

Original Article

Cite this article: Sullivan SS, de Rosa C, Li CS, Chang YP (2023). Dementia caregiver burdens predict overnight hospitalization and hospice utilization. *Palliative and Supportive Care* 21, 1001–1015. <https://doi.org/10.1017/S1478951522001249>

Received: 04 February 2022

Revised: 15 July 2022





Accepted: 30 August 2022

Keywords:

Alzheimer's disease; Dementia; NHATS; NSOC; Caregiver; End-of-life; Terminal care; Care transitions

Author for correspondence:

Suzanne S. Sullivan, School of Nursing, University at Buffalo, 3435 Main Street, 201A Wende Hall, Buffalo, NY 14214, USA.
Email: suzanne@buffalo.edu

Suzanne S. Sullivan, PH.D., M.B.A., R.N., C.H.P.N. , Cristina de Rosa, M.S.N., R.N. ,
Chin-Shang Li, PH.D.  and Yu-Ping Chang, PH.D., R.N., F.G.S.A., F.I.A.A.N., F.A.A.N. 

School of Nursing, University at Buffalo, Buffalo, NY, USA

Abstract

Objectives. To determine sociodemographics and caregiver burdens associated with overnight hospitalization, hospice utilization, and hospitalization frequency among persons with dementia (PWD).

Methods. Cross-sectional analysis of PWD ($n = 899$) of the National Health and Aging Trends Study linked to the National Study of Caregiving. Logistic and proportional odds regression determined the effects of caregiver burdens on overnight hospitalization, hospice use, and hospitalization frequency. Differences between PWD alive/not-alive groups were compared on overnight hospitalization and frequency.

Results. Alive PWD ($n = 804$) were 2.36 times more likely to have an overnight hospital stay ($p = 0.004$) and 1.96 times more likely to have multiple hospitalizations when caregivers found it physically difficult to provide care ($p = 0.011$). Decedents aged 65–74 ($n = 95$) were 4.55 times more likely to experience overnight hospitalizations than 85+, hospitalizations were more frequent (odds ratio [OR] = 4.84), and there was a significant difference between PWD alive/not alive groups ($p = 0.035$). Decedents were 5.60 times more likely to experience an overnight hospitalization when their caregivers had financial difficulty, hospitalizations were more frequent when caregivers had too much to handle (OR = 8.44) and/or no time for themselves (OR = 10.67). When caregivers had no time for themselves, a significant difference between alive/not alive groups ($p = 0.018$) was detected in hospitalization frequency. PWD whose caregivers had emotional difficulty helping were 5.89 times more likely to utilize hospice than caregivers who did not report emotional difficulty.

Significance of results. Care transitions among PWD at the end of life are impacted by the circumstances and experiences of their caregivers. Subjective caregiver burdens represent potentially modifiable risks for undesired care transitions and opportunities for promoting hospice use. Future work is warranted to identify and address these issues as they occur.

Introduction

The prevalence of dementia and chronic illnesses is significant and rising to the extent that the World Health Organization recently declared a public health emergency to support family caregivers, improve access to palliative care services, and reduce suffering at the end of life (EOL) (World Health Organization [WHO] 2021). Supportive care programs such as palliative and hospice care may benefit persons with dementia (PWD) and their family caregivers, given its holistic approach focusing on optimizing quality of life and role in minimizing nonbeneficial treatments and hospitalizations near the EOL (Ashbourne et al. 2021; Teno et al. 2018).

Dementia is a progressive, terminal condition that affects the memory, behavioral and physical functioning of individuals (Melis et al. 2019). Although circumstances vary, many dementia caregivers often experience intense feelings of subjective burden when caring for PWD that can increase the risk of hospitalization and institutionalization of PWD under their care (Ashbourne et al. 2021; Graessel et al. 2014; Kasper et al. 2015; Wolff et al. 2018b). Subjective burdens, defined as “a person’s subjective evaluation of feeling burdened” (Pendergrass et al. 2018, p. 2), may arise from a range of life circumstances such as socioeconomic status characteristics, being overloaded with responsibilities, and having personal conflicts (e.g., family, job, and social) and from intrapsychic (emotional) strains that can lead to high levels of stress that affect the caregiver and PWD bidirectionally (Pearlin et al. 1990). There are more than 6 million PWD receiving assistance from family caregivers in the United States, placing the responsibility for the health and well-being of PWD squarely on the shoulders of family caregivers in the home (Alzheimer’s Association 2021). Family caregivers are individuals such as spouses, partners, adult children, other relatives, friends, or neighbors who provide care based on a personal, rather than paid, relationship with the PWD (Committee on Family Caregiving for Older Adults 2016). Older adults with dementia typically receive care from spouses and adult daughters (Kasper et al. 2015; Kumar et al. 2020), averaging more than 30 hours per week for up to 4 years

or more (Wolff *et al.* 2018a). However, family caregivers rarely receive any financial assistance or other support to meet the needs of PWD near the EOL, despite providing more than double the number of hours of care per week compared to caregivers of those with other serious illnesses (Ornstein *et al.* 2017; Porock *et al.* 2015). These experiences may exacerbate subjective feelings of burden among caregivers that can be further compounded by other family responsibilities, or by their own physical and emotional health concerns (Pristavec and Pruchno 2019). Thus, the demands of dementia caregiving can have profound effects on family caregivers' quality of life, rates of anxiety and depression, and ability to care for themselves (Centers for Disease Control and Prevention [CDC] 2019; Graessel *et al.* 2014). Consequently, PWD are more likely to have unmet care needs at the EOL, and caregivers are more likely to become overwhelmed in their role (Beach *et al.* 2020; Graessel *et al.* 2014; Riffin *et al.* 2019).

PWD also require more help than those without the condition, often resulting in high levels of subjective caregiving burdens, more frequent transitions between health-care settings, and fragmented care (Leniz *et al.* 2019; Teno *et al.* 2018; Vick *et al.* 2019). Although PWD and their caregivers often prefer in-home care for the PWD through the EOL, and the proportion of PWD who remain at home through the EOL is increasing, this typically requires the presence of a willing and able caregiver and ideally the support of in-home hospice care (Ornstein *et al.* 2017; Teno *et al.* 2018). Without this essential support, caregivers may reach their "tipping point," when they realize that they can no longer care for their loved one at home, which can lead to hospitalizations and other undesired health-care transitions for PWD (Saragosa *et al.* 2021). Transitions in care are stressful for PWD and may accelerate physical and cognitive decline. Therefore, there is a clear need to develop approaches to reduce hospitalizations of PWD as much as possible to facilitate early transitions to supportive care services such as palliative and hospice care, which can improve EOL care outcomes, reduce caregiving burdens, and decrease unplanned hospitalizations near the EOL (Institute of Medicine [IOM] 2015; Wright *et al.* 2018). However, there is insufficient research investigating the unique needs of dementia caregivers such as how caregiving burdens drive overnight hospitalization and hospice use near the EOL (Cagle *et al.* 2020; Hirschman and Hodgson 2018; Romo *et al.* 2019). Identification of potentially modifiable risks for undesired care transitions may aid the development of new approaches to reduce caregiver burdens that simultaneously address unmet needs of PWD and improve access to hospice care services for PWD who are nearing the EOL.

The purpose of this study is to better understand potential relationships between subjective caregiver burdens and overnight hospitalization incidence and number of overnight hospitalizations and hospice use in the last year of life. The study is guided by the following research questions: (1) what is the relationship between subjective caregiver burden and (a) overnight hospitalizations (incidence and frequency) and (b) hospice utilization among deceased PWD, and (2) what are the differences in overnight hospitalizations (incidence and frequency) between PWD who either live or die within a year?

Methods

This is a cross-sectional, secondary data analysis of the National Health and Aging Trends Study (NHATS) linked to the National

Study of Caregiving (NSOC). This study received human subject approval from the university institutional review board (#MODCR00005076).

