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Research Article

Informal Caregiver Burden, Benefits, and Older Adult Mortality: A Survival Analysis

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Abstract

Objective: Informal caregivers are crucial to maintaining older adults' health, but few studies examine how caregiving receipt is associated with older person longevity. In a nationally representative sample, we prospectively explore whether and how having an informal caregiver is associated with older adult overall mortality, and how caregivers' burden and benefits perceptions relate to care recipient mortality.
Methods: We match six National Health and Aging Trends Study waves (2011–2016) with 2011 National Study of Caregiving data, conducting survival analysis on 7,369 older adults and 1,327 older adult-informal caregiver dyads.
Results: Having an informal caregiver is associated with 36% ($p < .001$) higher mortality risk over 6-year follow-up, adjusting for demographic, economic, and health factors. Older adults whose caregivers perceive only burden have 38% higher ($p < .05$) mortality risk than those with caregivers reporting neither burden nor benefits. This risk is reduced from 38% higher to 5% higher ($p < .001$) for older adults with caregivers reporting benefits alongside burden, compared to those with caregivers reporting neither perception.
Discussion: Having a caregiver may signal impending decline beyond known mortality factors. However, interventions to increase caregivers' benefit perceptions and reduce their burden may decrease mortality risk for older adults with declining health and functional ability.

Keywords: Benefits, Burden, Mortality, NHATS, NSOC

This paper explores whether informal caregiving receipt is associated with care recipient mortality risk for older adults aged 65+. First, we examine whether having an informal caregiver is associated with recipient death risk, independent of known sociodemographic and health factors predicting older adult mortality. Second, among older adults with informal caregivers, we use dyadic data to explore how caregivers' care provision experiences relate to recipient mortality. Accounting for known recipient-reported mortality risk factors, we examine how caregiver-reported subjective (perceived burden and benefit), objective (caregiving duration, intensity), and social (gender, education, and relationship to recipient) caregiving experience aspects are associated with care recipient mortality risk.

Older Adult Mortality Risk

Factors increasing mortality risk among older adults are well documented. Age is a key factor, with mortality risk increasing steadily between 65 and 84 years and sharply among adults 85+ (Lee, Lindquist, Segal, & Covinsky, 2006; Schonberg, Davis, McCarthy, & Marcantonio, 2009). Men have greater mortality risk than women (Lee et al., 2006; Schonberg et al., 2009). Having lower socioeconomic status (SES) is also associated with greater mortality, although differences decrease among older adults (Elo & Preston, 1996; Masters, Link, & Phelan, 2015). Racial/ethnic minority groups have higher age-adjusted death rates than whites, but among older adults this reverses in a "mortality cross-over" (Geronimus, Hicken, Keene, & Bound, 2006); adjusting for SES and risk environment, non-Hispanic Blacks and Hispanics have comparable or lower mortality risk than whites (Hummer & Chinn, 2011; Murphy, Xu, Kochanek, Curtin, & Arias, 2017). Comorbidities such as diabetes, cancer, lung disease, and heart failure also increase mortality risk, as do frailty and functional limitations including difficulty bathing, managing finances, and walking several blocks (Lee et al., 2006; Schonberg et al., 2009).

Informal Caregiving and Care Recipient Mortality Risk

Less is known about how informal caregiving is associated with older adult mortality risk, although informal caregivers are integral in older adults' daily lives and the U.S. long-term care system. Annually, 17.7 million individuals provide informal care to community-dwelling adults aged 65+ (National Academies of Sciences and Medicine [NASM], 2016). U.S. informal caregiving amounts to 37 billion care hours, or $470 billion in unpaid labor (Reinhard, Feinberg, Choula, & Houser, 2015). Over three-quarters of caregivers are close family members—over half are spouses or adult daughters—although distant family members, friends, and others also provide care (NASM, 2016). They assist with essential and instrumental activities of daily life (ADLs), increasingly taking on nursing tasks and medical care management (NASM, 2016). As Baby Boomers continue to age, the older adult population will grow to 72.8 million by 2030, furthering need for informal caregivers (NASM, 2016).

Given unpaid caregivers' significant role in caring for aging and dying populations, it is important to understand how informal caregiving receipt and caregivers' experiences are associated with care recipient mortality. Older adults' frailty and disability—both key mortality predictors—are often primary impetus for receiving informal care (NASM, 2016), and we do not argue that receiving caregiving causes recipient mortality. Instead, informal caregiving receipt may signal an individual's health deteriorations and approaching end-of-life beyond measurable factors. Receiving informal care is associated with heightened institutionalization and hospitalization risk (Miller and Weissert 2000). Conversely, caregiving receipt might be protective against mortality. Caregivers provide instrumental support, assisting with activities like bathing and meal preparation that can offset disability-induced deficits, improve illness management, and avoid institutionalization (Martire, Schulz, Wrosch, & Newsom, 2003; Miller & Weissert, 2000; NASM, 2016; Reinhard et al., 2015; Riffin, Van Ness, Wolff, & Fried, 2017). Caregivers provide emotional support, decreasing older adults' feeling isolated. Emotional connectedness is associated with better quality of life, health maintenance, medication regimen adherence, and decreased mortality risk among older adults (Berkman, 2000; DiMatteo, 2004).

Caregivers' Experiences and Care Recipient Mortality Risk

Caregiving may also be associated with care recipient mortality beyond simply having versus not receiving informal care. Caregiving relationships represent social ties between caregivers and recipients that involve frequent interactions and are potentially close and intimate (Spillman, Wolff, Freedman, & Kasper, 2014). Not all caregiving experiences are equal, and recipients have diverse needs requiring different responses (NASM, 2016). Some older adults may need several caregiving hours daily for weeks or months while recovering from acute health episodes. Others require help that only takes several hours weekly, but over multiple years. Accordingly, caregivers have varying care provision and caregiving relationship perceptions. Whether and how these informal caregiver experiences are associated with recipient mortality is not clearly established (Miller & Weissert, 2000).

