Original Article

Does Caregiving Strain Increase as Patients With and Without Dementia Approach the End of Life?

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Abstract

Context. Family caregivers play critical and demanding roles in the care of persons with dementia through the end of life.

Objectives. The objective of this study was to determine whether caregiving strain increases for dementia caregivers as older adults approach the end of life, and secondarily, whether this association differs for nondementia caregivers.

Methods. Participants included a nationally representative sample of community-living older adults receiving help with self-care or indoor mobility and their primary caregivers (3422 dyads). Older adults' death within 12 months of survey was assessed from linked Medicare enrollment files. Multivariable logistic regression was used to assess the association between dementia and end-of-life status and a composite measure of caregiving strain (range: 0–9, using a cut point of 5 to define "high" strain) after comprehensively adjusting for other older adult and caregiver factors.

Results. The prevalence of dementia in our sample was 30.1%; 13.2% of the sample died within 12 months. The proportion of caregivers who experienced high strain ranged from a low of 13.5% among nondementia, non–end-of-life caregivers to a high of 35.0% among dementia caregivers of older adults who died within 12 months. Among dementia caregivers, the odds of high caregiving strain were nearly twice as high (aOR = 1.94, 95% CI: 1.10–3.45) for those who were assisting older adults nearing end of life. Among nondementia caregivers, providing care near the end of life was not associated with high strain.

Conclusion. Increased strain toward the end of life is particularly notable for dementia caregivers. Interventions are needed to address the needs of this population. J Pain Symptom Manage 2019;57:199–208. © *2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Family caregiving, strain, dementia, end-of-life care

Introduction

By 2050, 8 to 12 million adults in the U.S. will be living with dementia,[1] and dementia-related deaths are projected to exceed 40% of all deaths among older Americans.[2] For persons with dementia, family members are often critical in hands-on care and decision making over the course of disease and through the end of life: an estimated 70% of community-dwelling older adults with dementia receive assistance from a family member or other unpaid caregiver.[3] Caring for someone with dementia poses unique difficulties[4–6] as deficits in memory and executive functioning may necessitate assistance with intimate self-care activities, and some older adults with dementia may be reluctant to accept help.[4,7–11] When demands exceed capacity, caregiving imposes role-related strain.[12,13] Strain may be more

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pronounced during advanced stages of dementia due to challenges of managing pain, dyspnea,[14,15] and neuropsychiatric symptoms,[16] inadequate access to palliative care,[17–19] and burdensome interventions[14,20] that exact a toll on caregivers.[21,22] In addition, decision making regarding nursing home entry, hospitalizations, and use of life-sustaining and prolonging treatment (e.g., artificial nutrition) may contribute to increased strain among caregivers of all persons approaching end of life, regardless of dementia status.

Despite the plausibility of increased strain for end-of-life caregivers, relatively little is known about whether dementia caregivers experience increased strain as the care recipient approaches the end of life.[15,23–28] Most prior research has been qualitative, restricted to persons living in institutionalized settings, or conducted outside of the U.S. Few studies have drawn on population-based, prospective data to compare caregiving experiences by survival status of the persons they assist.[27] A recent national study found significantly greater strain among dementia caregivers of persons in the last year of life,[29] but the analysis was descriptive and did not adjust for other contributors to caregiving strain. Therefore, we used nationally representative data and adjusted models in this analysis to determine whether caregiving strain increases for dementia caregivers as older adults approach the end of life, as we hypothesized it would. Secondarily, we sought to determine whether the end-of-life period is associated with increased strain for nondementia caregivers.

Methods

Data Sources

We draw on data from two nationally representative surveys and their linked caregiver surveys: the National Long-Term Care Survey (NLTCS) and the Informal Care Survey (ICS) from 1999 to 2004, and the National Health and Aging Trends Study (NHATS) and the National Survey of Caregiving (NSOC) from 2011 to 2015. Both surveys relied on the Medicare Enrollment Files as their sampling frame and both involved a complex sampling strategy with oversampling of specific subgroups. Additional details regarding the construction of the study sample and comparability of the NLTCS/ICS and NHATS/NSOC are elaborated in prior work.[30]

Participants

Our sample included community-living adults aged 65 years and older receiving assistance with self-care (eating, dressing, bathing, toileting) or indoor mobility (e.g., transferring) and the family or other unpaid caregiver who was identified as helping the most, that is, their "primary" caregiver. The ICS was conducted with a "primary" caregiver defined as the caregiver providing the most hours of care (in 1999) or helping the most (in 2004). Because all caregivers in NHATS are eligible for NSOC, we followed a similar process in identifying the primary caregiver as the caregiver who provided the greatest number of hours of care, as described in earlier work.[30] In total, our study sample comprised 3422 older adult–caregiver dyads.