Data sets

NHATS is an annual national survey of 12,427 Medicare beneficiaries sampled from the Medicare enrollment file who are aged 65+ and residing in the contiguous United States (2011 to current) (Montaquila *et al.* 2012). NHATS is a collection of data around key content areas in the domains of health conditions, mobility and physical function, cognitive capacity (including dementia), self-care capacity and participation in valued activities, and items related to social determinants of health to further understanding of aging and disability trends among older adults residing in the community. The NSOC, which complements NHATS, interviews up to 5 family caregivers of a subset of NHATS research respondents at 3 time points (2011, 2015, and 2017) on a range of topics related to caregiving activities including positive and negative aspects of caregiving, intensity and duration of caregiving, health and well-being, and socioeconomic items. There are 3,305 NHATS respondents with a primary caregiver represented across the 3 time points in the NSOC. The NHATS/NSOC studies are conducted at the Johns Hopkins University and are sponsored by a grant from the National Institutes of Aging (NIA) (NIA U01AG32947). Our method for preprocessing and linking the NHATS to the NSOC data sets longitudinally, including SAS coding statements, is published elsewhere (Sullivan *et al.* 2022).

Theoretical framework

The caregiver stress model developed by Pearlin *et al.* (1990) guides this study. The model identifies and describes caregiving background and context components, such as socioeconomic status, as well as specific stressors and strains that contribute to the overall experience of caregiver burden. The caregiver stress model is made up of the following domains: background and context (e.g., sociodemographics), primary stressors (e.g., caregiver overload), secondary role strains (e.g., family and employment caregiving conflicts), secondary intrapsychic strains (e.g., global and situational), caregiver outcomes (not considered in this analysis), and mediators (e.g., coping and social support).

In addition, Lazarus and Folkman's (1984) transactional stress model emphasizes that the perception of stress is relative to the caregiver's cognitive appraisal of the current situation and capacity to fulfill its demands (Pendergrass *et al.* 2018). Together, these models comprise the conceptual basis for the Burden Scale for Family Caregivers (BSFC), a psychometrically valid and reliable instrument that measures multiple aspects of subjective caregiver burden that can increase the risk of institutionalization of older adults with dementia (Graessel *et al.* 2014; Pendergrass *et al.* 2018).

The BSFC includes items that operationalize the assessment of caregiver emotional, physical, personal, and social stressors (Graessel *et al.* 2014; Pendergrass *et al.* 2018) and was therefore used to guide the selection of specific NHATS and NSOC items indicating caregiver burden. Although the BSFC is not completely or directly replicated in NHATS/NSOC items (prohibiting our ability to calculate a measure of caregiver burden), conceptual similarities allowed a crosswalk between like questions based on the content expertise of the authors. For example, the BSFC item

“I often feel physically exhausted” closely approximates the NSOC item “you are exhausted when you go to bed at night.”

Population

Sample

While NHATS collects longitudinal data annually, it does not enroll new respondents in every round, so the lower age limit for continuing respondents increases as the sample ages. To ensure the representation of person aged 65+, the data were limited to NHATS respondents and their primary caregivers who enrolled in round 5 (2015), when the second NHATS cohort was enrolled. NHATS respondents were linked to their primary caregiver who responded to the NSOC II (2015) in dyads as NHATS round 5 also aligns with the NSOC II (2015).

Persons living with dementia

Individual NHATS respondents were identified as having either 1 = probable, 2 = possible, or 3 = no dementia based on a valid and reliable Eight-item Informant Interview to Differentiate Aging and Dementia (AD8) score using the SAS coding statements provided by the principal investigators of NHATS (Kasper and Freedman 2020; Kasper et al. 2013). Respondents with either a probable or possible dementia classification as indicated by the AD8, i.e., PWD, were included in the study. NHATS participants with “no dementia” were excluded.

The AD8 instrument assesses memory, temporal orientation, judgment, and function and assigns a “cutoff” point to estimate dementia status. The AD8 instrument has good to excellent internal consistency ($\alpha = 0.84$), interrater reliability ($\kappa = 0.67$), intra-class correlation coefficient of 0.80, and discrimination (area under the curve = 0.92) (Galvin et al. 2006). Moreover, factor analysis of the cognitive domains of NHATS tests has the following factor loadings: memory (range 0.738–0.804), orientation (range 0.633–0.640), and executive functioning (0.494) (Kasper et al. 2013).

Alive/not alive

PWD who died between the 2015 and the 2016 follow-up survey (rounds 5 and 6), identified by the presence of a last month of life (LML) interview in round 6, were considered to be “not alive” in the present study. PWD who did not have an LML interview were considered to be “alive.” The LML interview is administered when an NHATS respondent has died between rounds of data collection. The LML interview is conducted with proxy representatives (typically a family member) who report the experience (quality of EOL care and daily activities) of the NHATS respondent during their LML.

Caregivers

Paid or unpaid primary family caregivers were defined as the person providing the greatest number of hours of care to the PWD in the month preceding the NSOC interview, which is consistent with previously published research (Pristavec et al. 2020).

Outcome variables

Predictor variables were collected from round 5 (2015) and outcomes (overnight hospitalization, frequency of overnight hospitalizations, and hospice use) were identified in round 6 (2016) to capture EOL care transitions in the subpopulation of decedents (i.e., NHATS rounds 5 and 6 linked to NSOC data 2015–2016).

Overnight hospital stays

Care transitions to the hospital were defined as an overnight hospital stay within the previous 12 months (yes/no).

Number of overnight hospital stays

The number of (separate) overnight hospital stays was coded as follows: 0 = no overnight hospital stays; 1 = 1 overnight hospital stay; 2 = 2 overnight hospital stays; 3 = 3 overnight hospital stays; or 4 = ≥ 4 overnight hospital stays. The number of overnight hospital stays was chosen to determine if there was a relationship between the frequency of separate hospitalizations and subjective caregiver burden items in the year prior to death.

Hospice utilization

Hospice utilization (yes/no) was selected from a derived variable available in the NHATS data set to determine possible correlates at the EOL.

Predictor variables

Subjective caregiver burden variable selection was guided by the caregiver stress model and the BSFC questionnaire. Subjective caregiver burden predictor variables included NHATS and NSOC items representing a combination of PWD and caregiver sociodemographics (PWD age, sex, race, and socioeconomic status, and caregiver age, sex, and socioeconomic status) and PWD living situation. Table 1 provides a detailed description of the variable categories and frequencies.

PWD race

Race categories were grouped as white, African American, and others due to the relatively small frequency of racial subgroups and those reporting 2 or more races.

Age and sex

Three 10-year incremental age categories were created (65–74 through 80+ years) for PWD. Five 10-year incremental age categories were created (≤ 39 through 80+ years) for caregivers. PWD and caregivers' sex was binary (male/female).

Socioeconomic status

Socioeconomic status of the PWD or caregiver was indicated by 4 incremental income categories (e.g., 1 = less than \$30,000 through 4 = \geq \$66,000) based on their respective total income.

PWD living situation

The living situation of the PWD included whether the PWD lives alone, with a spouse/partner only, with a spouse/partner and with others, or with others only, if the caregiver lives with the PWD, the number of children in the household, and the total number of people residing in the household.

Subjective caregiver burden

In addition to sociodemographic and living situation items, subjective caregiver burden also included questions directly related to the caregiver experience: the amount of time the caregiver spends driving to or from home to care for the PWD; how much the caregiver enjoys being with the PWD; how often the PWD gets on the caregiver's nerves; whether caregiving poses financial, physical, or emotional challenges; to what extent the caregiver reports being exhausted at night, having more to do than they can handle, having no time for themselves; and how often the PWD's care routine changes.

