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Caregiver Burden and Neuropsychiatric Symptoms in Older Adults with Cognitive Impairment: The Aging, Demographics, and Memory Study (ADAMS)

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Abstract

OBJECTIVES—To estimate the quantity of informal care associated with neuropsychiatric symptoms in older adults with cognitive impairment

DESIGN—Cross-sectional analysis

SETTING—The Aging, Demographics, and Memory Study

PARTICIPANTS—A sample (n=450) of adults aged 71 and older with cognitive impairment drawn from the Health and Retirement Study

MEASUREMENTS—The presence of neuropsychiatric symptoms (delusions, hallucinations, agitation, depression, apathy, elation, anxiety, disinhibition, irritation, and aberrant motor behaviors) was identified using the Neuropsychiatric Inventory. Cognitive category (normal, cognitive impairment without dementia [CIND], or dementia) was assigned by a consensus panel. The hours per week of active help and supervision were ascertained by informant questionnaire.

RESULTS—Among older adults with CIND or dementia, those with no neuropsychiatric symptoms received an average of 10.2 hours of active help and 10.9 hours of supervision per week from informal caregivers. Those with 1 or 2 neuropsychiatric symptoms received an additional 10.0 hours of active help and 12.4 hours of supervision per week, while those with 3 or more symptoms received an additional 18.2 hours of active help and 28.7 hours of supervision per week ($p < .001$). The presence of irritation (14.7 additional hours) was associated with the greatest number of additional hours of active help. The presence of aberrant motor behaviors (17.7 additional hours) and disinhibition (17.5 additional hours) were associated with the greatest number of additional hours of supervision.

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CONCLUSIONS—Neuropsychiatric symptoms among those with CIND or dementia are associated with a significant increase in the provision of informal care. This care represents a significant time commitment for families and a significant economic cost to society.

Keywords

neuropsychiatric symptoms; informal caregiving; cognitive impairment

Introduction

Neuropsychiatric symptoms, such as agitation, depression, apathy, delusions, and hallucinations, are common in older adults with dementia and milder forms of cognitive impairment. Population-based studies have estimated that 40-50% of individuals with cognitive impairment without dementia (CIND) or mild cognitive impairment (MCI), 2-3 and 50-60% of those with dementia have at least one neuropsychiatric symptom, compared to only 10-20% of those with normal cognitive function.⁴⁻⁵⁻⁶⁻⁷ The pattern of presentation of individual neuropsychiatric symptoms differs in those with CIND and dementia, with psychotic symptoms and aberrant motor behaviors being more prevalent among demented persons.⁷ A greater number of neuropsychiatric symptoms and some specific individual symptoms (e.g., depression, anxiety, aberrant motor behaviors) were independently associated with functional limitations among those with CIND and dementia, even after adjusting for severity of cognitive impairment and other potentially confounding factors.⁷ Prior studies have identified some specific neuropsychiatric symptoms (e.g., psychotic symptoms, aggressive behaviors, and wandering) that are associated with a significantly higher risk of institutionalization⁸⁻⁹ and found that depression and hallucinations were associated with a significantly higher mortality.⁸⁻¹⁰

Older adults with cognitive impairment living in the community are usually cared for by family or friends, and the quantity of this informal care is substantial and increases sharply as cognitive impairment worsens.¹¹ There are only a few studies that have estimated the amount of informal caregiving attributable to neuropsychiatric symptoms among older adults with cognitive impairment. Two of them did not include individuals in the US (one from Canada,¹² another from Israel¹³), while the other used a sample of community-dwelling male veterans in the US.¹⁴ The results of these studies may not be representative of caregiving for older adults in the US. In addition, none of these prior studies examined the association of individual neuropsychiatric symptoms with the amount of informal care provided.

We hypothesized that a greater number of overall neuropsychiatric symptoms, as well as particular individual symptoms (e.g., depression and aberrant motor behaviors⁴) would be independently associated with an increased quantity of informal caregiving. To test this hypothesis we estimated the quantity of active help and supervision provided to a representative sample of older adults with CIND and dementia. Given the growing number of older adults in the US, accurate estimates of the social and economic burden associated with CIND and dementia are important for patients, families, and policy-makers.

