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Featured Article

# Effects of cognition, function, and behavioral and psychological symptoms on out-of-pocket medical and nursing home expenditures and time spent caregiving for persons with dementia

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**Abstract**

**Introduction:** Clinical features of dementia (cognition, function, and behavioral and psychological symptoms) may differentially affect out-of-pocket medical and nursing home (NH) expenditures and informal care received (outcomes).

**Methods:** We used cross-sectional data (Aging, Demographics, and Memory Study) to estimate probabilities of experiencing outcomes by clinical features. For those experiencing an outcome, we estimated effects of clinical features on the amount of the outcome.

**Results:** No clinical feature predicted the probability of having out-of-pocket medical expenditures. For those with medical expenditures, higher cognition and poorer function were associated with more spending. Poorer function predicted having out-of-pocket NH expenditures. For those with NH expenditures, no clinical feature predicted the amount. Poorer function and a greater number of behavioral and psychological symptoms predicted the probability of receiving caregiving. For those receiving care, poorer function was associated with more caregiving.

**Conclusions:** Clinical features differentially impact outcomes with poorer function associated with all types of costs and caregiving received.

*Keywords:* Dementia care; Out-of-pocket costs; Alzheimer's disease costs; Time caregiving; Caregiving

## 1. Introduction

Dementia affects more than five million Americans and results in cognitive and functional declines and behavioral and psychological symptoms (BPS) [1–4]. Declines in cognition and function combined with BPSD result in a disproportionate use of formal and informal long-term care [1–3,5,6]. Given this increased reliance on care, the direct and indirect costs of dementia per patient to society can exceed $50,000 per year [5]. A significant portion of costs is incurred by families and Medicaid [3,5–10].

The most reliable estimates for the total net cost and net out-of-pocket cost of dementia come from two RAND studies that used data from the Health and Retirement Study (HRS) [5,7]. However, these studies did not evaluate the independent contributions of each key clinical feature—cognition, function, and BPS—to out-of-pocket cost. These clinical features may impact out-of-pocket spending by requiring more care to manage symptoms and causing caregivers to spend more time in supervision.

Prior studies evaluating effects of clinical features on total cost suggest that function is an important predictor

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[11–15]. However, results have been inconsistent and conflicting for the effects of cognition and BPS. Moreover, previous cost studies have important limitations including the use of nonrepresentative data sources, lack of a clinical diagnosis of dementia to identify the analytic sample, not separating medical expenditures from nursing home (NH) expenditures, and not disaggregating out-of-pocket expenditures from those covered by insurance [11–18]. Understanding the type of out-of-pocket cost (medical or NH expenditure) based on clinical features can assist in care planning and developing targeted interventions.

To address previous research limitations, this study used data from a subsample of HRS, the Aging, Demographics, and Memory Study (ADAMS)—a nationally representative survey of cognitive impairment—to evaluate the effects of cognition, function, and BPS on out-of-pocket medical and NH expenditures and time spent receiving informal caregiving.

## 2. Methods

### 2.1. Sample and data

HRS is a nationally representative longitudinal survey of adults aged $\geq$51 years [19]. Although the core HRS has measures evaluating cognition and function, the survey lacks a clinical diagnosis of dementia and does not contain measures related to BPS. Rather than imputing dementia status in the full HRS and not having access to measures of BPS, we used ADAMS data instead. The ADAMS subsample was drawn from the HRS (individuals $\geq$70 years) and was developed to provide population-based data on risk factors, prevalence, outcomes, and costs of cognitive impairment and dementia in the United States [20]. ADAMS respondents participated in an in-home clinical assessment during which a trained nurse and neuropsychology technician administered a standardized protocol to collect cognitive, functional, and behavioral and psychological measures. Following the in-home assessment, an independent consensus panel determined if the individual had dementia, cognitive impairment not dementia, or normal cognitive function [20].

We linked ADAMS respondents to their HRS survey to obtain sociodemographic variables that were not collected in ADAMS (RAND HRS Version N [The RAND HRS data file is an easy to use data set based on the HRS data. The RAND HRS file combines multiple HRS files into a single data file and contains imputations for missing data. The RAND HRS file was developed at RAND with funding from the National Institute on Aging and the Social Security Administration.]) [20]. Specifically, in addition to identifying a sample of individuals with a dementia diagnosis, ADAMS provided measures for cognition, function, and BPS and estimates of time spent receiving informal care (Supplementary Table 1 details the data source of model variables). HRS data provided estimates of out-of-pocket medical and NH expenditures and additional sociodemographic information.