Table 1. Frequencies of care transitions, sociodemographics, and subjective caregiver burden

Characteristics	Entire group (n = 899)			Alive group (n = 804)			Not alive group (n = 95)		
	n = 4,595,265			n = 4,194,379			n = 400,886		
Care transitions	n	%	Valid %	n	%	Valid %	n	%	Valid %
Overnight hospital stay									
No	574	63.85	63.92	520	64.68	64.76	54	56.84	56.84
Yes	324	36.04	36.08	283	35.20	35.24	41	43.16	43.16
Number of overnight hospital stays									
0 Overnight hospital stays	500	55.62	55.62	443	55.10	55.10	57	60.00	60.00
1 Overnight hospital stay	239	26.59	26.59	221	27.49	27.49	18	18.95	18.95
2 Overnight hospital stays	88	9.79	9.79	76	9.45	9.45	12	12.63	14.94
3 Overnight hospital stays	35	3.89	3.89	31	3.86	3.86	≤11	4.21	2.33
≥4 Overnight hospital stays	37	4.12	4.12	33	4.10	4.10	≤11	4.21	3.26
Hospice utilization									
No							37	38.95	49.33
Yes							38	40.00	50.67
Sociodemographics									
Race (PWD)									
White	512	56.95	60.45	451	56.09	59.81	61	64.21	65.59
African American	237	26.36	27.98	211	26.24	27.98	26	27.37	27.96
Other	98	10.90	11.57	92	11.44	12.20	≤11	6.32	6.45
Socioeconomic status (PWD)									
PWD total income									
<\$30,000	275	30.59	65.95	247	30.72	66.22	28	29.47	63.64
\$30,000 to <\$43,000	50	5.56	11.99	45	5.60	12.06	≤11	5.26	11.36
\$43,000 to <\$66,000	45	5.01	10.79	39	4.85	10.46	≤11	6.32	13.64
≥\$66,000	47	5.23	11.27	42	5.22	11.26	≤11	5.26	11.36
Caregiver income									
<\$30,000	60	6.67	37.27	48	5.97	35.82	12	12.63	44.44
\$30,000 to <\$43,000	23	2.56	14.29	19	2.36	14.18	≤11	4.21	14.81
\$43,000 to <\$66,000	31	3.45	19.25	25	3.11	18.66	≤11	6.32	22.22
≥\$66,000	47	5.23	29.19	42	5.22	31.34	≤11	5.26	18.52
PWD age (years)									
65–74	211	23.47	23.47	196	24.38	24.38	15	15.79	15.79
75–84	338	37.60	37.60	313	38.93	38.93	25	26.32	26.32
85+	350	38.93	38.93	295	36.69	36.69	55	57.90	57.90
PWD sex									
Female	499	55.51	55.51	450	55.97	55.97	49	51.58	51.58
Male	400	44.49	44.49	354	44.03	44.03	46	48.42	48.42
Caregiver age (years)									
≤39	40	4.45	5.49	38	4.73	5.78	≤11	2.11	2.78
40–59	267	29.70	36.63	244	30.35	37.14	23	24.21	31.94
60–69	201	22.36	27.57	180	22.39	27.40	21	22.11	29.17
70–79	136	15.13	18.66	122	15.17	18.57	14	14.74	19.44
80+	85	9.45	11.66	73	9.08	11.11	12	12.63	16.67

(Continued)

Table 1. (Continued.)

Characteristics	Entire group (n = 899)			Alive group (n = 804)			Not alive group (n = 95)		
Estimated national population	n = 4,595,265			n = 4,194,379			n = 400,886		
Care transitions	n	%	Valid %	n	%	Valid %	n	%	Valid %
Caregiver sex									
Female	559	62.18	67.43	503	62.56	67.79	56	58.95	64.37
Male	270	30.03	32.57	239	29.73	32.21	31	32.63	35.63
Caregiver experience									
Time spent traveling to PWD home									
Minutes	77	8.57	88.51	65	8.08	89.04	12	12.63	85.71
Hours	10	1.11	11.49	8	1.00	10.96	≤11	2.11	14.29
Caregiver enjoys being with PWD									
A lot	242	26.92	84.03	202	25.12	83.82	40	42.11	85.11
Some/a little/not at all	46	5.12	15.97	39	4.85	16.18			
PWD gets on caregiver's nerves									
A lot	37	4.12	12.85	31	3.86	12.86	≤11	6.32	12.77
Some	82	9.12	28.47	73	9.08	30.29	≤11	9.47	19.15
A little	92	10.23	31.94	74	9.20	30.71	18	18.85	38.30
Not at all	77	8.57	26.74	63	7.84	26.14	14	14.74	29.79
Financial difficulty helping									
No	220	24.47	76.66	184	22.89	76.35	36	37.89	78.26
Yes	67	7.45	23.34	57	7.09	23.65			
Emotional difficulty helping									
No	133	14.79	46.34	114	14.18	47.30	19	20.00	41.30
Yes	154	17.13	53.66	127	15.80	52.70	27	28.42	58.70
Physical difficulty helping									
No	211	23.47	73.78	174	21.64	72.50	37	38.95	80.43
Yes	75	8.34	26.22	66	8.21	27.50			
Caregiver is exhausted at night									
Very much	74	8.23	25.78	62	7.71	25.73	12	12.63	26.09
Somewhat	91	10.12	31.71	76	9.45	31.54	15	15.79	32.61
Not so much	122	13.57	42.51	103	12.81	42.74	19	20.00	41.30
Caregiver has too much to handle									
Very much	57	6.34	20.07	47	5.85	19.75	≤11	10.53	21.74
Somewhat	79	8.79	27.82	69	8.58	28.99	≤11	10.53	21.74
Not so much	148	16.46	52.11	122	15.17	51.26	26	27.37	56.52
Caregiver has no time for self									
Very much	79	8.79	27.72	65	8.08	27.20	14	14.74	30.43
Somewhat	88	9.79	30.88	75	9.33	31.38	13	13.68	28.26
Not so much	118	13.13	41.40	99	12.31	41.42	19	20.00	41.30
Care routine changes									
Very much	40	4.45	13.99	33	4.10	13.75	≤11	7.37	15.22
Somewhat	79	8.79	27.62	66	8.21	27.50	13	13.68	28.26
Not so much	167	18.58	58.39	141	17.54	58.75	26	27.37	56.52

(Continued)

Table 1. (Continued.)

Characteristics	Entire group (n = 899)			Alive group (n = 804)			Not alive group (n = 95)		
	n = 4,595,265			n = 4,194,379			n = 400,886		
Care transitions	n	%	Valid %	n	%	Valid %	n	%	Valid %
Living situation									
Spouse lives with PWD									
No	12	1.33	3.42	11	1.37	3.50			
Yes	339	37.71	96.58	303	37.69	96.50	36	37.89	97.30
Living arrangement									
Alone	304	33.82	33.82	276	34.33	34.33	28	29.47	29.47
With spouse/partner only	257	28.59	28.59	227	28.23	28.23	30	31.58	31.58
With spouse/partner and with others	82	9.12	9.12	76	9.45	9.45	≤11	6.32	6.32
With others only	256	28.48	28.48	225	27.99	27.99	31	32.63	32.63
Caregiver lives with PWD									
No	38	4.23	7.55	32	3.98	7.14			
Yes	465	51.72	92.45	416	51.74	92.86	49	51.58	89.09
Total number of people in PWD's household									
1 person	304	33.82	33.82	276	34.33	34.33	28	29.47	29.47
2 persons	373	41.49	41.49	329	40.92	40.92	44	46.32	46.32
3 persons	127	14.13	14.13	115	14.30	14.30	12	12.63	12.63
4 persons	47	5.23	5.23	43	5.35	5.35	≤11	4.21	4.21
≥5 persons	48	5.34	5.34	41	5.10	5.10	≤11	7.37	7.37
Total number of children in PWD's household									
0 child	628	69.86	69.86	560	69.65	69.65	68	71.58	71.58
1 child	240	26.70	26.70	218	27.11	27.11	22	23.16	23.16
≥2 children	31	3.45	3.45	26	3.23	3.23	≤11	5.26	5.26

Note: PWD, persons with dementia.

Some data columns were collapsed or not reported in accordance with the data use agreement due to frequency ≤11. Overnight hospital stays and the number of overnight hospital stays are recorded as separate questions in the NHATS study and therefore have different response rates.

Analytic approach

The present study uses univariable logistic regression to determine the relationship between hospice utilization (yes/no) and each of the aforementioned predictors. Logistic regression with contrasts was used to determine the relationship between overnight hospital stay (yes/no) and each of the aforementioned predictors in each of the 2 PWD groups (alive/not alive) and to compare the relationships between the predictor variable and overnight hospital stay between the 2 groups by including the interaction term between the predictor variable and a group variable denoting whether the PWD lived or died in round 6.

Proportional odds (PO) regression with contrasts was used to examine the relationship between the ordinal outcome variable “number of hospital stays” and each of the aforementioned predictors in each of the 2 PWD groups and compare the relationships between the predictor variable and “number of hospital stays” between the 2 groups by including the interaction term between the predictor variable and a group variable denoting whether the PWD lived or died in round 6.