Methods

Sample

We used data from the Aging, Demographics, and Memory Study (ADAMS) and the 2000 and 2002 waves of the Health and Retirement Study (HRS). The HRS is an ongoing biennial longitudinal survey of a nationally representative cohort of more than 20,000 U.S. adults aged 51 or older who reside both in the community and in nursing homes throughout the 48

contiguous United States.¹⁵ The HRS sample is selected using a multi-stage area probability sample design and population weights are constructed so that valid inferences can be drawn for the entire US aged 51+ population. Weights are constructed in a two-step process, where the first step develops post-stratified household weights using the initial sampling probabilities for each household, as well as birth year, race/ethnicity, and gender of household members. The second step uses these household weights to then construct post-stratified respondent-level weights which are scaled to yield weight sums corresponding to the number of individuals in the US population as measured by the US Census Bureau's Current Population Survey (CPS) for the month of March in the year of data collection.¹⁶ The HRS is sponsored by the National Institute on Aging and performed by the Institute for Social Research at the University of Michigan.

The ADAMS is a sub-study of the HRS focused on identifying the prevalence and outcomes of cognitive impairment and dementia. The ADAMS sample was a stratified random subsample of 1770 individuals aged 71 years or older from 5 cognitive strata based on scores for the 35-point HRS cognitive scale (HRS cog)¹⁷ or proxy assessments of cognition from the 2000 or 2002 wave of the HRS.¹⁸ 109 individuals (13%) in the ADAMS sample resided in nursing homes at the time of the ADAMS assessment. Population weights for nursing home residents were derived using data from the 2000 Census and the Centers for Medicare and Medicaid Services (CMS) Minimum Data Set (MDS).¹⁸ Full details of the ADAMS sample design and selection procedures are described elsewhere.¹⁸ 19·20 The initial assessments of ADAMS subjects occurred between July 2001 and December 2003, on average, 13.3 months (SD, 6.9) after the most recent HRS interview. The study flow and additional details on participation rates have been reported previously.²⁰ A total of 856 individuals (mean age 81.5 years) received the initial ADAMS assessment. We excluded 16 individuals who did not have a completed Neuropsychiatric Inventory (NPI), 307 individuals with normal cognition, and 85 individuals who resided in a nursing home at the time of the initial assessment. We also excluded 2 cases for whom a paid caregiver completed the informant questionnaire. Therefore we used a total sample of 450 individuals with CIND or dementia who were residing in the community at the time of the study. To minimize the potential bias due to selective nonparticipation, the ADAMS performed a response propensity analysis and developed nonresponse adjustments to the ADAMS sample selection weights.¹⁸ The ADAMS then constructed population sample weights to take into account the probabilities of selection into the stratified sample design and to adjust for differential nonparticipation in the ADAMS.¹⁸

The ADAMS data are publicly available and can be obtained from the HRS web site (<http://hrsonline.isr.umich.edu>). The institutional review boards at Duke University Medical Center and the University of Michigan approved all study procedures, and study participants or their surrogates provided informed consent.

Measurements

Cognitive Evaluation—In the ADAMS, a nurse and a neuropsychology technician assessed all participants at their residence for cognitive impairment. The full details of the assessment and diagnostic procedures are described elsewhere.¹⁹·20 During the assessment, the participant completed a battery of neuropsychological measures; a self-reported depression measure, (the Composite International Diagnostic Interview-Short Form (CIDI-SF));²¹ a standardized neurological examination; a blood pressure measurement; collection of buccal DNA samples for apolipoprotein E (*APOE*) genotyping; and a 7-minute, videotaped segment covering portions of the cognitive status and neurological examinations. Proxy informants provided information about the participant's cognitive impairment, functional limitations, neuropsychiatric symptoms, and medical history. The informant was

usually a spouse or child (73%), and informants lived with the participant in just over half of the cases (53%). The ADAMS consensus expert panel of neuropsychologists, neurologists, geropsychiatrists, and internists reviewed all information collected during the in-home assessment and assigned cognitive diagnoses. Diagnoses were within three cognitive categories: normal cognitive function, cognitive impairment without dementia (CIND), and dementia. The Diagnostic and Statistical Manual of Mental Disorders, Revised Third Edition,²² and the Diagnostic and Statistical Manual of Mental Disorder, Fourth Edition²³ criteria were used for diagnosis of dementia. CIND was defined as mild cognitive or functional impairment reported by the participant or informant that did not meet criteria for dementia, or performance on neuropsychological measures that was both below expectation and at least 1.5 SDs below published norms on any test within a cognitive domain (e.g., memory, orientation, language, executive function, praxis).

Those with dementia were classified by the stage or severity using the Clinical Dementia Rating (CDR) Scale,²⁴⁻²⁵⁻²⁶ a widely used assessment tool that stages the severity of dementia based on information obtained from both the participant and informant during the course of the evaluation. As in prior studies,⁶⁻⁷⁻²⁷ we defined mild dementia as CDR stage 0.5 or 1, moderate dementia as CDR stage 2, and severe dementia as CDR stages 3-5.

