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Burden Among Caregivers of Elders Who Were Cognitively Impaired at the Time of Hospitalization: A Cross-Sectional Analysis

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Abstract

Objectives—Caregiver burden is a multidimensional outcome of the chronic stress associated with care giving. We aim to describe the factors associated with burden experienced by caregivers of older adults who were cognitively impaired (i.e. dementia, delirium or both) at the time of hospitalization..

Design—Cross sectional data analyses.

Setting—Three hospitals – one academic tertiary hospital and two associated community hospitals

Participants—495 caregivers of older adults who were cognitively impaired at the time of hospital admission.

Measurements—Multivariable linear regression was performed to analyze the effect of the independent variables (caregiver: demographics, presence of depressive symptoms and self-efficacy; patient: neuropsychiatric symptoms, delirium, functional deficits) on caregiver burden.

Results—In this cohort of caregivers, higher burden was associated with younger caregiverage ($p=0.02$), being a spouse ($p=0.03$), the presence of depressive symptoms ($p<0.001$), caregivers' lower perceived self-efficacy to manage patient symptoms ($p=0.002$) and limited finances at the end of the month ($p=0.01$). Additionally, caregiver burden was strongly associated with the following patient factors: distressing neuropsychiatric symptoms ($p=0.001$), the presence of delirium ($p=0.001$) and greater functional deficits in basic activities of daily living ($p=0.001$).

Conclusion—These findings suggest that caregivers of older adults who were cognitively impaired on hospital admission experience burden. Understanding the contributing factors to

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burden at the time of hospitalization for caregivers of persons with CI can inform the development of interventions targeted throughout the hospitalization that have the potential to decrease burden.

Keywords

Hospitalization; Dementia; Self-Efficacy; Caregiver Burden

INTRODUCTION

Almost 15 million people provide an estimated \$202 billion unpaid care for older adults with cognitive impairment (CI)¹ due to neurodegenerative diseases (e.g., Alzheimer's Disease), acute multi-factorial syndromes (e.g., delirium) or progressive chronic conditions (e.g., heart failure) that can result in disturbances in memory, orientation and behavior. Eighty percent of these caregivers are family members.¹ Often, this population of caregivers feels overwhelmed caring for older adults with multiple chronic conditions complicated by CI.² Older adults with CI from dementia have a higher incidence of hospitalization than older adults without a diagnosis of dementia.³ The period of hospitalization may provide opportunities to address and prevent further caregiver burden.

Caregiver burden is a multidimensional outcome of the chronic stress associated with caregiving and encompasses physical, psychological, social and financial aspects of providing care.⁴ Overall, burden impacts the time, physical, developmental, social and emotional demands of being a caregiver⁵; it is often influenced by caregiver demographics and characteristics (e.g., age, sex, finances, depression, self-efficacy)^{6,7} as well as the clinical characteristics of the cognitively impaired patient (e.g., dementia severity, impaired functional status, severity of comorbidities, neuropsychiatric symptoms).⁸ These factors can all lead to poor quality of life and nursing home placement.^{9,10}

To date, much of the literature on burden among caregivers of older adults with cognitive impairments has explored burden in the context of the outpatient, ambulatory or nursing home settings.^{9,11,12} The research on burden among caregivers of hospitalized older adults with cognitive impairments is scarce. The few studies that have examined burden among caregivers of hospitalized older adults are limited in size and diversity of the sample as well as the severity of the patient's neuropsychiatric symptoms.^{13,14} Evaluation of burden at the time of hospitalization would seem a plausible first time point for assessment, yet it is often overlooked. The purpose of this study is to describe the factors associated with burden experienced by caregivers of older adults (heretofore, referred to as patients) with diagnosed and undiagnosed cognitive impairments at the time of their hospital admission.

METHODS

Design

This is a cross-sectional data analysis from interviews with caregivers and cognitively impaired patients enrolled in a longitudinal non-randomized prospective intervention study designed to compare the effects of different evidence-based interventions of varying intensities on improving a range of health, quality of life and cost outcomes.¹⁵ The primary longitudinal outcome measures for the parent study included function, resource use, costs, and caregiver burden. This analysis includes the entire study sample at time of hospitalization before interventions were deployed.

