

Association Between Caregiver Depression and Emergency Department Use Among Patients With Dementia

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IMPORTANCE Current attempts to gauge the acute care needs of patients with dementia have not effectively addressed the role of caregivers, despite their extensive involvement in decisions about acute care management.

OBJECTIVE To determine whether caregiver depression is associated with increased use of the emergency department (ED) among patients with dementia.

DESIGN, SETTING, AND PARTICIPANTS This longitudinal cohort study used data from the Care Ecosystem study, a randomized clinical trial examining telephone-based supportive care for patients with dementia and their caregivers. Patients were 45 years or older with any type of dementia. A total of 780 caregiver-patient dyads were enrolled from March 20, 2015, until February 28, 2017, and 663 dyads contributed baseline and 6-month data and were included in the analysis.


EXPOSURES Caregiver depression (9-item Patient Health Questionnaire score of ≥ 10). Secondary analyses examined caregiver burden and self-efficacy.

MAIN OUTCOMES AND MEASURES The primary outcome was the number of ED visits in a 6-month period.

RESULTS Among the 663 caregivers (467 women and 196 men; mean [SD] age, 64.9 [11.8] years), 84 caregivers (12.7%) had depression at baseline. The mean incidence rate of ED visits was 0.9 per person-year. Rates of ED presentation were higher among dyads whose caregiver did vs did not have depression (1.5 vs 0.8 ED visits per person-year). In a Poisson regression model adjusting for patient age, sex, severity of dementia, number of comorbidities, and baseline ED use, as well as caregiver age and sex, caregiver depression continued to be associated with ED use, with a 73% increase in rates of ED use among dyads with caregivers with depression (adjusted incident rate ratio, 1.73; 95% CI, 1.30-2.30). Caregiver burden was associated with higher ED use in the unadjusted model, but this association did not reach statistical significance after adjustment (incident rate ratio, 1.19; 95% CI, 0.93-1.52). Caregiver self-efficacy was inversely proportional to the number of ED visits in the unadjusted and adjusted models (adjusted incident rate ratio, 0.96; 95% CI, 0.92-0.99).

CONCLUSIONS AND RELEVANCE Among patients with dementia, caregiver depression appears to be significantly associated with increased ED use, revealing a key caregiver vulnerability, which, if addressed with patient- and caregiver-centered dementia care, could improve health outcomes and lower costs for this high-risk population.

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Current attempts to gauge the acute care needs of patients with dementia have focused on health-related concerns and the financial burden of emergency department (ED) and hospital use.¹⁻¹⁰ Caregivers of patients with dementia have received considerably less attention despite their crucial role in health maintenance and resource use in this patient population.¹¹⁻¹³

When caregivers lack the outpatient support or emotional reserve to face the progressively challenging needs of the patient with dementia, the ED may present a practical source of health care.¹¹ The ED visit and any subsequent hospitalization may, in turn, result in increasing caregiver demands and depression through escalating financial strain and functional dependence.^{12,14} However, the prevalence of caregiver depression and how it is associated with ED use is poorly studied. Given the large cost of medical care among patients with dementia and the possibility that caregiver depression represents a modifiable problem, this association could have large, unexplored implications.^{3,12,14} We used data from a randomized clinical trial to study the association between caregiver depression and ED use to identify a potential caregiver vulnerability that could be targeted to improve dementia care and health outcomes while lowering costs.¹⁵⁻¹⁷

Methods

Study Design

We performed a cohort study using data from the Care Ecosystem trial, which examined a supportive care intervention for patients with dementia and their caregivers. A total of 2585 patient-caregiver dyads were screened for participation from March 20, 2015, until February 28, 2017, and 780 were enrolled and completed the baseline survey. Of these, 663 dyads provided complete information from the baseline and 6-month surveys and were included in this study. Dyads were assigned to surveillance or a specialized care team that provided telephone-based support. They completed a telephone survey at baseline and 6 months or until time of death. We used data to examine the association between baseline caregiver depression and subsequent ED use. This study was approved by the institutional review boards of the University of California, San Francisco and the University of Nebraska Medical Center. Dyads provided written informed consent prior to participating in the Care Ecosystem trial. For patients who did not have the capacity for informed consent, a legally authorized representation provided written informed consent.