Exposures

Older adult demographic and health characteristics included age, sex, race, education, Medicaid enrollment, self-reported health, number of activities of daily living for which they were receiving assistance, dementia, and end-of-life status. We used a composite measure of probable dementia based on self-reported diagnosis from a physician, knowledgeable informant's reports of dementia-related symptoms and behaviors, and cognitive performance measures, as previously described.[30,31] End of life refers to death within 12 months of survey from the Medicare Master Beneficiary File, as in prior literature.[15,29,32,33] Measures of caregiver characteristics included age, sex, relationship to older adult, distance to older adult residence, self-reported health, employment status, use of respite services, and number of hours per week devoted to caregiving. Finally, we also adjusted for survey year in our models.

Outcome

Our main outcome was derived from caregiver-reported measures. A composite measure of caregiving strain (range: 0–9) was constructed from six items.[30,34] High caregiving strain was defined based on a cut point of 5 or greater which corresponds to the 85th percentile of caregiving strain in our sample and has previously been found to have clinical relevance.[34] The six items of the composite caregiver strain measure included caregiver appraisal of the difficulty of helping in three domains—emotional, physical, and financial—as well as having no time for oneself, being overwhelmed, and being exhausted. Caregivers were asked to report the level of emotional, physical, and financial difficulty related to helping. In the ICS, participants were asked to assess the difficulty of helping on a scale from 1 ("not difficult at all") to 5 ("very difficult"). In the NSOC, participants were first asked "Is helping difficult?"; those responding "yes" were then asked to rate the difficulty of helping in each domain on a scale from 1 ("a little difficult") to 5 ("very difficult"). In this study, difficulty helping was categorized as follows: 0 = no difficulty; 1 = some difficulty (ICS 2 or 3; NSOC 1, 2, or 3), and 2 = a lot of difficulty (ICS 4 or 5; NSOC 4 or 5). For questions about having no time for oneself,

being overwhelmed, and being exhausted, affirmative responses were coded as 1, and negative responses as 0.

Statistical Analysis

We first described older adult and caregiver characteristics, stratified by the outcome of high caregiving strain. We then fit univariate logistic regression models to examine the associations of each older adult and caregiver characteristic with high caregiving strain. To identify independent factors associated with high caregiving strain, we then developed a full multivariable logistic regression model with conceptually relevant correlates of caregiving strain[13] in addition to survey year. Finally, we constructed a model that included all measures from our full model, as well as an interaction term (the product of dementia status and end-of-life status) to assess if the relationship to caregiver-associated strain differed for caregivers of older adults by both dementia and end-of-life status.

Both the NLTCS and NHATS involve a complex, multistage sampling design with stratification, clustering, and oversampling of age and race subgroups, requiring sampling weights and survey design variables to produce nationally representative estimates and account for the complex survey design. This analysis used the NLTCS and NHATS weights and design variables as described in prior work.[30] NLTCS and NHATS data are publicly available and deidentified. The JHSPH IRB reviewed the protocol for this study and deemed it to be exempt from human subjects board review. All analyses were conducted in Stata/IC 15.1.

Results

Characteristics of Older Adults

The prevalence of dementia in our sample of community-living older adults receiving help with self-care or mobility was 30.1%; 13.2% of older adults in the sample died within 12 months. Of those who died, the median time between interview and death was 170 days (interquartile range 85−262). The prevalence of high caregiving strain was greater among family caregivers assisting older adults who were male, with less than high school education, enrolled in Medicaid, and in worse health relative to those assisting older adults who were female, better educated, not enrolled in Medicaid, and in better health (Table 1). Caregivers of older adults with dementia were approximately twice as likely to have high strain in comparison with those assisting older adults without dementia (27.2% vs. 13.7%; $P < 0.001$). Caregivers of older adults who did not (vs. did) survive 12 months were also more likely to have high strain (23.8% vs. 16.8%; $P < 0.001$).

