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Characteristics of Depressed Caregivers of Veterans With Dementia

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Abstract

This study examined the characteristics of caregivers and persons with dementia (PWD) to determine their association with caregiver depression. Participants included 508 PWD (veterans) and 486 caregivers from Boston, Houston, Providence, Beaumont (Texas), and Oklahoma City, identified from diagnoses from medical records and recruited from February 2007 to July 2009, for a larger study evaluating Partners in Dementia Care, a care-coordination intervention. Characteristics evaluated for PWD included activities of daily living, instrumental activities of daily living, cognitive impairment, and disruptive behavior. Caregiver characteristics evaluated included caregiver unmet needs, support-service use, and number of informal helpers. Caregiver depression was measured using the Iowa form 11-item Center for Epidemiologic Studies Depression Scale. Depressed caregivers reported significantly more unmet needs than the nondepressed caregivers. Depressed caregivers also reported a high frequency of disruptive behavior in their PWD. Caregiver perceptions of unmet needs may be an important target for intervention.

Keywords

caregiver, depression, veterans, dementia, elders

Introduction

An increasing body of literature has explored the role of depression in the well-being of caregivers of persons with dementia (PWD). However, it has so far not clearly identified the complex relationship of causal and mediating factors, impeding the design of interventions to ameliorate its negative effects.

Characteristics of both the PWD and the caregiver have been examined. Regarding the effect of characteristics of the PWD, evidence is mixed about the role of cognitive function[1-5] and the PWD's function in the activities of daily living.[2,4,6-8] In contrast, substantial literature confirms that behavioral disturbances of PWD are associated with caregiver depression.[2,3,5,9-11] Some evidence suggests that younger age and lower levels of education of the PWD are associated with increased rates of caregiver depression.[2]

Several factors about the caregiver have been shown to affect depression, including a spousal relationship and gender (daughters reportedly being more depressed than sons),[2,4,6-8,12,13] caregiver physical health and functional states,[3,14,15] income and number of caregiver tasks,[2,7] and, again, gender (women caregivers reportedly being more frequently depressed than men, with some heterogeneity perhaps partly explained by spousal relationship).[3,6,12,13,16-18] Findings

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regarding caregiver age[2,4,6,8,19] and race/ethnicity[2,20-26] are mixed. Conceptual models such as the stress process model posit that the PWD's cognitive, behavioral, and functional symptoms of dementia and coexisting chronic conditions are primary stressors, which can be mediated by factors, such as coping mechanisms, informal support, and formal services.[27,28] Other models have included the use of formal service[29] and number of unmet needs as mediators in depressed individuals.[30] This study examined the characteristics of caregivers and PWD to determine their association with caregiver depression in a large cohort of veterans receiving their care through the Veterans' Administration (VA) health care system. This study adds to the literature because of its large sample and its attention to potentially modifiable contributors to caregiver depression: caregiver unmet needs, patient formal service utilization, and use of informal help by patients and caregivers.

Methods

This study was approved by the Houston VA Research and Development Committee and the Baylor College of Medicine institutional review board (IRB). Data for this study were gathered from structured baseline interviews with family caregivers participating in a larger study testing the efficacy of a 1-year, telephone-based, care-coordination intervention, Partners in Dementia Care (PDC). Partners in Dementia Care was designed to address the unmet care needs of veterans with dementia and their family caregivers across all dementia stages, and it was delivered through a partnership between VA medical centers and local Alzheimer's Association chapters.[11] Participants were mailed IRB-approved invitations and consent forms.

Participants

Participants were recruited over a 2½-year period (February 2007 to July 2009) from 5 different communities: Boston, Massachusetts; Houston, Texas; Providence, Rhode Island; Beaumont, Texas; and Oklahoma City, Oklahoma. Participants included PWD (either newly diagnosed or previously diagnosed and with a preexisting diagnosis of dementia recorded in the VA electronic medical records) and their primary caregivers. Eligibility criteria limited participation to PWD who received primary care from the VA, lived outside an institutional setting, and were 50+ years of age. Caregiver eligibility criteria included being an unpaid family member or friend and being the caregiver who provided more assistance than anyone else with the PWD's personal care, daily living tasks, and/or health-related decisions.