Participants

Caregivers and patients were screened for eligibility and enrolled within 24-hours of hospitalization. In the parent study, patients were eligible if they were 65 years or older;

lived within a 30 mile radius of the admitting hospital; spoke English; planned to return home after the hospitalization; had a caregiver (i.e., family or friend) who was identified as providing care to the patient, either lived with or had regular contact with the patient and was willing to participate in the study; and had either a documented diagnosis of dementia and/or delirium or screened positive for deficits in orientation, recall, or executive functioning. Potentially eligible patients who did not have documented diagnoses of dementia or delirium were assessed for deficits in orientation or recall using the Six Item Screener (SIS)¹⁶ and executive function using the CLOX1, clock drawing task.¹⁷ Patients who scored four or less on the SIS or 10 or less on the CLOX1 were eligible. Patients were excluded if they were enrolled in hospice, undergoing treatment for cancer, stroke, end-stage renal disease or had untreated psychiatric problems.

Eligible caregivers provided written informed consent for themselves and the patient and whenever possible the patient provided assent to participate in the study. All patients and caregivers were recruited from three different hospitals affiliated with a large academic medical center between February 2006 and the end of December 2009. The University of Pennsylvania Institutional Review Board approved the parent study, which included plans for cross-sectional analyses.

Data Collection Methods and Measures

Trained research assistants (RAs) conducted in person or telephone (<10%) interviews with caregivers and patients within 24–48 hours after enrollment. Caregivers responded to questions about themselves and answered functional and behavioral questions about the patient. Additional data on the patient were gathered from medical record review for each patient and the patient self-report (when possible).

Outcome Variable—The primary outcome, caregiver burden, was measured using the Caregiver Burden Inventory (CBI).⁵ This 24-item scale measures the construct of burden and provides a total score (range 0–96). Each item is rated for the “current situation” from not at all descriptive (=0) to very descriptive (=4). Internal consistency reliability coefficients for this scale range from 0.73 to 0.86.^{5,18} The CBI was chosen because it was designed specifically to assess the burden of caring for cognitively impaired patients⁵ and has good criterion validity.¹⁸ Higher scores indicate greater feelings of burden.

Independent Variables

Caregiver Variables—Two standardized instruments were used to assess the caregiver’s perceived 1) ability to manage symptoms and find services (e.g., self-efficacy) and 2) depressive symptoms.

Self-efficacy—Caregiver self-efficacy scale (10 items) determines how certain a caregiver is in managing the patient’s symptoms of CI (5 items) and in accessing community services, when needed.¹⁹ Response options range from 1 (not at all certain) to 10 (very certain) at the time of the interview. The internal consistency reliability coefficients are 0.77 (managing symptoms) and 0.78 (service use).^{20,21}

Depressive symptoms—Caregivers were asked two depression-screening questions about feeling down, depressed or hopeless and being bothered by loss of interest during the past month. For those who answered yes to either question, the 20-item Center for Epidemiological Studies-Depression (CES-D) inventory was completed.²² The internal consistency reliability coefficient for this scale ranges from 0.85 to 0.90.²² A dummy variable was created to indicate the presence of depressive symptoms (CES-D ≥ 16). All

subjects who answered no to the screening questions or scored less than 16 on the CES-D were scored as 0 in the dummy variable.

Caregiver demographics and characteristics—Caregivers self-reported demographic and related characteristics. These included: age, gender, race, education, relationship to patient, whether they lived with the patient, finances at the end of each month and availability of someone to help them after the hospitalization.

Patient Data

Several standardized instruments were used to assess patient behavioral symptoms and the severity and distress associated with those behaviors, delirium, level of function in basic activities of daily living and cognitive impairment.

