

Examining caregiving burden outcomes for informal and unpaid caregivers of older adults with dementia using a biopsychosocial framework

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BACKGROUND

- Although dementia caregiving has been widely studied, comparatively less attention has been given to examining caregiver burden through an integrated biopsychosocial perspective.
- Applying an integrated caregiver stress process and biopsychosocial framework allows burden to be understood as a complex, multidimensional experience.
- Examining these interconnected dimensions provides a more comprehensive understanding of how caregiving responsibilities affect caregiver health and quality of life.^{1,2}
- This study explores caregiver burden outcomes related to biological, psychological, and social factors, including a newly validated family caregiving strain measure developed by the National Study of Caregiving (NSOC).

METHODS

Data for this analysis was drawn from Round 12 (2022) of the National Health and Aging Trends Study (NHATS) and Round 12 of the National Study of Caregiving (NSOC)

- NHATS is a longitudinal cohort study that began in 2011 where an annual in-person interview is conducted along with cognitive and physical performance tests to study trends in disability and function among Medicare beneficiaries ages 65 years and older
- NSOC is conducted in conjunction with NHATS and is a nationally representative study of family and unpaid caregivers who assist NHATS participants with mobility, self-care, or household activities related to health and functioning reasons.
- Our sample included 1,904 caregivers of older adults with dementia that resided in the community or non-nursing home residential care facilities.
- We excluded caregivers with missing data on outcome variables or key covariates, and care recipients with missing covariate data.

Outcome Variables

We assessed multiple aspects of caregiver burden, capturing both subjective and objective burden aspects, that included the following

- Physical Difficulty (Yes/No)
- Emotional Difficulty (Yes/No)
- Financial Difficulty (Yes/No)
- Participation Restrictions (Yes/No)
- Overall Caregiver Strain (NCOS-CSS; No/Low [1-3] vs. Moderate/High [4-11])³

Independent Variable

- Care recipient dementia status (probable/possible dementia), determined using NHATS classification criteria (self-report, proxy AD8 screening, and cognitive testing).⁴

METHODS

Covariates

Caregiver sociodemographic characteristics

- Age
- Sex
- Race/ethnicity
- Education
- Marital status
- Employment status

Caregiver health

- Self-rated health
- Number of chronic conditions

Caregiving context

- Relationship to care recipient
- Co-residence
- Caregiving duration
- Weekly caregiving hours
- Respite care use

Caregiving characteristics

- Caregiving gains (lower vs. higher)
- Assistance provided:
- Activities of daily living (ADLs) and instrumental activities of daily living (IADLs)
- Health management tasks
- Health system logistics

Care recipient's characteristics

- Age group (65–74, 75–84, ≥85 years)
- Sex (Male/Female)

Statistical Analyses

- Descriptive statistics were used to characterize the study sample.
- Bivariate associations by care recipient dementia status were assessed using Pearson's chi-square tests
- Separate multivariable logistic regression models estimated associations between care recipient dementia status and each caregiver burden outcome
- Models were sequentially adjusted for:
 - Model 1:** Caregiver sociodemographic and health characteristics; care recipient age and sex
 - Model 2:** Model 1 + employment, dual eligibility, caregiver–care recipient relationship, co-residence, respite care use, caregiving hours, caregiving duration, caregiving gains
 - Model 3** (fully adjusted): Model 2 + types of assistance provided to the care recipient
- Statistical significance was set at $p < 0.05$
- results are presented as odds ratios (ORs) with 95% confidence intervals (CIs). Analyses were conducted using Stata 18
- All analyses incorporated NSOC survey weights to account for the complex survey design

RESULTS

- 23% of caregivers provided care to individuals with probable dementia.
- Among these caregivers who provided care to those with probable dementia, 67% were female, 42% were aged ≥65 years, 49% were non-Hispanic White.
- Nearly half had ≥2 chronic conditions.
- 54% were adult children of the care recipient.