Study Participants

Participants were patients with dementia and their caregivers. Patients were 45 years or older, had received a diagnosis of dementia from any medical professional, had a caregiver, had active or pending enrollment in Medicare or Medicaid, were not living in a nursing facility, and were residents of California, Nebraska, or Iowa. Additional details about the trial design have been reported previously.¹⁸

Key Points

Question Is caregiver depression associated with emergency department use among patients with dementia?

Findings This cohort study of patients with dementia and their caregivers included 663 caregiver-patient dyads. A total of 84 caregivers had depression at baseline and the presence of caregiver depression was associated with a 73% increase in the rates of emergency department use among patients with dementia.

Meaning Caregiver depression appears to be an important risk factor associated with increased health care use among community-dwelling individuals with dementia.

Study Outcomes

The primary outcome was the number of ED visits per patient in the subsequent 6 months, as reported by the primary caregiver in the trial's 6-month outcome survey. We defined an ED visit as any ED evaluation regardless of the institution or disposition (inpatient admission or discharge from the ED).

Patient and Caregiver Covariates

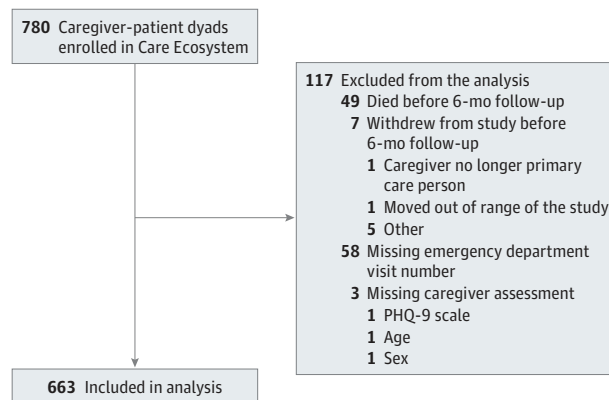
Patient and caregiver age, sex, race, Hispanic ethnicity, and highest educational level were collected at baseline, along with patient comorbidities and severity of dementia. The 15 patient comorbidities were asthma or chronic obstructive pulmonary disease, arthritis, hematologic or solid malignant neoplasm, type 1 or 2 diabetes, gastrointestinal tract illness, cardiac disease, HIV or AIDS, renal disease, hepatic disease, stroke, depression, hospitalization for pneumonia, dyslipidemia, hypertension, and peripheral vascular disease. We included the number of comorbidities as a single numeric variable in the adjusted model.¹⁹ Patient dementia severity was measured using the Quick Dementia Rating System (QDRS).²⁰ We used 6-month QDRS scores for 10 of 11 dementia patients who had missing baseline QDRS scores but had 6-month QDRS scores available.

Caregiver depression was our primary exposure and was measured using the 9-item Patient Health Questionnaire.²¹ Caregiver burden was measured using the 12-item version of the Zarit Burden Interview.²²⁻²⁴ Caregiver self-efficacy was assessed using a 4-item questionnaire using the following statements: (1) I know where to get the services I need, (2) I have people I can turn to when I need help with my problems, (3) I feel confident that I can manage future caregiving challenges, and (4) I feel confident that I can manage (the patient's) changes in behavior. Caregivers answered whether they strongly agree, agree, feel neutral, disagree, or strongly disagree on a 5-point scale (higher scores indicate higher self-efficacy).^{25,26}

Statistical Analysis

We used Pearson χ^2 tests and *t* tests to compare demographic data and baseline clinical characteristics between the dyads whose caregivers did and did not have depression. Our primary analysis compared rates of ED visits among patients with dementia whose caregivers were and were not depressed. We

Figure. Data Available on Caregiver Depression and Emergency Department Use as Recorded by the Primary Caregiver



PHQ-9 indicates 9-item Patient Health Questionnaire.

included depression as a binary variable, defined as a 9-item Patient Health Questionnaire score of 10 or higher to simplify the interpretation of the results, and performed a sensitivity analysis with depression as a continuous variable.²¹ Rates were defined as the number of ED visits during the first 6 months of the trial and reported as ED visits per person-year among dyads with or without a caregiver with depression. We then used unadjusted and adjusted Poisson regression models to examine the association between caregiver depression and the number of ED visits during a 6-month period, incorporating potential confounders (patient and caregiver age, patient and caregiver sex, patient dementia severity, number of comorbidities, and number of ED visits in the year before trial enrollment to account for baseline hospital use).