Caregivers can perceive their experiences negatively, positively, or as a combination. Most caregivers report financial, emotional, physical, or social caregiving burden (NASM, 2016). They experience greater psychological distress and higher chronic disease rates than noncaregivers (NASM, 2016; Reinhard et al., 2015), face immediate economic impact and longer-term penalties with reduced income and benefits due to caregiving limiting work hours (NASM, 2016), and face social life constraints during challenging periods like end-of-life caregiving (Ornstein et al., 2016). Alternatively, caregivers can perceive their experiences positively, recognizing beneficial emotional and practical caregiving outcomes (Kramer, 1997). Caregivers can experience benefits like satisfaction that loved ones are well cared-for, gaining new skills, or becoming more confident in their abilities (Martire et al., 2003; NASM, 2016). Caregiving burden and benefits coexist and are seldom separate perceptions. Caregivers typically report burden and benefits of different types (e.g., emotional and social burden and benefits) and intensity that occur together (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Pristavec, 2019a).

As caregivers have diverse backgrounds, their lived experiences also influence caregiving perceptions (NASM, 2016). For example, women are less likely to take on caregiving voluntarily and more frequently offer intensive assistance, potentially appraising caregiving as more burdensome (Pinquart & Sorensen, 2006). Lower SES caregivers may have limited resources facilitating caregiving and perceive more burden (Pinquart & Sorensen, 2005). Racial/ethnic minorities may face additional barriers, perceiving caregiving as more burdensome, or beliefs like familialism and Marianismo may give them broader support networks and facilitate more positive caregiving perceptions (Aranda & Knight, 1997).

Caregivers' burden and benefit perceptions shape caregivers' own health (Pinquart & Sorensen, 2003), but as caregiving revolves around interpersonal relationships and frequent interactions, they could further be associated with recipient outcomes (Burgener & Twigg, 2002; Pristavec, 2019b). Given recurring daily events and exchanges between caregivers and recipients, the stress process model (Pearlin, 2010) suggests that caregivers' negative and positive perceptions can engender stress or uplifts proliferating to recipients, shaping the latter's health (Pearlin, 1989). This may occur through psychosocial and physiological (e.g., cardiovascular and immune response) mechanisms (Kiecolt-Glaser, 1999). Burdened caregivers may also feel overwhelmed and have limited resources for high quality care provision, affecting recipients' physical health, or they may be negative during recipient interactions, worsening their psychological well-being (Hammen, 2005). Depressed mood, compromised immune response, physiological strain, and impaired functioning resulting from stressful daily interactions with a burdened caregiver may amount to higher recipient mortality. Caregivers perceiving primarily benefits may be better positioned to provide assistance and may interact with recipients more positively, alleviating stress or burden responses and potentially improving physical and psychological functioning, resulting in improved recipient outcomes (Han, Kim, & Burr, 2019). Caregiver-perceived stressors can thus become interacting partner stressors, or conversely, caregivers' positive perceptions may be associated with interactions that benefit recipient well-being directly or by moderating burden (Pearlin, 2010). Beyond recipient need and caregiver positionality, caregiver burden and benefit perceptions may thus explain how informal caregiving receipt is associated with recipient mortality beyond known mortality risks.

Present Paper

We conduct two analyses on caregiving and recipient mortality risk. First, we examine how informal caregiving receipt is associated with recipient mortality, controlling for sociodemographic and health factors linked to older adult mortality in a nationally representative sample. Second, among persons with informal caregivers, we explore the relationship between caregiving characteristics and recipient mortality risk. We analyze how subjective (perceived burden and benefit), objective (duration and intensity), and social (gender, education, relationship to care recipient) factors relate to recipient mortality. Given perceived burden and benefit typically co-occur, we also examine their interaction. As the older adult population grows and the U.S. long-term care system increasingly relies on informal caregivers, better understanding how caregiving receipt is associated with older adult mortality is critical for informed decision making on how best to support caregiver–recipient dyads and provide aging persons with quality assistance.

Method

Data

We link two nationally representative data sets to examine whether caregiving receipt and caregiver characteristics predict older person survival. We use older adult data from six U.S. National Health and Aging Trends Study (NHATS) waves (2011–2016) (Kasper & Freedman, 2018). NHATS is an annual longitudinal survey monitoring aging trends. It collects information on Medicare recipients aged 65+ living at home or residential care; 96% of U.S. older adults are Medicare enrollees (Montaquila, Freedman, Edwards, & Kasper, 2012). NHATS oversamples black and older adults aged 85+. Baseline response rate was 71%.

We link NHATS with 2011 National Study of Caregiving (NSOC) data (Freedman, Skehan, Wolff, & Kasper, 2018). NSOC surveys informal caregivers providing unpaid self-care, mobility, or household activity assistance to NHATS respondents. NSOC collects data on older adult care provision. Baseline response rate was 60%.

Analytic Samples

Sample 1: Informal caregiving receipt and mortality

To examine informal caregiving receipt and mortality risk, we analyzed 7,609 NHATS respondents community-dwelling at baseline (2011). We omitted 240 cases (3.2%) missing data on final model variables, resulting in a 7,369 older adults analytic sample.

Sample 2: Caregiving characteristics and mortality

To examine how caregiving characteristics are associated with mortality risk, we identified primary caregivers for 1,375 NHATS respondents with NSOC caregivers. We defined the primary caregiver as one providing the most caregiving hours to the older adult in the month preceding NSOC interview (Spillman et al., 2014). Where NHATS persons had two caregivers providing equal assistance hours ($N = 12$), we determined the primary caregiver as one offering higher frequency ADL, instrumental ADL, and medical task assistance. Secondary caregivers provided significantly smaller total care hours proportion to NHATS respondents ($M = 0.21, SD = 0.13$) than primary caregivers ($M = 0.90, SD = 0.17$). We omitted 48 cases (3.4%) missing data on final model variables, resulting in 1,327 analytic sample dyads.

Death and attrition sample loss

Older adults were followed up to 66 months (2011–2016). Of 7,369 persons in the first analytic sample in 2011, 1,585 (22%) died and 2,570 (35%) attrited by 2016. Of 1,327 older adults in the second analytic sample, 594 (45%) died and 303 (23%) attrited by 2016. Survival analysis, discussed below, handles death (events) and attrition (censoring).

Methods

We examined initial sample differences using log-rank tests for statistically significant differences between group survival curves (Harrington & Fleming, 1982). We conducted survival analyses using Cox proportional hazards (CPH) regression with time-varying covariates (Bradburn, Clark, Love, & Altman, 2003b) to examine how caregiving receipt and characteristics are associated with older adult survival over time. Given NHATS respondent-level outcome and analytic unit, we use NHATS respondent analytic weights to account for survey design and nonresponse bias, making the sample nationally representative (Kasper, Freedman, & Spillman, 2016).

