32.27) <0.001		9.41 (3.95-22.40) <0.001
Care recipient problematic behaviors ³					
Lowest tertile				ref	ref
Middle tertile				3.13 (1.34-7.33) 0.01	2.52 (1.02-6.19) 0.04
Highest tertile				9.22 (3.67-23.15) <0.001	5.26 (2.00-13.84) 0.001
Caregiver characteristics:					
Satisfaction with family life ⁴					0.48 (0.27-0.83) 0.01
Functional limitation ⁵					3.16 (1.70-5.85) <0.001
Medical comorbidity ⁶					1.60 (0.86-2.99) 0.14

	Base model ¹	Adjusted for care recipient close to death ¹	Adjusted for caregiver role captivity ¹	Adjusted for care recipient problematic behaviors ¹	Fully adjusted model ¹
Spouse of care recipient					1.54 (0.79-3.02) 0.21
Caregiving characteristics:					
Caregiver has time away from caregiving					1.07 (0.59-1.94) 0.83
ADL tasks requiring assistance ⁷					1.01 (0.85-1.19) 0.95

¹ Logistic regression adjusted odds ratios, all models adjusted for site, transition interval and clustering at level of individual using robust standard errors. Analysis at the assessment level, the number of assessments differ due to missing data.

² Sum of role captivity scale (range 0-9)

³ caregiver report of recipient's behaviors (range 0-42)

⁴ very satisfied vs. somewhat satisfied, somewhat or very dissatisfied

⁵ at least one ADL or IADL limitation

⁶ presence of two or more chronic medical conditions (hypertension, heart disease, diabetes, stroke or arthritis)

⁷ range 0-7