

Acute Care Utilization by Dementia Caregivers Within Urban Primary Care Practices

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BACKGROUND: Caring for an individual with Alzheimer's dementia (AD) is stressful, and studies show that this stress has an impact on both the physical and mental health of the caregiver. However, many questions remain about the characteristics of AD patients and their caregivers that contribute to this stress and how it impacts caregivers' use of healthcare resources.

OBJECTIVE: To study the impact of stress on the physical and mental health of the caregiver.

DESIGN: Patients underwent extensive testing to allow description of their degree of cognitive impairment, behavioral and psychological symptoms, medical comorbidities, and functional abilities. Caregivers were assessed for depressive symptoms and also for emergency department (ED) use and hospitalizations in the previous six months. Multivariate logistic regression was used to evaluate impact of patients' dementia symptoms on caregivers' acute care utilization.

PARTICIPANTS: One hundred and fifty-three AD patients and their caregivers attending two large, urban, university-affiliated primary care practices were enrolled in a cross-sectional study to examine the facets of dementia caregiving that impact caregiver acute health care utilization.

RESULTS: Twenty-four percent of the caregivers had at least one ED visit or hospitalization in the six months prior to enrollment. After adjusting for caregiver age, gender, and education, our logistic regression model found that the caregivers' acute care utilization was associated with their depression as measured by the PHQ-9 (OR 1.09, 95% CI 1.00–1.18), the patients' behavioral and psychological symptoms as measured by the NPI (OR 1.04, 95% CI 1.01–1.08), and the patients' functional status as measured by the ADCS-ADL (OR 1.05, 95% CI 1.01–1.09).

CONCLUSION: To improve the health of AD caregivers, a primary care system needs to reallocate resources to manage the functional, behavioral, and psychological symptoms related to the care-recipients suffering from AD.

KEY WORDS: health care utilization; ED visit; hospitalization; dementia; caregiver.

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INTRODUCTION

Approximately four million older adults in the United States have Alzheimer's dementia (AD), and three million of them are living in the community.¹ Family and friends are currently providing 75% of the daily care needs of these patients, with the remaining 25% being provided by purchased home care services.² Thus, dementing illnesses are complex in that they impact not only the health and function of the patient but also that of the caregiving family member or friend. With the aging of the population, the number of cases of AD is anticipated to increase to 18.5 million by 2050.³ If a similar proportion of AD patients remains in the community as now, the burden of caregiving on the family and friends by 2050 will increase exponentially.

Caregiving is a stressful endeavor, and caring for a patient with a dementing illness appears to be even more so. In a national survey of more than 1,500 family caregivers, the caregivers of demented patients described their duties as more stressful compared to how caregivers of physically-impaired but not demented older adults viewed theirs. The dementia caregivers also reported spending significantly more hours per week providing care, giving up their vacations or hobbies more often, having less time for other family members, and having more work-related problems.⁴

To evaluate the psychological effects of this stress of caregiving, Schulz et al. reviewed the dementia literature to evaluate the prevalence and magnitude of psychiatric complaints in caregivers.⁵ Almost all studies reported increased levels of depressive symptoms in caregivers, and this psychiatric morbidity was found to be correlated with not only patient problem behaviors but also caregiver income, self-rated health, perceived stress, and life satisfaction. In a more recent review, Cuijpers systematically examined the dementia caregiving literature for studies reporting actual diagnosis of a major depressive disorder.⁶ He found that incidence and prevalence of full-blown depression are also increased in caregivers of dementia patients when compared to the non-caregiving population. Thus, we know that the stress involved in caring

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for someone with dementia impacts the caregivers' mental health.

Studies have also examined whether dementia caregiving has an effect on the caregivers' physical health. Spousal caregivers of patients with AD appear to have a greater risk for developing serious illness,⁷ and being a caregiver under mental or emotional strain was found to be an independent risk factor for mortality in older spousal caregivers.⁸ Vitaliano et al. conducted a meta-analysis of the dementia caregiving literature.⁹ In the analysis, they combined the results of 23 studies that compared indicators of physical health in family caregivers of demented patients to health indicators in non-caregiver age- and sex-matched controls. Overall, caregivers were found to have higher amounts of circulating stress hormones and lower degrees of antibody responses compared to the non-caregivers, but a definitive conclusion of whether caregiving is directly hazardous to health could not be determined.