CPH models assume proportional and time-constant individual hazard functions (Bradburn, Clark, Love, & Altman, 2003a). We conducted proportionality assumption checks using scaled Schoenfeld residuals. We tested for independence between residuals and time for covariates and overall model formally (Grambsch & Therneau, 1994), and graphically with log(-log) function and residual plots. Health and age violated proportionality, but visual inspection showed even residuals clustered at $y = 0$ and parallel log(-log) functions, indicating no significant violations. This suggests formal tests highlighted minor proportionality departures due to sample size and covariate number. We kept factors in models given documented importance in predicting mortality.

Beyond assumption diagnostics, we used Martingale residuals to assess continuous variable nonlinearity and plotted deviance residuals to identify outliers (Bradburn et al., 2003a). Neither identified issues. Multicollinearity was not problematic; except variables with multiple dummies with variance inflation factors (VIF) size 3–4, VIF did not exceed 3. Coefficients remained stable in robustness tests with no inflated standard errors. Final tables display Akaike information criterion (AIC; lower value suggests better fit), concordance index (higher value suggests better predictive power), and global Wald test (significance suggests coefficients contribute to hazard prediction) as model fit indicators.

Measures

Key variables

Survival time

Survival start time is an older adult's first interview date (month, 2011). Survival endpoint is follow-up end date (month, year) in 2016 for persons with no event, loss to follow-up date for attrited persons, and death date for deceased persons. For 87 older adults without an exact death date, death date is the plausible death range midpoint (established using reported death month and/or year, prior and end-of-life interview month/year, and reported death age versus birth date). We assumed end-of-life interviews were conducted at least 1 month postdeath.

Analysis 1 (informal caregiving receipt and mortality)

Informal caregiver presence (Wave 1 measurement) indicates whether the NHATS respondent has an informal caregiver (CG) (=1). CGs are persons from whom older adults reported receiving mobility (getting around outside, inside, getting out of bed), self-care (eating, bathing, showering/washing up, getting to/using the toilet, dressing), or household help for health or functioning reasons (laundry, personal item shopping, preparing hot meals, paying bills/banking, tracking medications) in month preceding interview.

Analysis 2 (caregiver characteristics and mortality): Subjective measures (Wave 1)

CG burden indicates whether CG reported perceiving caregiving burden (=1). Indicator was constructed from affirmative responses to any items about negative experiences helping CR: whether caregiving was emotionally difficult, physically difficult, financially difficult, and whether they reported caregiving-related social difficulties (caregiving kept from visiting friends/family; attending religious services; going out for enjoyment; participating in meetings/clubs/group activities; volunteering; caring for others; Riffin et al., 2017; Spillman et al., 2014; Wolff, Spillman, Freedman, & Kasper, 2016). Items had good internal consistency (α = 0.77). *CG benefits* indicates whether CG reported perceiving any caregiving benefits (=1). Indicator was constructed from affirmative responses to any items about beneficial caregiving experiences: whether helping CR made them more confident in abilities, taught them to deal with difficulties, brought them closer to CR, or gave satisfaction that CR was well cared for. "Somewhat" and "very much" were recoded as agreement (=1), and "not so much" to disagreement (=0) (Spillman et al., 2014; Wolff et al., 2016). Items had good internal consistency (α = 0.67).

Informal caregiver factors

Objective caregiving experience (Wave 1)

Caregiving intensity indicates providing ≥40 caregiving hours monthly (=1). *Caregiving duration* indicates providing care ≥5 years (=1). Variables were CG-reported and dichotomized on medians.

CG characteristics (Wave 1)

We dichotomously measure self-reported gender (female = 1), education (≥BA = 1), and relationship to

CR. In weighted RQ2 sample, 36% of caregivers were spouses/partners, 46% were adult children, and 18% were others. After sensitivity analyses, we collapse the variable to close family (spouse/partner or adult child) versus others (=1).

Care recipient factors

CR demographics (Wave 1)

We coded CR-reported females as 1; grouped age into young old (65–74 years old; reference), old-old (75–84 years old), or oldest-old (85 years or older); race as non-Hispanic white (reference), non-Hispanic Black, Hispanic, or other; and marital status as married/partnered (reference), never married, separated/divorced, or widowed.

CR SES (Wave 1)

We coded CR-reported education as ≥ BA (=1; some college or less = 0); homeownership (=1); and receiving any social assistance (food stamps, other food assistance, or gas/electricity assistance = 1).

CR health (time-varying covariates, except diagnoses)

Three or more CR-reported ADL disabilities (eating, bathing, toileting, dressing, moving around inside, getting out of bed) were coded = 1. Frailty or poor functional capacity (=1) indicates the respondent was unable to perform at least one less challenging task from Nagi inventory pairs (e.g., walk three blocks/six blocks), consistent with prior literature (Freedman et al., 2011). Reported diagnoses (0–5) sums five leading older adult death causes (lung problems, stroke, diabetes, heart disease, cancer) and is the lone health variable measured only at baseline, due to limited ability to consistently code condition onset using NHATS. Dementia status indicates CR has no (reference), possible, or probable dementia (Kasper, Freedman, Spillman, & Skehan, 2013). Dementia is a leading older adult death cause but has distinct caregiving characteristics (National Alliance for Caregiving, 2017; Ory, Hoffman III, Yee, Tennstedt, & Schulz, 1999); we therefore kept it separate from other diagnoses. Possible depression and anxiety are separate dichotomous recipient-reported symptomatology measures ($r = .49$), constructed using validated screeners reflecting DSM-V diagnostic criteria (Löwe et al., 2010). PHQ-2 depression screener asks whether respondents had little interest or pleasure in doing things; or felt down, depressed, or hopeless, over the past month. GAD-2 anxiety screener asks whether respondents felt nervous, anxious, or on edge; or felt unable to stop or control worrying over past month. Original item response categories (not at all, several days, more than half the days, nearly every day) are scored 0–3, with total score range 0–6. Scores ≥3 are depression or anxiety cutoffs (Löwe et al., 2010). We recoded accordingly, indicating whether respondents met depression (=1) or anxiety criteria (=1). Self-rated health indicates person-reported health, ranging poor (0) to excellent (4).

