



Family Caregiver Factors Associated With Emergency Department Utilization Among Community-Living Older Adults With Disabilities

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Abstract

Background: Older adults with disability are frequent users of the emergency department (ED) and often rely on family caregiver support. We identify whether and which caregiver characteristics are associated with older adults' ED use. **Methods:** We use Cox proportional hazards regression to model the likelihood of all-cause ED use (defined as 1 or more visits within 12 months of survey) as a function of caregiver characteristics after adjusting for older adult sociodemographic and health characteristics. We draw from linked older adult and caregiver surveys and administrative claims, creating a sample of 2521 community-living older adults with mobility/self-care disability receiving care from a family or unpaid caregiver. **Results:** About half (52.5%) of older adults receiving mobility or self-care help incurred 1 or more ED visits within 12 months of interview. Adjusting for year of data collection, sociodemographic characteristics, and health status, these older adults were at greater risk of all-cause ED use if their primary caregiver provided greater than 40 hours of care per week (hazard ratio [HR] 1.22, 95% CI 1.04-1.43; $P = .02$), helped with health care tasks (HR 1.26; 95% CI 1.08-1.46; $P < .01$), or experienced physical strain (HR 1.18; 95% CI 1.03-1.36; $P = .02$). **Conclusion:** Caregiver strain, helping with health care tasks, and greater hours of help per week are associated with heightened risk of ED use among older adults receiving mobility or self-care help. Study findings suggest the potential benefit of caregiver assessment and support.

Keywords

health outcomes, emergency visits, disease management, caregiving, older adults, aging

Introduction

Older adults with disabilities are frequent users of the emergency department (ED)¹⁻³ and unmet need for help with daily activities is a major driver of ED use.^{4,5} Understanding factors that lead to ED use among older adults is important given that acute and emergency service use poses risk for adverse events² and is costly for public payers—in 2016, Medicare spent \$3.9 billion on ED visits, excluding the cost of subsequent hospitalization.⁶

The majority of community-living older adults with disability receive help from family and other unpaid caregivers.^{7,8} The availability and adequacy of assistance from a family caregiver affects older adults' likelihood of experiencing acute and/or emergent health events.^{2,4,5,9} Clinicians attribute social factors such as strained or over-protective family caregivers as contributing to potentially preventable hospitalization.^{9,10} However, no studies to date have examined the extent to which caregiver characteristics

are associated with ED use among older adults.¹¹ Having a better understanding of whether and which family caregiver factors affect ED use is particularly timely given recent reform efforts which have elevated awareness of non-medical factors' contributions to health^{12,13} and discussions regarding the possibility of better accounting for social factors in payment policy and quality measurement.^{14,15} Such information could also inform development of targeted training programs to better support family caregivers;^{7,16,17}

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by helping clinicians, health systems, and payers better understand and prioritize caregiver factors that are both amenable to intervention and relevant to ED use.

This study draws from a unique population-based dataset that includes survey data collected from both community-living older adults with disability and their primary family or other unpaid caregiver, as well as linked Medicare claims data. We assess the relationship between family caregiver factors and likelihood of older adult ED use, controlling for older adult demographics, health status, and prior acute care use.

Methods

Sample

This study draws on a pooled analytic sample from the 1999 and 2004 waves of the National Long-Term Care Survey (NLTC), the 2011 and 2015 National Health and Aging Trends Study (NHATS), linked surveys of family and unpaid caregivers, and Medicare claims and vital statistics files. The NLTC and NHATS are nationally representative surveys of adults aged 65 years and older. Both surveys rely on Medicare enrollment files for their sampling frame and conduct in-person interviews to comprehensively assess a broad range of sociodemographic and health factors. With sampling weights, both studies produce nationally representative estimates of older adults. The NLTC-linked Informal Caregivers Survey (ICS) and NHATS-linked National Study of Caregivers (NSOC) are nationally representative surveys of relatives and unpaid helpers to those participants who were receiving assistance with self-care, mobility, or household activities for health or function. Wolff, et al (2018) offer additional detail regarding dataset construction.¹⁸ This study was deemed exempt from review by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board (IRB #00006775).

