Dementia Patient Suffering and Caregiver Depression

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Abstract

Cross-sectional and longitudinal analyses were carried out to assess the relationship between dementia patient suffering, caregiver depression, and antidepressant medication use in 1222 dementia patients and their caregivers. We assessed the prevalence of 2 types of patient suffering, emotional and existential distress, and examined their independent associations with caregiver depression and antidepressant medication use when controlling for sociodemographic characteristics of caregivers and patients, cognitive and physical disability of the patient, the frequency of patient memory problems and disruptive behaviors, and the amount of time spent caring for the patient. Multiple linear regression models showed that both aspects of perceived patient suffering independently contribute to caregiver depression (emotional distress: $\beta = 1.24$; $P < 0.001$; existential distress: $\beta = 0.66$; $P < 0.01$) whereas only existential suffering contributes to antidepressant medication use: odds ratio = 1.25 95% confidence interval, 1.10–1.42; $P < 0.01$. In longitudinal analyses, increases in both types of suffering were associated with increases in caregiver depression (emotional distress: $\beta = 1.02$; $P < 0.01$; existential distress: $\beta = 0.64$; $P < 0.01$). This is the first study to show in a large sample that perceived patient suffering independently contributes to family caregiver depression and medication use. Medical treatment of patients that maintain or improve memory but do not address suffering may have little impact on the caregiver. Alzheimer disease patient suffering should be systematically assessed and treated by clinicians.

Keywords

suffering; dementia; caregiving; depression; anti-depressant use

Illness and disability in a close relative is a major source of distress for family caregivers, frequently compromising their health and well-being.[1-3] Emotional distress, burden, impaired self-care, and increased biologic vulner-abilities are commonplace among caregivers.[3] The negative effects of caregiving are typically attributed to a variety of patient illness-related

factors, including functional disability, cognitive impairment and confusion, problem behaviors, and the care demands engendered by the illness. Clinicians would also emphasize that patient distress or suffering plays a role in this process as well, but little attention has been paid to this construct in studies on family caregiving. The notion of suffering may be implicit in existing conceptualizations of illness and disability, but empirical research has not focused on patient suffering as a unique and independent contributor to caregiver outcomes. The purpose of this article is to provide evidence-based support for the importance of suffering in understanding the effects of patient illness and disability on caregiver outcomes.

Suffering is a broad construct defined as a state of distress associated with events that threaten the intactness of the person as a complex physical, social, psychologic, and spiritual being.[4-6] Some authors believe that attempting to measure suffering is inappropriately reductionistic because the experience of suffering is unique to the individual and is inherently inaccessible to scientific inquiry because it cannot be adequately expressed in spoken language.[7] Although we agree that the experience and meanings of suffering can be very personal, we also believe that suffering can be measured, and that this measurement is the key for determining the causes and consequences of suffering and for designing effective interventions to relieve suffering. Several recent studies of seriously ill patients suggest that there are measurable universal manifestations of suffering, including (1) physical symptoms such as chronic or acute pain, nausea, and dyspnea; (2) psychologic symptoms of distress, such as depression and anxiety; and (3) indicators of existential/spiritual well-being, which includes measures of inner harmony, meaning and purpose of life, and the extent to which individuals find comfort and strength in religious beliefs.[8-15]

Suffering is distinct from illness and disability because not all illnesses entail suffering, and individuals vary widely in the extent to which they experience and express their suffering in response to a given health problem. Some patients respond to illness or disability with equanimity and optimism whereas others may respond with fear and hopelessness. Our goal in this paper is to show how the perceived suffering of the patient affects the caregiver. We predict that controlling other illness-related factors (eg, patient physical and cognitive disability, the amount of care provided, the vigilance demands of caregiving), patients who exhibit high levels of existential and emotional distress about their condition will elicit greater depression in the caregiver. Although partial support for this prediction is provided by studies showing associations between dementia patient depression and caregiver depression and distress,[16-18] this prediction has not been systematically tested in the caregiving literature. Partial support for our hypothesis is also provided by several recently published treatment studies aimed at improving psychologic symptoms of Alzheimer disease (AD) patients such as depression. They show that reducing patient distress (an indicator of suffering) had the added benefit of reducing caregiver burden, even though the functional status of patients had not improved.[16,18]