Neuropsychiatric Inventory (NPI)—Neuropsychiatric symptoms were assessed by the caregiver using the Neuropsychiatric Inventory (NPI).²³ The NPI measures over the past month the frequency and severity of the patient's neuropsychiatric disturbances from the caregiver's perspective. This tool evaluates for the following symptoms: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability and aberrant motor behavior. Two summary scores are created: severity (NPI-S) and distress (NPI-D) associated with the 10 behavioral symptoms.²⁴

Delirium—The Confusion Assessment Method (CAM) is a sensitive and specific diagnostic algorithm that was used to determine the presence of delirium at the time of the interview at hospitalization.²⁵ Trained RAs assessed the patient using the CAM, reviewed the medical record, and interviewed both family caregivers and nursing staff about the past 24–48 hours using the CAM as a guide. Based on the full assessment, patients were identified as delirious if the features of acute onset/fluctuating course and inattention were present plus either disorganized thinking or altered level of consciousness were present in the past 24–48 hours. The CAM's sensitivity has been reported to be between 94%–97% and combined specificity between 85%–94%.²⁶

Patient Functional Status—The six-item Katz Index of Activities of Daily Living²⁷ (BADL) instrument was used to measure the patient's current abilities to: bath, dress, toilet, transfer, manage continence, and feed. Caregivers assessed these abilities with scores ranging from 0–6 where higher scores indicated greater independence. Inter-rater reliability of 0.95 and correct classification of 96% of people has been reported.²⁸

Cognitive Impairment—The Mini Mental State Examination (MMSE)²⁹ is a widely used tool that measures orientation to time and place, recall ability, short-term memory and arithmetic ability in older adults. Scores range from 0–30 with lower scores indicating greater CI.²⁹ Trained RAs completed this assessment with the patient at the bedside.

Patient demographics and characteristics—Patient data includes age (chart review), gender, race (patient reported, caregiver confirmed), education (patient reported, caregiver confirmed), reason for hospitalization (chart review), number of co-existing conditions (chart review) and history of dementia (chart review).

Statistical Analysis

Caregiver and patient characteristics are summarized as frequencies and percentages for categorical data and as means $\pm$ standard deviation, along with medians, for continuous variables. Seventy-seven percent of the sample had complete data on all variables. Eight

variables had some missing values (3%–26%, See Table 1). The majority of these variables were summary scores, which could not be computed due to individual missing items. Therefore, the MI procedure in SAS was used to impute missing data. Multiple imputation^{27,30} replaces each missing value with a set of plausible values that represent the uncertainty about the correct value to impute instead of filling in a single value for the missing score. The multiple imputed data sets were then analyzed using standard procedures for complete data and then combining the results from these analyses. We used the option designed to handle monotone missing patterns, using a parametric regression method that assumes multivariate normality.³⁰ Standard parametric tests were used to make comparisons to describe the sample (e.g., chi squares, t-tests, Fisher's exact test). Model and distributional assumptions were checked; caregiver burden demonstrated non-normality, and, thus, sensitivity analyses were generated using transformed (square root) data. Because the findings based on the original and transformed data were similar, and the residual plots suggested adequacy of the original model, results are provided using caregiver burden on the original scale. Bivariate and multivariable regression analyses were used to describe the relationship between the dependent variable, caregiver burden, measured on a continuum and characteristics of caregivers of hospitalized older adults who were cognitively impaired at the time of assessment. Full models included all variables significant at $p<0.20$ in bivariate regression analysis or based on the literature were included in the final model and demonstrating non-collinearity. In situations where collinearity was a problem decisions were made a priori regarding variables' inclusion in the multivariable model. Multi-collinearity was assessed using the variance inflation factor cut-off equal to 4.0. Finally, we performed sensitivity analyses with the complete data (minus subjects with any missing data) versus imputed data, and the results were similar. Models using the imputed data are presented. Statistical power was based on the primary outcome variable of function for the parent study, and, thus, is not presented here.

RESULTS

Among the 3635 patients screened to participate in the parent study¹⁵, 52% (1884/3635) either screened positive for cognitive deficits (N=1624) or had a diagnosis of dementia documented in their medical record (N=260). Among the 1884 with cognitive impairments, 66% (1246) met full eligibility criteria (see Figure 1). Forty-three percent of those eligible caregiver-patient dyads enrolled (536/1246). The most common reason for patients and caregivers not enrolling was lack of interest in participating in research. There were no differences in race or gender between enrollees and patients that declined. After enrollment, 41 patients were found ineligible (e.g., nursing home placement, primary cancer diagnosis)³¹ The final sample for this analysis includes data on 495 caregivers and 495 patients.

