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Medical Comorbidities of Dementia: Links to Caregivers' Emotional Difficulties and Gains

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Abstract

Objectives: To evaluate how eight major medical comorbidities of dementia (arthritis, cancer, diabetes, heart disease, hypertension, lung disease, osteoporosis, and stroke) are associated with caregivers' perceptions of emotional caregiving difficulties and caregiving gains (i.e., benefits or rewards from the care role).

Design: Nationally representative cross-sectional surveys of community-dwelling persons living with dementia (PLWDs) and their co-resident family caregivers in the United States.

Setting: 2011 National Health and Aging Trends Study and National Study of Caregiving.

Participants: Total of 356 co-resident family caregivers of community-dwelling PLWDs.

Measurements: Caregivers' sociodemographic and health characteristics, caregiving stressors, emotional caregiving difficulties, caregiving gains, and PLWDs' chronic health conditions.

Results: Caregivers most commonly cared for a PLWD with arthritis (65.5%), followed by hypertension (64.9%), diabetes (30.1%), stroke (28.8%), osteoporosis (27.1%), heart disease (23.3%), cancer (21.5%), and lung disease (17.2%). Logistic regressions revealed that caregivers were 2.63 and 2.32 times more likely to report higher than median emotional caregiving difficulties when PLWDs had diagnoses of diabetes and osteoporosis, respectively, controlling for caregiver gender, relationship to the PLWD (spouse versus non-spouse), educational attainment, self-rated health, and assistance with activities of daily living and medical care activities.

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Author's Contributions: CAP conceptualized and planned the study, conducted the analyses, and wrote the paper. LM and HCK assisted with the study design and interpretation of the findings. All authors critically revised the paper for important intellectual content.

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Conflict of Interest: The authors have no conflicts of interest to report.

Caregivers were also 2.10 times more likely to report lower than median caregiving gains when PLWDs had a diagnosis of osteoporosis.

Conclusions: Comorbid health conditions among PLWDs have distinct implications for caregiving outcomes. Clinical care and interventions to improve the well-being of both care dyad members should support caregivers in managing medical comorbidities of dementia.

Keywords

Alzheimer's; caregiving; chronic illness; comorbidity

INTRODUCTION

Medical comorbidities are prevalent among persons living with dementia (PLWDs).^{1,2} Relative to adults age 65 and older without dementia, PLWDs have significantly more chronic conditions and higher healthcare utilization.² PLWDs with greater medical morbidity also show increased rates of polypharmacy,^{1,3} hospitalizations,^{4,5} and cognitive and functional decline,^{6,7} placing additional burden on caregivers. Yet, little is known about comorbidities that are most consequential for caregiving outcomes. Drawing from a nationally representative U.S. sample, we evaluated how PLWDs' medical comorbidities are associated with caregivers' emotional caregiving difficulties and caregiving gains (i.e., benefits or rewards from caregiving).

Stress process models hold that dementia caregiving can be stressful and lead to greater emotional caregiving difficulties and lower caregiving gains.⁸ Most studies have focused on PLWDs' difficulty with activities of daily living (ADLs; e.g., bathing, dressing) and instrumental activities of daily living (IADLs; e.g., preparing meals, shopping). Medical comorbidities may be an understudied source of caregiver stress that magnifies emotional difficulties and dampens gains from caregiving. Cognitive impairment limits PLWDs' capacity for self-care,⁹⁻¹² and so caregivers are often responsible for managing comorbid conditions.

Comorbid diabetes, heart disease, and stroke may be particularly consequential because they require daily management activities (e.g., medication adherence, dietary restrictions) that pose numerous challenges. PLWDs commonly resist or lack understanding about illness management regimens due to impaired cognition and neuropsychiatric symptoms.⁹⁻¹¹ PLWDs' reduced self-management abilities raise risk of medical nonadherence and heighten responsibility on caregivers, potentially exacerbating caregiver burden.¹² Diabetes,^{13,14} heart disease,¹⁵⁻¹⁶ and stroke^{14,17} also predict diminished cognitive function that may accelerate dementia progression.

We examined eight major medical comorbidities of dementia (arthritis, cancer, diabetes, heart disease, hypertension, lung disease, osteoporosis, and stroke) and their independent links to emotional caregiving difficulties and caregiving gains. We predicted that PLWDs' diabetes, heart disease, and stroke are associated with greater odds of higher emotional difficulties and lower gains, controlling for caregiver gender, relationship to the PLWD, educational attainment, self-rated health, and care tasks.