For our secondary analyses, we examined whether caregiver burden and caregiver self-efficacy were associated with our primary outcome. As with depression, we treated caregiver burden as a binary variable, defined according to previous literature as a 12-item Zarit Burden Interview score of 17 or higher, to increase interpretability.^{24,27} We also included a sensitivity analysis examining caregiver burden as a continuous variable. Caregiver self-efficacy was treated as continuous only because cut-points have not been validated for this measure. We then performed the multivariable model, including caregiver depression, caregiver burden, and caregiver self-efficacy as independent variables in the model together.

To test the corollary hypothesis that ED use worsens caregiver depression, we used logistic regression to model the association between the number of ED visits and presence of caregiver depression at 6 months (vs at baseline). We repeated this model for 6-month caregiver burden and performed Poisson regression to examine 6-month caregiver self-efficacy. All models included the same potential confounders as the primary analysis.

We performed a series of sensitivity analyses. To address the possibility that assignment to the supportive care intervention and geographic differences could affect ED use, we repeated the primary analysis incorporating treatment group and

study site as covariates. We also treated caregiver depression and burden as continuous variables to avoid misclassifying these exposures as binary variables. Finally, we performed a series of interaction analyses to determine whether the association between caregiver depression and ED use was affected by household income, having supplemental private insurance, having long-term care insurance, dementia severity, caregiver's highest educational level, the relationship between the dyad, whether the dyad lived together, use of a paid caregiver during the past year, use of an assisted living facility during the past year, and the relationship between the dyad defined as a multilevel categorical variable and defined as a binary variable (spouse vs not) in 2 separate analyses. All tests were 2-sided, and we considered $P < .05$ statistically significant. Statistical analyses were performed using Stata, version 15.1 (StataCorp).

Results

A total of 780 caregiver-patient dyads were enrolled in the Care Ecosystem trial. Forty-nine patients (6.3%) died and 7 dyads (0.9%) withdrew within the first 6 months. Fifty-eight dyads (7.4%) were missing information about ED use at 6 months and 3 dyads (0.4%) had missing baseline characteristics. The remaining 663 dyads were included in the analyses (Figure). Caregivers had a mean (SD) age of 64.9 (11.8) years, 467 (70.4%) were female, and 625 (94.3%) were either the patient's spouse, domestic partner, or first-degree relative (Table 1). Patients with dementia had a mean (SD) age of 77.3 (9.2) years and 367 (55.4%) were female.

Baseline Caregiver Depression, Burden, and Self-efficacy

Among the 663 dyads, 84 caregivers (12.7%) had depression at baseline and 368 caregivers (55.5%) had a high caregiver burden (Table 1). Caregiver depression was more common among younger caregivers (mean [SD] age, 62.0 [11.0] years vs 65.3 [11.8] years) and those caring for patients who were younger (mean [SD] age, 75.4 [10.1] years vs 77.6 [9.0] years) and had more severe dementia (median QDRS score, 13.5 [interquartile range, 9.0-18.0] vs 10.5 [interquartile range, 6.5-15.5]). Caregiver burden demonstrated positive covariance with depression, with higher rates of burden among caregivers who were depressed (80 of 84 [95.2%] vs 288 of 579 [49.7%]; $P < .001$). Similarly, caregivers with depression had lower median self-efficacy scores (11.0 [interquartile range, 9.0-14.0] vs 14.0 [interquartile range, 12.0-16.0]).

Association Between Caregiver Depression and ED Use

A total of 196 patients with dementia (29.6%) had at least 1 ED presentation in the first 6 months of the study. The mean incidence rate was 0.9 ED visits per person-year. Rates of ED presentation were higher among dyads whose caregiver did vs did not have depression (1.5 vs 0.8 ED visits per person-year), with an unadjusted incident rate ratio (IRR) of 1.86 (95% CI, 1.42-2.46) (Table 2). After adjustment for age, sex, baseline ED use, dementia severity, and number of comorbidities, caregiver depression continued to have a significant association with ED

Table 1. Baseline Characteristics of 663 Caregiver-Patient Dyads Enrolled in the Care Ecosystem Trial and Evaluated by Caregiver Depression