We restricted our sample to ADAMS respondents (wave A) identified as having dementia with complete data on variables of interest (Fig. 1, Panels A and B). Although our analyses are cross-sectional, there was a lag between the ADAMS and HRS assessments (Table 1; mean lag = 7.42 months). To minimize potential bias associated with the lag and to maximize the available sample size, we linked ADAMS respondents to their closest available HRS wave (HRS wave 2000, 2002, or 2004). For out-of-pocket medical and NH expenditure analyses, but not time receiving care analyses, we excluded individuals who were linked to the HRS wave 2000 ($n$ = 18), as HRS combined out-of-pocket spending for medical and NH care in that wave. After the wave 2000, HRS distinguished between out-of-pocket medical and NH expenditures. To determine if the linking method impacted the analytic sample, we linked ADAMS respondents to the next HRS wave. Comparisons of the analytic sample based on linking method revealed no statistically significant differences in terms of outcome measures, clinical features, and key confounders (Supplementary Tables 2 and 3).

### 2.2. Measures of clinical features of dementia

Dementia was modeled using three clinical features, cognition, function, and BPS, evaluated in the ADAMS clinical assessment [1,2]. Cognition was measured using the Mini-Mental State Examination [21], scored from 0 to 30 with higher scores indicating greater cognitive function.

Function was assessed using an investigator-modified version of the Functional Activities Questionnaire (FAQ). The FAQ is a standardized measure to evaluate function that is used in other dementia surveys [22]. However, as it was not used in ADAMS, we identified survey questions that were administered and corresponded with the 10 functional domains assessed in the FAQ. For each domain, we evaluated if the individual had difficulty performing the representative tasks (yes/no): (1) handling small sums of money, (2) handling complicated financial transactions, (3) shopping independently, (4) performing hobbies, (5) carrying out routine household tasks, (6) feeding self, (7) recalling recent events, (8) understanding what she/he reads or sees on television, (9) remembering things about family and friends, and (10) finding one's way around familiar streets. For our analyses, we counted the number of "yes" responses to generate a summary score (0–10). Supplementary Table 4 compares the measures used in the FAQ with the investigator-developed version from ADAMS [23].

Finally, we evaluated the number of BPS that caregivers endorsed as occurring in the past month using the Neuropsychiatric Inventory Questionnaire which captures 12 symptoms: (1) delusions, (2) hallucinations, (3) agitation/aggression, (4) depression, (5) apathy, (6) elation, (7) anxiety, (8) disinhibition, (9) irritability, (10) motor disturbance, (11) sleep, and (12) appetite [24]. For each domain, caregivers indicated whether the behavior occurred (yes/no), and if yes, its frequency and severity. For our analyses, we