In this study, we test this hypothesis in a large multisite sample of dementia patients and their family caregivers. We assess the extent to which perceived patient symptoms of distress regarding their condition and indicators of existential well-being affects caregiver depression and antidepressant medication use above and beyond the effects of patient physical and cognitive disability, memory problems and disruptive behaviors exhibited by the patient, the amount of care provided by the caregiver, and sociodemographic characteristics of caregivers and patients. This hypothesis is tested both cross-sectionally and longitudinally using multiple outcomes reflecting caregiver depression.

METHODS

Study Sample

This study includes caregivers and patients enrolled in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) study, a multisite trial that tested the feasibility of providing numerous psychosocial interventions and their impact on the health and well-being of family caregivers living with and caring for persons with dementia. REACH is described in detail elsewhere.[19,20] Briefly, data for 1222 caregiver and care recipient dyads were collected from 1996 to 2000 at 6 sites in the United States: Boston, MA; Birmingham, AL; Memphis, TN; Miami, FL; Philadelphia, PA; and Palo Alto, CA. To assess the caregiving experience in different racial/ethnic groups, the study population included self-identified black or African American, Hispanic (Cuban American, Mexican American), and white family caregivers of patients with diagnosed AD or related dementia who were moderately to severely impaired. The research protocol was approved by the institutional review boards of all participating sites and the coordinating center, and written informed consent (or assent from patients) was obtained from all caregivers and patients enrolled in the study. After a baseline assessment that included standardized survey instruments and several open-ended questions, study participants were randomly assigned to either a treatment group or control group. Caregivers assigned to a treatment condition received a social/behavioral intervention whereas those in the control group received either usual care or minimal support (eg, periodic telephone calls to see how they were doing). At all 6 sites, the majority of treatment was delivered within 6 months of randomization. A follow-up assessment was administered at 6 months postintervention by trained and certified assessors who were masked with respect to treatment condition. This paper is based on data collected at baseline and the 6-month follow-up. To control for possible treatment effects, we control group assignment in all analyses using the 6-month data.

Procedures

Demographic data collected for both caregiver and care recipient at baseline included age, race/ethnicity, sex, education, income, and relationship between caregiver and care recipient (spouse or not). Patient (care recipient) cognitive function was assessed using the Mini-Mental State Examination (MMSE),[21] with scores ranging from 0 to 30, a higher score indicating higher cognitive functioning. Functional impairment was measured using the standardized assessment instruments for activities of daily living (ADL) (bathing, dressing, eating, getting out of a bed or chair, grooming, and using the toilet)[22] and instrumental activities of daily living (IADL) (using the telephone, shopping, preparing meals, housekeeping, doing laundry, traveling by car or bus, administering medications, and handling finances).[23] These instruments were completed by the caregiver.

Suffering was assessed using the depression subscale (9 items) of the Revised Memory and Behavior Problems Checklist (RMBPC).[24] Caregivers were asked, "within the past week has the patient...appeared sad or depressed, expressed feelings of hopelessness or sadness about the future, made comments about feeling worthless or being a failure, etc." Exploratory factor analysis using principal component analysis with Varimax rotation showed that these 9 items fall into 2 distinct categories reflecting 2 of the 3 dimensions of suffering. Three items assessed emotional distress (anxious, sad, and crying), and 6 items assessed existential distress (worthless, failure, hopelessness, lonely, talking of death, and threatened self) (see Table 1 for complete list of items in each subscale). Two summary scores were created by summing responses to these items.