If an omnibus test for the effect of a categorical predictor with more than 2 levels were significant, multiple pairwise comparisons between a reference group and the other groups were performed

with Bonferroni correction to decide if a pairwise comparison was significant. A *p*-value of an omnibus test <0.05 was considered statistically significant. All analyses were performed with SAS version 9.4 (SAS Institute Inc., Cary, NC, USA 2013). When using SAS PROC LOGISTIC with “clogit” link function to perform PO regression analyses, probabilities modeled are cumulated over the lower ordered values.

Results

There were 899 PWD in the sample linked to their primary caregiver and a subset of 95 PWD decedents. PWD were primarily White (60.45%), aged 85+ (38.93%), and female (55.51%) with an annual income <\$30,000 (65.95%) (Table 1). Caregivers were primarily ≤59 years old (42.12%) and female (67.43%) with an annual income ≥\$30,000 (62.73%) (caregiver race is not available). Subjective caregiver burden items were significantly associated with the incidence and frequency of overnight hospital stays between both subgroups (PWD who were either alive or not alive in round 6) and with hospice utilization. PWD age was a significant predictor of overnight hospital stays and frequency, and younger PWD decedents were more likely to

Table 2. Results of analyses of logistic regression of overnight hospital stay on sociodemographics and subjective caregiver burden (sample: PWD)

Predictor	n	Overnight hospital stay						
		Alive group			Not alive group			Comparison
		OR	95% CI	p	OR	95% CI	p	p
Sociodemographics								
Race (PWD)	846			0.338			0.153	0.153
African American		0.81	[0.57, 1.14]		1.42	[0.56, 3.58]		
Other reference group: "white"		1.13	[0.71, 1.80]		8.26	[0.91, 75.20]		
Socioeconomic status (PWD)								
PWD total income	417			0.854			0.335	0.336
\$30,000 to <\$43,000		1.28	[0.67, 2.43]		0.22	[0.02, 2.19]		
\$43,000 to <\$66,000		1.00	[0.50, 2.00]		0.43	[0.07, 2.76]		
≥\$66,000		0.89	[0.45, 1.76]		0.22	[0.02, 2.19]		
Reference group: <\$30,000								
Caregiver income	161			0.225			0.525	0.336
\$30,000 to <\$43,000		2.62	[0.87, 7.84]		1.00	[0.10, 9.61]		
\$43,000 to <\$66,000		1.41	[0.53, 3.73]		0.20	[0.02, 2.27]		
≥\$66,000		0.85	[0.36, 2.00]		1.50	[0.18, 12.46]		
Reference group: <\$30,000								
PWD age (years)	898			0.214			0.018	0.079
75–84		1.18	[0.81, 1.71]		0.64	[0.17, 2.41]		
85+		0.87	[0.60, 1.28]		0.22	[0.07, 0.76]		0.016
Reference group: 65–74								
PWD sex	898			0.593			0.238	0.197
Male		1.08	[0.81, 1.45]		0.61	[0.27, 1.39]		
Reference group: "female"								
Caregiver age (years)	728			0.282			0.137	0.334
40–59		1.67	[0.77, 3.59]		1.56	[0.09, 28.15]		
60–69		1.72	[0.78, 3.75]		0.91	[0.05, 16.54]		
70–79		1.47	[0.65, 3.31]		0.27	[0.01, 5.77]		
80+		0.99	[0.40, 2.40]		0.33	[0.02, 7.14]		
Reference group: ≤39								
Caregiver sex	828			0.127			0.324	0.687
Male		0.77	[0.56, 1.08]		0.63	[0.26, 1.57]		
Reference group: "female"								
Caregiver experience								
Time spent traveling to PWD home	87			0.161			0.482	0.167
Hours		0.21	[0.02, 1.85]		3.00	[0.14, 64.26]		
Reference group: "minutes"								
Caregiver enjoys being with PWD	288			0.070			0.639	0.243
Some/a little/not at all		0.51	[0.25, 1.06]		1.47	[0.29, 7.45]		
Reference group: "a lot"								
PWD gets on caregiver's nerves	288			0.971			0.250	0.266
Some		1.02	[0.44, 2.39]		0.25	[0.02, 3.10]		

(Continued)

Table 2. (Continued.)

Predictor	Overnight hospital stay							
	n	Alive group			Not alive group			Comparison p
		OR	95% CI	p	OR	95% CI	p	
A little		1.11	[0.48, 2.60]		0.10	[0.01, 1.06]		
Not at all		1.18	[0.50, 2.81]		0.20	[0.02, 2.18]		
Reference group: "a lot"								
Financial difficulty helping	287			0.372			0.045	
Yes		1.31	[0.72, 2.38]		5.60	[1.04, 30.20]		
Reference group: "no"								
Emotional difficulty helping	287			0.767			0.371	
Yes		1.08	[0.65, 1.80]		1.72	[0.53, 5.62]		
Reference group: "no"								
Physical difficulty helping	286			0.004			0.711	
Yes		2.36	[1.33, 4.21]		0.76	[0.18, 3.28]		
Reference group: "no"								
Caregiver is exhausted at night	287			0.103			0.132	
Somewhat		0.48	[0.24, 0.95]		0.29	[0.06, 1.53]		
Not so much		0.61	[0.33, 1.16]		0.19	[0.04, 0.97]		
Reference group: "very much"								
Caregiver has too much to handle	284			0.965			0.095	
Somewhat		1.10	[0.52, 2.33]		0.11	[0.01, 0.84]		
Not so much		1.04	[0.53, 2.05]		0.21	[0.04, 1.21]		
Reference group: "very much"								
Caregiver has no time for self	285			0.554			0.087	
Somewhat		0.73	[0.37, 1.42]		0.17	[0.03, 0.90]		
Not so much		0.73	[0.39, 1.37]		0.76	[0.18, 3.17]		
Reference group: "very much"								
Care routine changes	286			0.746			0.490	
Somewhat		0.89	[0.38, 2.05]		0.34	[0.05, 2.46]		
Not so much		0.76	[0.36, 1.64]		0.34	[0.06, 2.10]		
Reference group: "very much"								
Living situation								
Spouse lives with PWD	350							
Yes		-	-		-	-		
Reference group: "no"								
Living arrangement	898			0.256			0.661	
With spouse/partner only		1.45	[1.01, 2.10]		1.03	[0.36, 2.95]		
With spouse/partner and with others		1.22	[0.72, 2.09]		3.09	[0.48, 19.82]		
With others only		1.15	[0.79, 1.68]		1.27	[0.45, 3.59]		
Reference group: "alone"								
Caregiver lives with PWD	502			0.634			0.209	
Yes		1.21	[0.56, 2.62]		0.32	[0.05, 1.90]		
Reference group: "no"								

(Continued)

Table 2. (Continued.)

Predictor	n	Overnight hospital stay						
		Alive group			Not alive group			Comparison
		OR	95% CI	p	OR	95% CI	p	p
Total number of people in PWD's household	898			0.384			0.893	0.901
2 persons		1.35	[0.96, 1.89]		1.07	[0.41, 2.82]		
3 persons		1.04	[0.65, 1.67]		1.55	[0.40, 6.03]		
4 persons		1.29	[0.66, 2.51]		1.55	[0.19, 12.64]		
≥5 persons		1.54	[0.79, 3.01]		2.06	[0.38, 11.03]		
Reference group: 1 person								
Total number of children in household	898			0.586			0.762	0.674
1 child		0.92	[0.66, 1.28]		1.43	[0.54, 3.75]		
≥2 children		0.65	[0.27, 1.58]		0.95	[0.15, 6.08]		
Reference group: 0 children								

Note: PWD, persons with dementia; OR, odds ratio; CI, confidence interval.

Comparison of the relationship between a predictor and overnight hospital stay in the alive group and that in the not alive group.

experience frequent hospitalizations. More than two-thirds of caregivers reported that they did not have financial difficulty helping (76.66%) or physical difficulty helping the PWD (73.78%). Just under half reported having emotional difficulty helping the PWD (46.34%) and having too much to handle (very much or somewhat) (47.89%). Caregivers reported having no time for themselves “very much” (27.72%), “somewhat” (30.88%), or “not so much” (41.4%) (Table 1).