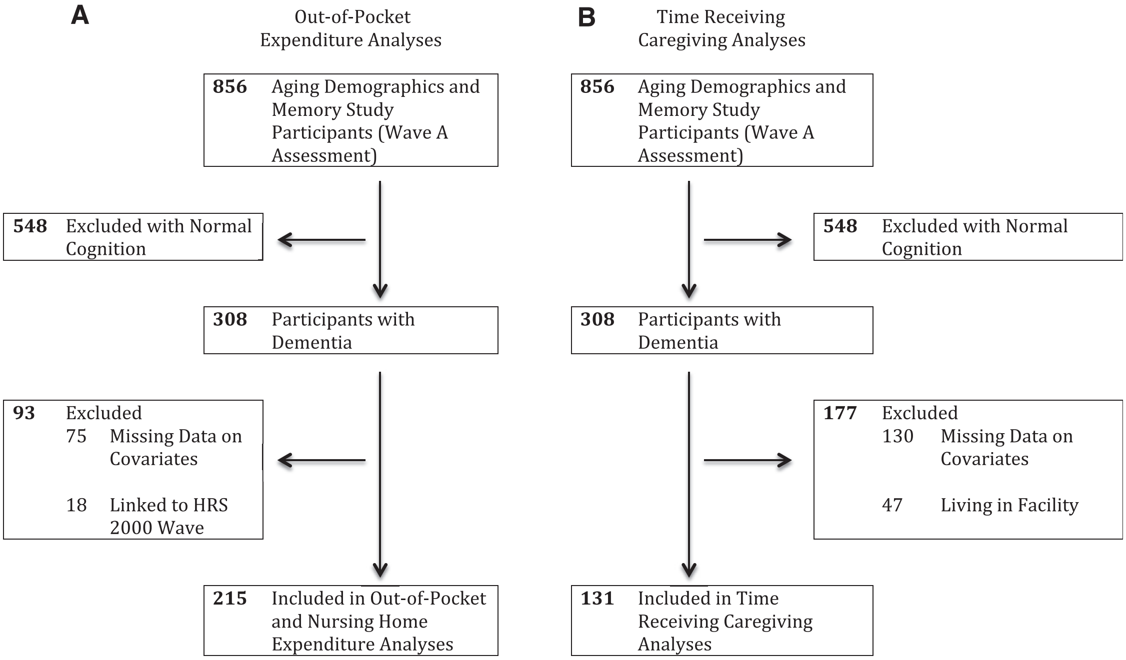

Fig. 1. Participation Cohort, Aging, Demographics, and Memory Study. (Panel A) The sample size in Panel A is for those included in the out-of-pocket expenditure analyses. Among those in the out-of-pocket medical and nursing home expenditure analyses 155 and 43 persons with dementia had expenditures >$0, respectively. (Panel B) The sample size in Panel B is for those included in the informal time receiving caregiving analyses (active care and supervision combined). Among those in the informal time receiving caregiving analyses 91 persons with dementia received >0 hours of active help and supervision combined. The time receiving caregiving analyses were limited to community-dwelling persons with dementia that had a caregiver and provide information on time caregiving.

counted the number of yes responses to generate a summary score reflecting the total number of behaviors endorsed (0–12). The number of BPS has been associated with caregiver burden and resource utilization [25–28].

### 2.3. *Outcomes*

We evaluated average monthly out-of-pocket medical care spending, average monthly out-of-pocket NH spending, and average monthly time in receipt of informal caregiving. All costs were converted to 2015 United States dollars using the medical care portion of the Consumer Price Index.

In the HRS, respondents or proxy respondents reported out-of-pocket expenditures over the previous 2 years for NH stays, hospital stays, medical visits, outpatient surgery, home health care, special services, and dental visits. Respondents or proxy respondents also reported out-of-pocket prescription drug spending over the previous month. Proxies responded for individuals who were unable to complete the survey without assistance ($n = 103$).

All spending (expect drug spending) was divided by 24 to estimate average monthly out-of-pocket spending. Measures of out-of-pocket medical spending (all categories expect NH spending) were summed together. Out-of-pocket NH spending was kept as a separate outcome measure.

ADAMS evaluated time that individuals with dementia received informal caregiving (informants were queried) in the previous month. The informal time receiving caregiving analyses were limited to community-dwelling persons with dementia that had a caregiver and provide information on time caregiving (Fig. 1, Panel B). Three measures of informal time caregiving were evaluated: (1) time spent receiving active help for assistance with functional tasks (e.g., cooking meals), (2) time spent receiving supervision to ensure safety, and (3) time spent receiving active care and supervision combined. Some informants reported providing one type of care (e.g., active help) but then had missing responses for the other types of care (e.g., supervision). When this occurred, the dyad was included in the analysis for which data were available. Consistent with other cost studies, we assumed caregivers could provide a maximum of 16 hours of care per day [5]. To evaluate the value of informal caregiving, we multiplied the market wage rate of a home health aide ($21 per hour) by time spent receiving care [29].