METHODS

Sample and Procedures

The sample for this cross-sectional study included 356 family caregivers of PLWDs from the 2011 National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC). In accordance with the University of Michigan's policies, ethical approval was not required because we used publicly available secondary data with no individual identifiers.

Participants were eligible for NHATS if they were Medicare enrollees aged 65 and older, lived in the contiguous U.S., and received health-related assistance in the last month.¹⁸ NHATS participants were eligible for NSOC if they had at least one unpaid caregiver. Of the 2,007 caregivers who participated in NSOC, 739 cared for a person with probable dementia based on:¹⁹ PLWD/proxy reported diagnosis, the AD8 criteria for diagnosis,²⁰ or scores at least 1.5 standard deviations below the mean in two or more cognitive testing domains. We selected 368 co-resident caregivers because of their greater exposure to the daily management and monitoring of medical comorbidities. Twelve were removed due to missing data, resulting in an analytic sample of 356. Most were the sole participating caregiver ($n = 252$), with other households having two ($n = 92$) or three ($n = 12$) participating caregivers.

Measures

Medical comorbidities of dementia.—PLWDs ($n = 149$) or proxies ($n = 121$ adult children; $n = 50$ spouses; $n = 36$ other relatives) reported whether the PLWD had received a physician diagnosis of eight major chronic health conditions: arthritis (including osteoarthritis or rheumatoid arthritis), cancer, diabetes, heart disease (including angina or congestive heart failure), hypertension or high blood pressure, lung disease (e.g., asthma, emphysema, or chronic bronchitis), osteoporosis, and stroke (1 = *yes*, 0 = *no*).

Emotional caregiving difficulties.—Caregivers reported whether helping their PLWDs is emotionally difficult (1 = *yes*, 0 = *no*) and, if yes, the extent of these difficulties from 1 (*a little difficult*) to 5 (*very difficult*). Caregivers with no reported difficulties were assigned a zero and caregivers reporting difficulties received a score based on their degree (0 = *no difficulty* to 5 = *high difficulty*). Caregivers scoring above this sample's weighted median (1.10) were categorized as having high difficulties (1 = *score of 2–5*, 0 = *score of 0–1*).

Caregiving gains.—Caregivers reported how much caregiving has made them more confident about their abilities; taught them to deal with difficult situations; brought them closer to the PLWD; and given them satisfaction that the PLWD receives good care from 1 (*not so much*) to 3 (*very much*). Items were averaged ($\alpha = .70$). Caregivers scoring below this sample's weighted median (2.54) were categorized as having low gains (1 = *score of 1.00–2.53*; 0 = *score of 2.54–3.00*).

Covariates.—Caregiver background characteristics included gender (1 = *female*, 0 = *male*), relationship to the PLWD (1 = *spouse*, 0 = *non-spouse*), and educational attainment (1 = *college graduate or post graduate*, 0 = *less than a college education*), and self-rated health (1 = *fair or poor*, 0 = *good, very good, or excellent*).

We also controlled for caregivers' assistance with ADLs, IADLs, and medical care activities. ADLs included bathing, dressing, eating, toileting, getting in/out of bed, and mobility inside and outside the home. IADLs included laundry, shopping, preparing meals, banking, and managing money. Medical care activities included keeping track of medications, giving shots/injections, managing medical tasks (e.g., ostomy care, IVs, testing blood), assisting with exercises, helping with a special diet, wound/sore care, teeth/denture care, foot care (e.g., clipping nails), ordering medication, scheduling medical appointments, speaking to medical providers, helping to change/add a health insurance or prescription drug plan, and other medical insurance matters. Summed scores were created for total ADL/IADL assistance (range = 0–12) and medical care activities (range = 0–13).

In *post hoc* tests, we controlled for self-reports or proxy reports on whether the PLWD had fallen in the past month (1 = *yes*, 0 = *no*) and had received a physician diagnosis of a fracture in their hip or another bone since age 50 (1 = *yes*, 0 = *no*). Both recent falls (27.7%) and history of fractures (35.2%) were relatively common. We also controlled for three self-rated indicators of caregivers' informal support (having friends or family to talk to about important things, help with daily activities, and help with care tasks) and three self-rated indicators of formal support (caregiver support group, respite service to take time away from caregiving, and caregiver training) received in the past year (1 = *yes*, 0 = *no*). Frequencies are reported in Supplemental Table 1.