Caregivers were primarily female (75.7%), black (60.2%), adult children (53.1%) with an average of 14 years of education and just under half the sample (42.2%) reported having some money left over at the end of the month. Slightly more than half of the caregivers reported living with the patient (277/495, 55.96%). The majority of spouses (112/116, 96.55%) resided with the patient, whereas only about 50% (119/263) of adult children and 40% of other types of relatives (46/116) resided with the patient (Fisher's exact test, $p<0.001$).

Approximately 8% of caregivers had depressive symptoms. Caregiver burden was on average mild (mean=17; median=13). Caregivers of patients with a known diagnosis of dementia had higher burden scores (mean=24.6) in comparison to caregivers of patients without a diagnosis of dementia (mean=14.8; Student's t-test, $p<0.001$). See Table 1.

Patients were mostly female (65.1%), came into the hospital for a cardiac or pulmonary medical reason (44.0%) and, on average, had five co-existing conditions. Average scores on the MMSE indicated mild CI with a range from normal to severely impaired. A small percentage (13/495, 2.6%) of patients could not complete the MMSE due to severe CI. Overall, patients had few deficits in their basic activities of daily living. Approximately 18% had a known diagnosis of dementia. Among all patients, 23.2% screened positive for delirium at the time of the hospitalization. Patients with a diagnosis of dementia were more likely to screen positive for delirium (36.4%; 43/118) in comparison to patients without a known diagnosis of dementia (11.3%; 40/355) (missing, n=25; $\chi^2(1)=40.9$, $P<0.001$). See Table 1.

Characteristics associated with caregiver burden among hospitalized older adults with cognitive impairments

Using separate bivariate regression models, several caregiver and patient characteristics were associated with caregiver burden, significant at the $p = 0.20$ level. Caregiver variables included their relationship to the patient, living with the patient, presence of depressive symptoms, ratings of self-efficacy (symptom management and service use), distress associated with the patient's neuropsychiatric behaviors (NPI-D) and how much money was left at the end of the month. Patient characteristics that were significant at the $p = 0.20$ level included: severity of the patient's neuropsychiatric behaviors (NPI-S), a diagnosis of dementia, screening positive for delirium, number of co-existing comorbid conditions, and physical and cognitive functional deficits. (See Table 2)

With the exception of the living situation variable, based on the results of the bivariate analysis as well as *a priori* decisions based on the literature,^{6,9,13} we built a final multivariable regression model to determine which patient and caregiver characteristics were associated with caregiver burden. The living situation variable was not included because it demonstrated multi-collinearity with the relationship to the patient variable. Holding all other variables constant, both caregiver and patient factors were strongly associated with caregiver burden at the time of hospitalization (See Table 3). A five-year decrease in age of the caregiver was associated with a 0.60 point increase in the caregiver burden score ($\beta=0.12$, $p=0.02$). Spouses and adult children had higher burden ($\beta=4.50$, $p=0.03$ and $\beta=2.50$, $p=0.10$, respectively) than 'other' caregivers (identified as any caregiver who was not an adult child or spouse of the patient). Caregivers with depressive symptoms had higher caregiver burden scores than caregivers who did not have depressive symptoms ($\beta=9.2$; $p<0.001$), and not having enough money to make ends meet was also associated with increased burden ($\beta= 4.71$; $p=0.01$). For every one-point increase in the symptom management self-efficacy score, the caregiver burden score decreased by 0.23 ($p=0.002$). For every one-point increase in distress caused by neuropsychiatric behaviors, the caregiver burden score increased by 0.32 points ($p=0.001$). Among caregivers of patients who screened positive for delirium, caregiver burden scores were 4.97 points higher in comparison to caregivers of patients who did not have delirium ($p=0.001$). While CI (MMSE score) was no longer significantly associated with caregiver burden, greater patient deficits in physical function were associated with higher caregiver burden. A one-point decrease on the basic activities of living scale was associated with a 1.07 increase in the caregiver burden score ($p=0.001$).