Overnight hospital stays

PWD who were alive in round 6 were 2.36 times more likely to experience an overnight hospital stay when their caregiver reported having physical difficulty helping the PWD compared to PWD whose caregivers did not have physical difficulty helping ($p = 0.004$, odds ratio [OR] = 2.36, 95% confidence interval [CI] = 1.33, 4.21).

Decedents aged 65–74 were 4.55 times more likely to experience an overnight hospital stay compared to those aged 85+ ($p = 0.016$, OR = 1/0.22 = 4.55, 95% CI = 1/0.76, 1/0.07 = 1.32, 14.29). (Note: the odds ratio is reversed to emphasize the group at highest risk, i.e., decedents aged 65–74 is associated with higher risk vs. decedents aged 85+ of being associated with lower risk [$p = 0.016$, OR = 0.22, 95% CI = 0.07, 0.76].) This relationship between age and an overnight hospital stay was not significant among PWD who were alive in round 6 ($p = 0.214$), but it was significant among PWD who were not alive ($p = 0.018$). There was a trend toward statistical significance in the relationship between groups (alive and not alive) ($p = 0.079$) (Table 2). Decedents with caregivers who reported having financial difficulty helping were 5.6 times more likely to experience an overnight hospital stay compared to decedents whose caregivers did not have financial difficulty helping ($p = 0.045$, OR = 5.6, 95% CI = 1.04, 30.20) (Table 2). There were no significant differences detected between groups (alive and not alive) on whether the PWD experienced an overnight hospital stay (Table 2).

Number of overnight hospital stays

Living PWD whose caregiver reported physical difficulty helping were 1.96 times more likely to experience one or more overnight

hospital stays compared to PWD whose caregiver did not have physical difficulty helping ($p = 0.011$, OR = 1/0.51 = 1.96, 95% CI = 1/0.85, 1/0.3 = 1.18, 3.33) (Table 3). (Note: the odds ratio is reversed to emphasize the group at highest risk, i.e., having difficulty helping is associated with higher risk vs. no difficulty helping being associated with lower risk [$p = 0.011$, OR = 0.51, 95% CI = 0.30, 0.85]).

Decedents aged 65–74 were 4.84 times more likely to experience one or more overnight hospital stays compared to those aged 85+ ($p = 0.004$, OR = 4.84, 95% CI = 1.64, 14.26). The relationship between age and frequency of hospitalizations was not significant among PWD who were alive in round 6 ($p = 0.276$), but it was significant among PWD who were not alive ($p = 0.007$). There was a statistically significant difference in this relationship between groups (alive and not alive) ($p = 0.035$) (Table 3).

Decedents whose caregiver agreed “very much” to having “too much to handle” were 8.44 times more likely to experience one or more overnight hospital stays compared to those whose caregivers reported “somewhat” ($p = 0.018$, OR = 8.44, 95% CI = 1.43, 49.62). Moreover, decedents whose caregiver agreed “very much” that they have “no time” for themselves were 10.67 times more likely to have more frequent overnight hospital stays compared to those whose caregivers responded “somewhat” ($p = 0.010$, OR = 10.67, 95% CI = 1.76, 64.78). This relationship was not significant among PWD who were alive in round 6 ($p = 0.276$), but it was significant among PWD who were not alive ($p = 0.023$). A statistically significant difference in the frequency of overnight hospital stays between groups (alive and not alive) was detected when the caregiver reported having no time for themselves ($p = 0.018$) (Table 3). There was a trend toward statistical significance between groups (alive and not alive) on the number of overnight hospital stays among caregivers reporting having too much to handle ($p = 0.053$) and whether the caregiver lived with the PWD ($p = 0.082$) (Table 3).

Hospice utilization

PWD decedents whose caregiver had emotional difficulty helping were 5.89 times more likely to utilize hospice compared to

Table 3. Results of analyses of proportional odds regression of number of overnight hospital stays on sociodemographics and subjective caregiver burden (sample: PWD)

Predictor	n	Number of overnight hospital stays						
		OR	Alive group		Not alive group		Comparison p	
			95% CI	p	OR	95% CI		p
Sociodemographics								
Race (PWD)	847			0.383			0.058	0.154
African American		0.97	[0.71, 1.32]		0.64	[0.26, 1.56]		
Other		0.74	[0.49, 1.13]		0.17	[0.04, 0.75]		
Reference group: "white"								
PWD total income	417			0.682			0.388	0.520
\$30,000 to <\$43,000		0.94	[0.52, 1.71]		3.48	[0.40, 29.96]		
\$43,000 to <\$66,000		1.04	[0.55, 1.97]		2.10	[0.35, 12.59]		
≥\$66,000		1.47	[0.77, 2.80]		4.70	[0.46, 48.57]		
Reference group: <\$30,000								
Caregiver income	161			0.431			0.502	0.483
\$30,000 to <\$43,000		0.47	[0.18, 1.27]		0.67	[0.08, 5.39]		
\$43,000 to <\$66,000		0.67	[0.27, 1.64]		4.70	[0.48, 45.76]		
≥\$66,000		0.94	[0.43, 2.05]		1.55	[0.21, 11.69]		
Reference group: <\$30,000								
PWD age (years)	899			0.276			0.007	0.035
75–84		0.90	[0.64, 1.27]		1.71	[0.53, 5.51]		
85+		1.16	[0.82, 1.64]		4.84	[1.64, 14.26]		0.004
Reference group: 65–74								
PWD sex	899			0.692			0.376	0.334
Male		0.95	[0.72, 1.24]		1.43	[0.65, 3.15]		
Reference group: "female"								
Caregiver age (years)	729			0.167			0.056	0.281
40–59		0.83	[0.43, 1.59]		0.37	[0.02, 6.17]		
60–69		0.94	[0.48, 1.84]		0.83	[0.05, 14.01]		
70–79		1.12	[0.56, 2.28]		2.68	[0.13, 53.19]		
80+		1.57	[0.72, 3.42]		1.81	[0.09, 35.43]		
Reference group: ≤39								
Caregiver sex	829			0.09			0.635	0.914
Male		1.29	[0.96, 1.75]		1.23	[0.52, 2.90]		
Reference group: "female"								
Caregiver experience								
Time spent traveling to PWD home	87			0.471			0.602	0.432
Hours		1.72	[0.39, 7.51]		0.45	[0.02, 8.98]		
Reference group: "minutes"								
Caregiver enjoys being with PWD	288			0.051			0.415	0.122
Some/a little/not at all		1.95	[1.00, 3.81]		0.54	[0.12, 2.37]		
Reference group: "a lot"								
PWD gets on caregiver's nerves	288			0.948			0.073	0.124
Some		0.95	[0.44, 2.08]		4.57	[0.70, 29.93]		

(Continued)

Table 3. (Continued.)

Predictor	Number of overnight hospital stays							
	n	Alive group			Not alive group			Comparison p
		OR	95% CI	p	OR	95% CI	p	
A little		1.05	[0.48, 2.30]		9.74	[1.74, 54.49]		
Not at all		0.87	[0.39, 1.94]		6.44	[1.11, 37.18]		
Reference group: "a lot"								
Financial difficulty helping	287			0.118			0.111	
Yes		0.65	[0.37, 1.12]		0.35	[0.10, 1.27]		
Reference group: "no"								
Emotional difficulty helping	287			0.465			0.511	
Yes		0.84	[0.52, 1.34]		0.69	[0.23, 2.10]		
Reference group: "no"								
Physical difficulty helping	286			0.011			0.723	
Yes		0.51	[0.30, 0.85]		1.29	[0.32, 5.17]		
Reference group: "no"								
Caregiver is exhausted at night	287			0.127			0.193	
Somewhat		1.34	[0.72, 2.48]		3.17	[0.76, 13.20]		
Not so much		1.82	[1.02, 3.28]		3.02	[0.78, 11.66]		
Reference group: "very much"								
Caregiver has too much to handle	284			0.341			0.047	
Somewhat		0.81	[0.41, 1.60]		8.44	[1.43, 49.62]	0.018	
Not so much		1.21	[0.65, 2.27]		3.60	[0.95, 13.68]		
Reference group: "very much"								
Caregiver has no time for self	285			0.276			0.023	
Somewhat		1.12	[0.61, 2.06]		10.67	[1.76, 64.78]	0.010	
Not so much		1.56	[0.87, 2.79]		1.09	[0.31, 3.82]		
Reference group: "very much"								
Care routine changes	286			0.699			0.486	
Somewhat		1.34	[0.62, 2.89]		2.86	[0.51, 15.89]		
Not so much		1.34	[0.67, 2.68]		1.99	[0.43, 9.16]		
Reference group: "very much"								
Living situation								
Spouse lives with PWD	351							
Yes		-	-					
Reference group: "no"								
Living arrangement	899			0.219			0.211	
With spouse/partner only		0.71	[0.50, 0.99]		0.78	[0.27, 2.22]		
With spouse/partner and with others		0.89	[0.54, 1.45]		0.20	[0.04, 1.01]		
With others only		0.78	[0.55, 1.10]		0.52	[0.19, 1.44]		
Reference group: "alone"								
Caregiver lives with PWD	503			0.334			0.141	
Yes		0.70	[0.34, 1.45]		3.18	[0.68, 14.79]		
Reference group: "no"								

(Continued)

Table 3. (Continued.)

