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Caregiver support and place of death among older adults

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Abstract

Background/objectives: As home becomes the most common place of death in the United States, information about caregiver support and place of death is critical to improve patient and caregiver experiences at end of life. We seek to examine (1) the association between family care availability and place of death; and (2) caregiving intensity associated with place of death.

Design: 2017 National Health and Aging Trends Study and National Study of Caregiving; nationally representative cross-sectional study of deceased older adults and last-month-of-life (LML) caregivers.

Setting: United States; all places of deaths.

Participants: Three-hundred and seventy-five decedents and 267 LML caregivers.

Measurements: Place of death (home, hospital, and nursing or hospice facility), family care availability (spouse/partner, household size, number of daughters and sons), caregiving intensity (hours of help provided at LML and a binary indicator for high care-related emotional difficulty).

Results: 38.9% of older adults died at home, followed by hospital (33.1%), and nursing or hospice facility (28.0%). In an adjusted multinomial logistic regression, decedents with larger household size (odds ratio [OR]: 0.441; 95% confidence interval [CI]: 0.269–0.724) and more daughters (OR: 0.743 [95% CI: 0.575–0.958]) had lower odds of dying in nursing or hospice facility relative to dying at home. For older adults who died at home, caregivers provided 209.8 h of help at LML. In contrast, when death occurred in nursing or hospice facility, caregivers provided 91.6 fewer hours of help, adjusted for decedent and caregiver characteristics. Dying in hospital was associated with higher odds of caregiver emotional difficulty relative to home deaths (OR: 4.093 [95% CI: 1.623–10.323]).

Conclusions: Household size and number of daughters are important determinants of place of death. Despite dying at home being associated with more hours of direct caregiving; caregiver emotional strain was experienced as higher for hospital deaths. Better support services for end-of-life caregivers might improve patient and caregiver experiences for home and hospital deaths.

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KEYWORDS
caregiving intensity, family care availability, place of death

1 | INTRODUCTION

Most Americans report a desire to die at home when terminally ill[1,2]; place of death has been proposed as a quality indicator for end-of-life care.[3] A recent study has found an increase in deaths at home and hospice facilities versus a decrease in deaths in hospitals and nursing homes from 2003 to 2017; in 2016, home surpassed hospital as the most common place of death for the first time since the early 20th century in United States.[4] But for many, dying at home may not be possible without appropriate resources, such as available caregivers or clinicians who can conduct home visits.[5] Although the trend towards more death at home may represent progress, it is important to consider the experiences of both individuals dying at home and their caregivers to develop policies and supportive services to ensure high-quality end-of-life care.

Unpaid family caregivers play a vital role in the care of older adults at end of life by helping with daily activities, communicating with doctors, and providing medical services.[6] While hospice services are a vital part of the care of patients at end of life,[7] home hospice (the most commonly provided model of hospice care) only provides a few weekly hours of additional hands-on care, with most support happening by phone and family caregivers bearing most caregiving tasks and strain.[8] Caregivers for older adults at the end of life report providing more intensive care and experience more care-related strain than caregivers for patients at other periods, while receiving fewer supportive services (e.g., assistance with personal care or housework, use of respite services and support groups).[9-11] Therefore, while the increased proportion of deaths at home may be concordant with patients' wishes, it is potentially worrisome if their caregivers report more strain and are not supported in providing the uniquely challenging care required at end of life.

Understanding the association between caregiver availability, time spent in direct caregiving activities, and place of death is critical to inform appropriate support services to ensure high-quality end-of-life care. However, little is known about family care availability and caregiving intensity associated with place of death. Caregiver information is not available in administrative and claims data, making ascertainment of the association between caregiver support and place of death challenging. The limited data available are limited to single programs/sites or focus only on particular patient populations, such as those with cancer.[12-14] This study uses the National Health and Aging Trends Study (NHATS), nationally representative of age-eligible Medicare beneficiaries in the United States, with analysis limited to deceased respondents and their last-month-of-life (LML) caregivers. First, we examined the association of family care availability with place of death. We hypothesized that those with more family (i.e., potential supply of caregivers) would be more likely to die at home than in other settings. Second, we evaluated caregiving intensity including hours of caregiving and emotional strain associated with place of death. We hypothesized that home deaths would be associated with more hours of informal caregiving and greater emotional difficulty.