### 2.4. *Statistical analysis*

We estimated separate regression models for each outcome of interest: out-of-pocket medical expenditures, out-of-pocket NH expenditures, and time spent receiving active care, supervision, or both. A two-part modeling approach was used for all analyses as more than 25% of individuals had zero expenditure or received zero hours of caregiving [30]. First, we used logistic regression to estimate the probability of experiencing the outcome of interest (i.e., any out-of-pocket medical expenditures, any out-of-pocket NH expenditures, or any informal caregiving). Second, we estimated the continuous outcome of interest among those who experienced that

Table 1
Sample characteristics*

| Characteristics | Out-of-pocket and nursing home expenditures ($n$ = 215) | Informal caregiving sample ($n$ = 131) |
|---|---|---|
| Characteristics of persons with dementia | | |
| Mean cognition (SD), MMSE[†] | 16.05 (10.54) | 17.89 (9.96) |
| Mean number of functional limitations[‡] (SD) | 6.02 (3.49) | 5.48 (3.61) |
| Mean number of BPS[§] (SD) | 2.68 (3.78) | 2.40 (3.88) |
| Mean age (SD), years | 83.42 (10.16) | 83.36 (10.08) |
| Male, % | 35.13 | 38.22 |
| Non-Caucasian, % | 19.57 | 17.57 |
| Married, % | 24.60 | 29.84 |
| Long-term care insurance, % | 2.72 | 3.94 |
| Medicaid, % | 27.31 | 23.00 |
| Supplemental insurance (e.g., Medigap), % | 24.86 | 26.51 |
| Mean household income (SD), $, in thousands | 21.30 (32.24) | 23.67 (34.34) |
| Mean number of children (SD) | 2.87 (4.47) | 3.07 (3.70) |
| Mean number of comorbidities (SD) | 2.92 (2.28) | 2.66 (2.13) |
| HRS proxy respondent,[‖] % | 47.69 | 35.27 |
| Mean months between ADAMS and HRS assessments (SD) | 7.42 (4.63) | 7.57 (5.76) |
| Caregiver characteristics[¶] | | |
| Relationship | | |
| Spouse, % | 21.86 | 26.88 |
| Child, % | 46.66 | 56.45 |
| Other, % | 31.48 | 16.67 |
| Live with person with dementia, % | 46.11 | 60.36 |

Abbreviations: ADAMS, Aging, Demographics, and Memory Study; BPS, behavioral and psychological symptoms; HRS, Health and Retirement Study; MMSE, Mini-Mental State Examination; SD, standard deviation.

*Aging Demographics and Memory Study sample weights were used.

[†] MMSE is scored from 0 to 30 with lower scores indicating greater cognitive impairment.

[‡] Measure of function is based on a modified version of the Functional Activities Questionnaire and is scored from 0 to 10 with higher scores indicating greater functional impairment.

[§] BPS is the number of BPS identified on Neuropsychiatric Inventory Questionnaire and is scored from 0 to 12 with higher scores indicating more symptoms.

[‖] The proportion of the sample that had a proxy respondent during the core HRS survey.

[¶] The proportions in the expenditure sample may not sum to 1 because of missing data. The informal caregiving sample is a subsample of the expenditure sample and does not have missing caregiver characteristics.

outcome using a generalized linear model with a log link and gamma distribution [30].

All models included main effects for cognition, function, and BPS. On the basis of a review of the literature, we identified potential confounding variables. The two-part model evaluating out-of-pocket medical expenditures controlled for age, gender, race, marital status, Medicaid status, supplemental insurance, household income, number of children, and an indicator for the total number of chronic conditions (0–8) among the following: stroke, diabetes, heart problems, hypertension, lung disease, cancer, psychiatric problems, or arthritis. The model also included terms for if an individual had a proxy respondent, and time between the ADAMS and HRS assessments. In a sensitivity analysis, we excluded terms for insurance status to evaluate their potential confounding effect on the relationship between clinical features and out-of-pocket spending.

Because of small sample sizes, the second part of the two-part models evaluating out-of-pocket NH expenditures ($>\$0$ $n = 45$) and time caregiving ($>0$ hours caregiving $n = 91$) did not include all potential confounders. Rather, based on theoretical and empirical considerations, we a priori identified confounders that we believed were most strongly associated with the clinical features and outcome. For the NH analysis, we included indicators for Medicaid and long-term care insurance status. For the time caregiving analysis, we included predictors for age, Medicaid status, number of chronic conditions, relationship between the caregiver and person with dementia (spouse, child, or other), and an indicator for whether the caregiver lived with the person with dementia. In another sensitivity analysis, we evaluated the effect of adding an additional covariate on the average marginal effects of the clinical features. The first part of the models had sample sizes sufficient to include all potential confounders. Finally, for the NH analysis, we conducted a similar sensitivity analysis (described previously) where we excluded terms for insurance status.