Results

Table 1 shows weighted sample descriptive statistics. Compared to persons without informal caregivers, those with caregivers were more likely to die, be female, older, nonwhite, and have lower SES. Those with caregivers reported more disability, serious illness, and mental health issues.

Tables 2 and 3 show weighted CPH model results predicting survival. Tables show hazard ratios (HR, exponentiated coefficients; HR > 1 indicates increased mortality hazard, HR < 1 reduced hazard) and 95% confidence intervals using robust standard errors. Estimates were obtained from models sequentially adjusted for demographic, socioeconomic, and health characteristics. Analysis 2 also adjusts for caregiver characteristics.

We removed nonsignificant Analysis 1 factors from Analysis 2 for parsimony. Robustness checks showed no coefficient size, direction, or magnitude differences compared to final models shown. Final models had good predictive power (Analysis 1 $c = 0.80$, Analysis 2 $c = 0.75$), with global Wald test indicating that factors contributed significantly to hazard prediction ($p < .001$). Consistent AIC decreases across models indicated fully-adjusted models provide best fit.

Analysis 1: Informal caregiving receipt and mortality

Median time-to-event is unavailable since the survivorship function never equals .50 ($min = 0.73$). Log-rank test indicates survival curves differ for older adults with informal caregivers versus without ($chi^2 = 786(1)$, $p < .001$). Five-year survival for those without caregivers is 83% compared to 52% for those with caregivers.

Model 1

In unadjusted baseline model, older adults with informal caregivers have death hazard ratios 3.80 times as high as those without informal caregivers ($p < .001$).

Model 2

Including recipient demographics partially explains association magnitude between informal caregiving receipt and mortality. After adjustment and all else equal, older adults with caregivers have death hazard ratios 2.80 times as high as individuals without informal caregivers ($p < .001$). Additionally, older age and nonmarried/partnered status are associated with higher mortality hazard ($p < .001$). Conversely, females are less likely to die than males ($p < .001$), and compared to whites, Hispanics are less likely to die ($p < .01$).

Model 3

Older adult SES further explains association magnitude of informal caregiving receipt and mortality risk. Older

Table 1. Weighted Sample Descriptive Statistics

Unweighted N	7,639				1,327
Sample	Analysis 1				Analysis 2
Variable	*Total prop./M(SE)*	*No CG*	*Has CG*	*Chi*^{2}	*Total prop./M(SE)*
Respondent has CG (=1)	0.26	0.00	1.00		
CG burden (=1)					0.67
CG benefits (=1)					0.32
Respondent deceased W1-W6 (=1)	0.17	0.10	0.36	***	0.41
Respondent female (=1)	0.57	0.52	0.68	***	0.66
Respondent age (years)				***	
Young old (65–74)	0.53	0.60	0.32		0.32
Old old (75–84)	0.34	0.32	0.39		0.38
Oldest old (85+)	0.13	0.08	0.29		0.30
Respondent race				***	
White	0.82	0.84	0.76		0.55
Black	0.08	0.07	0.10		0.12
Hispanic	0.07	0.05	0.10		0.08
Other	0.04	0.04	0.03		0.03
Respondent marital status				***	
Married/partnered	0.57	0.61	0.46		0.47
Never married	0.04	0.04	0.04		0.04
Separated/divorced	0.12	0.13	0.10		0.09
Widowed	0.27	0.23	0.40		0.40
Respondent BA+ education (=1)	0.24	0.28	0.15	***	0.15
Respondent social assistance (=1)[a]	0.12	0.09	0.20	***	0.19
Respondent owns home (=1)[a]	0.74	0.81	0.54	***	0.57
Respondent 3+ ADL (=1)	0.17	0.04	0.54	***	0.57
Respondent # comorbidities (0–5)	1.19 (0.02)	1.06(0.02)	1.57(0.03)	***	1.35(0.04)
Respondent likely depression (=1)	0.15	0.09	0.29	***	0.31
Respondent likely anxiety (=1)[a]	0.13	0.08	0.26	***	0.25
Respondent poor physical capacity (=1)	0.377	0.22	0.81	***	0.83
SP dementia status				***	
No dementia	0.79	0.88	0.55		0.54
Possible dementia	0.11	0.09	0.17		0.15
Probable dementia	0.10	0.03	0.28		0.31
SP self-reported health (0–4)	2.26(0.02)	2.51(0.02)	1.60(0.03)	***	1.59(0.04)
CG female (=1)					0.63
CG BA+ education (= 1)					0.25
CG nonclose family (=1)					0.17
CG 40hrs/week+ (=1)					0.58
CG long-term (=1)					0.52

Note: [a]Not in Analysis 2 model; shown for completeness and comparison. Analysis 1 = Informal caregiver and respondent mortality. Analysis 2 = Informal caregiver characteristics and respondent mortality. ADL = activities of daily life; CG = Informal caregiver. Prop = proportion. M = mean. SE = Standard error. Significance of Pearson's *chi*^{2} with Rao & Scott adjustment shown for RQ1 "has CG" to "no CG" comparisons. Source: NHATS 2011–2016, NSOC 2011.
*$p < .05$, **$p < .01$, ***$p < .001$.

persons with caregivers have hazard ratios 2.67 times as high as those without informal caregivers ($p < .001$). Associations between older adult demographics and mortality persist; while older age and nonmarried status are associated with higher mortality hazards, being female or Hispanic is associated with lower hazards. Among socioeconomic factors, which reduce demographics and mortality association strength, older persons with ≥ BA are less likely to die compared to less educated persons ($p < .001$).