Variable	Participants, No. (%)		P Value
	No Caregiver Depression (n = 579)	Caregiver Depression (n = 84)	
Treatment site			
Nebraska	255 (44.0)	28 (33.3)	.06
California	324 (56.0)	56 (66.7)	
Caregiver age, mean (SD), y	65.3 (11.8)	62.0 (11.0)	.02
Patient age, mean (SD), y	77.6 (9.0)	75.4 (10.1)	.04
Female caregiver	402 (69.4)	65 (77.4)	.16
Female patient	323 (55.8)	44 (52.4)	.56
Caregiver race, No./total No. (%)			
Asian and Pacific Islander	36/543 (6.6)	6/79 (7.6)	.73
Black or African American	25/543 (4.6)	2/79 (2.5)	
White	482/543 (88.8)	71/79 (89.9)	
Caregiver Hispanic ethnicity	55 (9.5)	11 (13.1)	.31
Patient race, No./total No. (%)			
Asian and Pacific Islander	34/541 (6.3)	5/80 (6.3)	>.99
Black or African American	26/541 (4.8)	3 (3.8)	
White	481/541 (88.9)	72 (90.0)	
Patient Hispanic ethnicity	60 (10.4)	9 (10.7)	.93
Caregiver educational level			
<High school	18 (3.1)	3 (3.6)	.66
High school graduate	61 (10.5)	6 (7.1)	
College, no degree	135 (23.3)	17 (20.2)	
College degree and higher	365 (63.0)	58 (69.0)	
Patient educational level			
<High school	57 (9.8)	6 (7.1)	.77
High school graduate	122 (21.1)	21 (25.0)	
College, no degree	117 (20.2)	16 (19.0)	
College degree and higher	283 (48.9)	41 (48.8)	
Household income, No./total No. (%)			
<\$50 000	222/576 (38.5)	32 (38.1)	.35
\$50 000-\$99 999	150/576 (26.0)	27 (32.1)	
\$100 000-\$149 999	77/576 (13.4)	9 (10.7)	
≥\$150 000	69/576 (12.0)	5 (6.0)	
Unknown	58/576 (10.1)	11 (13.1)	
Caregiver living with patient	416 (71.8)	57 (67.9)	.44
Caregiver relationship			
Spouse	330 (57.0)	47 (56.0)	.97
Daughter	160 (27.6)	28 (33.3)	
Son	40 (6.9)	4 (4.8)	
Sibling	8 (1.4)	1 (1.2)	
Other ^a	41 (7.1)	4 (4.8)	
Caregiver PHQ-9 score, median (IQR)	3.0 (1.0-5.0)	13.0 (11.0-15.0)	<.001
High caregiver burden	288 (49.7)	80 (95.2)	<.001
Caregiver self-efficacy score, median (IQR)	14.0 (12.0-16.0)	11.0 (9.0-14.0)	<.001
Patient QDRS, median (IQR)	10.5 (6.5-15.5)	13.5 (9.0-18.0)	<.001

Abbreviations: IQR, interquartile range; PHQ-9, 9-item Patient Health Questionnaire; QDRS, Quick Dementia Rating System.

^a Other includes other family member, friend, domestic partner, or hired caregiver.

Table 2. Poisson Regression Analysis of Emergency Department Use as a Function of Caregiver Depression, Burden, and Self-efficacy at Baseline

Variable	Crude Prevalence at Baseline (N = 663)	Incident Rate Ratio (95% CI)	
		Unadjusted	Adjusted
Caregiver depression, No. (%)	84 (12.7)	1.86 (1.42-1.46) ^a	1.73 (1.30-2.30) ^a
Caregiver burden, No. (%)	368 (55.5)	1.34 (1.07-1.69) ^b	1.19 (0.93-1.52)
Caregiver self-efficacy, median (IQR)	14 (11-16)	0.96 (0.92-0.99) ^b	0.96 (0.92-0.99) ^b

Abbreviation: IQR, interquartile range.