Primary care physicians provide most of the medical care both for patients with AD and for their caregivers. With the aging of the population and the subsequent increase in patients with AD, the effects of caregiving on the physical and mental health of caregivers will continue to be important at both the individual and societal level. A better understanding of what makes caregiving of the demented more stressful is needed, as is more study into how medical comorbidity of the patient and the caregiver impacts their respective clinical pictures. Where care of patients with AD is concerned, such study may indicate that primary care providers need to expand their definition of "patient" to include not only the demented individual but the caregiver as well.

We describe a clinical profile of the medical comorbidity and the cognitive, functional, behavioral and psychological symptoms (BPSD) of a cohort of patients with AD. We then use this profile to examine the impact of these symptoms on their caregivers' emergency department and hospital utilizations. Based on our clinical experience and previous research, our primary hypothesis is that AD patients' BPSD, not their cognition, will be associated with their caregivers' acute care utilization.

METHODS

The study was approved by the Indiana University Purdue University-Indianapolis Institutional Review Board. All subjects or their caregivers provided written informed consent for participation.

Patients with AD were recruited from two large primary care practices from January 2002 to August 2004. The first practice included seven community-based health centers affiliated with Wishard Health Services, a university-affiliated urban health care system serving medically indigent patients in Indianapolis. This practice serves approximately 5,000 older adults. The second site included three primary care practices at the Roudebush Veterans Affairs Medical Center in Indianapolis. This practice provides primary care to approximately 6,000 veterans age 65 and older.

Patients were recruited through two methods: (1) physician referral following a written prompt that the patient may be eligible due to a medical record diagnosis consistent with a dementing illness; and (2) physician referral following a written prompt from the research team that the patient screened

positive on cognitive testing. All patients aged 65 and older who were receiving primary care from one of the two sites were screened for dementia using a six-item screener instrument¹⁰ and an abbreviated version of the Community Screening Instrument for Dementia (CSI-D).¹¹ All referred patients completed a formal diagnostic evaluation that included neuropsychological testing, comprehensive physical examination, a structured interview with the caregiver, brain imaging, and reversible work-up for dementia. All results were reviewed by a consensus diagnosis panel including a psychologist, neuropsychologist, geriatrician, and a geriatric psychiatrist. Subjects were eligible if they met criteria for possible or probable AD based on ICD-10 criteria. This diagnostic method is described in more detail elsewhere.¹² Exclusion criteria included: residence in a nursing home, unable to understand English, no access to a telephone, or no caregiver willing to consent to participate in the study. The primary care physician could then refer the patient to be enrolled in a randomized trial to test the effectiveness of collaborative care management for older adults with AD compared with augmented usual care. In this study, caregivers were family members or friends who identified themselves as individuals who assisted the subjects with navigating daily life and who were willing to participate in the study.

Patient Data. Following enrollment into the clinical trial and as part of the baseline assessment, the caregivers completed an assessment by telephone and thus were the primary source of the patient's data. The baseline interview included standardized instruments developed by the Consortium of Alzheimer Disease Center investigators¹³ and are considered the current gold standard for health outcome measures for patients with AD and their caregivers. These included the Neuropsychiatric Inventory (NPI),¹⁴ the Alzheimer's Disease Cooperative Study-Activities of Daily Living Inventory (ADCS-ADL),¹⁵ and Resource Use Inventory (RUI).^{13,16} The NPI has been adopted by the Alzheimer's Disease Cooperative Studies (ADCS) Group to obtain information on the presence of psychopathology in ten behavioral areas, including delusions, apathy, hallucinations, disinhibition, agitation, depression, aberrant motor behavior, anxiety, night-time behavior, and euphoria. Possible scores range from 0-120, with high numbers indicating more behavioral problems. The test has excellent reliability and validity.^{14,17,18} The ADCS-ADL is a 23-item inventory developed by the ADCS Group and is administered to the patient's caregiver by a trained interviewer. The caregiver is asked to focus on the patient's performance over the past month. Notably, the caregiver reports on what the patient actually did rather than an assessment of what the patient might be able to do. Thus, the inventory focuses on observed actions. The instrument assesses the traditional basic activities of daily living as well as variations on instrumental activities of daily living and a number of more complex and explicit self-care tasks.¹⁵ Patients' scores range from 0-75, with higher scores indicating greater levels of function. The RUI is a 15-item questionnaire developed by the ADCS Group that is designed to measure the health care utilization and costs incurred by subjects with AD. Three categories of costs and use are assessed, including medical services, discretionary health care costs, and caregiver expenses. It inquires specifically about nursing home stays

