

Unmet Health Care Needs Among Patients with Dementia and Their Family Members: A Household-Level Analysis

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Background

- Caregiving in dementia is particularly demanding due to its prolonged course and the need to manage neuropsychiatric symptoms, functional decline, and the complex needs of advanced disease.
- Unmet health care needs are associated with lower quality of life, worse health outcomes, and increased subsequent health care utilization.

Methods

Data & study population

- 2012-2017 Medical Expenditure Panel Survey (MEPS) for the primary analysis.
- 688 patients with dementia and 1001 adult family members from 682 households.

Covariates

- sociodemographic characteristics
- health insurance coverage
- comorbidity burden
- body mass index (BMI)
- and functional status.

Outcome

- The primary outcome was any unmet health care need in the prior 12 months.
- It was defined as inability to obtain or delay in obtaining needed medical care, dental care, or prescription medications.
- Service-specific unmet needs were examined separately for medical care, dental care, and prescription medications.
- Cost-related unmet need was examined in secondary analyses.

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Results

Table 1. Within-household associations between patients with dementia and their family members in unmet health care needs

	Events, n (%)	Unadjusted	Adjusted model
Any unmet health care needs			
Patients with dementia (n=688)	72 (10.47%)	1.00 (Ref)	1.00 (Ref)
Family members (n=1001)	147 (14.69%)	1.88 (1.34–2.65)***	2.90 (1.40–6.04)**
Unmet medical care needs			
Patients with dementia (n=688)	27 (3.92%)	1.00 (Ref)	1.00 (Ref)
Family members (n=1001)	53 (5.29%)	1.54 (0.93–2.55)	3.31 (1.11–9.86)*
Unmet dental care needs			
Patients with dementia (n=688)	28 (4.07%)	1.00 (Ref)	1.00 (Ref)
Family members (n=1001)	76 (7.59%)	3.53 (1.94–6.43)***	18.43 (1.45–233.77)*
Unmet prescription medication needs			
Patients with dementia (n=688)	29 (4.22%)	1.00 (Ref)	1.00 (Ref)
Family members (n=1001)	63 (6.29%)	1.80 (1.09–2.98)*	11.19 (2.94–42.62)***

Adjusted model further adjusted body mass index, activities of daily living limitation, diabetes, hypertension, stroke, coronary heart disease, hypercholesterolemia, lung diseases (asthma or emphysema), hospitalization, emergency department visits, vision impairment, hearing impairment, self-rated physical health, and mental health status.