Our sample included older adults receiving help with activities of daily living such as self-care (eating, dressing, bathing, toileting) or indoor mobility (transferring, getting around inside) from relatives or unpaid nonrelatives. Eligibility criteria maximize cross-wave comparability in ascertainment of disability¹⁹ by focusing on forms of disability (ie, need for assistance with self-care or indoor mobility) with a similar battery of assessment questions in both the NLTC and NHATS. We excluded older adults who were living in nursing homes or residential care facilities at the time of interview as the nature of family help in such settings is likely to differ from help provided in the community. As we were unable to assess ED service use for older adults enrolled in Medicare Advantage plans, our sample was limited to those enrolled in fee-for-service Medicare with Parts A and B coverage. As the NLTC caregiver survey was administered to an identified “primary”

caregiver, defined as the caregiver who helped the most, we identified a “primary” caregiver for each eligible older adult in the NHATS, defined as the caregiver who offered the greatest number of hours of help per week among those interviewed. In total, our study sample comprised 2521 older adult/family caregiver dyads.

Measures

Measures of older adult characteristics were drawn from participant responses to the NLTC and NHATS surveys. The NLTC and NHATS collect comprehensive information on participants’ sociodemographic characteristics, health and function, and support from family and other unpaid caregivers during in-person interviews. We examine older adult demographic factors (age, sex, race), socioeconomic status (educational attainment, Medicaid enrollment), and health status (prior year hospitalization, number of chronic conditions, cognitive impairment). With the exception of cognitive impairment, characteristics are self-reported by participants or their proxy respondents. Cognitive impairment is ascertained from a combination of self-reported physician diagnosis of Alzheimer’s or dementia, proxy respondent responses to AD8 dementia screening, and older adult performance on cognitive tests related to memory, executive function, and orientation as reported in the NHATS, as described in Wolff et al (2018)¹⁸ and Kasper et al (2013).²⁰

Measures of family caregiver characteristics were drawn from caregiver responses to the NLTC-linked Informal Caregivers Survey (ICS) and NHATS-linked National Study of Caregivers (NSOC). We examine caregiver sociodemographic factors (age, sex, relationship to older adult), caregiving circumstances (self-rated health, hours of help per week, types of caregiving tasks, duration of care, employment, geographic proximity to older adult), and role-related appraisal (financial, emotional, and physical strain). Caregiver assistance with mobility tasks includes assisting with moving around inside the house or transferring in/out of bed, assistance with self-care tasks includes assisting with bathing, dressing, toileting, or eating, and assistance with health care tasks includes assisting with medication management and/or wound care. Caregiver employment refers to employment for pay for a job outside of their caregiving role.

ED use was assessed from dates of service, HCPCS, and revenue center codes listed in inpatient, outpatient, and carrier billing files.²¹ Any ED use refers to one or more ED visits that occurred within the 12 months following the older adults’ in-person interview, regardless of whether the visit resulted in hospital admission.

Statistical Analysis

First, we calculated descriptive statistics for older adult and caregiver characteristics, stratified by older adult ED utilization,

and used Rao-Scott chi-square tests to identify statistically significant differences between these groups. We next sought to determine the independent effect of family caregiver factors on likelihood of any ED use among community-living older adults with disability, while adjusting for relevant older adult characteristics and accounting for competing risks.²²⁻²⁵ To do this, we used multivariable cause-specific proportional hazard models that incorporate dates of each event of interest (eg, date of first ED visit) and censoring events (eg, death, end of study interval). This approach allows direct modeling of covariate effects,^{26,27} and produces valid estimates of association between covariates and outcome, regardless of correlation in outcome and censoring events.²⁸ Our models produced estimates of the cause-specific hazard; the instantaneous rate of experiencing each event of interest by a point in time (12 months) for those who remain at risk.^{29,30} We employed a proportional hazard model after testing the assumption of proportional hazards using an approach developed by Lin et al (1993)³¹ which considers the distribution of cumulative sums of Martingale-based residuals. Results suggest that the assumption of proportional hazards holds for all explanatory variables. As the NLCS and NHATS employ a complex multistage sampling strategy, we included both sampling weights and design variables in our analyses, as previously described.¹⁸ All analyses were performed using SAS 9.4.