Key Points

- Larger household size and more daughters are associated with higher likelihood of home deaths.
- Dying at home is associated with more hours of direct caregiving, whereas dying in hospital is associated with higher caregiver emotional strain.

Why Does this Paper Matter?

This study examines the associations between caregiver support, hours of informal caregiving, and place of death in a nationally representative older population in United States.

2 | METHODS

2.1 | Data and study population

We used the 2017 NHATS and National Study of Caregiving (NSOC), longitudinal, nationally representative surveys for U.S. older adults and their caregivers.[15,16] Using NHATS and NSOC together capture end-of-life care for both care recipient and caregiver, allowing for a nationally representative analysis of caregiver support and place of death.[16] While there are additional survey years for both surveys, we used only the 2017 NHATS and NSOC

since questions about LML helpers were not asked in previous rounds. Participants were eligible for NHATS if they were Medicare enrollees aged 65 and older and lived in the contiguous U.S. A LML interview was conducted with a proxy respondent to obtain information on the experience of deceased participants at the end of life; the response rate was 93.9%.[15] Of 6312 NHATS respondents in 2017, 459 were deceased (i.e., their 2017 NHATS interview was a LML interview completed by proxy respondent). We excluded those where place of death was not specified ($n = 18$). We further excluded those who were institutionalized and only had facility staff questionnaires for all rounds before death and thus missing information for key variables of interest such as family care availability ($n = 66$); those who were institutionalized and conducted any sample person interviews were included. Finally, we had an analytical sample of 375 deceased participants.

NSOC is a supplement of NHATS that surveys caregivers of NHATS participants, alive or deceased, who received assistance with self-care, mobility or household activities from at least one family and unpaid caregiver. Up to five caregivers per care recipient could be included, and the sample, when weighted, is nationally representative of caregivers to older adults receiving such assistance. All NSOC interviews to caregivers of deceased care recipients were conducted after their death (median = 6 months). The response rates for caregivers of deceased care recipients were 58.1%.[16] Of the 291 caregivers for deceased care recipients, we removed those who did not help at LML ($n = 3$) and those for deceased care recipients (i.e., NHATS respondents) missing information for key variables of interest ($n = 21$), yielding a final analytical sample of 267 caregivers for 186 deceased care recipients. Most were the sole participating caregiver ($n = 122$), with other deceased care recipients having two ($n = 100$), three ($n = 33$), or four ($n = 12$) participating caregivers.

2.2 | Measures

Information about place of death was obtained from the NHATS LML interview conducted with deceased participants' proxies. Place of death was categorized as home, hospital, and nursing or hospice facility. We grouped nursing home and hospice facility death due to the small sample of those who died in the hospice facility ($n = 25$ or 6.7% of total deaths) and that both nursing home and hospice facility provide intensive professional care that might alleviate caregiving intensity for family caregivers. If the proxy reported that an older adult died in the emergency room of hospital ($n = 8$), he or she was assigned place of death based on the originating location, which would have been the primary end-of-life setting (rather than the emergency room).[17]

In part I analysis, we used information from the 2016 NHATS survey to determine potential family care availability, socioeconomic status, and health characteristics for deceased participants because these items were not part of the 2017 LML interview. Potential family care availability included presence of spouse or partner, household size (i.e., number of persons in the household), and number of daughters and sons. We examined NHATS participants' socio-demographics (sex, age at death, race/ethnicity), socioeconomic characteristics (education, family income, Medicaid enrollment), living arrangement (community versus residential care), health risk factors (functional impairment, comorbidities), and use of hospice services at LML. We measured functional impairment as disabilities in activities of daily life (ADL) including bathing, dressing, eating, using the toilet, getting out of bed and getting around (0–6)[18]; and disabilities in instrumental activities of daily life (IADL) including doing laundry, cooking, shopping, doing banking, and handling medications (0–5).[19] We captured medical comorbidities with binary indicators for heart disease, cancer, stroke, lung disease, and diabetes mellitus, type II which are the five leading causes of death among older adults in the United States,[20] and are associated with place of death.[4] We also included a binary indicator for probable dementia due to its distinct caregiving demands[21] and high likelihood of nursing home death,[4] which is determined in NHATS through both self-reported diagnoses and standard cognitive tests.[22]