as well as home health visits, clinic visits, and hospitalizations. Even though studies have proven that the RUI provides data that are reliable and valid,¹⁶ in our previous studies we found that older adults have difficulty recalling use over the prior year.¹⁹ Thus, we completed the RUI for the previous six months to improve recall.

All patients themselves completed the Telephone Interview for Cognitive Status (TICS), a telephone version of the Mini-Mental State Examination²⁰ that has the same score range from 0 to 30 with the higher number indicating less cognitive impairment.

Using each patient's list of prescribed medications, we calculated the Chronic Disease Score (CDS) as a measure of medical comorbidity.²¹ The CDS excludes medications used for treatment of acute problems (such as antibiotics) or common symptoms (such as nasal congestion). Individual medications are assigned to pharmacy classes, which are then mapped to the chronic diseases that class of medication would treat. Each CDS class was assigned a weight by the original developers based on expert judgment. These weights are used to calculate the patient's total CDS (range 0–24). The CDS has been validated as an indicator of comorbidity, and its scores are correlated with future resource utilization. Higher scores indicate greater chronic disease burden and risk of healthcare resource utilization.

Caregiver Data. In addition to providing information about the patient's status, the caregiver provided information about their own demographics, their mood (PHQ-9), and their acute care utilization (RUI). The Patient Health Questionnaire-9 (PHQ-9)²² assesses incidence and severity of each of the nine DSM-IV criteria for depression, including anhedonia, appetite changes, low energy, and difficulty concentrating. Scores can range from 0–27, with higher scores indicating worsening depression. They also completed the RUI as a measure of their own acute healthcare utilization.

ANALYSIS

We used two sample T-tests and Fisher's exact test to compare the demographic, neuropsychiatric inventory, and survey measures of caregivers with an ED visit or hospital admission to those without. We then used multivariate logistic regression models to evaluate the impact of patients' overall medical comorbidity and dementia symptoms (functional, cognitive, behavioral, and psychological symptoms) on the caregiver acute utilization. Caregiver age, gender, education, and depression (PHQ-9 score) were specified for model inclusion regardless of p-value due to their clinical relevance and importance.

RESULTS

Our study included 153 patients meeting ICD-10 criteria for AD and their caregivers (Table 1). The patients' mean age was 77.7 years (SD 5.8), 43% were female, and 49% were African American. The average TICS score was 18.1 (SD 5.6) (indicating mild to moderate dementia), the mean ADCS-ADL scale score was 50.0 (SD 15.8) (indicating fair patient functional

level), and the average NPI-12 score was 11.8 (SD 18.2) (indicating moderate levels of BPSD). Caregivers had an average age that was 16 years younger than the patients, 69% of them lived with the patient, and 89% were female.

Twenty-four percent of caregivers had at least one ED visit or hospitalization. In assessing for caregiver characteristics associated with this acute care utilization, bivariate analyses found that these caregivers were caring for patients with more BPSD (mean NPI 20.5 vs. 9, $p=0.023$) and less cognitive impairment (mean TICS 19.1 vs. 16.6, $p=0.057$) and that these caregivers suffered from more depressive symptoms themselves (mean PHQ 6.1 vs. 3.4, $p=0.044$) (see Table 2).