We take 2 approaches to model associations between family caregiver characteristics and ED use, both of which use multivariable proportional hazard models. Approach 1 examines each caregiver factor individually while adjusting for survey wave only. As we also sought to understand whether caregiver factors were significantly associated with ED use after adjusting for relevant older adult characteristics, approach 2 examines each individual caregiver factor individually while adjusting for survey wave, older adult sociodemographic variables (age, sex, and race), and older adult characteristics that were found to differ significantly between those who did versus did not experience ED use, as determined via Rao-Scott chi-square test with a *P* value less than .05 (Table 1). These include number of chronic conditions, self-reported health status, and prior year hospitalization. Although functional impairment differs significantly between those who did versus did not experience ED use, we exclude this from our adjusted models as it is strongly correlated to several caregiver factors of interest; in particular, caregiver assistance in a given activity category is a direct response to the older adult's impairment within that category.

Results

More than half (52.5%) of community-living older adults with self-care or mobility disability incurred ED use within

12 months of interview and 1 in 5 (17.8%) died during the observation period (Table 1). Older adults were mostly white (79.2%) and female (66.4%); 41.9% were aged 85 years or older and 41.5% experienced hospitalization in the prior year. Nearly 1/3 (30.3%) of older adults were enrolled in Medicaid, and 46.2% reported fewer than 12 years of education. Those who incurred any ED use were less educated, reported worse health, and were more likely to have experienced one or more hospitalizations in the prior year (Table 1).

About 2 in 3 (68.3%) caregivers were female and nearly half (46.4%) were 65 years or older. A substantial proportion of caregivers reported emotional (56.5%), financial (33.6%), or physical (45.5%) strain due to caregiving (Table 2). Older adults who incurred any ED use were less likely to rely on caregivers who had been helping for more than 4 years and more likely to rely on a caregiver providing 40+ hours of care per week, assisting with household, self-care, mobility, and health care tasks, and reporting financial and physical strain (Table 2).

No sociodemographic caregiver characteristics were associated with risk of ED use. In approach 1 (adjusting only for survey wave) older adults were found to be at greater risk of ED use if their primary caregiver provided greater than 40 hours of care per week (hazard ratio [HR] 1.39; 95% CI 1.20-1.62; *P* < .001), helped with self-care (HR 1.24, 95% CI 1.05-1.47; *P* = .01) or health care tasks (HR 1.34; 95% CI 1.16-1.55; *P* < .001), or experienced physical strain (HR 1.24; 95% CI 1.08-1.42; *P* < .01). In approach 2 (adjusting for survey wave and older adult sociodemographic characteristics and health status factors), older adults were at greater risk of all-cause ED use if their primary caregiver provided greater than 40 hours of care per week (HR 1.22, 95% CI 1.04-1.43; *P* = .02), helped with health care tasks (HR 1.26; 95% CI 1.08-1.46; *P* < .01), or experienced physical strain (HR 1.18; 95% CI 1.03-1.36; *P* = .02) (Table 3).

Discussion

This is the first study to systematically examine whether and which family caregiver factors are associated with ED use among community-living older adults with disabilities. Our most important findings relate to the strong, consistent relationship between caregivers' assistance with health care tasks and older adults' risk of all-cause ED use. Also notable was that caregiver factors that were most highly associated with older adults' ED use were related to the intensity and demands of caregiving: greater hours of care, helping with more complex and demanding tasks, and reporting physical strain due to providing care. In contrast, sociodemographic characteristics and other caregiving characteristics less amenable to intervention were not significantly associated with ED use. These findings suggest

Table 1. Characteristics of Community-Dwelling Older Adults Receiving Help From a Family or Unpaid Caregiver With Self-Care or Mobility Disability, by Older Adult's Subsequent ED Use (n = 2521).