In order to ensure the accuracy of the outcome, the models were run using a variety of modifications. Interaction terms between caregiver age and relationship, finances and service-use self-efficacy and the symptom self-efficacy and the neuropsychiatric behavior variables were all tested but were not statistically significant. Lastly, the model was run

looking at the sub-types of co-existing condition; however there were no specific conditions associated with our outcome of burden.

DISCUSSION

To the best of our knowledge, this is the first reported study to examine the burden of caregivers of older adults with cognitive impairment (i.e. dementia, delirium, undiagnosed impairments) at the time of their hospitalization. Several caregiver and patient characteristics were associated with higher caregiver burden. The findings in this study support prior research on caregiver burden conducted in the community, specifically that burden is related to caregiver's age, spousal relationship status, caregiver depressive symptoms, limited finances at the end of the month, caregiver self-efficacy, and distress associated with neuropsychiatric symptoms.^{6,32–34} Regarding self-efficacy, only self-efficacy of symptom management was associated with caregiver burden at the time of hospitalization while finding services in the community was not statistically significant ($p=0.11$). Among patient characteristics, only delirium and basic activities of daily living (e.g., function) were associated with caregiver burden. Though the results for function and burden are similar to findings in the literature on community dwelling older adults⁶, the association between delirium and caregiver burden among cognitively impaired older adults at the time of hospitalization adds new findings to the growing body of research in delirium and caregiver burden.

It is important to note that the study was intentionally designed to enroll older adults using a broad definition of CI—some of which are modifiable and others that are not—with the focus on CI as a complicated condition for patients with multiple chronic conditions (mean=5). While having a diagnosis of dementia and level of cognitive impairment were both statistically significant in the bivariate modeling, these factors were no longer significant after adjustment in the multivariable analysis. Other variables such as the presence of delirium and the distress associated with neuropsychiatric behaviors appear to be more strongly correlated and explain more of the variability in caregiver burden. This finding may also indicate that both neuropsychiatric behaviors (more common in the moderate stage of dementias such as Alzheimer's disease) and delirium could be better indicators of burden than a patient's cognitive impairment severity or a diagnosis of dementia. Understanding these specific associations may be useful to guide the care provided throughout hospitalizations including preparation of patients and caregivers for next phase of care. (See Clinical Implications) Future studies examining interventions that target caregiver burden among this population are needed.

Finally, a majority of caregivers and patients in this study self-identified as African American, which is reflective of the urban location of the hospitals where patients and family caregivers were recruited. There was no association between the outcome of caregiver burden at the time of a hospitalization and race ($p=0.53$), though findings from several previous studies indicate that African Americans have a higher risk of developing dementia in comparison to white older adults^{35,36} and are often under diagnosed.^{37,38} With regards to caregiving, African-Americans have previously identified caregiving as a traditional family role, and, as a result, caregivers have higher satisfaction and resilience with their caregiving role due to their social support.³⁹ The findings in this study did not capture the experience of these caregivers accessing services prior to hospitalization, which may explain why service- use self-efficacy was not statistically associated with caregiver burden at the time of hospitalization. This may also highlight the greater importance of patient engagement with community networks over formal services to alleviate caregiving burden in the African-American population.

Clinical Implications

These findings have several clinical implications. First, the health care team could impact burden among caregivers of patients who were CI at the time of their hospitalization by assessing burden and self-efficacy upon hospital admission. Based on the assessment, the healthcare team could provide information about services, such as respite care for caregivers to help decrease their burden. Trending their level of burden may also be helpful information for the health care team in developing a personalized care plan for these patients and their caregivers at the time of discharge. It is the hope that such interventions will better equip caregivers to handle the complex care needs of patients throughout episodes of acute illness which may lead to lower readmission rates.