We also administered the RMBPC subscales for memory problems (7 items) and disruptive behaviors (8 items). The memory problem subscale assesses the extent to which the patient has trouble remembering recent events, loses or misplaces things, asks the same question over

and over, etc. The disruptive behavior subscale assesses the extent to which the patient has been destroying property, waking up family members at night, engaging in behavior that is potentially dangerous to himself/herself or others, etc. Caregivers responded yes or no to each item, and items within each subscale were summed to create a total score. Caregiver depressive symptoms were assessed using the 20-item Center for Epidemiological Studies-Depression (CES-D) scale[25] (range: 0 to 60, with higher values indicating more depressive symptoms). To assess antidepressant medication use, caregivers were asked to collect all prescription medications they took and show them to the interviewer who recorded them for later classification. Time spent caring for the patient was assessed in number of hours per day that caregivers reported spending doing things for the patient.

Statistical Analyses

Caregiver depression (CES-D) and antidepressant medication use were the outcome variables. Using baseline data from the entire sample, multiple linear regression models were fit in which caregiver depression was regressed onto patient suffering as measured by the emotional distress and existential distress subscales, while controlling for sociodemographic characteristics, patient physical and cognitive disability, memory problems, disruptive behaviors, and time spent caregiving. Because antidepressant medication use might affect reported depressive symptoms on the CES-D, that regression model was replicated using only caregivers who were not taking antidepressant medication.

A separate multiple logistic regression model was used to test whether patient suffering was associated with being at risk for clinical depression (CES-D $\geq$ 16) while controlling for sociodemographic characteristics, patient physical and cognitive disability, memory problems, disruptive behaviors, and time spent caregiving.

A third multiple linear regression model with change in caregiver depression as the dependent variable was used to examine if change in the 2 aspects of patient suffering was independently associated with change in caregiver depression, while controlling for changes in memory problems, disruptive behaviors, ADL, time spent caregiving, and assignment to either active treatment or control condition.

Finally, odds ratios (ORs) and 95% confidence intervals (CIs) were generated from a multiple logistic regression model to see if suffering was associated with antidepressant medication use.

RESULTS

Caregivers were, on average, 62 years of age, predominantly females (81%), and about half of them were spouses (48.2%) of the patients (Table 1). Patients were on average 79 years of age and approximately 60% were females. Patients had medium-to-high levels of cognitive impairment (an average of 13 on the MMSE) and averaged being impaired on 3 of the 6 basic ADL and all of the 8 Independent ADL. Caregivers reported moderately high levels of depressive symptoms with means of 15.4 (out of a possible 60). A score of 16 or higher indicates being at risk for clinical depression. A high percentage of caregivers reported that the patient exhibited anxiety (63.4%), sadness, and depression (63.4%); whereas, a moderate percentage of caregivers reported that the patient exhibited hopelessness (35.2%), feelings of worthlessness or being a burden (29.7%), and crying and tearfulness (27.1%).

A multiple linear regression model predicting base-line caregiver depression is shown in Table 2. As shown in the table, perceived patient emotional suffering (β = 1.24; $P < 0.001$), existential suffering (β = 0.66; $P < 0.01$), disruptive behaviors (β = 0.64; $P < 0.01$), and memory problems (β = 0.44; $P < 0.05$) were all significantly and positively associated with caregiver depressive symptoms. Other variables associated with baseline caregiver depression included race (β = −

1.81; $P < 0.05$, African Americans reported fewer depressive symptoms compared with whites), age ($\beta = 0.01$; $P < 0.05$, younger caregivers reported more depressive symptoms), education ($\beta = 2.32$; $P < 0.001$, caregivers with more than high school education had less depressive symptoms than those with a high school education or less), ADL disabilities of patient ($\beta = 0.45$; $P < 0.05$, greater disability was associated with more depressive symptoms), and time spent caregiving ($\beta = 0.30$; $P < 0.001$, more time associated with more depressive symptoms). In a separate analysis, this model was fit using only participants who were not taking antidepressant medications and the results were essentially the same with the exception that race and functional disability were not significant predictors of depressive symptoms. Both types of patient suffering were still independently associated with caregiver depression (emotional suffering: $\beta = 0.93$; $P < 0.05$; existential suffering: $\beta = 0.61$; $P < 0.05$) regardless of whether the analyses included all caregivers or only those who were not taking antidepressant medications. We further divided caregivers into 2 clinical subgroups, those with scores of less than 16 on the CES-D and those with scores of 16 and higher, the latter being a group considered to be at risk for clinical depression. The multiple logistic regression model using this cut score approach showed that patient suffering was significantly associated with clinical depression (emotional distress OR = 1.27, 95% CI, 1.10–1.47; existential distress OR = 1.11, 95% CI, 1.01–1.23). Other patient-related variables associated with clinical depression in this analysis were functional disability (OR = 1.09, 95% CI, 1.02–1.17) and time spent caregiving (OR = 1.05, 95% CI, 1.03–1.08).