Older Adult Characteristics	Full sample (n = 2521); n (%) ^a	All-Cause ED Use		P (χ^2 Test for Between-Group Difference)
		Those with All-Cause ED Use (n = 1342); n (%)	Those Without All-Cause ED Use (n = 1179); n (%)	
Percentage of total sample ^a	100.0	52.5	47.5	
Demographic characteristics				
Age (years)				.07
65-74	527 (20.9)	258 (32.1)	269 (36.7)	
75-84	938 (37.2)	502 (38.2)	436 (36.5)	
85+	1056 (41.9)	582 (29.7)	474 (26.8)	
Female	1673 (66.4)	889 (63.0)	784 (63.4)	.89
Race				.55
White	1997 (79.2)	1057 (82.5)	940 (82.9)	
Non-white	524 (20.8)	285 (17.5)	239 (17.1)	
Socioeconomic characteristics				
Married	1090 (54.2)	558 (51.9)	532 (56.7)	.07
Lives alone	482 (14.9)	254 (15.3)	228 (14.5)	.79
Medicaid enrolled	764 (30.3)	427 (27.8)	337 (25.0)	.08
Less than 12 years of education	1165 (46.2)	650 (38.7)	515 (36.3)	.02
Health status characteristics				
Chronic condition count ^{b,c}	1.53 (0.03)	1.63 (0.04)	1.42 (0.05)	<.001
Self-reported health status				<.001
Excellent	333 (14.1)	167 (12.3)	166 (16.0)	
Good	720 (27.4)	346 (24.6)	374 (30.6)	
Fair	860 (32.5)	474 (34.0)	386 (30.9)	
Poor	608 (25.9)	355 (29.0)	253 (22.5)	
Cognitively impaired	897 (31.0)	491 (31.8)	406 (30.2)	.26
Functional impairment				<.001
0-2 ADLs	1552 (63.2)	778 (59.0)	774 (67.9)	
3-4 ADLs	500 (20.4)	301 (23.9)	199 (16.5)	
5-6 ADLs	469 (16.4)	263 (17.2)	206 (15.5)	
Hospitalization in past year	1047 (41.5)	657 (53.4)	390 (35.2)	<.001

Abbreviations: ED, emergency department; ADLs, activities of daily living.

^aPercentages are weighted to account for NLTCS and NHATS complex survey design. Numbers may not sum exactly due to rounding. Percentages refer to column categories.

^bCount of conditions including diabetes, hypertension, lung disease, coronary disease, and stroke.

^cMean (standard error).

an opportunity for clinicians and health systems to better support family caregivers of older adults with disability and, in doing so, potentially reduce ED utilization among a vulnerable subpopulation of older adults. That cognitive impairment was not associated with ED use is a departure from the prevailing evidence which links dementia to greater intensity of services.³²⁻³⁴ However, our study is unique in having strong measures of function and caregiver supports, while prior work has relied on administrative claims for information about cognitive and functional impairment. Given that forms of functional disability are closely linked to cognitive function,^{35,36} the nature of previous data sources may have conflated these concepts.

Older adults living in the community with disability are frequent users of ED services^{2,3} and most rely on support from family and unpaid caregivers.^{7,8} Given growing evidence of the relevance of family caregiver availability and capacity to older adult health outcomes,^{4,5,37,38} previous work has called for clinicians and health systems to better incorporate family caregivers into the care team—including via systematic identification of caregivers,¹⁶ harnessing patient portals for improved information sharing,^{39,40} and implementing standardized caregiver assessments.^{16,41,42} Our findings suggest the potential benefits of eliciting information from caregivers regarding their capacity and experiences to (1) better understand which caregivers face strain or burden

Table 2. Characteristics of Primary Caregivers for Community-Dwelling Older Adults With Disability, by Older Adult's Subsequent Emergency Department (ED) Utilization (n = 2521).

Primary Caregiver Characteristics	Full Sample (n = 2521); n (%) ^a	All-Cause ED Utilization		P (χ^2 Test for Between-Group Difference)
		Those With All- Cause ED Utilization (n = 1342); n (%)	Those Without All- Cause ED Utilization (n = 1179); n (%)	
Demographic characteristics				
Age (years)				.33
14-44	227 (9.0)	118 (10.1)	109 (9.4)	
45-64	1124 (44.6)	617 (42.1)	507 (41.0)	
65+	1170 (46.4)	607 (47.7)	563 (49.6)	
Female	1721 (68.3)	900 (63.0)	821 (65.9)	.17
Caregiving circumstances				
Relationship to care recipient				.05
Spouse	884 (35.1)	447 (41.3)	437 (46.7)	
Nonspouse	1637 (64.9)	895 (58.7)	742 (53.3)	
Resides apart from care recipient	704 (27.9)	380 (25.3)	324 (24.5)	.64
Caregiving for 4+ years	1309 (51.9)	660 (50.8)	649 (54.9)	<.01
Employed for pay	789 (31.3)	436 (30.3)	353 (29.6)	.17
Hours of care provided per week				<.01
0-20	1069 (42.4)	538 (44.1)	531 (50.2)	
20-40	659 (26.1)	345 (22.4)	314 (24.3)	
>40	793 (31.5)	459 (33.5)	334 (25.5)	
Help provided				
Household tasks	2171 (86.1)	1177 (90.0)	994 (87.5)	.01
Self-care	1701 (67.5)	939 (72.0)	762 (66.9)	<.01
Mobility	1791 (71.0)	990 (76.1)	801 (71.6)	<.01
Health care tasks ^b	1530 (60.7)	863 (69.0)	667 (61.4)	<.001
Self-reported health				
Excellent/very good	795 (37.4)	415 (36.8)	380 (38.2)	.45
Good	1040 (36.2)	548 (35.9)	492 (36.6)	
Fair/Poor	686 (27.2)	379 (27.4)	307 (25.2)	
Support services				
Support group use	128 (5.1)	60 (3.8)	68 (4.9)	.14
Respite care use	379 (15.0)	209 (14.9)	170 (13.5)	.42
Caregiving appraisal				
Financial strain				.01
None	1674 (66.4)	862 (66.2)	812 (71.0)	
Some/A lot	847 (33.6)	480 (33.8)	367 (29.0)	
Emotional strain				.07
None	1098 (43.6)	562 (42.8)	536 (46.4)	
Some/A lot	1423 (56.5)	780 (44.4)	643 (53.6)	
Physical strain				<.001
None	1374 (54.5)	689 (55.6)	685 (62.3)	
Some/A lot	1147 (45.5)	653 (44.4)	494 (37.7)	