Statistical Analysis

We used logistic regressions to evaluate how medical comorbidities were independently linked to caregivers' odds of reporting high emotional difficulties and low gains. We entered PLWDs' eight medical comorbidities as separate predictors, along with the study covariates. Descriptive analyses and logistic regression models were estimated using SAS version 9.4 with the NSOC analytic weight and statistical procedures to account for the complex survey design.²¹

RESULTS

Table 1 presents caregiver background characteristics and scores on study variables. Caregivers most often cared for a PLWD with arthritis (65.5%), followed by hypertension (64.9%), diabetes (30.1%), stroke (28.8%), osteoporosis (27.1%), heart disease (23.3%), cancer (21.5%), and lung disease (17.2%).

As shown in Table 2, caregivers' odds of high emotional caregiving difficulties were 2.63 times higher when the PLWD had diabetes compared to no diabetes. Caregivers had 2.32 times the odds of reporting high emotional caregiving difficulties and 2.10 times the odds of reporting low caregiving gains when the PLWD had osteoporosis compared to no osteoporosis.

Post hoc tests evaluated whether the effect of osteoporosis was confounded by recent falling or history of fractures. The negative effect of osteoporosis was independent of these variables. We also tested the main models controlling for informal and formal caregiver support in a reduced sample of 354 caregivers with complete data. The findings did not

change in these models, suggesting that the associations in this study are independent of levels of caregiver support.

DISCUSSION

This study shows that medical comorbidities of dementia have distinct implications for caregiving outcomes. In line with our hypothesis, caregivers were more likely to report high emotional difficulties if the PLWD had diabetes. Unexpectedly, caregivers also had greater odds of high emotional difficulties and low gains from caregiving when the PLWD had osteoporosis that were independent of falls and fractures. Overall, these findings suggest that clinical care and interventions to promote caregiver well-being should explicitly support the management of comorbid diabetes and osteoporosis.

Diabetes requires high daily management demands that are likely to be problematic in the context of dementia. PLWDs' compromised ability to self-manage results in a growing need for caregivers to assume responsibility, which can be stressful for both parties.^{11,22} PLWDs might view caregivers' involvement as a threat to their own autonomy and competence, whereas caregivers may feel overwhelmed. Additionally, diabetes complications such as severe hypoglycemia are more frequent among PLWDs,^{13,23} partly due to their lower capacity for recognizing and responding to symptoms.^{9,11,12} Family members caring for a PLWD with diabetes also perceive inadequate support from healthcare providers.⁹ Thus, many caregivers may constantly monitor and worry, leading to hypervigilance that intensifies distress. Notably, however, these caregivers were not more likely to report low gains, which suggests that PLWDs' diabetes does not hinder positive caregiving experiences.

Although diagnosis and treatment of osteoporosis is seemingly straightforward (i.e., once-weekly bisphosphonates), several factors might explain its association with high emotional difficulties and low gains from caregiving. Relative to older adults without dementia, PLWDs are more likely to be hospitalized for fractures.⁵ Fractures are common among people with osteoporosis and can lead to increased morbidity, mortality, and subsequent falls.^{24,25} PLWDs have a heightened risk of falls resulting from cognitive impairment, and past month falls are linked to caregivers' greater emotional difficulties beyond background characteristics and care-related stressors.²⁶ PLWDs are also at higher risk of rehospitalization following fragility fractures,²⁷ indicating poorer recovery. Of note, the associations between PLWDs' osteoporosis and caregiving outcomes remained even after controlling for available information regarding recent falls and history of fractures. Hence, other unmeasured characteristics associated with osteoporosis which are complex to treat (e.g., malnutrition, low muscle mass, frailty) or unmeasured factors related to osteoporosis caregiving (e.g., caregivers' worries about future falls and fractures, complex medication administration) may play a key role in explaining the associations in this study. Another reason osteoporosis may be stressful for caregivers is that multiple geriatric conditions (e.g., dementia and comorbid osteoporosis) lead to more complex overall care and poorer quality of ambulatory care, likely resulting from more time and effort to treat these conditions.²⁸ This greater care complexity may both amplify caregivers' emotional strain and minimize gains from caregiving. Finally, bone loss is predictive of faster cognitive decline,^{29,30} and so osteoporosis may contribute to a worse trajectory of dementia that further complicates care.