Consistent with the cross-sectional models, change in perceived patient suffering was independently associated with change in depression (emotional distress: $\beta = 1.02$; $P < 0.01$; existential distress: $\beta = 0.64$; $P < 0.01$) (Table 3). The only other significant predictor of change in depressive symptoms was change in time spent caregiving, indicating that increasing time is associated with higher levels of depressive symptoms ($\beta = 0.12$; $P < 0.05$). As there is some controversy on how best to analyze change scores, we also tested models in which change in depression was regressed unto predictor variables controlling for baseline values of depression and models in which we regressed 6-month value of depression unto predictor variables, including baseline depression. All models essentially yielded the same results.

The results for the logistic regression model for antidepressant medication use (Table 4) showed that out of the 2 patient suffering measures only existential suffering was significantly associated with antidepressant medication use (OR = 1.25, 95% CI, 1.10–1.42, $P < 0.01$) when controlling for disruptive behaviors and memory problems of the patient, sociodemographic characteristics of caregivers and patients, disability status of the patient, and time spent on caregiving. African Americans and Hispanics were less likely to use medications than whites (OR = 0.29, 95% CI, 0.16–0.52 for whites and OR = 0.49, 95% CI, 0.31–0.80 for Hispanics), and caregiver spouses were less likely to use medications than were adult nonspousal caregivers (OR = 2.10, 95% CI, 1.02–4.33). Caregivers of female patients also had lower odds of antidepressant medication use (OR = 0.56, 95% CI, 33–0.93).

DISCUSSION

The goal of this article is to show that perceived patient suffering is an important and independent contributor to caregiver well-being. Overall, the prevalence of patient suffering was moderate-to-high as evidenced by indicators of perceived patient anxiety, sadness and depression, feelings of hopelessness, worthlessness, and being a burden. The findings reported here further show that these emotional and existential aspects of suffering are distinct from other attributes of AD, such as physical and cognitive disability, and are independently associated with caregiver depression and medication use. Consistent with other studies, levels of depressive symptoms among caregivers were high. Both depression and being a strained caregiver are risk factors for increased mortality in older individuals.[2,26]

These findings are important for several reasons. They provide a more fine-grained understanding of how illness and disability may affect patients and their family members. How a patient responds to illness and disability may be just as important as the illness itself in gauging its impact on family members.[6,27-29] Dementia is typically characterized by measures of cognition, function, and behavior, with the implicit assumption that these indicators are good surrogates for the quality of life of the patient.[30-33] Recent findings suggest that discrete measures of function capture only small components of quality of life and that assessment of dementia should be broadened to include indicators of health-related quality of life.[30,32-34] Suffering is an essential feature of quality of life. Randomized-controlled trials of antidementia medications and other treatments that rely exclusively on the assessment of specific functional domains may be missing additional positive effects of interventions or potential negative effects of interventions.[30,33] Our data suggest that patient suffering should be both assessed and targeted in intervention studies of AD patients and their family caregivers.

Current health and social policy focused on family caregiving emphasize the challenges of providing care to a loved one as a major source of distress among family members. As a result, legislation such as the National Caregiver Support Program has been enacted to provide assistance to family members providing care to ill or disabled relatives through programs such as respite care, home alterations, or skills training. Programs such as these are based on the assumption that caregiver distress is primarily the result of challenges involved in providing physical or instrumental care to their relative. The findings reported here indicate that mere exposure to suffering is an independent source of distress regardless of the care demands associated with an illness or disability. Thus, equal emphasis should be placed on minimizing or eliminating the suffering of the patient. Achieving this goal will require monitoring of patient affect, physical symptoms, and their spiritual/existential concerns, all of which are amenable to treatment. Clinicians have long recognized the importance of treating depression in AD patients,[16] and findings from this study suggest that it is also important to treat anxiety, loneliness, hopelessness, worthlessness, and feelings of failure.