Predictor	n	Number of overnight hospital stays						
		Alive group			Not alive group			Comparison
		OR	95% CI	p	OR	95% CI	p	p
Total number of people in PWD's household	899			0.105			0.609	0.727
2 persons		0.77	[0.56, 1.05]		0.70	[0.27, 1.83]		
3 persons		0.93	[0.61, 1.42]		0.37	[0.10, 1.37]		
4 persons		0.65	[0.36, 1.19]		0.44	[0.06, 3.15]		
≥5 persons		0.48	[0.26, 0.89]		0.48	[0.10, 2.33]		
Reference group: 1 person								
Total number of children in household	899			0.749			0.542	0.435
1 child		1.12	[0.83, 1.52]		0.60	[0.24, 1.49]		
≥2 children		0.99	[0.47, 2.10]		0.95	[0.16, 5.69]		
Reference group: 0 children								

Note: PWD, persons with dementia; OR, odds ratio; CI, confidence interval.

Number of overnight hospital stays categorized as follows: 0, no overnight hospital stays; 1, 1 overnight hospital stay; 2, 2 overnight hospital stays; 3, 3 overnight hospital stays; and 4, ≥4 overnight hospital stays. Probabilities modeled are cumulated over the lower ordered values.

Comparison of the relationship between a predictor and categorized number of overnight hospital stays in the alive group and that in the not alive group.

those whose caregiver did not have emotional difficulty helping ($p = 0.017$, OR = 5.89, 95% CI = 1.38, 25.23) (Table 4).

Discussion

Subjective caregiver burdens were significantly related to PWD overnight hospital stay incidence and frequency and hospice utilization. The age of the PWD who were not alive was associated with overnight hospitalizations, suggesting that the effect of age of the PWD on overnight hospitalizations differs depending on whether a PWD is in their last year of life. Younger PWD decedents in our study were more likely to experience an overnight hospital stay compared to older decedents, and the number of their overnight hospitalizations differed depending on whether the PWD was in their last year of life or not, which makes an interesting contribution to the literature. In contrast to our findings, a recent systematic review found that older age was associated with hospitalization of PWD, but the authors did not investigate EOL (Shepherd et al. 2019). While Williamson et al. (2021) found a relationship between PWD age and emergency department use near the EOL, the strength of evidence across studies was low. Although additional research into the relationship between age and PWD care transitions nearing the EOL is warranted, our study has important clinical implications to consider in regard to the value of promoting early access to community-based palliative care services for younger PWD as a means of reducing hospitalizations in the final months of life (Wright et al. 2018).

When their caregivers reported having no time for themselves, there was a significant difference between PWD alive and not alive groups on overnight hospitalizations, suggesting that caregiver burdens influencing overnight hospitalizations differ depending on whether a PWD is in their last year of life. Furthermore, among PWD who were alive in round 6, the primary driver of overnight hospital stay incidence and frequency occurs when caregivers feel that helping the PWD was physically difficult, but among decedents, physical difficulty caring for the PWD was not associated with any of the transition outcomes. Rather, decedents experienced

overnight hospital stay incidence when their caregivers reported having financial difficulties (Table 2) or overnight hospital stay frequency when they were personally or socially burdened by their role (i.e., “too much to handle” and “no time for self”) (Table 3). Caregivers who had emotional difficulty helping were more likely to access hospice care for the PWD at the EOL than those who did not have emotional difficulty (Table 4).

The findings of this study underscore the impact of EOL caregiving burdens on PWD outcomes and support the notion that the need for constant supervision and care of the PWD at the expense of the caregivers' own physical and mental health may become a “tipping point” for dementia caregivers when they realize they can no longer care for the PWD at home (Sadak et al. 2017; Saragosa et al. 2021). Indeed, caregiving burdens are high among dementia caregivers, particularly as the PWD nears the EOL (Nguyen et al. 2022; Ornstein et al. 2017; Vick et al. 2019), which can lead to undesired hospitalizations. However, surprisingly few studies investigate the link between subjective caregiver burdens of PWD and care transitions (Amjad et al. 2021; Shepherd et al. 2019; Williamson et al. 2021), and there is a scarcity of literature investigating dementia caregiver burden on EOL care transitions (Amjad et al. 2021; Shepherd et al. 2019). Thus, the findings of this study make a significant contribution in helping further our understanding of the subjective needs of dementia caregivers that may influence PWD care transitions, particularly through the EOL experience (Amjad et al. 2021; Shepherd et al. 2019; Vick et al. 2019; Williamson et al. 2021).

In the United States, there is a downward trend in the proportion of deaths occurring in hospitals and a concomitant increase in the proportion of deaths in home and community settings (Teno et al. 2018). In our study, only 51% of decedents utilized hospice care. It is possible that PWD in our study were not eligible, may not have been aware that they were eligible, may have declined hospice services, or faced other unknown barriers to care. Nevertheless, appropriately timed referrals to supportive care services could alleviate the very stressors leading to the incidence of hospitalization by meeting the emotional needs of dementia caregivers

Table 4. Results of analyses of univariable logistic regression of hospice on sociodemographics and subjective caregiver burden (sample: not alive PWD)

Predictor	Hospice			
	<i>n</i>	OR	95% CI	<i>p</i>
Sociodemographics				
Race (PWD)	73			0.735
African American		0.68	[0.23, 2.01]	
Other		1.28	[0.20, 8.32]	
Reference group: "white"				
Total income (PWD)	36			0.215
\$30,000 to <\$43,000		6.00	[0.52, 68.72]	
\$43,000 to <\$66,000		2.00	[0.32, 12.59]	
≥\$66,000		8.00	[0.75, 85.72]	
Reference group: <\$30,000				
Caregiver income	21			0.757
\$30,000 to <\$43,000		0.33	[0.02, 5.03]	
\$43,000 to <\$66,000		0.44	[0.05, 3.98]	
≥\$66,000		1.33	[0.09, 20.11]	
Reference group: <\$30,000				
PWD age (years)	75			0.357
75–84		2.04	[0.51, 8.23]	
85+		0.96	[0.27, 3.35]	
Reference group: 65–74				
PWD sex	75			0.912
Male		0.95	[0.38, 2.35]	
Reference group: "female"				
Caregiver age (years)	56			
40–59		–	–	
60–69		–	–	
70–79		–	–	
80+		–	–	
Reference group: ≤39				
Caregiver sex	68			0.491
Male		0.71	[0.27, 1.89]	
Reference group: "female"				
Caregiver experience				
Time spent traveling to PWD home	12			
Hours		–	–	
Reference group: "minutes"				
Caregiver enjoys being with PWD	37			0.419
Some/a little/not at all		2.13	[0.34, 13.40]	
Reference group: "a lot"				
PWD gets on caregiver's nerves	37			0.998
Some		1.00	[0.09, 11.03]	

(Continued)

Table 4. (Continued.)