Future research should consider mechanisms that explain the current findings to pinpoint intervention targets. Guidance in the management of comorbid diabetes, for example, is likely to benefit caregiver well-being. Strategies to maximize PLWDs' involvement may also help to ensure that both parties' care preferences are understood and honored. Similarly, strategies to manage risks and conditions that co-occur with osteoporosis might improve caregiver well-being. Healthcare providers may not always recognize the particular challenges faced by caregivers managing dementia with medical comorbidities.^{9,12,22} Consequently, integrative care models that enlist caregivers and PLWDs as active partners offer considerable promise.

Several limitations warrant comment. First, unmeasured aspects of comorbidities that were not directly associated with caregiving outcomes (e.g., complications, severity) may be consequential. Second, other medical comorbidities not assessed in the NHATS may have important implications for caregiver outcomes. Third, PLWDs (or proxies) reported on their diagnosed chronic health conditions, which may introduce bias. Fourth, the single-item measure of emotional caregiving difficulties is not ideal. Fifth, we lacked data on behavioral and psychological symptoms of dementia that complicate the management of comorbidities.⁹ Sixth, aligned with U.S. trends, most caregivers were women and spouses or adult children; but the findings may not generalize to more diverse samples. Nevertheless, this study provides a foundation for subsequent research and underscores the importance of supporting family caregivers in the complex long-term medical care of PLWDs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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The first author (CAP) affirms that all significant contributors to this work are named as authors.

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Table 1

Caregiver Background Characteristics and Scores on Study Variables

Variable	Caregivers	
	<i>M</i>	<i>SE</i>
Age in years	59.37	2.00
ADL/IADL assistance	5.32	0.22
Medical care activities	5.87	0.20
Emotional caregiving difficulties	1.80	0.16
Caregiving gains	2.55	0.04
	%	
Gender (female)	62.3	
Relationship to PLWD		
Spouse	33.0	
Adult child	43.5	
Child-in-law	6.0	
Grandchild	9.9	
Sibling	1.6	
Other relative	6.0	
Educational attainment		
High school graduate	30.0	
Some college	20.5	
College graduate	13.7	
Post graduate	7.9	
Self-rated health (fair or poor)	23.8	
High emotional caregiving difficulties ^a	51.2	
Low caregiving gains ^b	47.2	

Note. ADL = activities of daily living. IADL = instrumental activities of daily living. CG = caregiver. PLWD = person living with dementia. Values are weighted to produce nationally representative estimates.

^aScores above the sample weighted median value.

^bScores below the sample weighted median value.

N = 356 family caregivers.

Table 2

Logistic Regressions With Medical Comorbidities Predicting High Emotional Caregiving Difficulties and Low Caregiving Gains

Estimate	High Emotional Caregiving Difficulties ^a			Low Caregiving Gains ^b		
	OR	95% CI	<i>p</i> value	OR	95% CI	<i>p</i> value
PLWD Medical comorbidities						
Arthritis	0.55	0.28, 1.09	0.085	0.63	0.30, 1.34	0.225
Cancer	0.87	0.42, 1.80	0.705	1.33	0.65, 2.72	0.429
Diabetes	2.63	1.14, 6.11	0.025	1.34	0.55, 3.23	0.516
Heart disease	0.59	0.30, 1.19	0.139	0.78	0.43, 1.39	0.389
Hypertension	0.84	0.46, 1.50	0.543	1.39	0.76, 2.53	0.284
Lung disease	1.64	0.73, 3.66	0.223	0.82	0.36, 1.84	0.618
Osteoporosis	2.32	1.23, 4.36	0.010	2.10	1.06, 4.18	0.035
Stroke	1.12	0.48, 2.61	0.793	0.97	0.51, 1.86	0.928
CG Covariates						
Gender (female)	2.13	1.14, 4.00	0.019	0.84	0.43, 1.63	0.596
Relationship (spouse)	0.87	0.48, 1.57	0.644	0.89	0.48, 1.66	0.705
Education (college or higher)	1.91	1.16, 3.14	0.013	1.97	1.06, 3.69	0.033
Self-rated health (fair or poor)	1.44	0.76, 2.71	0.258	1.31	0.65, 2.64	0.444
ADL/IADL assistance	1.09	1.00, 1.19	0.047	0.98	0.88, 1.10	0.728
Medical care activities	1.06	0.96, 1.17	0.223	0.97	0.86, 1.10	0.671

Note. ADL = activities of daily living. IADL = instrumental activities of daily living. CG = caregiver. PLWD = person living with dementia. Degrees of freedom (*df* = 55) accounted for the complex survey design.

^aScores above the sample weighted median value.

^bScores below the sample weighted median value. Bolded values designate *p* values < .05.

N = 356 family caregivers.