Measures

Caregiver depression was measured using the Center for Epidemiologic Studies Depression Scale (CES-D), and the PWD/caregiver characteristics were measured with instruments developed by the Margaret Blenkner Research Institute (David Bass, director) and have been used in prior studies.[31,32]

Caregiver depression. Depressive symptoms were measured using the IOWA form 11-item CES-D.[33] Item scores are 0 (*hardly ever or never*), 1 (*some of the time*), and 2 (*much or most of the time*). The CES-D 20, originally developed for the National Institute of Mental Health studies, has high levels of reliability and validity for detecting clinical depression and nonclinical symptoms of depression in a wide range of study populations, including older adults. A cutoff score of 16 has been demonstrated to be a reliable and valid indicator of the presence of *Diagnostic and Statistical Manual of Mental Disorders* (Third Edition) criteria for clinical depression.[34]

The shorter, 11-item IOWA form was shown to have good reliability (Cronbach $\alpha = .76$) in a cohort of 3673 persons 65 years and older.[33] In a study of depression in noninstitutionalized older adults, a formula was developed to convert the scores of the CES-D 11 to correspond with the scores of the original CES-D 20, for which there are well-validated cutoff scores. The formula used is the following: standard CES-D = (modified CES-D $\times$ 1.866) + 0.5318.[35] Caregivers, in this study who had an adjusted score of 16 or higher were considered to be depressed.[34,36]

Persons with dementia characteristics. Several variables were examined for PWD, such as, ADLs, instrumental activities of daily living (IADLs), cognitive impairment, and disruptive behavior; and these are discussed in more detail below. Activities of daily living were measured using 6 items asking how much difficulty, from no difficulty, to some difficulty, to a great deal of difficulty, the PWD has dressing/undressing, eating, toileting, grooming, getting in and out of chair/bed and bathing/washing. This measure, with a range of 0 (*no difficulty*) to 12 (*a great deal of difficulty*), shows good internal consistency as measured by Cronbach α ($\alpha = .86$).[37]

Instrumental activities of daily living were measured with 6 items asking how much difficulty, from no difficulty to some difficulty, to a great deal of difficulty, the PWD has dealing with checks, bills, and checkbooks; traveling out of the neighborhood, driving, or taking buses; preparing a balanced meal; heating water, turning off a stove and playing a game of skill, or working on a hobby. This measure, with a range of 0 (*no difficulty*) to 12 (*a great deal of difficulty*), shows good internal consistency (Cronbach $\alpha = .87$).[37]

Cognitive impairment of the PWD was measured using the sum of 7 items that ask caregivers about how much difficulty the PWD had with the following tasks: tracking current events; knowing the day of the week; repeating things; paying attention; and remembering addresses, people, and appointments. Each item is scored from 0 (*no difficulty*), 1 (*some difficulty*) to 2 (*a great deal of difficulty*) and has good internal consistency (Cronbach $\alpha = .82$).[38]

Disruptive behavior was measured using the sum of 4 items scored from 0 to 3 (*none of the time* to *most of the time*) that ask about the following behaviors of the PWD: complaining or criticizing, interfering with family members, yelling or swearing, and being agitated. This measure has good internal consistency (Cronbach $\alpha = .79$).[38]

Caregiver characteristics. To measure caregiver unmet needs, the caregivers answered with *yes* or *no* in response to questions asking whether they or the PWD needed more help or information with the following 8 issues: (1) understanding dementia and its symptoms, (2) care tasks, (3) VA and other services, (4) legal and financial issues, (5) organizing family care, (6) alternative living arrangements, (7) emotional support, and (8) medical follow-up. This measure has good structural validity, with factor loadings on a single factor ranging from .63 to .84 and excellent internal consistency (Cronbach $\alpha = .92$).

Caregiver support-service use was measured using 2 items asking, *yes* (1) or *no* (0), whether caregivers received respite from caregiving or emotional support from family members or friends in the preceding 6 months.

The number of informal helpers who assisted the caregivers was measured by a single item asking caregivers how many family and friends helped them during the past 6 months because of the PWD's health problem/problems.

Statistical Analyses

Descriptive analyses were used to describe the differences between depressed and nondepressed caregivers regarding demographic characteristics and the above-mentioned variables. Chi-square tests were used for categorical measures (caregiver and patient gender, caregiver relationship to the patient, and patient income), and *t* tests were used for continuous measures (age, caregiver unmet needs, caregiver support-service use, number of informal helpers for caregiver, patient age, unmet needs, ADLs, IADLs, problem behavior, and cognitive impairment).