^a P < .001.^b P < .05.**Table 3. Logistic and Poisson Regression Analysis of Caregiver Depression, Burden, and Self-efficacy as a Function of Emergency Department Use in Preceding 6 Months**

Variable	Crude Prevalence at 6 mo (N = 663)	Odds Ratio or Incident Rate Ratio (95% CI)	
		Unadjusted	Adjusted
Caregiver depression, No. (%)	60 (9.1)	1.27 (1.05-1.55) ^{a,b}	1.26 (1.01-1.57) ^{a,b}
Caregiver burden, No. (%)	324 (48.9)	1.18 (1.01-1.41) ^{a,b}	1.17 (0.98-1.40) ^b
Caregiver self-efficacy, median (IQR)	15 (13-16)	0.97 (0.93-1.01) ^c	0.97 (0.93-1.01) ^c

Abbreviation: IQR, interquartile range.

^a P < .05.^b Odds ratio.^c Incident rate ratio.

use, with a 73% increase in rates of ED use among dyads with caregivers with depression (IRR, 1.73; 95% CI, 1.30-2.30).

We then examined the converse association and found that the number of ED visits was also associated with subsequent (as opposed to preceding) caregiver depression. After adjustment, every additional ED visit was associated with 1.26 times the odds of caregiver depression at 6 months (odds ratio, 1.26; 95% CI, 1.01-1.57) and caregiver depression at 6 months was associated with a 55% increase in rates of prior ED use (IRR, 1.55; 95% CI, 1.12-2.13) (Table 3).

Association Between Other Caregiver Markers and ED Use

In our secondary analysis, there was a 34% increase in the rates of ED use among dyads with high caregiver burden (IRR, 1.34; 95% CI, 1.07-1.69), but the association was no longer statistically significant after adjustment (IRR, 1.19; 95% CI, 0.93-1.52). Caregiver self-efficacy was inversely proportional to ED use in both the unadjusted and adjusted model, with a 4% decreased rate of ED use for every additional point on the self-efficacy scale (adjusted IRR, 0.96; 95% CI, 0.92-0.99) (Table 2). Conversely, ED use was not associated with subsequent caregiver burden or self-efficacy, as the odds of caregiver burden and change in self-efficacy were not associated with the number of ED visits in the preceding 6 months (odds ratio for caregiver burden, 1.17; 95% CI, 0.98-1.40; and IRR for self-efficacy, 0.97; 95% CI, 0.93-1.01) (Table 3). When caregiver depression, caregiver burden, and caregiver self-efficacy were included together in a single model, caregiver depression continued to be significantly associated with 6-month numbers of ED visits (IRR, 1.63; 95% CI, 1.21-2.21), while the associations with caregiver burden and caregiver self-efficacy were not statistically significant.

Sensitivity Analyses

Including treatment group and study site as covariates in our main model recapitulated the results. The interaction analyses demonstrated that there was not a statistically significant interaction between caregiver depression and household income, dementia severity, caregiver's highest educational level,

the relationship between caregiver and patient, whether the dyad lived together, use of private insurance, use of an assisted living facility, and use of long-term care insurance. There was an interaction between caregiver depression and use of paid care (IRR, 0.51; 95% CI, 0.28-0.94), such that caregiver depression was not associated with ED use among dyads involving a paid caregiver during the past year. When we included Patient Health Questionnaire-9 score as a continuous variable, we found that a higher Patient Health Questionnaire-9 score was associated with increased ED use, with every additional point associated with a 4% increased rate of ED visits at 6 months (IRR, 1.05; 95% CI, 1.02-1.08). Caregiver burden, when treated as a continuous variable, was also associated with ED use in the unadjusted and adjusted models, but effect size was small (IRR 1.01; 95% CI, 1.00-1.03 for both).

Discussion

Among community-dwelling individuals with dementia, those with a depressed caregiver had significantly higher rates of ED presentation compared with those whose caregivers were not depressed. After adjustment, caregiver depression at baseline led to a 73% increased rate of ED presentation in the subsequent 6 months. On an absolute scale, caregiver depression was associated with an additional 0.7 ED visits per person-year. This analysis identifies caregiver depression as a risk factor associated with ED use among individuals with dementia, although the degree to which decreasing the incidence of caregiver depression will lead to decreased ED use remains unknown.