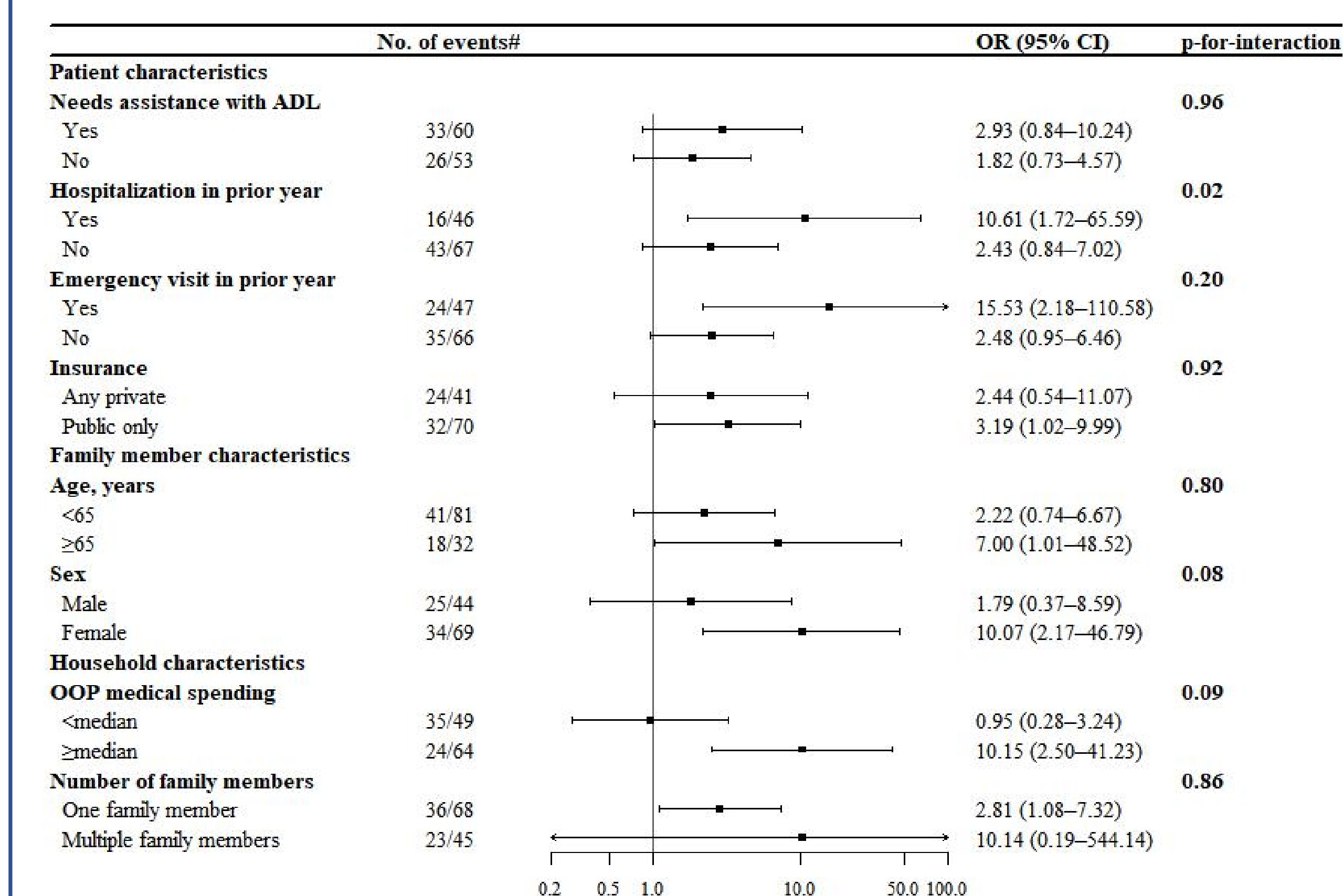
Table 2. Comparison of unmet health care needs among patients and family members across dementia, diabetes, and cancer households

	Events, n (%)	Unadjusted	Adjusted model
Any unmet health care needs			
Patients with diabetes (n= 9568)	1432 (14.97%)	1.00 (Ref)	1.00 (Ref)
Family members of patients with diabetes(n=13183)	1130 (8.57%)	0.46 (0.41–0.51)***	0.69 (0.60–0.80)***
Patients with cancer (n=6902)	895 (12.97%)	1.00 (Ref)	1.00 (Ref)
Family members of patients with cancer (n=9181)	935 (10.18%)	0.74 (0.66–0.83)***	0.86 (0.74–0.99)*
Family members of patients with diabetes (n=12776)	1077 (9.21%)	1.00 (Ref)	1.00 (Ref)
Family members of patients with dementia(n=528)	65 (12.31%)	1.53 (1.14–2.04)**	1.42 (1.04–1.94)*
Family members of patients with cancer(n=8838)	901 (10.20%)	1.00 (Ref)	1.00 (Ref)
Family members of patients with dementia(n=627)	96 (15.31%)	1.59 (1.23–2.06)***	1.42 (1.08–1.87)*

Consistent in additional sensitivity analyses

- Restricted to one patient–one family member households
- Among patients with self-reported outcomes
- For cost-related unmet health care needs

Figure 1. Within-household associations between dementia patients and their family members in unmet health care needs by patient, family member, and household characteristics



number of unmet need in patients vs. family members
Note: OOP household out-of-pocket medical spending

Conclusions

- Family members in dementia-affected households had higher odds of unmet health care needs than patients with dementia.
- This disparity was observed for overall unmet need and across medical, dental, and prescription medication needs.
- The association was stronger in households where patients had prior-year hospitalization, suggesting that greater care intensity may further constrain family members' access to care.
- These findings highlight family members in dementia-affected households as an overlooked high-risk population.
- Dementia care models should extend beyond patient-centered care to assess and address family members' own health care needs.