Neuropsychiatric Symptoms—The ADAMS assessed neuropsychiatric symptoms using the Neuropsychiatric Inventory (NPI). The NPI is a widely accepted measure of neuropsychiatric symptoms associated with cognitive impairment.²⁸⁻²⁹ It collects information on symptoms during the past month in 10 domains -- delusions, hallucinations, agitation, depression, anxiety, elation, apathy, disinhibition, irritability, and aberrant motor behaviors -- using a structured interview of a knowledgeable informant. For each symptom reported by the informant, additional information is obtained on the frequency (4-point scale), severity (3-point scale) and caregiver distress (6-point scale) associated with the behavior. We defined symptoms as clinically significant if the product of the frequency and severity score of the reported symptom was 4 or higher.³⁰ Psychometric properties of the NPI have been previously reported.²⁸ The NPI has been validated in prior studies and has also been shown to have very good reliability (Cronbach's alpha was 0.88 for internal consistency reliability).²⁸

Quantity of Active Help and Supervision—In the ADAMS, each informant was asked about the quantity of active help provided for the subjects' ADL/IADL limitations, as well as the amount of time spent supervising the subject to ensure safety. The questions were: "During the last month, how many days (and hours per day) did you provide active help to your friend or relative because of his/her health or memory problem?", "During the last month, how many days (and hours per day) did you supervise your friend or relative to ensure safety, provide reassurance, or to make sure that nothing went wrong?" We calculated the intensity (number of weekly hours) of informal care using the average number of days in the prior month and average number of hours per day that informants reported providing active help and supervision to respondents.¹¹⁻³¹ We imposed a limit of 16 hours of care per day for any individual caregiver to allow for 8 hours of sleep.¹¹⁻³²

Sociodemographic Characteristics—We obtained data on participants' age (71-79, 80-89, ≥90 years), sex, race (white, black, other), and years of formal education (<12, 12, >12 years) from the ADAMS. Household net worth (categorized by quartiles), and marital / living status (married/partnered living together, unmarried living with other, unmarried living alone) were determined using data from the 2000 and 2002 waves of the HRS.

Medical Comorbidities—The HRS collects data on the presence of chronic medical conditions (heart disease, chronic lung disease, diabetes, cancer, musculoskeletal conditions,

stroke, and psychiatric problems) in each wave of the survey.³³ Respondents report whether a physician has ever diagnosed each condition. We used data on chronic conditions from either the 2000 or 2002 wave of the HRS and included them in the analysis as dichotomous variables.

Statistical Analysis—We compared sociodemographic characteristics, total number of neuropsychiatric symptoms, and presence of individual neuropsychiatric symptoms across cognitive categories using chi-square tests. Since the goal of the analysis was to quantify the additional time for informal caregiving attributable to the presence of any neuropsychiatric symptoms, we adjusted for the presence of other factors that might independently affect the quantity of informal care, including sociodemographics, cognitive category, and medical comorbidities.

Because a substantial proportion of respondents received no informal care in the month prior to the assessment (e.g., 38% for active help, 33% for supervision), and because the distribution of informal caregiving time was highly skewed, we used a two-part multivariable regression model.³⁴⁻³⁵ For the first part, we used logistic regression to determine the relationship of neuropsychiatric symptoms to the likelihood of receiving any informal care, adjusting for the potentially confounding factors noted above. For the second part, we used ordinary least squares linear regression to examine the association between neuropsychiatric symptoms and the natural log of informal caregiving hours among those who received any informal care, again adjusting for the same potentially confounding factors. The results from the two parts of the model were then combined to obtain an estimate of the unconditional effect (i.e., not conditioned on receiving any informal care) of number of neuropsychiatric symptoms and the presence of individual symptoms on the quantity of informal care received. For ease of interpretation, regression results from the two-part model were retransformed from log hours to hours.³⁶ We repeated the analysis with the variables for clinically significant neuropsychiatric symptoms (frequency score times severity score ≥ 4) and compared these results with those from the previous analyses for the presence/absence of any neuropsychiatric symptoms.

All analyses were weighted and adjusted for the complex sampling design (stratification, clustering, and nonresponse) of both the ADAMS and the HRS.¹⁸ STATA, version 10.1 (Stata Corp, College Station, TX) was used for data analysis. All reported *p* values are two-tailed, and a *p* value < 0.05 was considered statistically significant.