In part II analysis, information about caregivers and the nature and intensity of the care they provided during deceased care recipients' LML were drawn from NSOC. Hours of help provided at LML include hours an individual caregiver spent providing any assistance, which could include help with activities beyond mobility, self-care, or household tasks, such as transportation.[21] Caregivers reported whether helping was emotionally difficult and if, yes, the extent of difficulties from 1 (a little difficult) to 5 (very difficult). We assigned a zero score to caregivers with no reported difficulties; we considered caregivers scoring above the sample's weighted average (3.1) as having high emotional difficulty (1 = score of 4–5; 0 = score of 0–3).[23] We examined caregiver characteristics including relationship to (spouse/partner, daughter/step-daughter/daughter-in-law, son/step-son/son-in-law, and other) and co-residence with the decedent.

2.3 | Statistical analysis

In part I analysis, we examined the association between potential family care availability and place of death using a multinomial logistic regression model, controlling for

decedent characteristics. Then we predicted the probability of death occurring at each setting for an average decedent across associated family care availability measures using estimates from the above multinomial logistic regression model. Analyses were conducted at the decedent level. In part II analysis, we examined the association between place of death and caregiving intensity using a linear regression model for hours of help provided at LML and a logistic regression model for high caregiver emotional difficulty, controlling for decedent and caregiver characteristics. At last, we predicted hours of help provided by an average caregiver across place of death using estimates from the above multivariate linear regression model. Analyses were conducted at the caregiver level. In all models, home death was the reference group.

We performed a sensitivity analysis that considered death in the emergency room as a hospital death because these patients might have ongoing symptoms or sudden events that could not be managed at the originating place. We also performed a sensitivity analysis stratified by living arrangement in 2016 (community versus residential care settings) because it is likely that those living in the community are with a household with more people than those living in residential care settings (2.2 vs 1.2, $p < 0.01$). Finally, we performed a sensitivity analysis in the part II analysis additionally adjusted for caregiver's helping network size measured by the total number of caregivers taking care of the deceased care recipient at the LML (mean = 3); more caregivers might indicate more people to share the caregiving tasks or higher caregiving needs from the care recipient, associated with either lower or higher intensity of caregiving.

For all analyses, we used weights that provide nationally representative estimates for deceased participants and LML caregivers and take into account differential probabilities of selection and nonresponse. We also used Stata *svy* commands to incorporate strata and clustering elements of the sample design in calculating standard errors of the estimates. All analyses were performed using STATA, version 15.1.

3 | STUDY RESULTS

3.1 | Summary statistics

The proportion of deaths that occurred at home was 38.9%, 33.1% in hospital, and 28.0% in nursing or hospice facility (Table 1). 38.4% of deceased older adults had a living spouse or partner. The average household size was 2, and average number of daughters and sons was both 1.4. Family and unpaid caregivers provided an average of 150.8 h (standard deviation [SD]: 56.5) at LML, and 45.5% of caregivers reported high emotional difficulty.

About half of deceased older adults (47.6%) were aged 85 and older, 52.8% were female, 75.4% were non-Hispanic whites, and 52.9% received hospice services at LML. Among LML caregivers, 46.2% were daughters and 40.5% co-resided with the deceased older adults.

3.2 | Association between potential family care availability and place of death

The association between family care availability and place of death is presented in Table 2. The unadjusted analyses showed that deceased older adults with larger household size and more daughters were more likely to die at home. Controlling for decedent characteristics, the multinomial regression estimates indicated that those with a larger household size (odds ratio [OR]: 0. 441; 95% confidence interval [CI]: 0.269–0.724) and more daughters (OR: 0.743 [95% CI: 0.575–0.958]) had lower odds of dying in nursing or hospice facility relative to dying at home. Presence of a living spouse or partner, and number of sons were not associated with place of death. Potential family care availability was not associated with dying in hospital relative to dying at home.