Characteristics of Family Caregivers

The proportion of caregivers who experienced high strain varied from a low of 13.5% among those caring for older adults without dementia not at the end of life to a high of 35.0% among caregivers of older adults with dementia who were approaching end of life (Fig. 1). Caregivers who were female were more likely to experience high strain than those who were male (21.8% vs. 10.5%; $P < 0.001$), as were adult children relative to spouses or caregivers of "other" relationships (20.6% and 17.4% vs. 11.9%; $P < 0.001$; Table 2). Caregivers who were themselves in fair or poor health were more than twice as likely to experience high strain than those in excellent, very good, or good health (29.2% vs. 13.7%; $P < 0.001$). Those with high caregiving strain contributed an average of 49.9 hours per week, whereas those with low or moderate strain contributed an average of 28.8 hours ($P < 0.001$).

Correlates of High Caregiving Strain

Both dementia and end-of-life status were associated with high caregiving strain in unadjusted logistic regression models (Table 3, middle column). In the full multivariable model that adjusted for older adult and caregiver factors (Table 3, right column), the association of end-of-life status and caregiving strain was attenuated and no longer statistically significant, but the odds of experiencing high strain remained higher among dementia (vs. nondementia) caregivers (aOR = 1.67, 95% CI: 1.26−2.22). Aside from dementia, functional status was the only older adult factor that was significantly associated with high caregiving strain in the full multivariable model. Relative to assisting an older adult with two or fewer activities of daily living (ADLs), assisting an older adult with three to four or five to six ADLs was associated with a roughly two-fold greater odds of high caregiving strain (aOR = 1.77, 95% CI 1.28−2.46 for three to four ADLs and 2.55, 95% CI 1.85−3.53 for five to six ADLs).

Several caregiver factors were associated with high strain in the fully adjusted multivariable model (Table 3). The likelihood of experiencing high strain was significantly greater among female (vs. male) caregivers (aOR = 2.15, 95% CI 1.48−3.14), as well as caregivers in poor or fair (vs. good or excellent) health (aOR 2.65, 95% CI 2.04−3.45). Caregivers who were employed (aOR = 1.50, 95% CI 1.14−1.97) and provided greater than 20 hours of care per week (aOR = 1.83, 95% CI 1.37−2.45) also had a greater odds of high caregiving strain. Caregivers who were not spouses or adult children were less likely to

Table 1
Characteristics of Community-Living Older Adults Receiving Help With Self-Care and Indoor Mobility From a Family/Unpaid Caregiver, Stratified by Caregiver Strain

	Full Sample ($N = 3422$)	Low or Moderate Strain ($n = 2702$)	High Strain ($n = 720$)	
Older Adult Characteristic	Column Percentages	Row Percentages		*P*-value
Age [mean (95% CI)]	78.7 (78.3, 79.0)	78.5 (78.3, 78.7)	79.2 (78.8, 79.6)	0.18
Gender				
Male	36.6%	78.8%	21.2%	<0.001
Female	63.4%	84.2%	15.8%	
Race				
White	78.7%	82.0%	18.0%	0.53
Black or other	21.3%	83.2%	16.8%	
Education				
Less than 12 years	37.3%	78.8%	21.2%	<0.001
12 or more years	62.7%	84.3%	15.7%	
Medicaid recipient				
No	77.9%	83.0%	17.0%	<0.05
Yes	22.1%	79.7%	20.3%	
Self-rated health				
Excellent or good	43.8%	86.4%	13.6%	<0.001
Fair or poor	56.2%	79.0%	21.0%	
Assistance with activities of daily living				
Standby, 1, or 2 ADLs	65.4%	87.8%	12.2%	<0.001
3 or 4 ADLs	19.0%	77.4%	22.6%	
5 or 6 ADLs	15.6%	64.7%	35.3%	
Dementia status				
Without dementia	70.0%	86.3%	13.7%	<0.001
With dementia	30.1%	72.8%	27.2%	
End-of-life status				
Survived 12 months	86.8%	83.2%	16.8%	<0.001
Died within 12 months	13.2%	76.2%	23.8%	