We would further expect that caregivers who appraise their loved one's suffering as inevitable, over-whelming, and feel they can do little to alleviate it would experience more distress, whereas those who feel they can ameliorate the suffering should experience less, and indeed may benefit from helping the patient. As such, educational or counseling interventions that empower the caregiver to address the suffering of the patient and/or help caregivers appraise their loved one's suffering as less threatening should be beneficial. Clinicians can play an important role in this process by monitoring the suffering of the patient, observing its impact on the caregiver, and intervening to address patient suffering and/or the caregiver's concerns about patient suffering.

This study has several limitations. Our analyses are based on the perceived suffering of the patient; we did not have available independent or self-report assessments of suffering, although such ratings would be difficult to obtain from severely impaired dementia patients. A caregiver who interacts with the patient daily and has extensive historical knowledge is likely to be in the best position to make judgments about the suffering in individuals with moderate-to-severe cognitive impairment. Nevertheless, efforts should be made to assess suffering from the patient's perspective. Recent findings from quality of life studies indicate that even moderately impaired patients can reliably complete self-report questionnaires regarding their quality of life.[31] A second issue concerns limitations in our measure of suffering. The measures used were not explicitly designed to assess suffering and include only 2 of the 3 dimensions of suffering, accounting in part for the relatively small effect sizes observed in this study. Future studies should develop measurement strategies explicitly designed to assess all dimensions of suffering in the patient, including physical signs of suffering, psychologic aspects of suffering,

and existential/spiritual dimensions of suffering.[14] Finally, these data are consistent with but do not prove that patient suffering affects caregiver well-being.

The purpose of this article is to shed light on suffering as a construct worthy of future research, discussion, and policy debate. To be sure, these constructs have been the province of philosophical and religious scholars for centuries, but they have not figured prominently in the empirical literature on illness and disability. As populations throughout the world increasingly must deal with the challenges of late life illness and disability, it will be essential that we understand the reciprocal relation between patient and caregiver outcomes and ways in which we might break the cycle of suffering between patients and family caregivers.

Acknowledgments

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TABLE 1

Baseline Characteristics of Caregivers and Care Recipients/Patients (n = 1222)

Characteristic	Caregiver	Patient
Age, mean (SD), y	62.3 (13.6)	79.1 (8.2)
Race or ethnic group, no. (%)		
White	684 (56.0)	683 (55.9)
Black	295 (24.2)	300 (24.6)
Hispanic	232 (19.0)	220 (18.0)
Other	10 (0.8)	19 (1.6)
Sex, no. (%)		
Female	995 (81.4)	680 (55.7)
Male	227 (18.6)	542 (44.4)
Education, no. (%)		
High school or less	532 (43.5)	817 (69.1)
More than high school graduation	690 (56.5)	365 (30.9)
Income, no. (%)		
< $20,000	447 (37.5)	
$20,000–39,999	412 (34.6)	
≥ $40,000	333 (27.9)	
Employment, no. (%)		
Full-time or part-time	384 (31.5)	
Homemaker or retired	711 (58.2)	
Not employed	126 (10.3)	
Relationship to patient, no. (%)		
Spouse	589 (48.2)	
Nonspouse	633 (51.8)	
Median Score of MMSE, mean (IQR)		13 (6–19)
ADL, mean (IQR)		3 (1–5)
Independent ADL, mean (IQR)		8 (7–8)
Suffering: emotional distress items		
Within the past week, has (CR)..., no. (%)		
Appeared anxious or worried?		772 (63.4)
Appeared sad or depressed?		773 (63.4)
Been crying and tearful?		331 (27.1)
Suffering: existential distress items		
Within the past week, has (CR)..., no. (%)		
Threatened to hurt him/herself?		53 (4.3)
Been expressing feelings of hopelessness about the future (such as "Nothing worthwhile ever happens" or "I never do anything right")?		430 (35.2)
Been commenting about the death of him/herself or others (such as "Life isn't worth living" or "I'd be better off dead")?		288 (23.6)
Been talking about feeling lonely?		270 (22.1)
Made comments about feeling worthless or being a burden to others?		362 (29.7)
Made comments about feeling like a failure or about not having any worthwhile accomplishments in life?		150 (12.3)
CES-D, mean (SD)	15.4 (11.5)	
Center for Epidemiological Studies-Depression, percentage ≥ 16	40.8	
Hours a day spent doing things for CR, median (IQR)	6 (4–12)	
Use antidepressant medication, no. (%)	178 (14.6)	