Second, higher self-efficacy in the management of symptoms is associated with lower caregiver burden.²⁰ This is another area where health care professionals involved in the transition of the patient to the next setting of care could use a self-efficacy assessment tool in conjunction with the clinical assessment to further target the post-hospitalization transition plan to the needs of the patient and the caregiver. For instance, interventions using the Progressively Lowered Stress Threshold Model^{40–42} to reduce environmental stressors surrounding the cognitively impaired older adult has been shown to improve the self-efficacy of caregivers.⁴³ Additionally, caregiver recognition of the value of greater self-efficacy may contribute to a positive caregiving experience and decrease rates of patient hospitalization and institutionalization. While service use self-efficacy was not statistically significant, this variable trends toward significance and is worth considering during planning discussions for the transition after the hospitalization to provide information to caregivers about available support services (e.g., the Family Caregiver Alliance). Such efforts could result in improved quality of life for both the patient and caregiver.

Third, there was a clear association with higher caregiver burden and the presence of delirium among patients at the time of hospitalization after adjustment for multiple other important clinical factors. Use of both pharmacological and non-pharmacological interventions during the hospitalization have been found to improve the reduction of delirium, especially among those at high risk, such as cognitively impaired hospitalized older adults.⁴⁴ In addition, the findings presented in this study further support the use of delirium assessment scales, such as the Confusion Assessment Method⁴⁵ and/or the Family Confusion Assessment Method (FAM-CAM)⁴⁶ at the start of hospitalization. The results of these scales can be used to trend patient symptomatology during the hospitalization and stimulate discussions with caregivers on how to identify and manage such symptoms at home.

Fourth, given that the distress associated with neuropsychiatric behaviors was related to higher burden in this sample, it appears worthwhile for the health care team to acknowledge these distressing behaviors and use their expertise to assist in the development of an inpatient plan to troubleshoot these issues. Furthermore, since distressing behaviors reported by family caregivers were recalled from the prior month, referrals to evidence-based, community programs targeted towards dementia patients and their caregivers⁴⁷ may improve the patient's behaviors and decrease caregiver distress.

Finally, greater functional deficits in basic activities of daily living were associated with caregiver burden. While these may not be completely reversed given their association with disease burden and severity of cognitive impairment, there is evidence that some of this decline can be reduced.^{43,48} Thus, healthcare providers may still be able to identify which resources may help manage some of these areas of functional deficit, decrease caregiver burden and prevent further decline.

There were limitations in this study. First, while burden was assessed at the time of hospitalization, neither the level of burden prior to hospitalization nor that at discharge was known. Regardless, these data capture a critical point in time at the start of a hospitalization, which can provide valuable information to the health care team. There were several variables that may influence burden but were not available in the data set, such as amount of family support or conflict, years of caregiving experience and amount of time-per-week dedicated to caregiving, whether the caregiver had another occupation and the presence of formal service providers involved in the care of the patient prior to the hospitalization. Second, the caregiver's relationship was associated with living with the patient. While this finding was not surprising, there were too few spouses reporting they did not reside with the patient, thus, precluding our ability to control for this in the model. In addition, the collection of longitudinal observation data from caregivers who do not reside with the patient may underreport neuropsychiatric behaviors and physical limitation. Third, there was a small amount of missing data at baseline that required the use of multiple imputation methods. We did build the final model with complete data (no imputations for missing data) and found the same associations in the bivariate model building as we did with the fuller imputed dataset and we chose to report the larger imputed dataset findings. In addition, log transformation of skewed variables (such as the NPI scores) did not change the findings and we chose to report the data without log transformation. Therefore, we feel confident in these results. Finally, the sample reported here is a convenience sample in an urban setting and results of this may not be generalizable across all hospital settings or all older adults with cognitive impairments.

These findings suggest that the caregivers of patients with cognitive impairment at time of hospitalization, with or without a diagnosis of delirium or dementia, are experiencing burden. There is some research to support that involvement of caregivers in the care planning and transition of hospitalized older adults can result in fewer rehospitalizations.^{15,49–51} Therefore, targeted interventions towards both the caregiver and older adult with cognitive impairment at the time of hospitalization may decrease caregiver burden. Further research will be needed to assess the impact of such targeted, caregiver interventions during the hospitalization and the effect on burden and other outcomes during critical points of transition post-hospitalization.

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Figure 1.
Number of caregiver-patient dyads who were screened, enrolled and completed study.