We predicted probability of death occurring at each setting across household size and number of daughters the deceased older adults had using estimates from the above multinomial regression model (Figure 1). With household size ranging from 1 to 5 or above, the probability of dying at home increases from 27.0% to 71.3% and the probability of dying in nursing or hospice facility deceases from 40.8% to below 5%. With number of daughters ranging from 0 to 4 or above, the probability of dying at home increases from 31.1% to 56.9% and the probability of dying in nursing or hospice facility decreases from 34.3% to 13.5%.

3.3 | Association between place of death and caregiving intensity

Caregiving intensity associated with place of death controlling for decedent and caregiver characteristics is presented in Table 3. For older adults who died at home, caregivers provided an average of 209.8 (SD: 63.4) hours of help in their LML, higher than for those who died in hospital (114.8 [SD: 44.2]), and in nursing or hospice facility (81.2 [SD: 11.0]). The multivariate linear regression model estimates indicated that, compared with dying at home, dying in nursing or hospice facility was

TABLE 1 Weighted sample descriptive statistics

Proportion/mean (SD)	Part I (NHATS)[a]	Part II (NHATS linked to NSOC)[b]
Decedent characteristics	***N* = 375[c]**	***N* = 186 unique decedents[c]**
Place of death		
Home	38.9%	40.6%
Hospital	33.1%	30.3%
Nursing or hospice facility	28.0%	29.1%
Potential family care availability		
Presence of spouse/partner	38.4%	38.3%
Household size	2.0 (1.4)	—
Number of daughters	1.4 (1.5)	—
Number of sons	1.4 (1.5)	—
Socio-demographics/socioeconomics		
Female	52.8%	52.3%
Age at death		
65–74	18.1%	14.5%
75–84	34.3%	34.3%
85+	47.6%	51.3%
Non-Hispanic white	75.4%	79.9%
Some college or above	39.1%	36.3%
Family income	$34,869 (44,080)	$38,204 (53,383)
Medicaid enrollment	27.1%	28.0%
Living arrangement (community = 1; residential setting = 0)	76.8%	78.6%
Health and functional status		
ADL (0–6)	2.6 (2.9)	2.8 (2.8)
IADL (0–5)	2.1 (2.3)	2.2 (2.3)
Heart disease	50.2%	53.8%
Cancer	35.0%	39.8%
Stroke	24.2%	26.7%
Lung disease	27.8%	27.3%
Diabetes mellitus, type II	35.8%	38.9%
Dementia	35.2%	37.2%
Hospice at LML	52.9%	63.6%
Caregiver characteristics		***N* = 267 LML caregivers**
Hours of care provided		150.8 (56.5)
High emotional burden providing care		45.5%
Relationship to decedent		
Spouse		15.6%
Daughter/step-daughter/daughter-in-law		46.2%
Son/step-son/son-in-law		20.5%
Other		17.7%
Co-residing with decedent		40.5%

Abbreviations: ADL, activities of daily life; IADL, instrumental activities of daily life; LML, last-month-of-life; NHATS, National Health and Aging Trends Study; NSOC, National Study of Caregiving; SD, standard deviation.

[a]Descriptive analyses were weighted to produce national representative estimates using NHATS weights for decedents and using NSOC weights for their LML caregivers.

[b]Among the 375 decedents, 186 had at least one caregiver completed the 2017 NSOC with a total of 267 caregivers included in the analysis. Data were weighted using NHATS weights for decedents for decedent characteristics and using NSOC weights for LML caregivers for caregiver characteristics.