Earlier estimates of ED use among patients with dementia demonstrate that 30% to 80% of patients with dementia visit the ED at least once per year, similar to the rates that we found.^{4,10,19,28,29} Rates of caregiver depression in our study were also similar to those found in past studies.³⁰ To our knowledge, there has been only 1 past study assessing the association between caregiver depression and ED use. This study was important in exploring health care use as a function of care-

giver factors and found that caregiver depression was not associated with ED use; however, this analysis was performed on a smaller cohort, used a different instrument to identify depression, and did not report the number of caregivers with depression, making it difficult to determine whether the analysis was appropriately powered to evaluate this association.³¹ The size of the Care Ecosystem trial and use of a validated instrument to diagnose caregiver depression in more than 10% of our sample allowed us to explore the question with greater power and lower potential for misclassification. Our findings are also consistent with past studies demonstrating that poorer caregiver mental health is associated with increased ED use, hospitalization, cost, and mortality.^{32,33}

The high prevalence of caregiver burden in our study is comparable with prior estimates.^{14,27} When caregiver burden was dichotomized into high and low levels, it was not associated with ED use after adjustment. Dichotomizing caregiver burden (Zarit Burden Interview score ≥ 17) may have led to non-differential misclassification of the exposure and biased our results toward the null; in fact, higher scores on the continuous burden measure had a statistically significant association with greater ED use. Similarly, higher caregiver self-efficacy was associated with lower rates of ED use, but ED use did not affect subsequent self-efficacy ratings, which suggests that caregiver self-efficacy might help prevent ED use but is not associated with ED use.

Caregiver depression, however, was associated with subsequent ED use and ED use was also associated with subsequent depression, suggesting that patients with dementia and their caregivers can fall into a negative cycle of health care use and depression. In addition, we found that use of paid care affected the association between caregiver depression and subsequent ED use. Among those who used paid care during the study period, caregiver depression was no longer associated with subsequent ED use, suggesting that additional paid care may be protective in this scenario. To our knowledge, there have been no prior attempts to examine the association between these markers of caregiver well-being and health care use. This analysis extends the literature by building a more complete picture of caregiver health, while elucidating ways it can be associated with a patient's health care.

Acute care use among patients with dementia places a large financial burden on our health care system.³ This care may be avoidable and effective methods for preventing ED use could significantly reduce costs for this high-risk patient population.¹⁰ These findings complement past work quantifying health care costs associated with caring for individuals with dementia by identifying new targets for interventions designed to improve care and reduce ED use.

A better understanding of what drives caregiver depression could guide the design of effective interventions to reduce it. Past efforts have been met with varying degrees of success.³⁴

Psychosocial interventions have led to reductions in caregiver depression, caregiver burden, and rates of institutionalization, although the effect sizes are at times small and many studies have not examined the association with hospital and ED use.^{16,17,35-38} Thus, while promising, there is an ongoing need to refine and understand our approach to caregiver health and health care use among patients with dementia.

Limitations

There are limitations to this study. In examining patient-caregiver dyads enrolled in a randomized clinical trial, we expose ourselves to possible selection bias. Because dyads were invited to participate in the trial to contribute to research and were not told that there would be any benefit to them, dyads with higher depression and levels of burden likely declined enrollment because they lacked the capacity to complete surveys every 6 months. In this circumstance, selection would bias our results toward the null. Second, assignment to the intervention group could affect ED presentation; however, we repeated the model incorporating intervention group as a covariate, which did not change our results. We also restricted our analysis to data collected within the first 6 months of trial enrollment to limit confounding by treatment effects because the trial intervention was gradual and the association with health care use was not hypothesized to occur by 6 months. Third, there continue to be potential sources of residual confounding. For instance, socioeconomic status and behavioral characteristics of the caregiver or patient may affect both caregiver depression and ED use. Thus, these findings do not imply that improving caregiver depression will directly lead to fewer ED presentations. We also did not have a method of validating our primary outcome, caregiver-reported number of ED visits; however, prior studies have shown high accuracy for self-reported hospitalization information, the rates were comparable with those of previous studies examining ED use among patients with dementia, the number of visits was low, and collecting information biennially optimized reporting accuracy.³⁹ Finally, this study included patients in only 3 states (California, Nebraska, and Iowa), thus limiting its generalizability to different clinical environments.

Conclusions

Caregiver depression is associated with higher rates of ED use among patients with dementia. This finding identifies an important risk factor for health care use. By overlooking caregiver depression in our clinical encounters, we may be neglecting an important component of care and limiting our ability to maximize patient outcomes. The next challenge will be determining whether interventions that decrease caregiver depression can result in better health and lower costs for patients and caregivers alike.

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