Model 4

In final model, adjusted for demographic, socioeconomic, and time-varying health factors, informal caregiving receipt remains a significant mortality predictor. Older adults with caregivers are 36% more likely to die during follow-up than individuals without informal caregivers ($p < .001$). Consider an older, white, educated homeowner female aged 75–84 years, with good self-rated health, one major diagnosis, and 3+ ADL disabilities (Figure 1). Her

Table 2. Analysis 1. Results from Cox Proportional Hazards Model Predicting Relationship Between Having a Caregiver and Deceased Status

	Has CG			Demographics			Socioeconomics			Health		
	HR	*95% CI*		*HR*	*95% CI*		*HR*	*95% CI*		*HR*	*95% CI*	
Has CG (ref = no CG)	3.81	3.44	4.23***	2.80	2.46	3.19***	2.67	2.34	3.05***	1.36	1.18	1.57***
Female (ref = male)				0.57	0.49	0.66***	0.56	0.48	0.65***	0.59	0.50	0.69***
Age (ref = young old [65–74])												
Old old (75–84)				2.47	2.14	2.86***	2.45	2.13	2.83***	2.08	1.81	2.40***
Oldest old (85+)				4.91	4.03	5.99***	4.93	4.03	6.02***	3.76	3.08	4.61***
Race (ref = non-Hispanic white)												
Non-Hispanic Black				1.07	0.92	1.24	1.02	0.88	1.19	0.88	0.76	1.02
Hispanic				0.71	0.56	0.89**	0.66	0.52	0.83***	0.57	0.44	0.74***
Non-Hispanic other				0.92	0.58	1.47	0.89	0.56	1.41	0.80	0.50	1.28
Marital (ref = married/partnered)												
Never married				1.43	1.00	2.05*	1.34	0.93	1.94	1.27	0.88	1.83
Separated/divorced				1.49	1.15	1.94**	1.39	1.07	1.81*	1.32	1.03	1.71*
Widowed				1.46	1.26	1.70***	1.38	1.18	1.61***	1.28	1.08	1.51**
Education BA+ (ref = <BA)							0.72	0.60	0.87***	0.86	0.72	1.03
Social assistance (ref = no)							1.04	0.87	1.24	0.87	0.72	1.04
Homeowner (ref = no)							0.90	0.79	1.02	0.97	0.85	1.11
Likely depression (ref = no)										1.09	0.98	1.21
Likely anxiety (ref = no)										0.94	0.82	1.07
Self-report health (0 poor—4 excel.)										0.80	0.76	0.84***
# comorbidities (0–5)										1.13	1.06	1.20***
3+ ADL (ref = <3 ADL)										1.40	1.24	1.57***
Poor physical capacity (ref = good)										1.60	1.41	1.81***
SP dementia (ref = no dementia)												
Possible dementia										1.47	1.31	1.65***
Probable dementia										1.81	1.55	2.12***
Concordance (*SE*)	0.66 (0.01)			0.76 (0.01)			0.77 (0.01)			0.80 (0.01)		
AIC	57,364.85			55,858.43			55,800.36			54,853.39		
Wald test (df)	644.9 (1)***			1,266 (10)***			1,277 (13)***			2,948 (21)***		

Note: *N* = 7,369. Confidence intervals derived from robust standard errors. ADL = activities of daily life; AIC = Akaike information criterion; CI = confidence interval; CG = Caregiver; df = degrees of freedom; HR = hazard ratio; SE = standard error. Source: NHATS 2011–2016, NSOC 2011.
$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$.

predicted 5-year survival probability is 73% when she does not have an informal caregiver, but 65% when she does. Demographics similarly remain important in explaining mortality. Old-old have death hazard ratios 2.08 times as high ($p < .001$), and oldest-old 3.76 times as high ($p < .001$) as young old. Separated/divorced older adults are 32% more likely to die ($p < .05$), and those widowed 28% more likely ($p < .01$) compared to married/partnered counterparts. Conversely, females are 41% less likely to die than males ($p < .001$) and compared to whites, Hispanics are 43% less likely to die ($p < .001$). Health factors explain away the SES-mortality association and predict mortality risk: older adults with ≥3 ADL disabilities are 40% more likely to die during follow-up than those with fewer ($p < .001$). Those with possible dementia are 47% more likely ($p < .001$), and those with probable dementia are 81% more likely to die ($p < .001$) than persons without dementia. Each additional major illness is associated with older adults' 13% ($p < .001$) higher mortality hazard. Older adults with poor physical capacity are 60% more likely to die compared to individuals with good capacity ($p < .001$). Conversely, better self-reported health is associated with lower death risk. For each self-reported health level improvement, older adults have 20% lower mortality hazard ratios ($p < .001$).

In sum, in fully-adjusted model, female gender, racial/ethnic minority status, and better self-reported health are associated with lower death hazard ratios. Older age, nonmarried status, ADL disabilities, dementia, poor

Table 3. Analysis 2. Results from Cox Proportional Hazards Model Predicting Caregiver Characteristics Relationship to Deceased Status

	CG burden + benefits			CG burden × benefits			CR characteristics			CG characteristics		
	HR	*±95% CI*		*HR*	*±95% CI*		*HR*	*±95% CI*		*HR*	*±95% CI*	
CG burden (=1)	1.44	1.13	1.83**	1.90	1.39	2.59***	1.43	1.05	1.93*	1.38	1.04	1.84*
CG benefits (=1)	0.96	0.75	1.23	1.59	1.03	2.44*	1.50	1.00	2.27*	1.50	1.00	2.26*
CG burden (=1) × CG benefits (=1)				0.48	0.30	0.78**	0.51	0.34	0.75***	0.51	0.34	0.75***
CR female (ref = male)							0.72	0.56	0.93*	0.75	0.58	0.97*
CR age (ref = young old [65–74])												
Old old (75–84)							1.86	1.28	2.72**	1.82	1.24	2.67**
Oldest old (85+)							3.44	2.39	4.95***	3.25	2.23	4.72***
CR race (ref = non-Hispanic white)												
Non-Hispanic Black							0.74	0.59	0.93**	0.74	0.59	0.93**
Hispanic							0.58	0.35	0.97*	0.61	0.37	1.02*
Non-Hispanic other							0.70	0.39	1.27	0.71	0.39	1.26
CR marital (ref = married/ partnered)												
Never married							1.14	0.60	2.15	1.35	0.69	2.64
Separated/divorced							1.23	0.78	1.95	1.31	0.83	2.06
Widowed							1.16	0.90	1.51	1.17	0.89	1.52
CR education BA+ (ref = <BA)							1.10	0.85	1.43	1.08	0.86	1.37
CR likely depression (ref = no)							1.17	1.01	1.35*	1.17	1.01	1.35*
CR self-report health (0 poor—4 excel.)							0.86	0.79	0.94***	0.85	0.78	0.93***
CR # comorbidities (0–5)							1.16	1.04	1.29**	1.17	1.05	1.30**
CR 3+ ADL (ref = <3 ADL)							1.24	1.02	1.52*	1.26	1.03	1.53*
CR poor physical capacity (ref = good)							1.76	1.29	2.39***	1.79	1.31	2.43***
CR dementia (ref = no dementia)												
Possible dementia							1.40	1.14	1.72**	1.40	1.14	1.72**
Probable dementia							1.95	1.53	2.50***	1.97	1.55	2.50***
CG 40 hr/week+ (=1)										0.95	0.76	1.19
CG long-term (=1)										0.84	0.69	1.03
CG female (ref = male)										1.20	0.97	1.47
CG education BA+ (ref = <BA)										1.15	0.89	1.48
CG nonclose family (ref = family)										0.81	0.62	1.06
Concordance (*SE*)	0.55 (0.02)			0.57 (0.02)			0.75 (0.01)			0.75 (0.01)		
AIC	18,720.71			18,687.29			17,872.57			17,853.48		
Wald test (df)	9.54 (2)**			20.29 (3)***			528.00 (20)***			608.10 (25)***		