Table 1

Caregiver and Patient Characteristics and Descriptive Statistics N=495

Variables	Caregiver ^a	Patient
Age, years		
Mean±sd (range)	59.78±13.90 (18–100)	80.00 ± 7.19 (65–102)
Median	59	81
Missing, n (%)	27 (5.45)	0 (0)
Sex, n (%)		
Male	120 (24.24)	173 (34.95)
Female	375 (75.76)	322 (65.05)
Race, n (%)		
Black	298 (60.20)	298 (60.20)
White	186 (37.58)	188 (37.98)
Other	11 (2.22)	9 (1.82)
Education, years		
Mean±sd (range)	13.69 ± 2.75 (2–26)	
Median	13	
Missing, n (%)	38 (7.68)	
Living Situation: Lives with patient	277 (55.96)	
Relationship to Patient, n (%)		
Adult Child	263 (53.13)	
Spouse	116 (23.43)	
Other ^b	116 (23.43)	
Depressive Symptoms, n (%)		
CES-D 16 – present	38 (7.68)	
CES-D < 16 – absent	401 (81.01)	
Missing	56 (11.31)	
Self-efficacy ^c		
Symptom Management		
Mean±sd (range)	37.36 ± 10.98 (5–50)	
Median	40	
Missing, n (%)	43 (8.69)	
Use of Services		
Mean±sd (range)	30.15± 9.28 (4–40)	
Median	32	
Missing, n (%)	42 (8.48)	
Caregiver Burden Inventory ^d		

Variables	Caregiver ^a	Patient
Mean±sd (range)	16.48 ± 16.34 (0–92)	
Median	13	
Missing, n (%)	30 (6.06)	
Caregiver's finances at the end of the month, n (%)		
Some money left over	214 (42.23)	
Enough to make ends meet	156 (31.52)	
Not enough to make ends meet	78 (15.76)	
Missing, n(%)	47 (9.49)	
Hospital Diagnosis on Admission, n (%)		
Cardiac/Pulmonary		218 (44.04)
Gastrointestinal/Genitourinary		77 (15.56)
Orthopedic/Mechanical		72 (14.55)
Neurologic		67 (13.54)
Endocrine/Metabolic		61 (12.32)
Medical History of Dementia, n (%)		88 (17.78)
Delirium present, n (%) ^e		115 (23.23)
Missing, n(%)		25 (5.05)
Number of Co-Existing Conditions ^f		
Mean±sd (range)		5.09 ± 2.55 (0–13)
Median		5
Mini Mental State Examination ^g		
Mean±sd (range)		21.77 ± 5.73 (1–30)
Median		23
Unable to complete scale, n (%)		13 (2.63)
Basic Activities of Daily Living ^h		
Mean±sd (range)		4.55 ± 1.94 (0–6)
Median		6
Missing, n(%)		56 (11.31)
Neuropsychiatric Inventory (NPI) ⁱ		
Severity subscale (NPI-S)		
Mean±sd (range)		5.23 ± 5.94 (0–30)
Median		3
Missing, n (%)		115 (23.23)
Distress subscale (NPI-D)		
Mean±sd (range)		6.79 ± 9.51 (0–43)
Median		3
Missing, n (%)		129 (26.06)

^a Percentages may not add to 100% due to rounding.

^b Identified as any caregiver who was not categorized as an adult child or spouse of the patient.

^c Higher scores equates to higher self efficacy.

^d Higher score equates to higher caregiver burden.

^e Missing, n (%) = 18 (4.4).

^f Number of co-existing conditions did not count the Hospital Diagnosis on Admission.

^g Lower score equates to greater cognitive impairment

^h Higher score equates to greater independence.

ⁱ Higher score equates to higher severity and distress of neuropsychiatric symptoms.

CES-D= Center for Epidemiological Studies-Depression.