A logistic regression was used to estimate the association between characteristics and depression as a binary outcome (depressed vs not depressed, per the CES-D 11). We chose to look at depression as a dichotomous variable because the presence of clinical depression has more clinical value than looking at depression as a continuous variable. All variables with a *P* value less than .05 in the univariate analyses were included as covariates in the model (gender was included, as it was close to .05; but spouse was also included for equipoise).

Results

Of the 1726 PWD referred to the parent study, 508 PWD and 486 caregivers provided signed consent forms, representing a 29.4% participation rate. Data were gathered through structured telephone interviews with the 486 caregivers.

Demographics and Clinical Features of Participants

The study population comprised 486 caregivers of PWD, of whom 66 (13.6%) were depressed, as defined by a score of 16 or higher. The mean age was 68.4 ± 12.6; 94% were women, 81% white, 72% were married, and 198 (40.8%) had attended high school or less, with 287 (59.2%) having some college or vocational school. Of the 508 patients included, the mean age was 79.4 ± 8.2 years. Most (97.5%) were men, 83% were white, 47.2% had an income of less than $30 000 a year, and 254 (53.3%) had attended high school or less, with 223 (46.7%) having some college or vocational school.

Caregivers were divided into 2 groups, based on the adjusted CES-D score: those with an adjusted score $\geq$16 were considered depressed and the rest were considered nondepressed.

Characteristics of the PWD

Some variables examined regarding the PWD were significantly different between groups, but others did not appear to be associated with depression. For example, age, gender, and income were not significantly different between the depressed and nondepressed caregiver groups (see Table 1). The ADL scores of the PWD were higher (meaning more ADL difficulties) in PWD with depressed vs nondepressed caregivers (4.4 ± 3.9 vs 3.0 ± 3.3, $P \leq .0021$). The IADL scores, reflecting PWD difficulties with IADLs, were also significantly higher in PWD with depressed caregivers (10.5 ± 2.3) than in PWD with nondepressed caregivers (9.2 ± 3.4, $P \leq .0045$). Severity of cognitive impairment was greater in PWD with depressed caregivers than in those with nondepressed caregivers (8.22 ± 3.4 vs 6.90 ± 3.7; $P \leq .0074$). Rates of disruptive behaviors were also higher in PWD with depressed caregivers (3.91 ± 2.9 vs 2.69 ± 2.81; $P \leq .0021$).

Caregiver Characteristics

Depressed caregivers reported a significantly higher number of unmet needs than the nondepressed caregivers (21.0 ± 11.7 vs 16.4 ± 11.7, $P \leq .0035$). There were no significant differences in age, gender, relationship to the PWD, caregiver support-service use, or number of informal helpers between depressed and nondepressed caregivers (see Table 2).

Regression Analysis

Table 2 shows the results of the logistic-regression analyses. After including in the model, all the variables significantly associated with caregiver depression, as well as the caregiver relationship to the PWD, only 2 variables accounted for significant variance in caregiver depression. The strongest association of increased depression was with caregiver unmet needs (odds ratio [OR]: 1.030, confidence interval [CI]: 1.001-1.05, $P = .0130$). Higher frequency of disruptive behavior was also associated with increased depression in caregivers (OR: 1.10, CI: 1.01-1.20, $P \leq .0311$; see Table 2).

Discussion

In our sample of caregivers of PWD, 13.6% of caregivers were found to be depressed. Caregivers' age, gender, number of informal helpers, and relationship to the PWD were not associated with

Table 1. Demographic and Clinical Features of Participants.

	Depressed, n = 66	Not depressed, n = 420	Total, n = 486	*P* value, *t* or χ^2
Caregiver				
Age	67.6 ± 11.5	68.5 ± 12.8	68.4 ± 12.6	.5932
Gender				
Female	60 (90.9)	397 (94.5)	457 (94.0)	.2491
Male	6 (9.1)	23 (5.5)	29 (6.0)	
Race				
White	53 (80.3)	339 (81.1)	392 (81.0)	.8780
Non-White	13 (19.7)	79 (18.9)	92 (19.0)	
Spouse				
Yes	44 (66.7)	307 (73.1)	351 (72.2)	.2784
No	22 (33.3)	113 (26.9)	135 (27.8)	
Unmet need	21.02 ± 11.7	16.41 ± 11.7	17.03 ± 11.8	.0035
Caregiver support service use	0.4 ± 0.7	0.5 ± 0.7	0.4 ± 0.7	.5382
Number of informal helpers for caregivers	1.1 ± 0.8	1.1 ± 0.8	1.1 ± 0.8	.7955
Care recipient				
Age	78.9 ± 8.0	80.0 ± 8.2	79.4 ± 8.2	.5362
Race				
White	52 (78.8)	349 (83.1)	491 (78.8)	.3918
Nonwhite	14 (21.2)	71 (16.9)	85 (17.5)	
Gender				
Male	62 (93.9)	412 (98.1)	474 (97.5)	.0431
Female	4 (6.1)	8 (1.9)	12 (2.5)	
Income				
≤30 000	37 (17.1)	179 (82.9)	216 (47.2)	.0905
>30 000	28 (11.6)	214 (88.4)	242 (52.8)	
PWD				
ADLs	4.39 ± 3.9	2.99 ± 3.3	3.2 ± 3.4	.0021
IADLs	10.45 ± 2.3	9.16 ± 3.4	9.3 ± 3.3	.0045
Cognitive impairment	8.22 ± 3.4	6.90 ± 3.7	7.08 ± 3.7	.0074
Problem behavior	3.91 ± 2.9	2.69 ± 2.81	2.85 ± 2.9	.0021

