

Out-of-Pocket Costs For Dementia Care in the United States: A Systematic Literature Review

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OBJECTIVES

- To characterize out-of-pocket (OOP) costs among persons living with dementia (PLWD).
- To examine cost variation by type of care and dementia severity.

BACKGROUND

- U.S. PLWD face substantial financial burden due to high OOP costs.
- Quantifying OOP spending by type of care and dementia severity:
 - Helps PLWD and their families anticipate financial burden of dementia care and make informed care and financial decisions.
 - Informs policies to alleviate the financial burden of dementia care.

METHODS

- Systematic literature review** of U.S. studies (2010–2026) reporting OOP costs associated with dementia care.
- Literature search:** PubMed, Embase, and reference lists
- Literature screening and abstraction:**
 - AI-assisted Nested Knowledge AutoLit systematic review platform.
 - Abstracts screened by a reviewer and AI, discrepancies adjudicated by a second reviewer.
 - Full texts screened by two independent reviewers and AI, discrepancies resolved by consensus.
 - Data extracted by one reviewer and validated by a second.
- Extracted mean OOP costs:**
 - By type of care
 - Medical care (e.g., hospitalization, outpatient visits)
 - Long-term care (LTC): Community-based services (e.g., home modifications), residential LTC (assisted living, nursing home)
 - Care-related supplies (e.g., hygiene products)
 - By dementia severity: Mild, moderate, severe
- Costs annualized and inflation-adjusted to 2026 U.S. dollars.

RESULTS

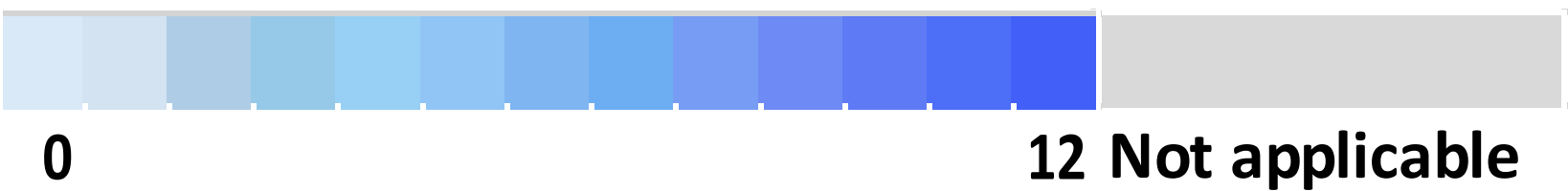
Table 1. Range of Extracted Annual Mean Out-of-Pocket Costs by Type of Care and Dementia Severity

	Dementia	Mild dementia	Moderate dementia	Severe dementia
Total OOP	\$8,420 - \$21,027	\$5,544 - \$5,584	\$10,864 - \$11,054	\$11,920 - \$12,008
Medical OOP§	\$2,155 - \$4,625	--	--	--
LTC OOP	--	\$3,500-\$5,256	--	--
Community-based services†	--	--	--	--
Assisted Living	\$39,615	--	--	--
Nursing home	\$7,617-\$22,610	--	--	--
Care-related supplies‡	--	--	--	--

Note: OOP, out-of-pocket. LTC, long-term care. Studies reporting total OOP costs included expenditures for medical care and nursing home care. §Medical OOP costs include expenditures for inpatient care, outpatient care, prescription medications, home health, and dental visits. †Community-based services include home modifications, care-related transportations, adult day care, paid home help, etc. ‡Care-related supplies include OOP expenditures for durable (canes, walkers, wheelchairs) and absorbent (hygiene products, incontinence supplies, etc.) medical products. --, not reported.

Table 2. Heat Map: Number of Out-of-Pocket Cost Studies by Type of Dementia Care, Data Sources, and Dementia Severity

		By Data Source				By Dementia Severity		
		HRS	MCBS	NHATS	Other Sources	Mild	Moderate	Severe
Total OOP		12	1	0	2	2	2	2
OOP Costs by Type of Care	Medical OOP	2	2	0	2	0	0	0
	LTC OOP	0	0	0	2	2	0	0
	Community-based services	0	0	1	0	0	0	0
	Assisted living	0	0	1	0	0	0	0
	Nursing home	5	1	1	0	0	0	0
Care-related supplies		0	0	0	0	0	0	0
OOP Costs by Dementia Severity	Mild	2	0	0	2			
	Moderate	2	0	0	0			
	Severe	2	0	0	0			



Note: OOP, out-of-pocket. LTC, long-term care. HRS, Health and Retirement Study. MCBS, Medicare Current Beneficiary Survey. NHATS, National Health and Aging Trends Study. HRS, MCBS, and NHATS are nationally representative surveys of older U.S. adults

- PLWD’s annual mean total OOP costs ranged from **\$8,420 to \$21,027 (17% to 42%** of an estimated mean \$50,000 household income).
- Nursing home OOP costs varied widely; estimates ranged from **\$7,617 – \$11,039** (from HRS and MCBS) to **\$22,610** (from NHATS).
- Only **one study** reported OOP costs for community-based services, **one** for assisted living, and **none** for care-related supplies.
- Only **two** studies (both HRS-based) examined mean total OOP costs by dementia severity.

CONCLUSION

- Critical data gaps remain in PLWD’s OOP costs for LTC, care-related supplies, and costs by dementia severity.
- Addressing these gaps
 - Facilitates dementia care and financial planning for PLWD and families.
 - Guides policies (e.g., Medicaid home and community-based services waivers and Program of All-Inclusive Care for the Elderly) that improve access to LTC services and care-related supplies, alleviating the financial burden for vulnerable families.