All analyses were conducted using ADAMS survey weights and Stata version 12 survey commands (Stata, College Station, TX).

## 3. Results

Of individuals with dementia that met inclusion criteria for out-of-pocket expenditure analyses ($n$ = 215), the mean age was 83.42 years (standard deviation [SD]

10.16); 35.13% were male, and 80.43% were White (Table 1; Supplementary Table 2 compares those included/excluded in the expenditure analysis). A subsample of individuals with dementia resided in the community and had a caregiver informant provide information on time caregiving ($n$ = 131). The mean age of individuals with dementia in the time caregiving analyses was 83.36 years (SD 10.42); 40.12% were male, and 26.88% were cared for by a spouse (Table 1; Supplementary Table 3 compares those included/excluded in the time caregiving analysis).

### 3.1. *Out-of-pocket medical expenditures*

The average (obtained from regressions) probability of having any out-of-pocket medical spending ($n$ = 215) was 0.77 (95% confidence interval [CI]: 0.67, 0.88) with average spending among those with these expenditures ($n$ = 155) of $252.23 (95% CI: $195.50, $308.97) per month.

Cognition, function, and the number of BPS did not significantly predict if a person with dementia had out-of-pocket medical expenditures (Table 2). However, not being on Medicaid, non-Whites, and having comorbidities were associated with a higher probability of having expenditures (Supplementary Table 5 reports complete results of the two-part model).

In the second part of the model, cognition and function significantly predicted the amount of out-of-pocket medical expenditures (Table 2). A one-unit improvement in cognition was associated with $8.90 (95% CI: $1.18, $16.62) additional spending per month. Conversely, one-additional functional limitation was associated with $24.68 (95% CI: $1.11, $48.25) additional spending per month. More household income also was significantly associated with spending (Supplementary Table 5). The inclusion/exclusion of the insurance covariates did not alter effects of the clinical features on spending.

### 3.2. *Nursing home expenditures*

The average probability of having any out-of-pocket NH spending ($n$ = 215) was 0.26 (95% CI: 0.15, 0.37), with average spending for those with these expenditures ($n$ = 43) being $2494.40 (95% CI: $863.20, $4126.17) per month.

One-additional functional limitation was associated with a .05 (95% CI: 0.01, 0.09) increase in the probability of having out-of-pocket NH expenditures in a month. Neither cognition nor the number of BPS significantly predicted the probability of having NH expenditures; however, being White and not being married increased the risk of having expenditures (Table 2; Supplementary Table 6 reports complete results of the two-part model). Among those with NH expenditures, no clinical feature predicted the amount. Being on Medicaid and having long-term care insurance were associated with less out-of-pocket spending. In the sensitivity analysis, the inclusion of additional confounders and

Table 2
Two-part model results for average monthly out-of-pocket medical and nursing home expenditures

| Variable | Out-of-pocket medical expenditures (Part 1 $n$ = 215; Part 2 $n$ = 155) | | Out-of-pocket nursing home expenditures (Part 1 $n$ = 215; Part 2 $n$ = 43) | |
|---|---|---|---|---|
| | Coefficient (95% CI) | Marginal effect (95% CI) | Coefficient (95% CI) | Marginal effect (95% CI) |
| Part 1 (logistic regression): probability of having a positive expenditure | | | | |
| Cognition | 0.06 (−0.02, 0.14) | 0.01 (−0.01, 0.01) | −0.08 (−0.21, 0.05) | −0.01 (−0.03, 0.01) |
| Function | −0.04 (−0.39, 0.31) | 0.00 (−0.04, 0.03) | 0.36 (0.05, 0.67) | 0.05 (0.01, 0.09) |
| BPS | −0.22 (−0.47, 0.03) | −0.02 (−0.05, 0.00) | −0.11 (−0.31, 0.09) | −0.01 (−0.04, 0.01) |
| Part 2 (generalized linear model log link and gamma distribution): expenditures conditional on positive expenditures | | | | |
| Cognition | 0.04 (0.01, 0.06) | $8.90 ($1.18, $16.62) | −0.03 (−0.11, 0.05) | −$75.11 (−$297.44, $147.22) |
| Function | 0.10 (0.01, 0.18) | $24.68 ($1.11, $48.25) | −0.13 (−0.88, 0.61) | −$336.60 (−$2329.57, $1656.36) |
| BPS | 0.02 (−0.06, 0.09) | $4.21 (−$15.15, $23.57) | 0.00 (−0.38, 0.38) | −$6.27 (−$953.41, $940.87) |