^aPercentages are weighted to account for NLTCs and NHATS complex survey design. Numbers may not sum exactly due to rounding. Percentages refer to column category.

^bMobility tasks include moving around inside the house or transferring in/out of bed, self-care tasks include bathing, dressing, toileting, or eating, and health care tasks include assisting with medication management and/or wound care.

that may negatively impact their ability to confidently and effectively provide care and (2) to connect these caregivers with supportive interventions. Primary care clinicians are well-positioned to lead these conversations, given their

holistic understanding of patients' care needs and their emerging role as the strategic center of the care team.⁴³⁻⁴⁵

Our study findings also point to areas of vulnerability in the current environment of caregiver support. Caregivers

Table 3. Primary Caregiver Characteristics and Hazard of Subsequent ED Utilization Among Care Recipients (n = 2521).^a

	Model 1: Adjusting for Survey Wave Only		Model 2: Adjusting for Survey Wave, Sociodemographic Characteristics, Health Status ^b	
	All-Cause ED Utilization		All-Cause ED Utilization	
	HR	95% CI	HR	95% CI
Caregiver age (years)				
14-44		Reference		Reference
45-64	0.91	.69, 1.21	0.86	0.65, 1.13
65+	0.89	.69, 1.16	0.90	0.70, 1.17
Female gender	.93	.79, 1.11	0.85	0.72, 1.00
Relationship to care recipient				
Spouse		Reference		Reference
Nonspouse	1.16	0.97, 1.38	1.09	0.87, 1.37
Resides apart from care recipient	1.04	0.88, 1.23	1.00	0.85, 1.17
Caregiving for 4+ years	0.91	0.79, 1.04	0.97	0.84, 1.12
Self-reported health				
Excellent/Very good		Reference		Reference
Good	0.99	0.84, 1.18	0.98	0.83, 1.15
Fair/Poor	1.05	0.86, 1.29	.85	0.85, 1.26
Employed for pay	1.04	0.87, 1.24	1.06	0.89, 1.28
Hours of care provided per week				
0-20		Reference		Reference
20-40	1.06	0.88, 1.27	1.01	0.84, 1.21
>40	1.39	1.20, 1.62	1.22	1.04, 1.43
Help provided ^c				
Household tasks	1.20	0.98, 1.48	1.23	0.92, 1.38
Self-care	1.24	1.05, 1.47	1.16	0.97, 1.40
Mobility	1.20	1.00, 1.44	1.11	0.91, 1.35
Health care tasks	1.34	1.16, 1.55	1.26	1.08, 1.46
Supportive services				
Support group use	0.84	0.59, 1.19	0.86	0.61, 1.22
Respite care use	1.17	0.93, 1.47	1.08	0.86, 1.36
Financial strain				
None		Reference		Reference
Some/A lot	1.15	1.00, 1.34	1.05	0.89, 1.23
Emotional strain				
None		Reference		Reference
Some/A lot	1.15	0.99, 1.34	1.08	0.93, 1.27
Physical strain				
None		Reference		Reference
Some/A lot	1.24	1.08, 1.42	1.18	1.03, 1.36

Abbreviations: ED, emergency department; HR, hazard ratio.