Using multivariate logistic regression analyses to adjust for the caregivers' age, gender, education, and level of depression, we found that caregiver acute care utilization was associated with the patients' behavioral and psychological symptoms (OR=1.04, 95% CI 1.01–1.08 for each one point increase on the NPI) and their functional status (OR=1.05, 95% CI 1.01–1.09 for each one point increase on the ADCS-ADL). However, we found no association between caregivers' acute care utilization and the patients' comorbidity or their cognitive function (see Table 3).

DISCUSSION

Our cross-sectional study conducted among AD patients and their caregivers found that patients' function and BPSD were associated with utilization of acute care services by their caregivers. We found no association between patients' level of cognitive impairment and caregivers' acute care utilization. Interestingly, this is somewhat different from what Shaw et al. found in their study focusing on spousal caregivers of AD patients. As in our study, when compared to controls, spousal caregivers in Shaw et al.'s study showed a trend of higher risk for having a serious illness that was associated with providing

Table 1. Characteristics of Patients and Caregivers

	N=153
Patient variables	
% Female	43.1
% African American	49.0
Mean age	77.7 (5.8)
Mean years of education	9.2 (4.2)
% Married	48.4
Mean TICS	18.1 (5.6)
Mean ADCS-ADL	50.0 (15.8)
Mean NPI	11.8 (18.2)
Mean CDS	7.8 (3.9)
Caregiver variables	
% Female	88.9
Mean age	60.9 (15.0)
Mean years of education	11.9 (2.7)
% Live with patient	69.3
% Patient's spouse	44.4
Mean PHQ-9	4.1 (5.3)
% ED visit prior 6 months	20.9
% Inpatient admission prior 6 months	10.5
% ED visit or inpatient admission prior 6 months	24.2

* TICS = Telephone Interview for Cognitive Status, ADCS-ADL = Alzheimer's Disease Cooperative Study-Activities of Daily Living, NPI = Neuropsychiatric Inventory, CDS = Chronic Disease Score, ED = emergency department, PHQ-9 = Patient Health Questionnaire

Table 2. Comparison of Caregivers by ED Visit or Inpatient Admission

	ED visit or inpatient admission by caregiver		P-value
	None N=116	Any N=37	
Mean age: patient	78.0 (5.6)	76.7 (6.3)	0.271
Mean years of education: patient	9.3 (4.4)	8.6 (3.7)	0.362
Mean ADCS-ADL score: patient	49.4 (16.3)	52.0 (14.0)	0.352
Mean CDS: patient	7.9 (4.1)	7.4 (3.5)	0.464
Mean TICS: patient	17.2 (8.1)	18.6 (6.2)	0.293
Mean NPI: patient	9.0 (12.1)	20.5 (28.7)	0.023
% Female: patient	20.7	28.8	0.259
Mean age: caregiver	61.8 (14.7)	58.0 (15.5)	0.199
Mean years of education: caregiver	12.1 (2.6)	11.5 (2.8)	0.264
Mean PHQ-9: caregiver	3.4 (4.2)	6.1 (7.6)	0.044
% Female: caregiver	29.4	23.5	0.595

* ADCS-ADL = Alzheimer's Disease Cooperative Study-Activities of Daily Living, CDS = Chronic Disease Score, TICS = Telephone Interview for Cognitive Status, NPI = Neuropsychiatric Inventory, PHQ-9 = Patient Health Questionnaire

more ADL and functional assistance to the patient; however, they found no association with the patients' BPSD.⁷ As Shaw's study focused exclusively on spousal caregivers and ours, however, included any informal caregiver, direct comparisons cannot be made.

This association between patients' function and BPSD and caregiver use of health care services is an indicator of the difficulty of managing and caring for patients suffering from AD. In fact, BPSD, but not cognitive impairment, have been shown to be a prominent factor in the caregiver's decision to seek long-term residential placement for the patient.²³ Thus, it is not as much the patient's loss of cognitive function that stresses caregivers, perhaps because the caregiver expects and is prepared for this as part of the dementing illness. Rather, the agitation, aggression, and other symptoms contribute most heavily to caregiver stress and burden.