Bivariate Regression Models Predicting Burden among Caregivers of Older Adults with Cognitive Impairment at the Time of Hospitalization, N= 495

Table 2

Variable	Beta Coefficient	Standard Error	95% Conf. Interval	P-value
Sex (Male)	-0.76	1.71	-4.12 – 2.60	0.657
Race (White)	0.09	1.51	-2.88 – 3.07	0.951
Age (years)	-0.08	0.05	-0.18 – 0.03	0.146
Relationship to patient:				
Other ^a	Reference	--		--
Adult Child	5.56	1.80	2.02 – 9.10	0.002
Spouse	3.40	2.12	-0.77 – 7.57	0.110
Living Situation: lives with patient	6.47	1.45	3.62 – 9.31	<0.001
Depressive symptoms (CES-D 16)	14.09	1.91	10.35 – 17.84	<0.001
Symptom Self-efficacy	-0.48	0.07	-0.60 – -0.35	<0.001
Service Use Self-efficacy	-0.44	0.08	-0.59 – -0.29	<0.001
NPI – Severity	0.99	0.12	0.75 – 1.23	<0.001
NPI – Distress	0.70	0.08	0.55 – 0.85	<0.001
Existing diagnosis of dementia	9.80	1.87	6.13 – 13.46	<0.001
Presence of delirium	11.60	1.61	8.43 – 14.77	<0.001
No. of Co-existing conditions	0.70	0.28	0.14 – 1.26	0.014
Mini Mental State Examination	-0.62	0.12	-0.86 – -0.38	<0.001
Basic Activities of Daily Living	-2.27	0.37	-3.00 – -1.54	<0.001
Money Left Over at the End of Each Month: Enough Money Left Over Enough Money to Make Ends Meet	Reference 2.19	-- 1.58	-- -0.92 – 5.30	-- 0.167

Variable	Beta Coefficient	Standard Error	95% Conf. Interval	P-value
Not Enough Money to Make Ends Meet	9.06	2.06	5.01 – 13.11	<0.001

Note: CES-D= Center for Epidemiological Studies-Depression. Reference = reference category; NPI = Neuropsychiatric Inventory
a Identified as any caregiver who was not categorized as an adult child or spouse of the patient.

Table 3

Multivariable Regression Model Predicting Burden among Caregivers of Older Adults with Cognitive Impairment at the Time of Hospitalization, N=495

Variable	Beta Coefficient	Standard Error	95% Conf. Interval	P-value
Sex (Male)	-1.40	1.41	-4.18 – 1.38	0.321
Race (White)	1.53	1.43	-1.28 – 4.34	0.286
Age (years)	-0.12	0.05	-0.23 – -0.02	0.022
Relationship to patient:				
Other ^a	Reference			
Adult Child	2.50	1.53	-0.51 – 5.51	0.103
Spouse	4.50	2.04	0.49 – 8.51	0.028
Depressive symptoms (CES-D 16)	9.17	1.70	5.84 – 12.50	<0.001
Symptom Self-efficacy	-0.23	0.07	-0.37 – -0.09	0.002
Service Use Self-efficacy	-0.13	0.08	-0.29 – 0.03	0.114
NPI – Severity	0.15	0.15	-0.15 – 0.44	0.333
NPI – Distress	0.32	0.09	0.14 – 0.51	0.001
Existing diagnosis of dementia	3.05	1.77	-0.43 – 6.54	0.086
Presence of delirium	4.97	1.53	1.97 – 7.98	0.001
No. of Co-existing conditions	0.41	0.24	-0.06 – 0.88	0.087
Mini Mental State Examination	-0.23	0.12	-0.47 – 0.01	0.059
Basic Activities of Daily Living	-1.07	0.33	-1.72 – -0.42	0.001
Money Left Over at the End of Each Month:				
Enough Money Left Over	Reference			
Enough Money to Make Ends Meet	0.48	1.38	-2.24 – 3.19	0.730
Not Enough Money to Make Ends Meet	4.71	1.84	1.09 – 8.32	0.011

Notes: Reference = reference category; NPI = Neuropsychiatric Inventory; CES-D= Center for Epidemiological Studies-Depression; Variance inflation factors (VIP)= 1.48. Living Situation (resides with patient) was not included in the final model due to multi-collinearity.

^a Identified as any caregiver who was not categorized as an adult child or spouse of the patient.