[c]NHATS decedents linked to NSOC were slightly older, had more ADL and IADL, and were more likely to have comorbidities or hospice services because the eligibility for NSOC requires that NHATS respondents have at least one family and unpaid caregiver and those with caregivers might be older and sicker.

associated with 91.6 (standard error [SE]: 21.3) fewer hours of caregiving help provided. For older adults who died at home, 37.3% of caregivers reported high emotional difficulty, lower than for those who died in hospital (60.2%), and in nursing or hospice facility (45.2%). The multivariate logistic regression model estimates indicated that compared with dying at home, caregivers for deceased older adults who died in the hospital were more likely to report high caregiver emotional difficulty (OR: 4.093 [95% CI: 1.623–10.323]), whereas there was no significant difference in emotionally difficulty for deaths in nursing or hospice facility.

Finally, we predicted hours of help provided by an average LML caregiver across place of death using estimates from the above multivariate linear regression model, overall and by selected decedent and caregiver characteristics (Figure 2). Overall, an average caregiver provided 179.9 (SE: 19.8) hours of caregiving help at LML for deceased older adults dying at home, 159.6 (SE: 22.0) hours for those dying in hospital, and 88.4 (SE: 13.0) hours for those dying in nursing or hospice facility. Caregivers for deceased older adults who were younger (65–74), having more ADL and IADL disabilities, or living with dementia provided slightly more hours of help in most settings. Caregivers who were spouse or daughter

TABLE 2 Potential family care availability and place of death

Family care availability	Proportion/mean (SD)				Adjusted odds ratio (95% CI)[b]	
	Home	Hospital	Nursing/hospice facility	*p*-value[a]	Hospital versus home	Nursing/hospice facility versus home
Presence of spouse/partner	43.3%	36.7%	33.5%		0.934 (0.449–1.942)	1.558 (0.706–3.438)
Household size	2.3 (1.7)	1.9 (1.2)	1.5 (1.0)	***	0.919 (0.699–1.207)	0.441*** (0.269–0.724)
Number of daughters	1.6 (1.6)	1.4 (1.5)	1.2 (1.4)	***	0.922 (0.737–1.153)	0.743*** (0.575–0.958)
Number of sons	1.5 (1.5)	1.3 (1.5)	1.4 (1.6)		0.865 (0.648–1.156)	1.105 (0.872–1.400)

Note: Data source: National Health and Aging Trends Study (NHATS) in 2017. Sample size: 375. Analyses were performed at the decedent level and were weighted to produce national representative estimates using NHATS weights for decedents.

Abbreviations: CI, confidence interval; SD, standard deviation.

[a]Chi-square tests were performed to compare presence of spouse/partner and ANOVA tests were performed to compare household size, number of daughters and sons across place of death.

[b]Multinomial logistic regression was performed adjusted for decedents' socio-demographics (sex, age, race), socioeconomic variables (education, family income, Medicaid enrollment, living arrangement), and health and functional status (activities of daily life, instrumental activities of daily life, comorbidities, use of hospice services).

***$p < 0.05$.

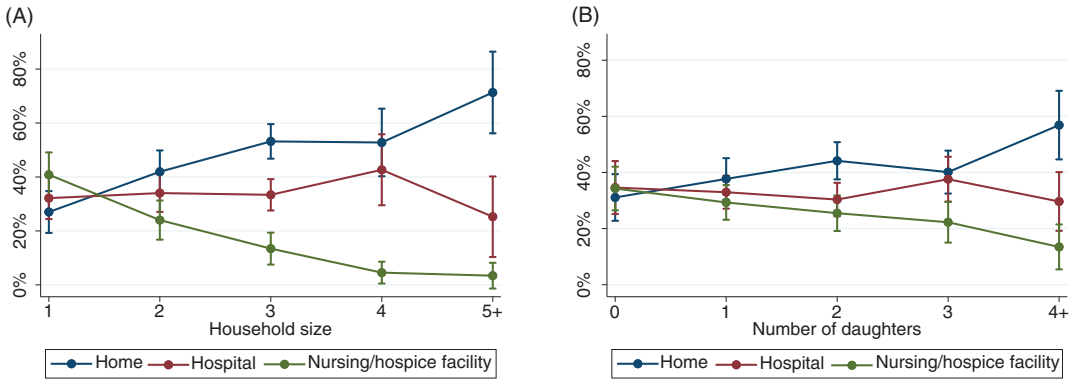


FIGURE 1 Estimated probability of place of death by household size and number of daughters. Using estimates from the multinomial logistic regression model in Table 2, we predicted the probability of death occurring at each setting for an average decedent across household size (A) and number of daughters (B)

provided slightly more hours of help at LML; caregivers who co-resided with the deceased older adults provided significantly more hours of help across all settings.