ADLs = activities of daily living; NLTCS = National Long-Term Care Survey; NHATS = National Health and Aging Trends Study.
Data drawn from National Long-Term Care Survey/Informal Care Survey data from 1999 (n = 791 dyads) and 2004 (n = 1149 dyads) and National Health and Aging Trends Study/National Survey of Caregiving from 2011 (n = 736 dyads) and 2015 (n = 746 dyads). Data were weighted using NLTCS and NHATS weights as described in prior work.[30] Statistical significance was assessed using chi-squared tests for categorical variables and t-tests for continuous variables. High caregiving-associated strain was defined on the basis of a cut point of 5 or greater on a scale of 0–9 based on six elements: emotional strain (0 = none; 1 = some; 2 = a lot), physical strain (0–2), financial strain (0–2), having no time for oneself (0 = false; 1 = true), being overwhelmed (0 or 1), and being exhausted (0 or 1). Dementia status identified through composite measures as specified in prior work.[30,31] Older adults identified as nearing the end of life if they died within a year of survey completion as documented in the Medicare Master Beneficiary File. "Standby" assistance refers to data from the NLTCS only and is grouped with one to two self-care/mobility activities so as to make the NLTCS and NHATS comparable, as previously described.[30]

experience high caregiving strain relative to spousal caregivers (aOR = 0.45, 95% CI 0.27–0.77).

Association of Strain and End-of-Life Status for Dementia Caregivers and for Nondementia Caregivers

Dementia remained significantly associated with high caregiving strain in a third model that interacted dementia and end-of-life status and controlled for older adult and caregiver factors (Supplementary Tables 1 and 2). In this model, the association of dementia and caregiving strain was stronger for older adults nearing the end of life (Fig. 2). Focusing specifically on dementia caregivers, the odds of high caregiving strain were nearly two-fold higher

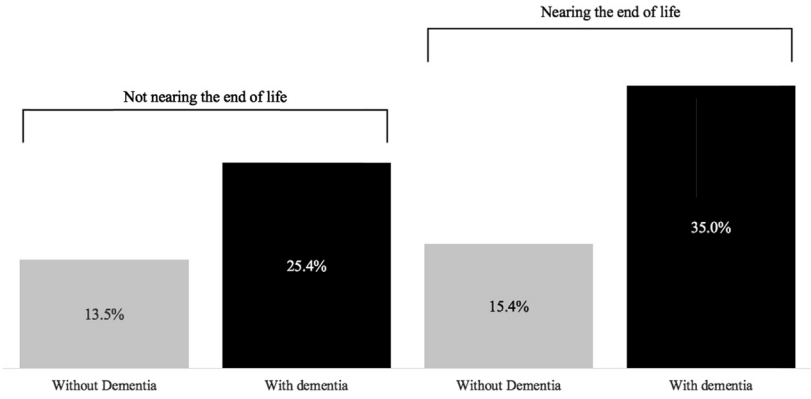

Fig. 1. Proportion of high caregiving strain among family caregivers, by older adult dementia and end-of-life status.

Table 2
Characteristics of Caregivers Assisting Community-Living Older Adults Receiving Help With Self-Care and Indoor Mobility From a Family/Unpaid Caregiver, Stratified by Caregiver-Associated Strain

	Full Sample ($N = 3422$)	Low or Moderate Strain ($n = 2702$)	High Strain ($n = 720$)	
Caregiver Characteristic	Column Percentages	Row Percentages		*P*-value
Age [mean (95% CI)]	62.8 (62.1, 63.5)	63.0 (62.6, 63.4)	61.9 (61.2, 62.6)	0.11
Gender				
Male	35.8%	89.5%	10.5%	<0.001
Female	64.2%	78.2%	21.8%	
Relationship to OA				
Spouse	44.6%	82.6%	17.4%	<0.001
Child	39.3%	79.4%	20.6%	
Other	16.1%	88.1%	11.9%	
Distance to older adult				
Coreside	75.9%	81.4%	18.6%	0.10
Less than 10 minutes	14.5%	84.7%	15.3%	
More than 10 minutes	9.6%	85.1%	14.9%	
Self-rated health				
Excellent or good	73.7%	86.3%	13.7%	<0.001
Fair or poor	26.3%	70.8%	29.2%	
Employed for pay				
No	71.1%	83.0%	17.0%	0.17
Yes	28.9%	80.5%	19.5%	
Respite use				
No	86.3%	83.7%	16.3%	<0.001
Yes	13.7%	73.1%	26.9%	
Hours per week of care provided [mean (95% CI)]	32.6 (30.8, 34.4)	28.8 (27.8, 29.8)	49.9 (47.8, 52.0)	<0.001