CR indicates care recipient/patient; IQR, interquartile range.

TABLE 2

Multiple Regression Model for the CES-D at Baseline (N = 1169)

Independent Variables	Unstandardized β Coef.	Standar- dized β Coef.	P
Emotional distress subscore[*]	1.24	0.11	< 0.001
Existential distress subscore[*]	0.66	0.09	0.008
Disruption subscore[*]	0.64	0.10	0.001
Memory subscore[*]	0.44	0.06	0.04
Race (white)—reference category			
African American	−1.81	−0.07	0.02
Hispanic	1.25	0.04	0.15
Other	−3.05	−0.02	0.42
CG age, y	−0.01	−0.11	0.02
CG education (high school or less vs. more than high school)	−2.32	−0.10	< 0.001
CG sex (male vs. female)	1.47	−0.05	0.15
Spouse vs. nonspouse	−1.28	−0.06	0.33
Patient age, y	−0.002	−0.02	0.63
Patient male vs. female	−1.41	−0.06	0.15
Score of MMSE	0.07	0.05	0.12
ADL	0.45	0.08	0.01
Time spent doing things for patient	0.30	0.14	< 0.001
Model adjusted R^2	0.16		

Coef. indicates coefficient; CG, caregiver.

[*] Subscore from RMBPC.

TABLE 3

Multiple Regression Model for 6-month Change in CES-D (N = 849)

Independent Variables	Unstandardized β Coef.	Standardized β Coef.	*P*
Change in emotional distress subscore[*]	1.02	0.12	0.001
Change in existential distress subscore[*]	0.64	0.10	0.005
Change in disruption subscore[*]	0.23	0.05	0.19
Change in memory subscore[*]	−0.12	−0.02	0.57
Change in ADL	0.38	0.06	0.07
Change in time spent doing things for patient	0.12	0.07	0.03
Control vs. intervention	−0.75	−0.04	0.20
Model R^2	0.06		

Coef. indicates coefficient

[*] Subscore from RMBPC.

TABLE 4

Multiple Logistic Regression Model of Antidepressant Medication Use at Baseline (N = 1169)

Predictor Variables	OR (95% CI)	*P*
Emotional distress subscore[*]	1.15 (0.94–1.41)	0.17
Existential distress subscore[*]	1.25 (1.10–1.42)	0.001
Disruption subscore[*]	0.99 (0.90–1.10)	0.87
Memory subscore[*]	0.99 (0.88–1.12)	0.87
Race (white)		
African American	0.29 (0.16–0.52)	< 0.001
Hispanic	0.49 (0.31–0.80)	0.004
Other	0.81 (0.09–6.92)	0.85
CG age, y	1.00 (0.99–1.00)	0.17
CG education (high school or less vs. more than high school)	0.94 (0.66–1.35)	0.75
CG male vs. female	0.75 (0.43–1.31)	0.31
Spouse vs. nonspouse	0.2.10 (1.02–4.33)	0.04
Patient age, y	1.00 (0.996, 1.00)	0.10
Patient male vs. female	0.56 (0.33–0.93)	0.03
MMSE	1.02 (0.996–1.05)	0.10
ADL	1.02 (0.93–1.12)	0.67
Time spent doing things for patient	1.01 (0.98–1.05)	0.44

CG indicates caregiver

[*] Subscore from RMBPC.