Note: *N* = 1,327. Confidence intervals derived from robust standard errors. ADL = activities of daily life; AIC = Akaike information criterion; CG = caregiver; CI = confidence interval; CR = Care recipient; df = degrees of freedom; HR = hazard ratio; SE = standard error. Source: NHATS 2011–2016, NSOC 2011.
*$p < .05$, **$p < .01$, ***$p < .001$.

physical capacity, and diagnosed major disease are associated with higher mortality. Importantly, even after controlling for demographic, socioeconomic, and health factors, informal caregiving receipt significantly predicts mortality.

Analysis 2: Caregiver characteristics and recipient mortality

Median time-to-event was 57 months. Log-rank test indicates survival curves of older adults whose informal caregivers report burden versus not are different (chi^2 = 23.9(1), $p < .001$). Five-year survival for those with burdened caregivers is 44% compared to 57% for those with nonburdened caregivers. The test indicates no differences between older persons whose caregivers report benefits versus not (chi^2 = 2.5(1), $p < .1$).

Model 1

Unadjusted baseline model shows associations of caregiver burden and benefits with recipient survival. Caregiver

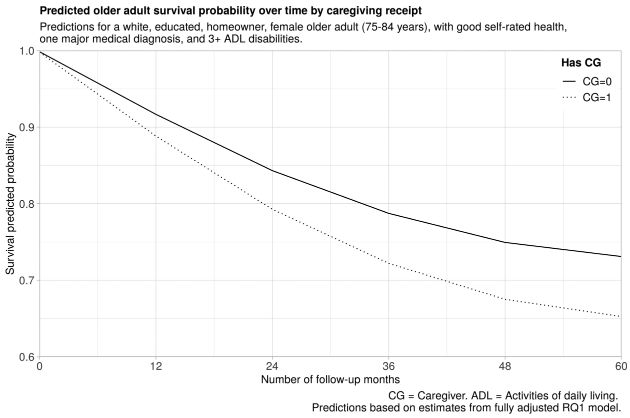

Figure 1. Analysis 1. Predicted older adult survival over time by informal caregiving receipt.

benefits are not associated with recipient mortality, but older adults whose caregivers perceive burden have 44% higher relative mortality risk ($p < .01$).

Model 2

As informal caregiver burden and benefits frequently co-occur, we first adjust for their interaction. Caregiver burden, benefits, and the interaction are associated with recipient mortality. Given that caregiver burden but not benefits alone were associated with recipient survival in the additive model, this suggests their interaction acts as negative confounder that is associated with recipient survival and suppresses or controls for shared variance, lowering analysis noise. Further, both burden and benefits have a negative association with survival. Compared to recipients with informal caregivers not reporting burden or benefits, those with caregivers perceiving burden only are 90% more likely to die during follow-up ($p < .001$); similarly, those with caregivers reporting benefits only are 59% more likely to die ($p < .05$). However, when caregivers report burden with benefits, recipients' mortality probability decreases to 44% higher ($p < .01$; exp(coef[burden]+coef[benefits]+coef[burden*benefits]). Negative interaction term suggests a ceiling (nonadditive) and, in the stress process model context, a potentially moderating effect in burden and benefit co-occurrence. That is, the caregiver burden effect on recipient survival is smaller in the presence of benefits (and vice versa).

Model 3

To explain associations between informal caregivers' burden and benefits perception and recipient mortality, we adjust for known older adult mortality predictors. As in Analysis 1, being female, racial minority, and better self-reported health are associated with lower mortality. Conversely, poor health indicators are associated with higher death risk. Importantly, associations between caregiver burden, benefits, and their interaction with recipient mortality persist. Compared to recipients with caregivers reporting neither perception, those with informal caregivers perceiving burden are 43% more likely to die during follow-up ($p < .05$). Recipients whose caregivers perceive benefits only are 50% more likely to die than counterparts reporting neither experience ($p < .05$). When caregivers report burden with benefits, older adults' mortality probability is again lower than when reporting individual perceptions, at 9% higher ($p < .001$; exp(coef[burden]+coef[benefits]+coef[burden*benefits]).

Model 4

Final model adjusts for caregiving and caregiver characteristics. Among caregiving factors, neither caregiving intensity nor duration reduce association magnitude between caregiver experiences and recipient mortality, and neither predicts recipient mortality. The same holds for caregiver characteristics. Older adult demographic, socioeconomic, and health factors maintain their mortality associations, but do not reduce association magnitude for caregiver burden, benefits, or perception interaction with recipient mortality. In fully-adjusted model, recipients whose informal caregivers report only burden are 38% more likely to die during follow-up than counterparts whose caregivers who perceive neither burden or benefits ($p < .05$), and those with caregivers reporting only benefits are 50% more likely to die ($p < .05$); we discuss this unexpected finding later. Simultaneously, benefits do not have an additive relationship with burden, and burden associations with recipient survival are smaller when accompanied by benefits ($p < .001$). Recipients whose caregivers perceive both burden and benefits, compared to reporting neither, are only 5% more likely to die during follow-up ($p < .001$; exp(coef[burden]+coef[benefits]+coef[burden*benefits]). Mortality hazard contrast between persons whose caregivers perceive burden only and those reporting burden and benefits—38% versus 5% higher than when having a caregiver with neither burden nor benefits perceptions—is significant ($p < .001$). Consider a well-educated, married, white female care recipient aged 75–84 years (Figure 2). If her informal caregiver reports neither burden nor benefits, she has the lowest death hazard and 62% 5-year survival probability. If her caregiver reports only benefits, her death hazard is highest, with 48% 5-year survival probability. The same woman whose caregiver reports only burden similarly has a 51% 5-year survival probability. However, her survival probability is higher, at 60%, if her caregiver reports perceiving benefits alongside burden. This 60% survival probability does not differ from the 62% likelihood of her aforementioned counterpart whose informal caregiver reports neither perception.