NLTCS = National Long-Term Care Survey; NHATS = National Health and Aging Trends Study.
Data drawn from National Long-Term Care Survey/Informal Care Survey data from 1999 ($n = 791$ dyads) and 2004 ($n = 1149$ dyads), and National Health and Aging Trends Study/National Survey of Caregiving from 2011 ($n = 736$ dyads) and 2015 ($n = 746$ dyads). Data were weighted using NLTCS and NHATS weights as described in prior work.[30] Statistical significance was assessed using chi-squared tests for categorical variables and t-tests for continuous variables.
High caregiving-associated strain was defined on the basis of a cut point of 5 or greater on a scale of 0–9 based on six elements: caregiver appraisal of the difficulty of helping in three domains—emotional (0 = no difficulty; 1 = some difficulty; 2 = a lot of difficulty), physical (0–2), and financial (0–2)—as well as having no time for oneself (0 = false; 1 = true), being overwhelmed (0 or 1), and being exhausted (0 or 1).

(aOR = 1.94, 95% CI 1.10–3.45) for those assisting an older adult nearing (vs. not nearing) end of life (see Supplementary Table 2 for more details on how this ratio was computed). Among nondementia caregivers, the odds of high caregiving strain were not significantly different by virtue of whether they were approaching end of life.

Discussion

This study used nationally representative data to determine whether caregiving strain increases among dementia caregivers as older adults approach the end of life, and secondarily, whether there is an association of high strain and end-of-life status among nondementia caregivers. We found that dementia caregivers were more likely to experience high caregiving strain as older adults near end of life. For those caring for older adults without dementia, the end-of-life period was not associated with increased strain. In addition to dementia status, other factors that were independently associated with increased odds of high caregiving strain included greater functional impairment among older adults and caregivers: being female, employed, and providing greater than 20 hours of care.

Our findings are consistent with evidence of the disproportionate impact of dementia-related caregiving[5,7,35] and expert opinion that has endorsed the notable challenges of caring for persons with dementia and at the end of life.[36–38] In prior work, Ornstein et al. described the higher prevalence of physical difficulty among caregivers of older adults with dementia at the end of life compared to caregivers of older adults with dementia before the end of life.[29] Our analysis differs from this earlier work in several ways. First, it examines the experiences of primary caregivers (rather than all caregivers) to older adults with mobility or self-care disability, a subset that is at greater risk of caregiving strain. Our study also builds on this prior research by examining correlates of high caregiving strain in multivariable models. These correlates may serve as the basis for intervention research and efforts to alleviate role-related strain through supportive policies and programs.

Despite the apparent challenges of the end-of-life period in dementia, caregiver and care recipient needs, and how to best mitigate them, are not well described.[23,39–41] A recent systematic review determined that seven of 11 international Clinical Practice Guidelines for dementia care had minimal or no discussion of end-of-life care, with only one specifically

Table 3
Simple and Multivariable Logistic Regression Models Examining High Caregiver Strain: Primary Caregivers of Community-Living Older Adults With Self-Care/Mobility Disability