As our population ages and the numbers of AD cases increases, by necessity the number of caregivers, both formal and informal, will also increase. Unless our medical system can begin better to address and treat the BPSD of the demented patient, caregiver stress will continue unabated. In addition, our study found that the caregivers with more depressive symptoms were more likely to utilize acute health-

care resources. This is in line with the results of other studies of depression and its impact on use of health resources.²⁴ Thus, to truly impact the care of the AD patient and caregiver, we need to include assessment and treatment of psychological symptoms of the caregiver, too.

Our study demonstrated that AD caregiving produces significant stress that impacts both the medical and psychological wellbeing of caregivers. Thus, our primary health care system needs to change its approach to providing medical care to AD patients. Rather than caring only for the demented patient, primary care providers will need to expand their definition of "patient" to include the caregiver as well.

Collaborative care programs within the primary care and home settings offer the best possibility for managing patients' symptoms while supporting the caregivers' efforts to care for them at home and reducing the need for utilization of acute care services.²⁵⁻²⁷ Recent trials of such collaborative interventions included in-home education and psychosocial support for the caregiver on issues such as caregiver depression and burden and patients' BPSD.²⁵⁻²⁷ The collaborative interventions studied were successful in reducing caregiver stress and improving quality of life.²⁵⁻²⁷ In addition, patient's behavioral and psychological symptoms were reduced as a result of the collaborative interventions.²⁵ However, further research is needed to fully describe such a program and to evaluate its feasibility in clinical practice.

Our study has important internal and external validity limitations. First, the external validity of the findings is limited because our data are from patient-caregiver dyads that were willing to pursue both an evaluation of cognitive impairment, enroll in a clinical trial, and receive care in two specific health care systems. Our study group had a high percentage of African Americans, so the results may not be generalizable to all populations. On the other hand, minorities tend to be underrepresented in many studies of AD, so our report offers a unique glimpse into how AD impacts a minority population. Second, the cross-sectional design of our study limits its internal validity and its capability of determining a cause-and-effect relationship. Third, our information on ED/hospital utilization over the six months prior to the study was obtained from caregiver interview using the RUI. Thus, it is conceivable that some acute care visits were not reported and that our prevalence rate is conservative. Fourth, we did not collect information on the specific reasons for the caregivers' ED visits or hospitalizations, so we cannot comment on whether these were ambulatory care sensitive conditions such that caregiving duties might have interfered with non-emergent treatment or if an episode of patient's BPSD led directly to a caregiver ED visit.

Our study reveals the importance and impact of functional and BPSD symptoms in Alzheimer dementia on caregivers' use of acute healthcare services. Improved management of such symptoms in the primary care system may lead to a significant decrease in the burden of AD, not just for the patient and caregiver but also for the healthcare system at large. Further research efforts are necessary to better describe effective, practical methods to provide this management in primary care.

Table 3. Logistic Regression Model of ED Visit or Inpatient Admission by Caregivers

	Odds ratio	95% CI	P-value
Caregiver age	0.99	(0.97, 1.03)	0.974
Female caregiver	0.47	(0.13, 1.64)	0.235
Caregiver education	0.88	(0.74, 1.05)	0.153
Caregiver PHQ-9	1.09	(1.00, 1.18)	0.048
NPI	1.04	(1.01, 1.08)	0.014
ADCS-ADL	1.05	(1.01, 1.09)	0.023
TICS	1.02	(0.96, 1.09)	0.540
CDS	0.98	(0.88, 1.10)	0.780

PHQ-9 = Patient Health Questionnaire, NPI = Neuropsychiatric Inventory, ADCS-ADL = Alzheimer's Disease Cooperative Study-Activities of Daily Living, TICS = Telephone Interview for Cognitive Status, CDS = Chronic Disease Score

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Conflicts of Interest: There are no conflicts of interest for these authors.

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