Abbreviations: ADAMS, Aging, Demographics, and Memory Study; BPS, behavioral and psychological symptoms; CI, confidence interval; HRS, Health and Retirement Study; MMSE, Mini-Mental State Examination.

NOTE. Cognition is evaluated using the MMSE (scored 0–30). Higher MMSE scores indicate greater cognitive abilities. Function (scored 0–10) is evaluated as the number of functional limitations. Higher functional scores indicate more limitations. BPS are evaluated as the number of symptoms endorsed by caregivers as occurring using the 12 items of the Neuropsychiatric Inventory Questionnaire. Higher BPS scores indicate more symptoms. Marginal effects in the first part (second part) represent the change in probability (out-of-pocket expenditures) given a change in a measure of clinical feature. Both parts of the out-of-pocket medical expenditure models adjusted for age, gender, race, marital status, Medicaid status, supplemental insurance, household income, number of children, number of comorbidities, if respondent had an HRS proxy, and time between the ADAMS and HRS assessment. The first part of the out-of-pocket nursing home model adjusted for age, gender, race, marital status, Medicaid status, long-term care insurance, supplemental insurance, household income, number of children, number of comorbidities, if respondent had an HRS proxy, and time between the ADAMS and HRS assessment. The second part of out-of-pocket nursing home model adjusted Medicaid status and long-term care insurance.

the inclusion/exclusion of insurance covariates did not alter effects of the clinical features on spending.

### 3.3. *Time spent caregiving*

On average, the probability of receiving informal caregiving was 0.50 (95% CI: 0.37, 0.63) for active care ($n$ = 129), 0.46 (95% CI: 0.32, 0.60) for supervision ($n$ = 124), and 0.52 (95% CI: 0.38, 0.66) for both ($n$ = 131). Average hours of informal caregiving received per month among those who received caregiving were 215.75 (95% CI: 169.51, 262.00) for active care ($n$ = 86), 228.06 (95% CI: 174.74, 281.38) for supervision ($n$ = 80), and 286.37 (95% CI: 245.26, 327.48) for both ($n$ = 91).

Function and the number of BPS, but not cognition, were significantly associated with an increase in the probability of receiving all types of informal caregiving (Table 3; Supplementary Tables 7–9 report complete results of the two-part models). Specifically, one-additional functional limitation and one-additional BPS were associated with .07 (95% CI: 0.01, 0.12) and .05 (95% CI: 0.00, 0.09) increases in the probability of receiving both types of care in a month, respectively. Function was the only clinical feature to significantly predict the amount of all types of caregiving. One-additional functional limitation was associated with 43.65 (95% CI: 18.19, 69.12) additional hours of receiving both types of care in a month (Table 3). On the basis of the replacement cost ($21 per hour) of purchasing similar care in the market, one-additional functional limitation equals $916.65 worth of additional care being provided by a family caregiver in a month. In the sensitivity analysis, the inclusion of confounders did not change model conclusions.

## 4. Discussion

This is the first study of its kind to use nationally representative data with a sample that has a clinical diagnosis to estimate the effect of three important clinical features of dementia—cognition, function, and BPS—on out-of-pocket medical and NH expenditures and time spent caregiving. We found differential effects of these clinical features on type of cost incurred and time spent caregiving.

Cognition, function, and BPS did not predict if an individual incurred any out-of-pocket expenditure, but having comorbidities were associated with a greater risk of having expenditures. The presence of comorbidities may amplify the effect of clinical features on out-of-pocket expenditures [31,32] and speaks to the importance of identifying and managing comorbidities in individuals with dementia. Future studies with larger sample sizes are warranted to investigate the combined effect of comorbidities and clinical features on expenditures.