Older Adult and Family Caregiver Characteristics	Unadjusted	Full Model
Older adult characteristics		
Age	1.01 [1.00, 1.02]	0.99 [0.97, 1.01]
Female	0.69 [0.56, 0.86]	0.93 [0.69, 1.27]
Black or other race	0.91 [0.69, 1.21]	0.76 [0.54, 1.08]
12+ years of school	0.69 [0.56, 0.85]	0.92 [0.72, 1.18]
With Medicaid	1.24 [1.02, 1.51]	0.98 [0.74, 1.31]
In fair or poor health	1.68 [1.34, 2.12]	1.14 [0.88, 1.48]
Help with ADLs		
Standby, 1, or 2	REF	REF
3 to 4	2.11 [1.60, 2.80]	1.77 [1.28, 2.46]
5 to 6	3.94 [3.07, 5.06]	2.55 [1.85, 3.53]
Dementia	2.36 [1.84, 3.03]	1.67 [1.26, 2.22]
End of life (EOL)	1.54 [1.20, 1.99]	1.04 [0.78, 1.39]
Caregiver characteristics		
Age	0.99 [0.99, 1.00]	0.99 [0.98, 1.00]
Female	2.37 [1.78, 3.16]	2.15 [1.48, 3.14]
Relationship to older adult		
Spouse	REF	REF
Adult child	1.23 [0.97, 1.55]	0.77 [0.47, 1.25]
Other	0.64 [0.48, 0.85]	0.45 [0.27, 0.77]
Distance to older adult		
Co-reside	REF	REF
<10 minutes	0.79 [0.58, 1.07]	0.92 [0.64, 1.31]
>10 minutes	0.76 [0.57, 1.03]	0.95 [0.67, 1.36]
In fair or poor health	2.61 [2.08, 3.28]	2.65 [2.04, 3.45]
Employed for pay	1.18 [0.93, 1.50]	1.50 [1.14, 1.97]
Greater than 20 hours of caregiving each week	2.86 [2.19, 3.72]	1.83 [1.37, 2.45]
Use of respite services	1.89 [1.40, 2.56]	1.67 [1.17, 2.39]

ADLs = activities of daily living; NLTCS = National Long-Term Care Survey; NHATS = National Health and Aging Trends Study.
Data drawn from National Long-Term Care Survey/Informal Care Survey data from 1999 (n = 791 dyads) and 2004 (n = 1149 dyads), and National Health and Aging Trends Study/National Survey of Caregiving from 2011 (n = 736 dyads) and 2015 (n = 746 dyads). Data were weighted using NLTCS and NHATS weights as described in prior work.[30] The fully adjusted model also accounted for wave of data. High caregiving-associated strain was defined on the basis of a cut point of 5 or greater on a scale of 0–9 based on six elements: High caregiving-associated strain was defined on the basis of a cut point of 5 or greater on a scale of 0–9 based on six elements: caregiver appraisal of the difficulty of helping in three domains—emotional (0 = no difficulty; 1 = some difficulty; 2 = a lot of difficulty), physical (0–2), and financial (0–2)—as well as having no time for oneself (0 = false; 1 = true), being overwhelmed (0 or 1), and being exhausted (0 or 1). Dementia status identified through composite measures as specified in prior work.[30,31] Older adults identified as being at the end of life if they died within a year of survey completion as documented in the Medicare Master Beneficiary File. "Standby" assistance refers to data from the NLTCS only and is grouped with one to two self-care/mobility activities so as to make the NLTCS and NHATS comparable, as previously described.[30]

recommending a conversation about a person's preferences on place of death.[42] In addition, older adults with dementia and their families are no more likely to receive government or insurance support for paid caregivers at the end of life than before this period, in contrast to other medical conditions.[29] How and when clinicians engage family members with decision making around end-of-life care in patients with dementia has been shown to affect what decisions are made, what care is provided, and how family members conceive of their role,[43–45] but a robust understanding of the ways in which clinicians interact with patients and families on these matters, and how they could do it better, is lacking. Our study joins the accumulating body of evidence that this is an area of utmost public health importance.

The need for interventions for this caregiver population, however, begs the question of how best to identify them. Prognosticating death in patients with dementia is well known to be difficult, with a disease trajectory less predictable than for other conditions.[14,46,47] In one study of nursing home residents with advanced dementia, for example, only 1% of the 883 residents were predicted to die within six months, but 71% of them actually did.[48] By contrast, another study documented that 44% of a sample of 165 community members with dementia who met criteria for hospice (including a prognosis of less than six months) did not die within the six-month period.[49] Strategies for supporting caregivers of older adults with dementia throughout disease progression—such as caregiver assessment, family engagement, and expanding access to palliative care—bypass this prognostication problem. Caregiver assessment refers to the systematic determination of caregiver ability and willingness to assist a care recipient,[36,37,50] and this assessment is part of the process of family engagement through which family members are involved as active members of the health care team.[51] Both caregiver assessment and engagement dovetail with early and iterative advance care planning with initial diagnosis of cognitive impairment,[52] and the approach of palliative care, which prioritizes communication and psychosocial support for patients and families.[42] Although challenging, there is an increasing need to expand palliative care for those with dementia for the benefit of both those with the disease and those who care for them.[53]