Predictor	Hospice			
	<i>n</i>	OR	95% CI	<i>p</i>
A little		1.14	[0.13, 10.39]	
Not at all		1.00	[0.10, 10.17]	
Reference group: "a lot"				
Financial difficulty helping	37			0.250
Yes		2.86	[0.48, 17.11]	
Reference group: "no"				
Emotional difficulty helping	37			0.017
Yes		5.89	[1.38, 25.23]	
Reference group: "no"				
Physical difficulty helping	37			0.942
Yes		0.94	[0.16, 5.39]	
Reference group: "no"				
Caregiver is exhausted at night	37			0.695
Somewhat		0.78	[0.15, 4.13]	
Not so much		0.50	[0.10, 2.60]	
Reference group: "very much"				
Caregiver has too much to handle	37			0.679
Somewhat		1.33	[0.19, 9.31]	
Not so much		0.66	[0.13, 3.19]	
Reference group: "very much"				
Caregiver has no time for self	37			0.337
Somewhat		3.73	[0.65, 21.58]	
Not so much		1.60	[0.35, 7.40]	
Reference group: "very much"				
Care routine changes	37			0.494
Somewhat		3.50	[0.43, 28.44]	
Not so much		2.00	[0.30, 13.51]	
Reference group: "very much"				
Living situation				
Spouse lives with PWD	29			
Yes		–	–	
Reference group: "no"				
Living arrangement	75			
With spouse/partner only		–	–	
With spouse/partner and others		–	–	
With others only		–	–	
Reference group: "alone"				
Caregiver lives with PWD	42			

(Continued)

Table 4. (Continued.)

Predictor	Hospice			
	<i>n</i>	OR	95% CI	<i>p</i>
Yes		–	–	
Reference group: “no”				
Number of people in household ^a	75			0.595
2 persons		1.90	[0.67, 5.42]	
3 persons		1.88	[0.40, 8.74]	
4 persons		4.50	[0.41, 49.63]	
≥5 persons		0.75	[0.06, 9.42]	
Reference group: 1 person				
Total number of children in PWD's household	75			0.338
1 child		2.50	[0.69, 9.06]	
≥2 children		0.74	[0.12, 4.77]	
Reference group: 0 children				

Note: PWD, persons with dementia; OR, odds ratio; CI, confidence interval.

(LaValley 2017) and helping reduce subjective caregiving burdens (Amjad *et al.* 2021; Lindt *et al.* 2020). Yet, it is important to note that reliance on family caregivers to meet EOL care needs could intensify caregiving burdens particularly when caregivers have unmet training and support needs (Cross *et al.* 2020). This concern is particularly relevant in the present study where decedents were much more likely to experience hospitalizations when their caregiver reported having too much to handle or having no time for themselves. Policy-level barriers may also prevent caregivers from accessing supportive care services including the shortage of community-based palliative care programs under current reimbursement models in the United States. Consequently, many PWD do not qualify for supportive care programs until the very EOL (LaValley 2017), or when they do access hospice care early, they risk being discharged, and caregivers risk losing this essential support (Luth *et al.* 2021; Wladkowski *et al.* 2020).

Notably, many subjective caregiver burden items analyzed in this study were not associated with hospitalization or hospice use among PWD. However, several key caregiver burden items stand out as potentially modifiable risk factors for reducing caregiver burdens, reducing overnight hospitalizations, and improving access to hospice care services for PWD approaching the EOL. Personalizing supportive care interventions may help facilitate positive perspectives on caregiving and improve care outcomes of older adults with advanced serious illness (Pristavec *et al.* 2020; Pristavec and Pruchno 2019). It is also possible that many dementia caregivers may not perceive caregiving tasks and responsibilities negatively and instead may hold positive perceptions of their role despite the high burdens of care (Cross *et al.* 2018).

This study has several limitations. First, NHATS does not account for the cause of death, so it is possible that some respondents experienced sudden death and did not have the opportunity to enroll in hospice care or that hospice utilization was not identified in the LML survey. Second, the presence of other caregivers may have an impact on overnight hospitalizations and hospice utilization that could not be determined by limiting our study to the primary caregiver. Third, although we hoped to weight the study data in accordance with NHATS guidelines, survey weights are

provided by the round in which respondent data were collected. Since we studied the relationships between predictors in round 5 and outcomes in round 6, it was not possible to apply survey weights for this analysis. Moreover, the sample size of the decedents was small, it was not possible to fit a multivariable model due to missing values, and we cannot draw conclusions of causality given the study design. The strengths of this analysis are that it uses a national data sample and the prospective design of the NHATS study reduces recall bias. However, the small sample available within this national data sample underscores the challenges of conducting research in this important area.

This study identified PWD age and subjective caregiver burden factors associated with overnight hospitalization incidence and frequency of PWD who were alive/not alive and subjective care burden factors associated with hospice utilization in a national data set of older adults linked to their primary caregivers in dyads, which is an understudied area (Cagle *et al.* 2020; Hirschman and Hodgson 2018). Future longitudinal analyses linking caregiving burden to Medicare data for PWD such as health-care encounters, health assessment, and date of death may provide additional insights into patterns of EOL care transitions. This information may aid in the development of personalized approaches to avoid overnight hospitalizations and improve timely access to supportive care services, when desired, by PWD and their care partners.

In summary, this is one of the first studies to explore the relationship between subjective caregiver burden and care transitions (overnight hospital stay and hospice use) among PWD near the EOL. Our findings suggest that caregivers who are physically, financially, personally, and socially burdened from caregiving need additional resources and support to reduce the burden of care and subsequent undesirable care transitions for PWD, particularly among those nearing the EOL. Systemic approaches at the policy and health system level that aim to address unmet needs contributing to the burdens of dementia caregivers could make a significant contribution to the reduction of undesired care transitions near the EOL and could potentially promote early access to community-based supportive care services.

Funding. This work was supported by the National Institute of Aging of the National Institutes of Health [grant number 1R03-AG067159-01].

Conflicts of interest. The authors have no known conflict of interest to disclose.

References

- Alzheimer's Association (2021) Facts and figures. <https://www.alz.org/alzheimers-dementia/facts-figures> (accessed 27 November 2021).
- Amjad H, Mulcahy J, Kasper JD, *et al.* (2021) Do caregiving factors affect hospitalization risk among disabled older adults? *Journal of the American Geriatrics Society* **69**(1), 129–139. doi:10.1111/jgs.16817
- Ashbourne J, Boscart V, Meyer S, *et al.* (2021) Health care transitions for persons living with dementia and their caregivers. *BMC Geriatrics* **21**(1), 285. doi:10.1186/s12877-021-02235-5
- Beach SR, Schulz R, Friedman EM, *et al.* (2020) Adverse consequences of unmet needs for care in high-need/high-cost older adults. *The Journals of Gerontology: Series B* **75**(2), 459–470. doi:10.1093/geronb/gby021
- Cagle JG, Lee J, Ornstein KA, *et al.* (2020) Hospice utilization in the United States: A prospective cohort study comparing cancer and noncancer deaths. *Journal of the American Geriatrics Society* **68**(4), 783–793. doi:10.1111/jgs.16294
- Centers for Disease Control and Prevention [CDC] (2019) Caregiving for a person with Alzheimer's disease or a related dementia. <https://www.cdc.gov/aging/caregiving/alzheimer.htm> (accessed 28 November 2021).