Abbreviations: ADLs, activities of daily living; IADLs, instrumental activities of daily living; PWD, persons with dementia.

depression in this study. Characteristics, income, age, and gender of the PWD also were not associated with depression. However, the number of unmet needs of the caregiver (most significant variable) and amount of problem behavior of the PWD were significantly associated with caregiver depression.

The rate of depression of caregivers in our sample is lower than that found in most nationally representative caregiver samples, in which depression rates range between 30% and 80%.[6] However, rates vary wildly, depending on depression-measurement approaches, sample inclusion criteria, study populations, recruitment methods, and selection bias[6]; and our study relied only on an assessment with the CES-D, without a formal physician diagnosis. Studies with strict diagnostic criteria have reported lower rates, ranging from 15% to 32%,[39] which are more consistent with our findings. We suspect that our assessment tool, the CES-D 11, may be a more stringent approach to defining a depression group than those used in some other studies.[40] The CES-D 11 cutoff we used was validated to identify clinically significant depression[33,34]; but assessments such as the Geriatric Depression Scale, designed specifically for older adults, have higher sensitivity in this population.[40]

Regarding caregiver variables, female gender and relationship to patient are considered increased risks for depression.[12,16,38] Given that our sample consisted of male veterans for which most of the caregivers were women, there was too little variability in gender to allow prediction of depression. It was more surprising that relationship to care recipient was not associated with depression; but, given the preponderance of spouse caregivers, variance was low.

Unmet dementia-related needs remained associated with caregiver depression in the regression analysis. This is consistent with the findings of other studies that describe a variety of negative health and psychosocial caregiver outcomes associated with dementia-related unmet needs.[41,42] Identifying specific needs of caregivers is likely to be important for interventions aimed at improving mental health status.[43]

Caregivers play an integral role in the care of PWD, assuming up to 40% of care-related tasks; thus, failing to meet caregiver dementia-related needs jeopardizes the home care situation.[38] However, in most cases they are not included in the medical encounter as active participants.[44] Caregiver needs include education about the disease, treatment administration, and side-effects; and education to help them identify behavioral

Table 2. Results of the Logistic-Regression Analyses.

Effect	Point estimate	95% Wald confidence limits	*P* value
Spouse no versus yes	1.31	0.73-2.35	.3674
Total IADLs	1.10	0.96-1.26	.1790
Total unmet needs	1.03	1.001-1.05	.0130
ADLs	1.06	0.97-1.16	.1728
Cognitive impairment	1.00	0.91-1.11	.9342
Patient gender	2.55	0.681-9.55	.1647
Total behavior problems	1.10	1.01-1.20	.0311

Abbreviations: IADLs, instrumental activities of daily living; ADLs, activities of daily living.

symptoms and their pharmacological and nonpharmacological treatments, as well as assess their own well-being, and care-related strains, in addition to referral to appropriate services.[11,45]

Musil et al reported that increased level of perceived support provided to caregivers by the clinical provider of the PWD was not associated with decreased risk of caregiver depression. Perhaps this lack of relationship can be explained by provider efforts not being targeted to meeting caregivers' needs.[46] It has also been suggested that a single person's contribution might not be sufficient and that the involvement of an interdisciplinary team as offered in a care-coordination setting is needed to decrease service fragmentation and increase communication between all components of dementia care to better meet the needs of caregivers.[44,46]