Sensitivity analysis that categorized death at the emergency room ($N = 8$) as a hospital location of death and among those living in the community showed consistent results with the main findings; whereas among those living in the residential care settings there was no detected association between family care availability, caregiving intensity, and place of death (Tables S1 and S2). Sensitivity analysis additionally adjusted for caregiver's helping network size in the part II analysis examining place of death and caregiving intensity showed consistent results with the main findings (Table S3).

4 | DISCUSSION

This is the first study to examine the associations between caregiver support, hours of informal caregiving, and place of death in a nationally representative older population. While many terminally ill older adults prefer to die at home, our findings show that this is associated with a far higher requirement of caregiver time. This may help account for the fact that household size (i.e., availability of people to provide caregiving) was associated with location of death—larger household size was associated with lower odds of death in a nursing or hospice facility. Despite being associated with increased caregiving hours, death at home was associated with less

TABLE 3 Place of death and caregiving intensity

	Hours spent providing care in LML		Perceived high emotional burden	
	Summary statistics[a]	Linear regression[b]	Summary statistics[a]	Logistic regression[b]
Place of death	Mean (SD)	Coef. (SE)	Proportion	Odds ratio (95% CI)
Ref: home	209.8***	—	37.3%***	—
	(63.4)	—		—
Hospital	114.8	−20.358	60.2%	4.093***
	(44.2)	(32.221)		(1.623–10.323)
Nursing/hospice facility	81.2	−91.566***	45.2%	1.190
	(11.0)	(21.310)		(0.528–2.682)

Note: Data source: National Study of Caregiving (NSOC) linked with National Health and Aging Trends Study (NHATS) in 2017. Sample size: 267. Analyses were performed at the caregiver level (267 caregivers for 186 decedents) and weighted to produce national representative estimates using NSOC weights for LML caregivers.

Abbreviations: CI, confidence interval; LML, last-month-of-life; SD, standard deviation; SE, standard error.

[a]Chi-square tests were performed to compare perceived high emotional burden and ANOVA tests were performed to compare hours of help across place of death.

[b]Covariates adjusted in both models included decedents' socio-demographics (sex, age, race, marital status), socioeconomic variables (education, family income, Medicaid enrollment, living arrangement), health and functional status (activities of daily life, instrumental activities of daily life, comorbidities, use of hospice services), and caregivers' socio-demographics (relationship to and co-residence with decedents).

***$p < 0.05$.

caregiver emotional difficulty than death in hospital settings.

We found that home was the most common place of death among U.S. older adults, followed by hospital, and nursing or hospice facility, which is consistent with the findings from a recent study among decedents of all ages.[4] Our analysis showed that living in a larger household and having more daughters was associated with a higher likelihood of dying at home compared with in a nursing or hospice facility.

Potential family care availability, that is, household size and number of daughters, was significantly associated with place of death. This is consistent with the finding in a previous study that having a caregiver was less likely to die in nursing home.[24] We extended this prior work by examining the various family care resources including household size, number of daughters, number of sons, and presence of a spouse or partner. Deceased older adults living in a larger household might have more available caregivers to call upon to share care tasks, or the primary caregiver(s) could have someone to help when they need to take a break; thus, the caregiving needs could be better met at home than in smaller households. The association between family care availability and place of death was particularly prominent among community-dwelling deceased older adults, but not among those living in the residential care settings, possibly because most of them (52.0%) continuously lived in the residential care settings and died here regardless of family care availability. As the primary source of family care, daughters (46.2%) might be less likely to place older adults in a nursing home compared with other caregivers including spouse[25]; therefore deceased older adults with more daughters might be less likely to die in a nursing or hospice facility. In addition to daughters, the majority of burden of caregiving tends to fall on women; daughters, wives and other female relatives constitute 73.1% of family caregivers in this study. Presence of spouse or partner was not associated with higher likelihood of home death. This may be due to older spousal partners having worse health status[26] and experiencing more care-related strain than other caregivers[27]; thus they might not be able to meet decedents' end-of-life caregiving needs at home.