Results

Characteristics of the Study Sample

Table 1 shows the sociodemographic characteristics and the presence of neuropsychiatric symptoms stratified by cognitive category (e.g., CIND, mild dementia, moderate dementia, and severe dementia). Those with more advanced cognitive impairment were older, and more likely to be women. More severe cognitive impairment was associated with an increased risk for presence of neuropsychiatric symptoms.

Total Number of Neuropsychiatric Symptoms and Informal Caregiving

Figure 1 shows the estimated hours per week provided by informal caregivers for active help and supervision stratified by the total number of neuropsychiatric symptoms. There was a positive association of number of neuropsychiatric symptoms and weekly hours of informal care, even after adjusting for cognitive category and medical comorbidities. Older adults with 1-2 neuropsychiatric symptoms received an additional 10.0 hours per week of active help and 12.4 hours per week of supervisory care compared to those without any

neuropsychiatric symptoms, while those with 3 or more neuropsychiatric symptoms received an additional 18.2 hours of active help and 28.7 hours of supervision. Those with one or more clinically significant neuropsychiatric symptoms received an additional 13.2 hours of active help and 28.4 hours of supervision ($P < 0.001$).

Individual Neuropsychiatric Symptoms and Informal Caregiving

Figure 2 shows the adjusted incremental weekly hours of active help and supervision provided by informal caregivers for each individual neuropsychiatric symptom. Older adults with depression, anxiety, irritation, or aberrant motor behaviors received an additional 10 or more hours of active help compared to those without these symptoms. An additional 20 or more hours of active help was provided for those with clinically significant agitation, anxiety, or irritation. Those with depression, disinhibition, and aberrant motor behaviors received an additional 10 or more hours of supervision compared to those without the symptoms. An additional 20 or more hours of supervision was provided to those with clinically significant agitation, depression, disinhibition, or aberrant motor behaviors. Those with agitation received a substantial amount of both active help and supervision, but only when the agitation was clinically significant.

Discussion

In this study using a nationally representative sample of older adults with CIND and dementia, we found that a greater number and increased severity of neuropsychiatric symptoms was independently associated with an increased quantity of informal care, even after adjusting for potentially confounding factors including severity of cognitive impairment and medical comorbidities. We also identified individual neuropsychiatric symptoms among those with CIND and dementia that significantly increased the caregiving burden on family members.

It may be difficult to compare our estimates of the quantity of informal care attributable to neuropsychiatric symptoms with other studies because the study methodology was substantially different. One study using relatively similar methods estimated that caregivers provided 27.7 weekly hours for active help for functional limitations and 24.7 hours for supervisory care to demented individuals.¹³ These estimates are somewhat greater than ours, probably due to a higher level of cognitive impairment in the study sample.

To our knowledge, this is the first study to estimate the quantity of active help and supervisory care provided by informal caregivers according to the number, severity, and clinical significance of neuropsychiatric symptoms. Most symptoms that were associated with a greater amount of active help (e.g., depression, anxiety, aberrant motor behaviors) have been previously shown to be linked with a higher level of functional limitations.⁷ Our study also highlights the frequency and importance of supervisory care for neuropsychiatric symptoms in those with CIND and dementia; we found that many individual symptoms, including agitation, depression, disinhibition, and aberrant motor behaviors were associated with receiving supervisory care, probably because these symptoms are likely associated not only with functional limitations, but also a higher risk of falls and unsafe behaviors such as wandering, binge eating, and aggressiveness.

The strengths of this study include a nationally representative population-based sample that included the full range of cognitive function in those with CIND or dementia, the use of a well-validated comprehensive assessment of neuropsychiatric symptoms, and the ascertainment of the quantity of informal care by questionnaire completed by knowledgeable informants. A number of potential limitations should also be considered when interpreting the results. Measurement error may have occurred for the assessment of neuropsychiatric

symptoms even though the NPI has been shown to have good psychometric characteristics. 28 Ascertainment of the quantity of active help and supervision may also be susceptible to measurement error due to difficulty with the accurate recall of caregiving activities.¹¹

This population-based analysis of informal care for CIND and dementia confirms that neuropsychiatric symptoms likely increase the burden of care for families, independent of the severity of cognitive impairment and the presence of medical comorbidities. This burden also increases sharply as the number and severity of neuropsychiatric symptoms increases, and with a number of specific individual symptoms. These findings suggest that identifying and treating neuropsychiatric symptoms in older adults may be important for limiting the caregiving burden for family members of those with CIND and dementia. The active help and supervision required for those with CIND and dementia represents a significant time commitment for families and a significant economic cost to society that will grow with the increasing number of older adults.