Among those with any out-of-pocket expenditure, better cognition and poorer function, but not the number of BPS and comorbidities, predicted more spending. Others have similarly reported this differential effect [12,14]. With

Table 3
Two-part model results for average monthly time spent caregiving

| Variable | Time providing active help (Part 1 $n$ = 129; Part 2 $n$ = 86) | | Time providing supervision (Part 1 $n$ = 124; Part 2 $n$ = 80) | | Time providing any help (Part 1 $n$ = 131; Part 2 $n$ = 91) | |
|---|---|---|---|---|---|---|
| | Coefficient (95% CI) | Marginal effect (95% CI) | Coefficient (95% CI) | Marginal effect (95% CI) | Coefficient (95% CI) | Marginal effect (95% CI) |
| Part 1 (logistic regression): probability of any time spent caregiving | | | | | | |
| Cognition | −0.02 (−0.20, 0.16) | 0.00 (−0.03, 0.02) | −0.07 (−0.25, 0.12) | −0.01 (−0.03, 0.02) | −0.05 (−0.23, 0.14) | −0.01 (−0.03, 0.02) |
| Function | 0.45 (0.03, 0.87) | 0.07 (0.01, 0.13) | 0.52 (0.12, 0.91) | 0.07 (0.01, 0.13) | 0.44 (0.03, 0.84) | 0.07 (0.01, 0.12) |
| BPS | 0.37 (0.15, 0.60) | 0.05 (0.02, 0.09) | 0.34 (0.01, 0.66) | 0.05 (0.00, 0.09) | 0.30 (0.03, 0.57) | 0.05 (0.00, 0.09) |
| Part 2 (generalized linear model log link and gamma distribution): time caregiving conditional on any caregiving | | | | | | |
| Cognition | −0.03 (−0.08, 0.01) | −7.17 (−16.81, 2.48) | −0.01 (−0.06, 0.04) | −2.54 (−13.32, 8.24) | −0.03 (−0.08, 0.01) | −9.58 (−22.58, 3.05) |
| Function | 0.19 (0.06, 0.32) | 40.68 (10.10, 71.26) | 0.27 (0.19, 0.36) | 61.72 (40.87, 82.56) | 0.15 (0.06, 0.24) | 43.65 (18.19, 69.12) |
| BPS | −0.02 (−0.10, 0.07) | −3.68 (−21.84, 14.48) | −0.01 (−0.10, 0.08) | −2.20 (−23.16, 18.75) | 0.01 (−0.08, 0.09) | 2.44 (−22.18, 27.07) |

Abbreviations: BPS, behavioral and psychological symptoms; CI, confidence interval; MMSE, Mini-Mental State Examination.

NOTE. Cognition is evaluated using the MMSE (scored 0–30). Higher MMSE scores indicate greater cognitive abilities. Function (scored 0–10) is evaluated as the number of functional limitations. Higher functional scores indicate more limitations. BPS are evaluated as the number of symptoms endorsed by caregivers as occurring using the 12 items of the Neuropsychiatric Inventory Questionnaire. Higher BPS scores indicate more symptoms. Marginal effects in the first part (second part) represent the change in probability (number of hours caregiving) given a change in clinical feature. The first part of all time spent caregiving models adjusted for age, gender, race, Medicaid status, household income, number of children, number of comorbidities, caregiver relationship to person with dementia, and if the caregiver lives with the person with dementia. The second part of the models adjusted for age, Medicaid status, number of comorbidities, caregiver relationship to person with dementia, and if the caregiver lives with the person with dementia.

greater cognitive impairment, medical care may be less aggressive reflecting either advance care directives or clinical judgment concerning the marginal value of aggressive care, especially in the context of limited interventions for treating cognitive decline [33]. In contrast, functional limitations can be managed throughout the disease with formal caregiving such as home care [34].

Poorer function predicted having NH expenditures, but no clinical feature significantly predicted the amount of such expenditures. Although other studies show that cognition, function, and BPS predict NH placement, this is the first study to our knowledge to evaluate their independent effect on actual out-of-pocket NH payments [35]. In our analysis, the probability of experiencing NH expenditures represents the probability of being in and paying out-of-pocket for the stay in the past 2 years. This is different than the probability of being institutionalized at a given point in time. The clinical features may not have predicted the amount of NH expenditures because individuals in our sample had been living in a facility over a long period of time (>1 year) leading to possibly lack of variation in expenditures. We were unable to distinguish between out-of-pocket payments for subacute care and long-term NH stays. However, given the long duration of NH stays of this sample and limited Medicare NH benefit, the observed out-of-pocket spending is most likely attributed to long-term stays.