We also were surprised that variables related to formal and informal help did not appear to predict depression. There is evidence that social support is associated with lower depressive symptomatology[3]; but caregiver outcomes correlate more strongly with satisfaction with support, rather than the amount of support provided.[47] Furthermore, in our study, only 2 domains of service use were assessed for caregivers. Cox and colleagues reported that caregiver psychological health was a perquisite for caregiver service use, suggesting that interventions that strengthen caregiver well-being should be offered early in the caregiving process.[25]

Severity of cognitive impairment and personal care dependency (measured by ADLs and IADLs) was associated with caregiver depression in the univariate analyses; but the association was not maintained in the regression analysis, suggesting it was better explained by other variables. This finding is consistent with those of other studies reporting that cognitive impairment is not associated with increased depression rates in caregivers.[3,38] The association between personal care dependency and depression in caregivers is more controversial; most studies have identified it as an independent factor.[4,8] It may be that unmet needs were correlated with personal care dependency. That is, when personal care dependency is identified as an unmet need by caregivers, it is more likely to be related to caregiver depression.

Disruptive behaviors are strongly associated with depression in caregivers. This study is consistent with previous studies showing that the frequency of disruptive behavior is the single most reliable risk factor in the development of caregiver depression[48]; the uncontrollable and unpredictable nature of disruptive behaviors might cause extra stress,[49] and caregivers might interpret them as showing lack of appreciation, even after they have been conceptualized as a symptom of the disease.[38] Caregivers of patients with disruptive behavior are less likely to receive adequate levels of social support[50] and tend to become isolated to hide their embarrassment about the situation.[38] It becomes necessary to help caregivers identify the triggers and to educate them about pharmacological and nonpharmacological management of these symptoms, while trying to connect them with more opportunities for support.[3]

Another factor could be caregiver self-efficacy. Rabinowitz et al[51] failed to find a direct association between self-efficacy in managing disruptive behaviors and caregiver depression, suggesting that perhaps caregiver confidence in certain aspects of self-efficacy (ability to control upsetting thoughts and ability to obtain respite from caregiving stressors) might affect depressive symptoms more than caregiver confidence in managing the PWD's disruptive behaviors. It has also been suggested that the plethora of mixed results in studies of caregiver depression of PWD suggests that primary caregiving stressors are perhaps not directly related to caregiver symptoms but instead are more strongly related to factors such as the caregiver's perception of his or her caregiving situation.[52]

On the other hand, although they have higher unmet needs, caregivers of PWD use fewer offered services than caregivers of persons without dementia. This leads researchers to think that many obstacles remain in terms of assessing and addressing unmet needs.[48] One key element might be to move the assessment of unmet needs from a "normative," objective approach led by the professional to a greater emphasis on "felt" needs, as stated by caregivers, in an attempt to capture all the complex components of unmet needs, which could lead to offering more flexible and individualized care.

Our study population consists mainly of women who are caregivers of men and, thus, our results may not be generalizable to male caregivers. Second, the cross-sectional design of the study does not allow conclusions to be drawn about causal relationships; knowing the major risk factors remains, however, crucial for a better identification of caregivers who are at increased risk of depression. Our choice to look at depression as a dichotomous variable may have decreased our power to find some difference found in prior studies, but we believe that this dichotomization adds clinical value and meaning. Finally, a selection bias cannot be excluded, as the caregivers we recruited might be experiencing less stress than caregivers in the general community, being already connected with a primary care physician at the VA and knowing that the patient will be able to receive care, regardless of economic considerations.

In conclusion, we identified several caregiver- and patient-related predictors of caregiver depression. Of these predictors, caregivers' perceptions of unmet needs may be the most mutable and may, thus, be an important target for intervention. Unmet needs appear to be an important mediator of other factors in the literature that predict depression, such as personal care dependency. Meeting caregiver needs may be the most powerful approach toward positively impacting both caregivers' and PWD's well-being, decreasing caregiver burnout and increasing the PWD's chances to be cared for in the community.[43,45] A care-coordination intervention such as PDC appears to be a potential solution; it decreases service fragmentation by coordinating care through formal VA-Alzheimer Association partnerships; it also provides assessment and treatment of a wide range of medical and nonmedical care needs for patients and caregivers and includes the family caregiver as an active participant in the treatment of dementia.[38]

Author's Note

This study was conducted at the Michael E. DeBakey Veterans Affairs Medical Center in Houston, Texas. The views expressed are those of the authors and do not necessarily reflect those of the Department of Veterans Affairs, US government, or Baylor College of Medicine.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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