Beyond our findings about the relationship of caregiving strain, and dementia and end-of-life status, other results merit comment as they provide useful insight for targeting high-risk caregivers and tailoring interventions for characteristics associated with high strain. Our finding that caregiver strain was associated with severity of older adults' functional impairment is consistent with prior work[8] and supports the need for more practical interventions to ameliorate burdens of providing hands-on assistance with activities of daily living. Similarly, our finding that strain was higher among female caregivers is consistent with prior literature[8,54] and forthcoming systematic review[55] and is particularly salient in light of the association of financial strain and mortality[56,57] and the continuing predominance of women as dementia caregivers.[3] Our finding that caregiver employment is associated with an increased odds of high strain supports the growing policy interest in developing "caregiver-friendly" workplace policies[58–60] as caregiving strain could be reduced by more supportive policies at work.

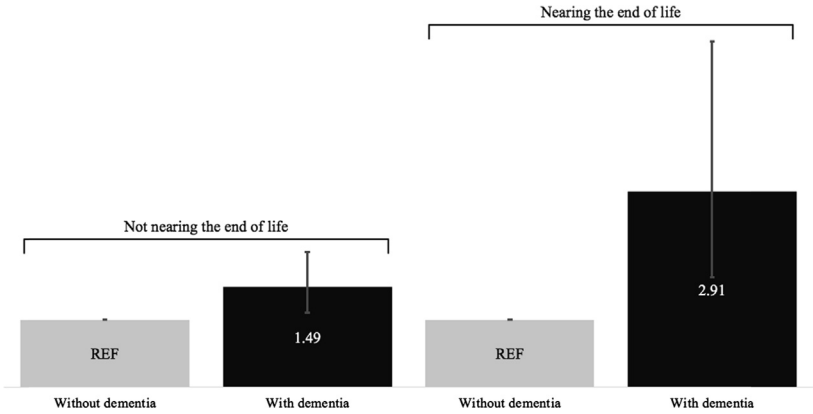

Fig. 2. Adjusted odds ratios of high caregiving strain within older adult end-of-life status strata.

Strengths of our study include the prospective collection of data and the linked nature of older adult and caregiver surveys. Most studies of caregiving at the end of life rely on follow-back surveys in which the decedent's family members are asked to reflect on the time before the patient's death.[61] Retrospective data collection of this manner is subject to recall bias, as family members may overestimate or underestimate the degree of strain they experienced. This study is the first, to our knowledge, that uses nationally representative data to consider how strain varies by both dementia and end-of-life status in a nationally representative sample of community-dwelling older adults needing assistance with self-care and indoor mobility.

Our study had limitations. The sample population was restricted to older adults greater than 65 years, living in the community, and receiving assistance from a "primary" family or unpaid caregiver helping with self-care and indoor mobility. It is not clear to what extent the results could be generalized to caregivers of older adults without disability, to older adults not living at home, or adults who died before the age of 65 years. Our analysis is also limited by available measures. In particular, we were unable to account for caregiver depression, use of palliative care, personal rewards associated with caregiving, whether the older adult had additional paid in-home help in addition to their "primary caregiver," and the availability of additional family or unpaid family caregivers other than the "primary caregivers" included in the analysis. Caregiver coping mechanisms were not assessed in either survey, despite evidence that it is caregiver psychological qualities and resilience that most affects the caregiver's experience of caregiving.[62] In addition, our definition of end of life as within the last year of life, though based on prior work,[15,29,32,33,63] may not correspond to what older adults and caregivers subjectively experience as the end-of-life period. For example, a recent mixed-methods study reported that family members of recently deceased patients—nearly half of whom had dementia—identified the end-of-life period as starting a median of 3.25 years before death.[64] Defining the end-of-life period in research is challenging, as definitions may differ according to disease trajectory, study design, and outcomes of interest.[27,65]

Our study has important implications for policy and resource allocation. Caregiver experience affects outcomes such as older adult hospitalization,[66,67] Medicare spending,[67] nursing home placement,[68] neuropsychiatric symptoms,[69] and emotional distress at the end of life,[70] and caregiver personal health care costs and acute care utilization.[71,72] This context and our findings thus suggest that the continued refinement of interventions for caregivers of persons with dementia throughout the disease trajectory would benefit both caregivers and those for whom they provide care.