Unlike we had hypothesized, dying in hospital was associated with a higher degree of emotional difficulty than dying at home. This is in contrast to the findings among patients with cancer, where dying in hospital did not cause markedly increased caregiver emotional burden.[14] In this prior analysis, it may be that caregivers of patients with cancer experience high emotional burden regardless of place of death. On the one hand, for these NHATS decease older adults, in-hospital death may reflect an acute, potentially unexpected decompensation with intensive medical interventions, potentially in conflict with preferences for end-of-life care in the home.[28] Indeed, among those NHATS participants who died in hospital, the LML survey asked the proxy respondent "where the respondent stayed just before the hospitalization" and the majority had been transferred there from home (78.2%), another hospital (10.6%) or nursing home

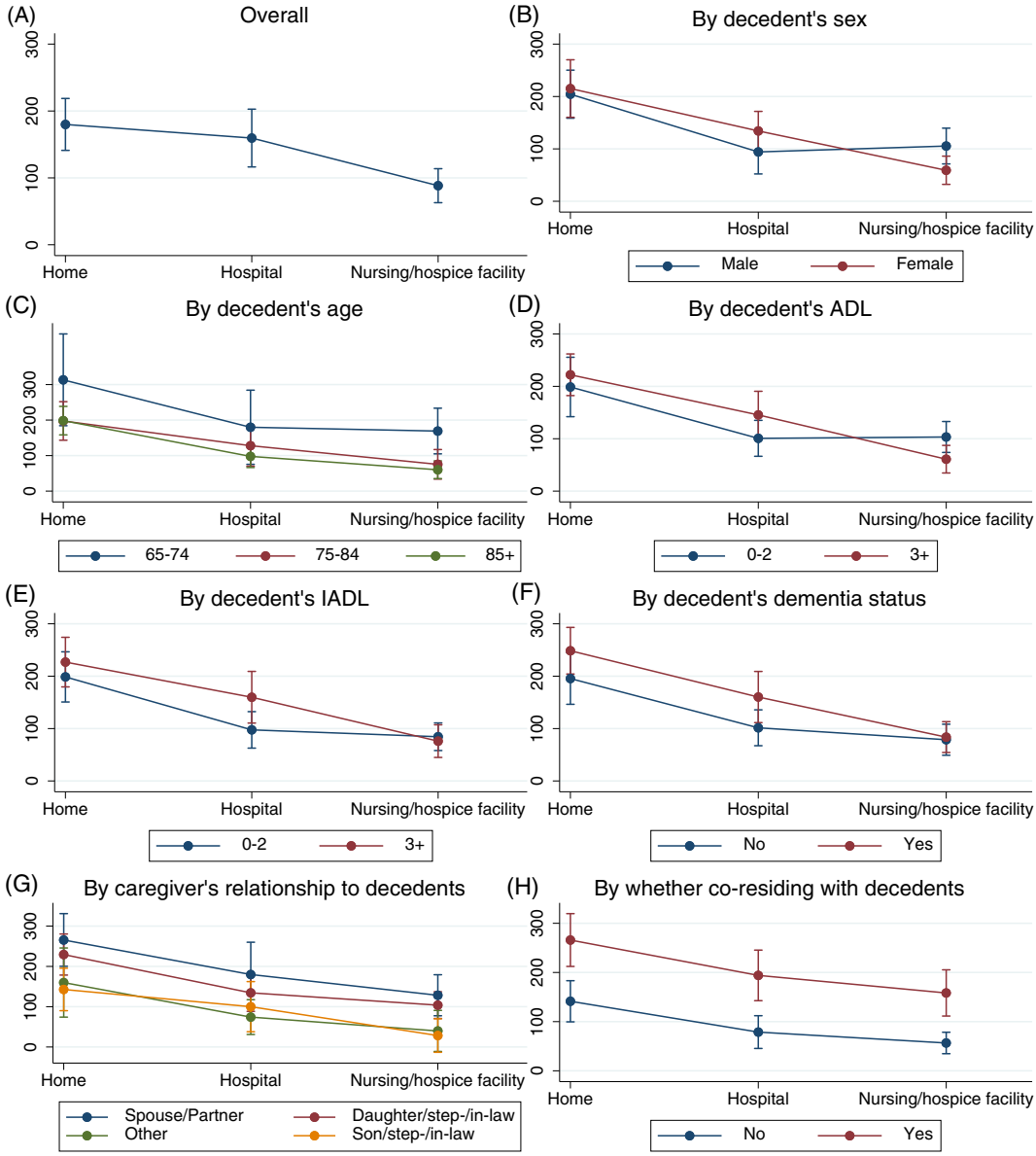


FIGURE 2 Estimated hours of help by place of death, overall and across strata. Using estimates from the multivariate linear regression model in Table 3, we predicted hours of help for an average LML caregiver across place of death, overall (A) and by decedents' sex (B), age at death (C), ADL (D), IADL (E), and dementia status (F); and caregivers' relationship to (G) and co-residence with decedents (H). ADL, activities of daily life; IADL, instrumental activities of daily life; LML, last-month-of-life

(8.8%) before death. Our findings suggest that transitions between locations of care at end of life, which are already associated with worse perceptions of quality of end-of-life care,[29] are also associated with increased caregiver emotional strain. In addition, while there is a trend towards more people dying at home, there is also a trend towards increased transitions and more intensive care unit use at end of life,[30] which might indicate a trend for increasing caregiver emotional strain.

There are several limitations in this study. First, the deceased care recipient sample was drawn from a survey of age-eligible Medicare beneficiaries, so this study does not consider deaths among younger individuals. Second, place of death in this analysis only provides information on where a person was at the moment of death and cannot fully capture the experiences of end-of-life care, including care settings and transitions between locations of care.[29-31] Future study should look at how family caregiver support may impact end-of-life healthcare utilization and transitions between locations of care to comprehensively evaluate the role of caregiver support on end-of-life experiences. Third, self-reported caregiving intensity measures were subject to recall bias (median = 6 months after death at the time of NSOC