^aAll models include sampling weights and design variables to adjust for nonprobability sampling in the NLTCS and NHATS surveys.

^bSociodemographic characteristics include age, sex, race, and educational attainment. Health status factors include number of chronic conditions, self-reported health status, and prior year hospitalization.

^cMobility tasks include moving around inside the house or transferring in/out of bed, self-care tasks include bathing, dressing, toileting, or eating, and health care tasks include assisting with medication management and/or wound care.

are often expected to manage older adults' needs in the community, whether that means coordinating between multiple providers, assisting with bathing, administering medications, or a multitude of other tasks.^{7,46} Although caregiver

involvement often extends to health system interactions,^{47,48} and may ultimately affect health outcomes and service use,^{4,5,37,38} caregivers rarely perceive themselves to be included as members of the care team or receive training

and preparation for the responsibilities and tasks they are expected to assume.^{16,49} Previous work suggests that offering formal training to family caregivers of older adults reduces caregiver strain, increases caregivers' self-efficacy, and improves outcomes for older adults.^{7,50-52} The Resources for Enhancing Alzheimer's Caregiver Health (REACH) and Helping Invested Families Improve Veterans' Experiences Study (HI-FIVES) are examples of community-based interventions to educate and support family caregivers that have been shown to improve caregiver and older adult outcomes.⁵³⁻⁵⁵ Development and implementation of additional caregiver training programs in the ambulatory care setting, especially those tailored to caregivers assisting with health care tasks or experiencing physical strain, could benefit both caregivers, who are often patients themselves, as well as older adults.

Limitations

As we rely on observational data, we cannot draw causal inferences regarding the impact of caregiver characteristics on older adult care recipients' ED use. We are limited to the measures gathered by both the NLTCs and NHATS and their linked caregiver surveys, and therefore cannot test potentially relevant caregiver characteristics such as measures of self-efficacy or reported receipt of training. Additionally, we do not have information on patient's geographic location or their specific service environment, factors which may affect use patterns at the community level.

Conclusion

In summary, this study finds that family caregiver characteristics have relevance to ED use among community-living older adults with disability. Multiple caregiver factors related to caregiver burden or strain are associated with greater risk of ED use in this population and could be amenable to intervention. These findings highlight an opportunity to improve care delivery for a subpopulation that are frequent ED users, and suggest that interventions which consider the needs of family caregivers and support the family unit may contribute to reductions in ED use among older adults.

Declaration of Conflicting Interests

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References

- Centers for Disease Control and Prevention. National Hospital Ambulatory Medical Care Survey: 2010 emergency department summary tables. https://www.cdc.gov/nchs/data/ahcd/nhamcs_emergency/2010_ed_web_tables.pdf. Accessed August 26, 2019.
- Aminzadeh F, Dalziel WB. Older adults in the emergency department: a systematic review of patterns of use, adverse outcomes, and effectiveness of interventions. *Ann Emerg Med.* 2002;39:238-247.
- Castillo EM, Brennan JJ, Howard J, et al. Factors associated with geriatric frequent users of emergency departments. *Ann Emerg Med.* 2019;74:270-275.
- Hass Z, DePalma G, Craig BA, Xu H, Sands LP. Unmet need for help with activities of daily living disabilities and emergency department admissions among older Medicare recipients. *Gerontologist.* 2017;57:206-210.
- Gruneir A, Silver MJ, Rochon PA. Emergency department use by older adults: a literature review on trends, appropriateness, and consequences of unmet health care needs. *Med Care Res Rev.* 2011;68:131-155.
- Medicare Payment Advisory Commission. Report to Congress: Medicarepaymentpolicy. http://www.medpac.gov/docs/default-source/reports/mar19_medpac_entirereport_sec_rev.pdf?sfvrsn=0. Published March 2018. Accessed August 26, 2019.
- National Academies of Sciences, Engineering, and Medicine. *Families Caring for an Aging America*. Washington, DC: National Academies of Sciences, Engineering, and Medicine; 2016.
- Freedman VA, Spillman BC. Disability and care needs among older Americans. *Milbank Q.* 2014;92:509-541.
- Freund T, Campbell SM, Geissler S, et al. Strategies for reducing potentially avoidable hospitalizations for ambulatory care-sensitive conditions. *Ann Fam Med.* 2013;11:363-370.
- Davies S, McDonald KM, Schmidt E, Schultz E, Geppert J, Romano PS. Expanding the uses of AHRQ's prevention quality indicators: validity from the clinician perspective. *Med Care.* 2011;49:679-685.
- Freedman VA, Spillman BC. *Disability and Care Needs of Older Americans: An Analysis of the 2011 National Health and Aging Trends Study*. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation; 2013.
- Braveman P, Gottlieb L. The social determinants of health: it's time to consider the causes of the causes. *Public Health Rep.* 2014;129(suppl 2):19-31.
- Shortell SM. Bridging the divide between health and health care. *JAMA.* 2013;309:1121-1122.
- Fiscella K, Burstin HR, Nerenz DR. Quality measures and sociodemographic risk factors: to adjust or not to adjust. *JAMA.* 2014;312:2615-2616.
- National Academies of Sciences, Engineering, and Medicine. *Accounting for Social Risk Factors in Medicare Payment*. Washington, DC: National Academies of Science, Engineering, and Medicine; 2017.