Older adult characteristics are associated with mortality similarly to Analysis 1. Among demographics, females are 25% less likely to die compared to males ($p < .05$); Blacks are 26% less ($p < .01$) and Hispanics are 39% less likely to die compared to whites ($p < .05$). Conversely, advanced age is associated with poorer outcomes. Old old

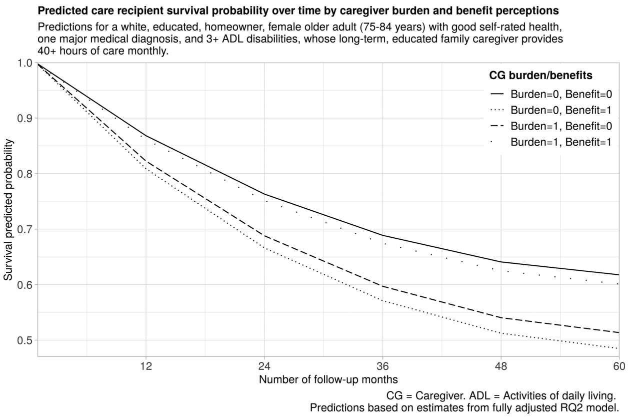

Figure 2. Analysis 2. Predicted care recipient survival probability over time by informal caregiver burden and benefit perceptions.

are 82% more likely to die during follow-up (*p* < .01) and oldest old have mortality hazard ratios 3.25 times as high as young old (*p* < .001). Among health factors, older persons with likely depression are 17% more likely to die than counterparts without depression (*p* < .05), and those with ≥3ADL difficulties are 26% more likely to die (*p* < .01). Those with possible dementia are 40% more likely (*p* < .01) and those with probable dementia are 97% more likely to die than those without (*p* < .001). Each medical diagnosis increases older adults' mortality risk by 17% (*p* < .01). Better self-reported health is associated with lower mortality risk. For each self-reported health level improvement, older adults have 15% lower mortality hazard ratios (*p* < .001).

In sum, we find similar demographic and health associations with older adult mortality among older persons with informal caregivers as we do among older adults generally. However, here, caregiver burden and benefit perceptions are associated with higher mortality risk over and above known sociodemographic and health factors. Further, informal caregiver burden and benefits interact in association with recipient mortality. While older adults with caregivers reporting benefits only or with burdened-only caregivers have higher mortality hazards, this hazard is also heightened but lower for recipient whose informal caregivers perceive burden and benefits simultaneously. That is, caregiver burden and benefits are associated with still heightened yet lower recipient mortality risk when perceived alongside each other than when reported in isolation. This is important given that caregiving experiences frequently encompass both perceptions.

Discussion

We explored whether informal caregiving receipt and caregivers' experiences are prospectively associated with older adult mortality, yielding three main findings. First, adjusting for older person sociodemographic and health factors, we find that individuals with informal caregivers have greater mortality risk than those without. Second, exploring caregiver experiences as potential pathway, we find that having a caregiver reporting only burden or benefits—a surprising finding—is associated with higher recipient mortality risk. Third, although persons with caregivers reporting benefits alongside burden also have elevated mortality risk compared to individuals with caregivers reporting neither, this risk is lower than when caregivers report burden or benefits alone. We discuss these findings below.

Analysis 1: Informal Caregiving Receipt and Recipient Mortality

Informal caregiving receipt is associated with increased older adult mortality risk, even after sociodemographic and health factors adjustment. Consistent with age-adjusted mortality rates, racial/ethnic minority older persons have decreased mortality risk, as do females. Conversely, those in nonmarried status, with more disability, and cognitive impairment have higher mortality. These recipient characteristics partially mediate association magnitude, but informal caregiving receipt remains significant in full models.

Given substantial evidence indicating social support protective benefits against mortality (Holt-Lunstad, Smith, & Layton, 2010), it is unlikely that observed associations between caregiving receipt and recipient mortality is due to detrimental social support effects. Rather, informal caregiving receipt may be proxy for illness type or disability not considered, indicating decline that eventually leads to death in ways not captured in NHATS. We include extensive health controls to minimize this possibility, including major death causes, dementia, mental health status, disability, and self-reported health. Alternatively, needing caregiving may make recipients feel burdensome to family. Perceived burdensomeness, linked to suicide ideation, may affect psychological well-being and contribute to mortality (Cukrowicz, Cheavens, Van Orden, Ragain, & Cook, 2011). Receiving caregiver help with mobility, self-care, or health and functioning may be a general "beginning of the end" signal, even in noncontinuous caregiving relationships. Another possibility, discussed below, is that caregiver experiences can explain recipient outcomes like mortality.

Analysis 2: Informal Caregiver Experiences and Recipient Mortality

Among older adults with informal caregivers, we find caregiver-reported burden, benefits, and their interaction are associated with higher recipient mortality hazards even after controlling for relevant socioeconomic, health, and caregiving factors. However, while caregiver benefits perceived alongside burden are associated with still elevated recipient mortality risk, this risk is lower than when caregivers report burden or benefits in isolation.

The finding that older adults have higher mortality risk when caregivers perceive burden is consistent with the stress process model. Interacting with burdened caregivers may be a stressor worsening recipient health. Caregivers' poor experiences may prevent them from providing necessary care; older adults whose caregivers experience burden and stress report poorer treatment adherence, symptom monitoring, and heightened institutionalization risk (Buck, Mogle, Riegel, McMillan, & Bakitas, 2015; McClendon & Smyth, 2015). Caregiver stress may also proliferate to recipients through interpersonal interactions, activating psychosocial and physiological pathways that worsen recipient outcomes (Kiecolt-Glaser, 1999).