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Appendix

Supplementary Table 1

Interaction of Dementia and Survival Status, and Caregiver Strain among Primary Caregivers of Community-Living Older Adults with Self-Care/Mobility Disability

Older Adult and Family Caregiver Characteristics	Full Model With Interaction
Older adult characteristics	
Age	0.99 [0.97, 1.01]
Female	0.94 [0.70, 1.28]
Black or other race	0.77 [0.54, 1.08]
12+ years of school	0.92 [0.72, 1.18]
With Medicaid	0.98 [0.74, 1.31]
In fair or poor health	1.13 [0.87, 1.48]
Help with ADLs	
Standby, 1, or 2	REF
3 to 4	1.79 [1.29, 2.49]
5 to 6	2.54 [1.84, 3.51]
Dementia	1.50 [1.12, 2.01]
End of life (EOL)	0.74 [0.49, 1.11]
Dementia−EOL interaction	1.94 [1.10, 3.45]
Caregiver characteristics	
Age	0.99 [0.98, 1.00]
Female	2.22 [1.53, 3.21]
Relationship to older adult	
Spouse	REF
Adult child	0.76 [0.47, 1.22]
Other	0.45 [0.26, 0.76]
Distance to older adult residence	
Co-reside	REF
<10 minutes	0.91 [0.64, 1.29]
>10 minutes	0.96 [0.67, 1.37]
In fair or poor health	2.64 [2.04, 3.42]
Employed for pay	1.51 [1.15, 1.99]
Greater than 20 hours of caregiving each week	1.85 [1.38, 2.48]
Use of respite services	1.67 [1.17, 2.39]

Data drawn from National Long-Term Care Survey/Informal Care Survey from 1999 (n = 791 dyads) to 2004 (n = 1149 dyads), and National Health and Aging Trends Study/National Survey of Caregiving from 2011 (n = 736 dyads) to 2015 (n = 746 dyads). Data were weighted using NLTCS and NHATS weights as described in prior work.[30] The fully adjusted model also accounted for wave of data. High caregiving strain was defined on the basis of a cutpoint of 5 or greater on a scale of 0−9 based on six elements: emotional strain (0 = none; 1 = some; 2 = a lot), physical strain (0−2), financial strain (0−2), having no time for oneself (0 = false; 1 = true), being overwhelmed (0 or 1), and being exhausted (0 or 1). Dementia status identified through composite measures as specified in prior work.[30,31] Older adults identified as nearing the end of life if they died within a year of survey completion as documented in the Medicare Master Beneficiary File. "Standby" assistance refers to data from the National Long-Term Care Survey only and is grouped with 1−2 self-care/mobility activities so as to make the National Long-Term Care Survey and National Health and Aging Trends Study comparable, as previously described.[30]

Supplementary Table 2

Heterogeneity of Association of High Caregiver-Associated Strain and Dementia by End-of-Life Status

Survival Status	Without Dementia, OR [95% CI]	With Dementia, OR [95% CI]	Within Stratum, OR [95% CI]
Not nearing end of life	REF	1.49 [1.11−2.01]	1.49 [1.11−2.01]
Nearing end of life	0.74 [0.49−1.11]	2.16 [1.36−3.44]	2.91 [1.64−5.16]

Data drawn from National Long-Term Care Survey/Informal Care Survey data from 1999 (n = 791 dyads) to 2004 (n = 1149 dyads), and National Health and Aging Trends Study/National Survey of Caregiving from 2011 (n = 736 dyads) to 2015 (n = 746 dyads). Data were weighted using National Long-Term Care Survey and National Health and Aging Trends Study weights as described in prior work.[30] High caregiving-associated strain was defined on the basis of a cutpoint of 5 or greater on a scale of 0−9 based on six elements: emotional strain (0 = none; 1 = some; 2 = a lot), physical strain (0−2), financial strain (0−2), having no time for oneself (0 = false; 1 = true), being overwhelmed (0 or 1), and being exhausted (0 or 1). Dementia status identified through composite measures as specified in prior work.[30,31] Older adults identified as being at the end of life if they died within a year of survey completion as documented in the Medicare Master Beneficiary File.

Estimates in this table were derived from a multivariable model that included wave of data, older adult characteristics, caregiver characteristics, and a term that interacted end of life and dementia, therefore accounting for different associations between end of life and strain among those caring for an older adult with and without dementia. The full model is available as *Supplementary Table 1*.