16. Wolff JL, Feder J, Schulz R. Supporting family caregivers of older Americans. *N Engl J Med*. 2016;375:2513-2515.
17. Centers for Medicare and Medicaid Services. Medicare and Medicaid program: conditions of participation for home health agencies. <https://www.federalregister.gov/documents/2017/01/13/2017-00283/medicare-and-medicaid-program-conditions-of-participation-for-home-health-agencies>. Published January 13, 2017. Accessed August 26, 2019.
18. Wolff JL, Mulcahy J, Huang J, Roth DL, Covinsky K, Kasper JD. Family caregivers of older adults, 1999-2015: trends in characteristics, circumstances, and role-related appraisal. *Gerontologist*. 2018;58:1021-1032.
19. Freedman VA, Crimmins E, Schoeni RF, et al. Resolving inconsistencies in trends in old-age disability: report from a technical working group. *Demography*. 2004;41:417-441.
20. Kasper J, Freedman V, Spillman B. *Classification of Persons by Dementia Status in the National Health and Aging Trends Study* (Technical Paper #5). Baltimore, MD: Johns Hopkins University School of Public Health; 2013.
21. Venkatesh AK, Mei H, Kocher KE, et al. Identification of emergency department visits in Medicare administrative claims: approaches and implications. *Acad Emerg Med*. 2017;24:422-431.
22. Mazzaglia G, Roti L, Corsini G, et al. Screening of older community-dwelling people at risk for death and hospitalization: the Assistenza Socio-Sanitaria in Italia project. *J Am Geriatr Soc*. 2007;55:1955-1960.
23. Goodwin JS, Howrey B, Zhang DD, Kuo YF. Risk of continued institutionalization after hospitalization in older adults. *J Gerontol A Biol Sci Med Sci*. 2011;66:1321-1327.
24. Teno JM, Gozalo PL, Bynum JP, et al. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA*. 2013;309:470-477.
25. Temkin-Greener H, Zheng NT, Xing J, Mukamel DB. Site of death among nursing home residents in the United States: changing patterns, 2003-2007. *J Am Med Dir Assoc*. 2013;14:741-748.
26. Koller MT, Raatz H, Steyerberg EW, Wolbers M. Competing risks and the clinical community: irrelevance or ignorance? *Stat Med*. 2012;31:1089-1097.
27. Wolbers M, Koller MT, Wittman JC, Steyerberg EW. Prognostic models with competing risks: methods and application to coronary risk prediction. *Epidemiology*. 2009;20:555-561.
28. Andersen PK, Geskus RB, de Witte T, Putter H. Competing risks in epidemiology: possibilities and pitfalls. *Int J Epidemiol*. 2012;41:861-870.
29. Allison PD. Competing risks. In: *Survival Analysis Using SAS: A Practical Guide*. 2nd ed. Cary, NC: SAS Institute; 2010:204-233.
30. Varadhan R, Weiss CO, Segal JB, Wu AW, Scharfstein D, Boyd C. Evaluating health outcomes in the presence of competing risks: a review of statistical methods and clinical applications. *Med Care*. 2010;48(6 suppl):S96-S105.
31. Lin D, Wei L, Ying Z. Checking the Cox model with cumulative sums of Martingale-based residuals. *Biometrika*. 1993;80:557-572.
32. Feng Z, Coots LA, Kaganova Y, Wiener JM. Hospital and ED use among Medicare beneficiaries with dementia varies by setting and proximity to death. *Health Aff (Millwood)*. 2014;33:683-690.
33. Deb A, Sambamoorthi U, Thornton JD, Schreurs B, Innes K. Direct medical expenditures associated with Alzheimer's and related dementias (ARD) in a nationally representative sample of older adults—an excess cost approach. *Aging Ment Health*. 2018;22:619-624.
34. Leibson CL, Long KH, Ransom JE, et al. Direct medical costs and source of cost differences across the spectrum of cognitive decline: a population-based study. *Alzheimers Dement*. 2015;11:917-932.