interview) and subjective bias. Fourth, the response rate in the NSOC was relatively low (58.1%). However, we used the NSOC weights for LML caregivers which accounted for the differential probabilities of nonresponse to make the sample nationally representative of caregivers of deceased care recipients. Last, the survey questionnaire does not include information regarding the patient's preferred location of death to know if this was concordant with patient and family wishes. Location of death that is discordant with patient and family preference may be associated with increased emotional difficulty.

In conclusion, for older adults who die at home, caregivers provide a significant number of care hours, whereas potential family care availability and caregiving intensity are associated with place of death. Despite being associated with higher caregiving hours, caregivers of older adults who die at home report less emotional strain as compared with deaths in the hospital. As deaths continue to shift to the home setting, to improve end-of-life experiences of both older adults and their caregivers, it will be important to provide supportive services such as assistance with personal care or housework, respite services, supportive groups, and service of taking care of the care recipient to help relieve burdensome caregiving tasks and emotional strain for caregivers and ensure high-quality end-of-life care. Improving access to in-home visits and telemedicine for patients at end of life might also help alleviate caregiving intensity and improve the patient care experiences.

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CONFLICT OF INTEREST

All the authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

Lei and Maust: study concept and design. All authors: acquisition, analysis or interpretation of data. Lei: drafting of the manuscript. All authors: critical revision of the manuscript for important intellectual content. All authors: approval of the submitted version.

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No sponsor had any role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

Table S1. Sensitivity analysis: potential family care availability and site of death, odds ratio and 95% confidence interval.

Table S2. Sensitivity analysis: place of death and caregiving intensity.

Table S3. Sensitivity analysis: place of death and caregiving intensity—adjusted for caregiver helping network size.

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