- Committee on Family Caregiving for Older Adults** (2016) Families caring for an aging America. <https://www.nap.edu/catalog/23606> (accessed 13 September 2022).
- Cross AJ, Garip G and Sheffield D** (2018) The psychosocial impact of caregiving in dementia and quality of life: A systematic review and meta-synthesis of qualitative research. *Psychology & Health* **33**(11), 1321–1342. doi:10.1080/08870446.2018.1496250
- Cross SH, Kaufman BG, Taylor DH, Jr, et al.** (2020) Trends and factors associated with place of death for individuals with dementia in the United States. *Journal of the American Geriatrics Society* **68**(2), 250–255. doi:10.1111/jgs.16200
- Galvin JE, Roe CM, Xiong C, et al.** (2006) Validity and reliability of the AD8 informant interview in dementia. *Neurology* **67**(11), 1942–1948. doi:10.1212/01.wnl.0000247042.15547.eb
- Graessel E, Berth H, Lichte T, et al.** (2014) Subjective caregiver burden: Validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. *BMC Geriatrics* **14**(1), 23. doi:10.1186/1471-2318-14-23
- Hirschman KB and Hodgson NA** (2018) Evidence-based interventions for transitions in care for individuals living with dementia. *The Gerontologist* **58**, S129–S140. doi:10.1093/geront/gnx152
- Institute of Medicine [IOM]** (2015) *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: National Academies Press.
- Kasper JD and Freedman VA** (2020) *National Health and Aging Trends Study (NHATS) User Guide: Rounds 1–9 Final Release*. Baltimore, MD: Johns Hopkins University School of Public Health. https://www.nhats.org/sites/default/files/2021-04/NHATS_User_Guide_R9_Final_Release_0.pdf.
- Kasper JD, Freedman VA and Spillman BC** (2013) Classification of persons by dementia status in the National Health and Aging Trends Study. *Technical Paper No. 5*. https://nhatspubdemo.westat.com/scripts/documents/NHATS_Dementia_Technical_Paper_5_Jul2013.pdf.
- Kasper JD, Freedman VA, Spillman BC, et al.** (2015) The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Affairs* **34**(10), 1642–1649. doi:10.1377/hlthaff.2015.0536
- Kumar V, Ankuda CK, Aldridge MD, et al.** (2020) Family caregiving at the end of life and hospice use: A national study of Medicare beneficiaries. *Journal of the American Geriatrics Society* **68**(10), 2288–2296. doi:10.1111/jgs.16648
- LaValley SA** (2017) End-of-life caregiver social support activation: The roles of hospice clinicians and professionals. *Qualitative Health Research* **28**(1), 87–97. doi:10.1177/1049732317732963
- Lazarus RS and Folkman S** (1984) *Stress, Appraisal, and Coping*. New York: Springer.
- Leniz J, Higginson IJ, Stewart R, et al.** (2019) Understanding which people with dementia are at risk of inappropriate care and avoidable transitions to hospital near the end-of-life: A retrospective cohort study. *Age and Ageing* **48**(5), 672–679. doi:10.1093/ageing/afz052
- Lindt N, van Berkel J and Mulder BC** (2020) Determinants of overburdening among informal carers: A systematic review. *BMC Geriatrics* **20**(1), 304. doi:10.1186/s12877-020-01708-3
- Luth EA, Russell DJ, Xu JC, et al.** (2021) Survival in hospice patients with dementia: The effect of home hospice and nurse visits. *Journal of the American Geriatrics Society* **69**(6), 1529–1538. doi:10.1111/jgs.17066
- Melis RJE, Haaksma ML and Muniz-Terrera G** (2019) Understanding and predicting the longitudinal course of dementia. *Current Opinion in Psychiatry* **32**(2), 123–129. doi:10.1097/YCO.0000000000000482
- Montaquila J, Freedman VA, Edwards B, et al.** (2012) National Health and Aging Trends Study Round 1 sample design and selection. *NHATS Technical Paper No. 1*. https://www.nhats.org/scripts/sampling/NHATS_Round1_Sample_Design_05_10_12.pdf.
- Nguyen HQ, Haupt EC, Duan L, et al.** (2022) Hospital utilisation in home palliative care: Caregiver health, preparedness and burden associations. *BMJ Supportive and Palliative Care*. doi:10.1136/bmjspcare-2021-003455
- Ornstein KA, Kelley AS, Bollens-Lund E, et al.** (2017) A national profile of end-of-life caregiving in the United States. *Health Affairs* **36**(7), 1184–1192. doi:10.1377/hlthaff.2017.0134
- Pearlin LI, Mullan JT, Semple SJ, et al.** (1990) Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist* **30**(5), 583–594. doi:10.1093/geront/30.5.583
- Pendergrass A, Malnis C, Graf U, et al.** (2018) Screening for caregivers at risk: Extended validation of the short version of the Burden Scale for Family Caregivers (BSFC-s) with a valid classification system for caregivers caring for an older person at home. *BMC Health Services Research* **18**(1), 229. doi:10.1186/s12913-018-3047-4
- Porock D, Bakk L, Sullivan SS, et al.** (2015) National priorities for dementia care: Perspectives of individuals living with dementia and their care partners. *Journal of Gerontological Nursing* **41**(8), 9–16. doi:10.3928/00989134-20150710-02
- Pristavec T** (2019) The burden and benefits of caregiving: A latent class analysis. *The Gerontologist* **59**(6), 1078–1091. doi:10.1093/geront/gny022
- Pristavec T and Luth EA** (2020) Informal caregiver burden, benefits, and older adult mortality: A survival analysis. *The Journals of Gerontology: Series B* **75**(10), 2193–2206. doi:10.1093/geronb/gbaa001
- Riffin C, Van Ness PH, Wolff JL, et al.** (2019) Multifactorial examination of caregiver burden in a national sample of family and unpaid caregivers. *Journal of the American Geriatrics Society* **67**(2), 277–283. doi:10.1111/jgs.15664
- Romo R, Carpenter J, Buck H, et al.** (2019). Hospice and Palliative Nurses Association (HPNA) research agenda 2019–2022. *Hospice and Palliative Nurses Association* **21**(4), E17–E23. doi:10.1097/NJH.00000000000000580
- Sadak T, Foster Zdon S, Ishado E, et al.** (2017) Potentially preventable hospitalizations in dementia: Family caregiver experiences. *International Psychogeriatrics* **29**(7), 1201–1211. doi:10.1017/s1041610217000217
- Saragosa M, Jeffs L, Okrainec K, et al.** (2021) Using meta-ethnography to understand the care transition experience of people with dementia and their caregivers. *Dementia* **21**(1), 153–180. doi:10.1177/14713012211031779
- Shepherd H, Livingston G, Chan J, et al.** (2019) Hospitalisation rates and predictors in people with dementia: A systematic review and meta-analysis. *BMC Medicine* **17**(1), 130. doi:10.1186/s12916-019-1369-7
- Sullivan SS, Li CS, de Rosa C, et al.** (2022) Development of a longitudinal dataset of persons with dementia and their caregivers through the end-of-life: A Statistical Analysis System algorithm for joining National Health and Aging Trends Study/National Study of Caregiving. *American Journal of Hospice and Palliative Care* **39**(9), 1052–1060. doi:10.1177/10499091211057291
- Statistical Analysis Software Institute** (2013) *SAS® 9.4 Statements*. Cary, NC: SAS Institute Inc.
- Teno JM, Gozalo P, Trivedi AN, et al.** (2018) Site of death, place of care, and health care transitions among US Medicare beneficiaries, 2000–2015. *JAMA* **320**(3), 264–271. doi:10.1001/jama.2018.8981
- Vick JB, Ornstein KA, Szanton SL, et al.** (2019) Does caregiving strain increase as patients with and without dementia approach the end of life? *Journal of Pain and Symptom Management* **57**(2), 199–208.e2. doi:10.1016/j.jpainsymman.2018.11.004
- Williamson LE, Evans CJ, Cripps RL, et al.** (2021) Factors associated with emergency department visits by people with dementia near the end of life: A systematic review. *Journal of the American Medical Directors Association* **22**(10), 2046–2055.e35. doi:10.1016/j.jamda.2021.06.012
- Wladkowski SP, Wallace CL and Gibson A** (2020) A theoretical exploration of live discharge from hospice for caregivers of adults with dementia. *Journal of Social Work in End-of-Life & Palliative Care* **16**(2), 133–150. doi:10.1080/1524256.2020.1745351
- Wolff JL, Mulcahy J, Huang J, et al.** (2018a) Family caregivers of older adults, 1999–2015: Trends in characteristics, circumstances, and role-related appraisal. *The Gerontologist* **58**(6), 1021–1032. doi:10.1093/geront/gnx093
- Wolff JL, Mulcahy J, Roth DL, et al.** (2018b) Long-term nursing home entry: A prognostic model for older adults with a family or unpaid caregiver. *Journal of the American Geriatrics Society* **66**(10), 1887–1894. doi:10.1111/jgs.15447
- World Health Organization [WHO]** (2021) WHO takes steps to address glaring shortage of quality palliative care services. <https://www.who.int/news/item/05-10-2021-who-takes-steps-to-address-glaring-shortage-of-quality-palliative-care-services>.
- Wright CM, Youens D and Moorin RE** (2018) Earlier initiation of community-based palliative care is associated with fewer unplanned hospitalizations and emergency department presentations in the final months of life: A population-based study among cancer decedents. *Journal of Pain and Symptom Management* **55**(3), 745–754.e8. doi:10.1016/j.jpainsymman.2017.11.021