35. Farias ST, Lau K, Harvey D, Denny KG, Barba C, Mefford AN. Early functional limitations in cognitively normal older adults predict diagnostic conversion to mild cognitive impairment. *J Am Geriatr Soc*. 2017;65:1152-1158.
36. Andrews JS, Desai U, Kirson NY, et al. Functional limitations and health care resource utilization for individuals with cognitive impairment without dementia: findings from a United States population-based survey. *Alzheimers Dement (Amst)*. 2017;6:65-74.
37. Wolff JL, Mulcahy J, Roth DL, et al. Long-term nursing home entry: a prognostic model for older adults with a family or unpaid caregiver. *J Am Geriatr Soc*. 2018;66:1887-1894.
38. Covinsky KE. Hospitalization in older persons: not just a medical outcome, a social outcome as well: comment on "Elder abuse as a risk factor for hospitalization in older persons." *JAMA Intern Med*. 2013;173:919.
39. Chimowitz H, Gerard M, Fossa A, Bourgeois F, Bell SK. Empowering informal caregivers with health information: OpenNotes as a safety strategy. *Jt Comm J Qual Patient Saf*. 2018;44:130-136.
40. Wolff JL, Darer JD, Larsen KL. Family caregivers and consumer health information technology. *J Gen Intern Med*. 2016;31:117-121.
41. Levine C. Putting the spotlight on invisible family caregivers. *JAMA Intern Med*. 2016;176:380-381.
42. Shugrue N, Kellett K, Gruman C, et al. Progress and policy opportunities in family caregiver assessment: results from a national survey. *J Appl Gerontol*. 2019;38:1319-1341.
43. Okie S. The evolving primary care physician. *N Engl J Med*. 2012;366:1849-1853.
44. Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health. *Milbank Q*. 2005;83:457-502.
45. Phillips C. Care coordination for primary care practice. *J Am Board Fam Med*. 2016;29:649-651.
46. Wolff JL, Spillman BC, Freedman VA, Kasper JD. A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Intern Med*. 2016;176:372-379.
47. Wolff JL, Roter DL. Family presence in routine medical visits: a meta-analytical review. *Soc Sci Med*. 2011;72:823-831.
48. DiMatteo MR. Social support and patient adherence to medical treatment: a meta-analysis. *Health Psychol*. 2004;23:207-218.
49. Burgdorf J, Roth D, Riffin C, Wolff J. Factors Associated With Receipt of Training Among Caregivers of Older Adults. *JAMA Intern Med*. 2019;179(6):833-835. doi: 10.1001/jamainternmed.2018.8694

50. Teri L, Logsdon RG, McCurry SM, Pike KC, McGough EL. Translating an Evidence-based Multicomponent Intervention for Older Adults With Dementia and Caregivers [published online October 9, 2018]. *Gerontologist*. doi:10.1093/geront/gny122
51. Nuckols TK, Keeler E, Morton S, et al. Economic evaluation of quality improvement interventions designed to prevent hospital readmission: a systematic review and meta-analysis. *JAMA Intern Med*. 2017;177:975-985.
52. Sörensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist*. 2002;42:356-372.
53. Nichols LO, Martindale-Adams J, Burns R, Zuber J, Graney MJ. REACH VA: moving from translation to system implementation. *Gerontologist*. 2016;56:135-144.
54. Burns R, Nichols LO, Martindale-Adams J, Graney MJ, Lummus A. Primary care interventions for dementia caregivers: 2-year outcomes from the REACH study. *Gerontologist*. 2003;43:547-555.
55. Van Houtven CH, Smith VA, Lindquist JH, et al. Family caregiver skills training to improve experiences of care: a randomized clinical trial [published online August 6, 2019]. *J Gen Intern Med*. 2019. doi:10.1007/s11606-019-05209-x