Results of Weighted Logistic Regression Analyses of Care Recipient's Dementia Status and Caregiver Burden Outcomes

Caregiving Burden Outcomes	Dementia Status (Reference =No Dementia)						
	Model 1		Model 2		Model 3		
	OR (95% CI)	<i>p</i>	OR (95% CI)	<i>p</i>	OR	95% CI	<i>p</i>
Physical Difficulty							
Possible Dementia	0.64 (0.37, 1.11)	0.11	0.55 (0.31, 0.95)	0.04	0.50 (0.28, 0.91)		0.02
Probable Dementia	1.17 (1.29, 4.84)	0.39	0.92 (0.62, 1.37)	0.69	0.81 (0.53, 1.23)		0.32
Emotional Difficulty							
Possible Dementia	0.81 (0.71, 1.75)	0.62	0.99 (0.60, 1.62)	0.98	0.90 (0.54, 1.49)		0.67
Probable Dementia	2.65 (1.86, 3.78)	<0.01	2.30 (1.55, 3.43)	<0.01	1.85 (1.22, 2.81)		0.00
Financial Difficulty							
Possible Dementia	0.78 (0.45, 1.37)	0.39	0.68 (0.36, 1.31)	0.25	0.61 (0.30, 1.22)		0.16
Probable Dementia	1.10 (0.70, 1.59)	0.79	0.86 (0.54, 1.41)	0.56	0.68 (0.41, 1.12)		0.13
Participation Restriction							
Possible Dementia	0.64 (0.92, 3.54)	0.16	0.55 (0.28, 1.07)	0.08	0.47 (0.23, 0.97)		0.04
Probable Dementia	2.47 (1.17, 4.91)	<0.01	1.76 (1.16, 2.68)	0.01	1.34 (0.84, 2.13)		0.21
Caregiver Strain							
Possible Dementia	0.70 (0.39, 1.27)	0.35	0.56 (0.28, 1.10)	0.09	0.48 (0.24, 0.99)		0.05
Probable Dementia	2.40 (1.56, 3.70)	<0.01	1.79 (1.07, 3.01)	0.03	1.39 (0.81, 2.40)		0.23

Note. OR = odds ratio; CI = confidence interval. Bold values denote statistical significance at the $p < 0.05$ level.

Model 1 adjusted for caregiver's age, gender, race, education, marital status, health status, number of chronic conditions and care recipient's age and gender.

Model 2: Model 1 + adjusted for additional caregiver characteristics such as work for pay in the last month, relationship with care recipient, co-residence with care recipient, caregiver's use of respite care, average hours per week care provided, caregiving duration, caregiving gain.

Model 3: Model 2 + types of assistance provided, i.e. ADL-IADL, health management, and health system logistics.

CONCLUSIONS

- Caregiving for probable dementia** was associated with higher odds of multiple caregiver burden outcomes.
- After adjusting for **type of care provided**, these associations were attenuated.
- Only increased emotional burden** remained significantly associated with dementia caregiving after adjustment.
- Findings suggest caregiver burden is influenced by factors beyond patient care needs.
- Interventions should include **streamlined health system navigation** and strategies to **strengthen caregiver resilience**.

REFERENCES

- Liu Z, Heffernan C, Tan J. Caregiver burden: A concept analysis. *Int J Nurs Sci.* 2020;7(4):438-445. doi:10.1016/j.ijnss.2020.07.012
- Wennberg AM, Anderson LR, Chen-Edinboro LP, Cagnin A, Pini L. Positive Aspects of Caregiving Are Associated With Lower Risk of Frailty and Sleep Disruption in the National Study of Caregiving. *Innov Aging.* 2022;6(7):igac058. doi:10.1093/geroni/igac058
- Freedman VA, Wolff JL. The National Study of Caregiving (NSOC) Caregiver Strain Scale. NHATS Technical Paper # 54. *Baltimore: Johns Hopkins Bloomberg School of Public Health.* Published online 2025.
- Kasper JD, Freedman VA, Spillman BC. Classification of Persons by Dementia Status in the National Health and Aging Trends Study. Published online 2013.

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