Less intuitively and inconsistent with the stress process model, we also find that having a caregiver reporting benefits is associated with elevated older adult mortality risk. We do not assume that positive caregiver experiences are detrimental to recipients (Holt-Lunstad et al., 2010). We surmise that informal caregivers reporting benefits may be providing care for persons in poor health, but that these caregivers are not the ones providing intensive assistance. Instead, as formal and informal care supplement each other especially for older adults with extensive needs, their recipients may be receiving the most burdensome care from formal helpers (Davey et al., 2005). We are unable to control for formal care receipt, and we discuss this limitation later. However, additional analyses (not shown) indicate that benefits-only caregivers provide less frequent ADL help and are more likely nonfamily than burdened caregivers. This suggests formal care receipt may explain associations between informal caregivers reporting only benefits and heightened recipient mortality. Alternatively, these may be racial minority caregivers, who report more beneficial experiences despite typically offering intensive assistance (Aranda & Knight, 1997; NASM, 2016). Caregiver race is missing in 2011 NSOC, but compared to other caregiver groups, caregivers who reported only benefits in our sample were disproportionately caring for racial/ethnic minorities (not shown). Finally, these informal caregivers' recipients may have distinct or expected illness trajectories, or die unexpectedly without difficult symptoms. We cannot access Medicare-linked data or death cause information, and cannot establish whether this explanation holds. However, supplemental analyses (not shown) suggest these caregivers' recipients are less likely to have dementia or ≥ ADL disabilities than persons whose caregivers report burden only, lending partial support to the distinct illness trajectory idea. Given this finding and insights discussed below, further research is needed to better understand caregivers reporting benefits only.

Finally, as caregiver burden and benefits often co-occur, we tested their potential moderating effects. We find that associations between caregiver burden and recipient mortality differ by caregiver benefits perception. As discussed, older adults whose informal caregivers report only burden have increased mortality risk compared to recipients whose caregivers report no burden and no benefit. However, when burdened caregivers also report benefits, recipient mortality risk is elevated but reduced compared to having isolated perceptions, and not different from persons whose caregivers report neither experience. Supplemental analyses (not shown) indicate this relationship persists regardless care recipient death year modeled. This concurs with the stress process model in which benefit perceptions moderate burden, as well as with research showing that older adults with caregivers perceiving benefits alongside burden have reduced anxiety levels, and that persons with caregivers reporting only benefits are less likely to be depressed compared to those with burdened-only caregivers (Pristavec, 2019b). The finding signals that associations between informal caregiver burden and benefits with recipient mortality are not additive, and among burdened caregivers, deriving satisfaction, competencies, or other benefits may moderate stress transmission. It suggests that informal caregiver support interventions should target reducing caregiver burden or, when caregiver burden is present and not possible to alleviate, increasing perceived benefits. Dementia caregiving research points to interventions achieving both goals (Czaja, Loewenstein, Schulz, Nair, & Perdomo, 2013). Additional work should translate such interventions beyond dementia-focused settings (Gitlin, Marx, Stanley, & Hodgson, 2015). Importantly, further research should explore psychosocial and physiological mechanisms elucidating how informal caregiver experiences and caregiving dyad interactions are associated with recipient health.

Limitations

This analysis has several limitations. We only use 2011 NSOC and could only measure caregiving receipt in that year. Caregiver networks change, but we cannot account for caregiving receipt over time. NSOC currently provides three nonsequential waves, and initial caregiver pool was not reinterviewed. We conducted sensitivity analyses using key independent variables measured in 2011 to predict recipient mortality at each wave 2012–2016 separately before using data from all waves to confirm our finding robustness. As sufficient longitudinal resampling NSOC waves become available, analyses should explore time-dependent caregiving receipt and caregiver experience effects. Further, although we include extensive health controls (possible depression and anxiety, dementia, five major medical diagnoses, ADL disability, self-reported health, physical capacity), we acknowledge that poor health engenders caregiving need; we cannot establish causal processes between caregiving receipt and recipient mortality. We considered other potential NHATS frailty measures (e.g., nursing home relocation, poor physical performance, falls, hospitalizations) and observed robust results. An important but unavailable factor was formal assistance receipt in addition to informal assistance. NSOC includes a question asking informal caregivers whether they paid for live-in assistance for recipients, but this question aims at financial burden and is a limited formal assistance receipt proxy. Few caregivers in our sample responded affirmatively ($N = 71$), and the variable was insignificant in sensitivity analyses. Similarly, although secondary caregivers in our sample provided significantly less assistance to recipients than primary caregivers, we conduct analyses using older adult and primary caregivers dyads only. Finally, although social support is associated with longer older adult survival (Blazer, 1982), we cannot account for caregiver–recipient relationship quality. NSOC includes four relationship quality measures, but these capture caregiver perceptions only and have poor internal consistency; they were inappropriate to include as index. Future studies should consider older adult social embeddedness measures and relationship quality, ideally from both dyad members' perspectives, when exploring caregiving receipt and recipient mortality associations.

Conclusion

We examine relationships between informal caregiving receipt and characteristics with older adult mortality in a nationally representative sample. We find that informal caregiving receipt remains associated with higher older person mortality risk even after mortality-related health, socioeconomic, and demographic factors adjustment. This highlights the need to better understand mechanisms linking caregiving receipt and mortality. Additionally, we find caregiver-reported burden or benefits are associated with higher recipient mortality. Caregiver burden may be capturing recipient health declines that contribute to mortality beyond measurable factors, or caregiver burden may contribute to mortality through psychosocial and physiological mechanisms requiring further exploration. Caregiver benefits were similarly associated with higher recipient mortality, which may be linked to unmeasured formal assistance receipt, cultural attitudes towards caregiving, or distinct disease trajectories. Finally, the caregiving and mortality relationship does not operate uniformly. When caregivers perceive benefits alongside burden, effects are not additive and benefits may moderate burden. This suggests interventions targeting both reducing caregiving burden and increasing perceived benefit when reducing burden is not possible may support recipient longevity.

Supplementary Material

Supplementary data is available at *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* online.

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Conflict of Interest

None reported.

Author Contributions

T. Pristavec and E. A. Luth jointly planned the study, prepared data, conducted statistical analysis, and wrote the manuscript.

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