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Figure 1. Informal Caregiving Hours Attributable to Neuropsychiatric Symptoms

Adjusted informal care hours were estimated using a two-part multivariable regression model that adjusted for sociodemographic characteristics, cognitive category (cognitive impairment without dementia; mild, moderate, or severe dementia), and medical comorbidities.

*Clinically significant symptoms are defined as a frequency score times severity score of ≥ 4 . Whiskers indicate 95% confidence intervals. NPI = Neuropsychiatric Inventory.

Figure 2. Incremental Caregiving Hours Attributable to Individual Neuropsychiatric Symptoms

Adjusted informal care hours were estimated using a two-part multivariable regression model that adjusted for sociodemographic characteristics, cognitive category (cognitive impairment without dementia; mild, moderate, or severe dementia), medical comorbidities, and other co-occurring symptoms.

*Clinically significant symptoms are defined as a frequency score times severity score of ≥ 4 . Caregiving hours for elation could not be estimated because of small sample size.

Whiskers indicate 95% confidence intervals.

Table 1

Sample Characteristics by Cognitive Category

	CIND	Mild	Dementia Moderate	Severe	P-value [†]
Sample (Weighted % [‡])	227 (67.6)	139 (22.2)	45 (4.2)	39 (6.0)	
Age					<0.001
71-79y	93 (44.2)	34 (22.7)	11 (19.8)	8 (16.6)	
80-89y	104 (45.1)	73 (62.2)	18 (33.1)	20 (69.4)	
90y+	31 (10.7)	32 (15.1)	17 (47.1)	11 (14.0)	
Sex					0.046
Female	113 (53.3)	83 (59.6)	34 (74.4)	32 (84.6)	
Male	115 (46.7)	56 (40.4)	12 (25.6)	7 (15.4)	
Race					0.066
White	165 (85.1)	94 (81.6)	33 (81.9)	28 (67.2)	
Black	50 (10.7)	40 (15.6)	10 (13.8)	9 (9.4)	
Other	13 (4.2)	5 (2.8)	3 (4.3)	2 (23.4)	
Education					0.275
<12y	138 (43.5)	90 (55.9)	29 (56.4)	19 (31.1)	
=12y	52 (31.2)	31 (29.0)	8 (14.8)	13 (39.5)	
>12y	38 (25.3)	18 (15.1)	9 (28.8)	7 (29.4)	
Household Net Worth					0.190
Quartile 1	63 (19.6)	38 (21.7)	21 (37.8)	12 (34.5)	
Quartile 2	73 (26.4)	46 (40.1)	11 (25.6)	9 (32.9)	
Quartile 3	47 (23.5)	30 (20.3)	8 (20.2)	11 (20.6)	
Quartile 4	45 (30.5)	24 (17.9)	6 (16.4)	7 (12.0)	
Living Situation					0.083
Living Alone	79 (34.2)	53 (45.3)	19 (45.0)	10 (32.6)	
Living With Spouse	44 (20.5)	40 (22.6)	16 (34.1)	18 (42.4)	
Living With Others	105 (45.3)	46 (32.1)	11 (20.9)	11 (25.0)	
NPI Symptom(s)					0.002
0	143 (55.1)	66 (54.6)	9 (14.5)	6 (30.2)	

	CIND	Dementia		P-value [†]
		Mild	Moderate	
1-2	63 (34.0)	45 (32.9)	16 (34.7)	16 (27.1)
3-	22 (10.9)	28 (12.5)	21 (50.8)	17 (42.7)
Delusions	7 (4.2)	16 (7.3)	17 (37.1)	15 (38.8)
Hallucinations	6 (2.3)	12 (7.2)	11 (27.4)	14 (18.9)
Agitation	26 (13.0)	23 (9.6)	18 (38.9)	20 (51.5)
Depression	49 (29.0)	39 (24.7)	16 (45.6)	7 (28.4)
Apathy	22 (14.0)	20 (10.7)	13 (38.9)	16 (42.8)
Elation	1 (0.1)	0 (0)	0 (0)	2 (2.8)
Anxiety	18 (8.4)	25 (12.1)	16 (43.5)	9 (11.4)
Disinhibition	9 (10.1)	13 (6.2)	10 (30.2)	6 (8.9)
Irritation	29 (16.8)	20 (9.0)	12 (28.8)	8 (13.5)
Aberrant Motor Behaviors	4 (2.6)	13 (11.8)	11 (23.4)	16 (39.8)

NPI = Neuropsychiatric Inventory. CIND = cognitive impairment without dementia.

* Values in parentheses are weighted percentages derived by using the ADAMS sample weights to adjust for the complex sampling design of the ADAMS.

[†] P-values were derived from the χ^2 test for association between the indicated variable and the cognitive category.