Poorer function and a greater number of BPS significantly increase the probability of receiving informal care. In addition, function predicted the amount of informal care that was received. As some interventions have been shown to improve or maintain daily function and reduce occurrences of BPS, they may also impact the need for informal care and the amount provided [36–43]. With few exceptions, trials have not evaluated the effect of interventions on time spent caregiving [44,45]. Future cost-effectiveness studies can use the information in our analyses to connect the clinical benefits of interventions with associated reductions in time caregiving and hence related costs.

In our analyses, poorer function was a leading predictor of out-of-pocket expenditures suggesting that functional decline is an important target for interventions [39]. Little is known about the effect of function on costs across other diseases and how it compares to individuals with dementia. A recent study by Zhang et al. [46] found that community-dwelling adults >50 years with three or more functional limitations incurred $48.54 more in out-of-pocket expenditures per month than those without limitations. Conversely, we found that one-additional functional limitation resulted in $24.68 additional out-of-pocket medical spending. Three limitations would result in $74.04 of additional spending. Thus, the effect of a functional limitation in a person with dementia is likely greater than the same limitation in someone without dementia.

Our objective was to evaluate the effect of each clinical feature on out-of-pocket spending, but Medicare and Medicaid expenditures represent other important components of the total cost of dementia care as well. Although less is known about the effect of each key feature on Medicaid expenditures, others have found that functional limitations are associated with more Medicare spending [47]. Future studies should continue to investigate the relationship between each clinical feature and Medicare and Medicaid expenditures to identify specific intervention targets for care planning and projecting care costs.

Our study is not without limitations. We rely on reported data from individuals with dementia (47% of the sample had a proxy respondent during the core HRS survey from which out-of-pocket spending data were obtained), and consequently, we may underestimate out-of-pocket spending. However, HRS has validated procedures to limit under reporting of spending [7]. Although our results provide a basis for understanding out-of-pocket NH expenditures and time caregiving, we were unable to control for all potential confounders because of small sample sizes. Nevertheless, in sensitivity analyses our results were robust to the inclusion of additional confounders and overall conclusions did not change. Because of missing data (Fig. 1, Panels A and B) on outcomes of interest and key covariates, we were unable to use all ADAMS participants identified as having dementia. This may limit the generalizability of findings. Yet, comparisons between those included and those excluded in the out-of-pocket expenditure analyses revealed few statistically significant differences (Supplementary Table 2). Compared with those with dementia excluded from the time receiving caregiving analyses, those with dementia included were slightly younger, more cognitively intact, and had fewer functional limitations. This is not surprising given the time caregiving analyses were limited to those residing in the community (Supplementary Table 3). Finally, we used cross-sectional data and did not have information on total time living with dementia. This may limit our view of the long-term implications of costs of dementia care such that our figures are underestimations.

In conclusion, poorer function is associated with more of out-of-pocket medical spending, an increase in the risk of having out-of-pocket NH expenditures, and an increase in the risk and amount of informal caregiving received. Better cognition predicted more out-of-pocket medical spending, but cognition did not predict any other outcome. A greater number of BPS predicted an increase in the risk of receiving all types of caregiving. Thus, BPS and function should be targeted by interventions.

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## Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.jalz.2016.12.011.

### RESEARCH IN CONTEXT

1. Systematic review: There is limited information on the effect of three important clinical features of dementia—cognition, function, and behavioral and psychological symptoms—on out-of-pocket medical and nursing home expenditures and informal care received.
2. Interpretation: Poorer function is associated with more of out-of-pocket medical spending, an increase in the probability of having out-of-pocket nursing home expenditures, and an increase in the probability and amount of informal care received. Higher cognition only predicted more out-of-pocket medical spending, and a greater number of behavioral and psychological symptoms predicted an increase in the probability of receiving informal care.
3. Future directions: Studies should investigate the effect of clinical features on specific types of out-of-pocket spending (e.g., inpatient and outpatient care) and on Medicare expenditures.

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