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Do caregiver experiences shape end-of life care perceptions? Burden, benefits, and care quality assessment.

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Abstract

Context.—Researchers, hospices, and government agencies administer standardized questionnaires to caregivers for assessing end-of-life care quality. Caregiving experiences may influence end-of-life care quality reports, which have implications for caregiver outcomes, and are a clinical and policy priority.

Objectives.—This study aims to determine whether and how caregivers' end-of-life care assessments depend on their burden and benefit perceptions.

Methods.—This study analyzes data from 391 caregivers in the 2011 National Study of Caregiving and their Medicare beneficiary care recipients from the 2011-2016 National Health and Aging Trends Study. Caregivers assessed five end-of-life care aspects for decedents. Logistic regression was used and predicted probabilities of caregivers positively or negatively assessing end-of-life care based on their burden and benefit experiences calculated. Analyses adjusted for caregiver and care recipient demographic and health characteristics.

Results.—No or minimal caregiving burden is associated with 0.70 probability of caregivers reporting they were always informed about the recipient's condition and that the dying person's care needs were always met, regardless of perceived benefits. High perceived caregiving benefit is associated with 0.80 probability of giving such reports, even when perceiving high burden.

Conclusion.—Caregiver burden and benefit operate alongside one another regarding two end-of-life care evaluations, even when years elapse between caregiver experience reports and care recipient death. This suggests that caregiver interventions reducing burden and bolstering benefits may have a positive and lasting impact on end-of-life care assessments.

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Disclosures

Dr. Luth has nothing to disclose.

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Keywords

Caregiver benefit; caregiver burden; end-of-life care; National Health and Aging Trends Study (NHATS); National Study of Caregiving (NSOC)

Introduction

End-of-life (EOL) care provision that improves quality of life for dying individuals and their family members is a priority among medical providers and policy makers.¹⁻⁴ In the United States (US), patient autonomy, involvement in decision-making, and maintaining personal dignity are core components of high-quality EOL care.⁵⁻⁷ Hospice organizations are required to and routinely measure EOL care aspects such as healthcare decision involvement, being informed about one's condition, avoiding unwanted care, treating patients with respect, and addressing their personal care needs (e.g. being kept clean, dressing).^{3,8}

EOL care quality questionnaires used in evaluations are typically administered to the family member who was the deceased individual's primary caregiver.^{9,10} An estimated 2.3 million caregivers provided assistance to older individuals at EOL in 2011.⁹ Individuals at EOL are typically older and in poorer health, and receive on average twice as many assistance hours as other older adults.⁹ Caregiving for seriously ill and dying family members is a heterogeneous experience varying in duration and intensity.¹¹ Caregiving may engender perceived burden, perceived benefits, or both.¹²⁻¹⁴ Caregiver burden refers to the physical, emotional, relational, and financial problems due to caregiving; benefits describe the satisfaction, gains, or rewards that individuals experience from providing care.¹²

Past research focuses on the outcomes of experiencing either caregiver burden or benefits, with emphasis on the former.¹³ However, caregivers often experience both dimensions simultaneously.¹⁴ One of few studies examining benefits and burden simultaneously found one in ten caregivers experienced high burden levels with low benefits, and one fifth experienced high levels of burden and benefits.¹⁵ However, little research focuses on how burden and benefits may jointly shape caregiving experiences. Given the complex combinations of perceived burden and benefit that can characterize caregiving experiences, it is important to consider how the two interact.

Caregiving burden and benefits can shape caregiver physical and mental health,^{11,14,16-18} in different type and intensity combinations.¹⁵ Moreover, caregiver burden and benefits can shape care recipient outcomes.¹⁹ Beyond impacting their own and care recipients' health and well-being, caregivers' perceptions of their experience (e.g. burden, benefit) may also positively or negatively shape how they evaluate their loved one's EOL care. Bereaved family members experiencing depression or significant caregiver burden may provide negatively biased EOL care assessments, while those involved in caregiving who experience satisfaction may positively evaluate EOL care to reinforce their belief that they did everything possible to support their dying loved one.²⁰⁻²²

This potential relationship between caregiver experiences and EOL care perceptions is important for two reasons. First, negative perceptions EOL care are linked to bereaved family members' poorer health and well-being.^{14,20,23} Increasing caregivers' perceived and objective benefits and reducing burden could help shape EOL care quality perceptions and improve health outcomes associated with negative perceptions. Second, family members' EOL care perceptions are important for better understanding EOL care quality in the US. Hospice organizations and Centers for Medicare & Medicaid Services use caregivers' subjective EOL care assessments to determine care quality and as a requirement for Medicare hospice benefit reimbursement.⁸ Yet, how caregiver experiences influence those assessments is not well established.²⁴

Other caregiver factors like age, education, and relationship to decedent are known EOL care quality reports predictors,²⁵ but these characteristics are static. Less is known about whether and how family members' caregiving experiences prior to their loved one's death—which are potentially modifiable—influence their EOL care perceptions. Burdened caregivers may feel unable to adequately meet or advocate for their dying loved one's EOL care needs, feel guilt or resentment when other providers become involved (e.g., hospice, hospital care), and may therefore negatively assess EOL care quality.²⁶ Alternatively, caregivers feeling satisfaction from caregiving may take comfort in their role or be more included and involved with EOL care, thus providing more positive assessments.²⁷

This study examines how caregiving benefit and burden experiences operate jointly and relate to EOL care perceptions. We analyze data from caregivers to a sample of Medicare beneficiaries deceased between 2012 and 2016. We examine the relationship between caregivers' 2011 caregiving perceptions and their family member EOL care assessments. Accounting for caregiving complexity, we explore how perceived burden and benefit together shape EOL care perceptions. Caregiving experiences are amenable to change; understanding the link between these experiences and EOL care perceptions may elucidate areas where caregiver support interventions might improve EOL care assessments,⁴ ultimately positively impacting caregivers' own long-term health and well-being. Moreover, understanding the relationship between caregiver burden and benefits experiences and EOL care quality perceptions has implications for how we evaluate EOL care quality in hospice and palliative care, and potentially reimburse hospice providers.

Methods

Data.

We linked 2011 National Study of Caregiving (NSOC) data to six National Health and Aging Trends Study (NHATS) data waves (2011-2016). NSOC was conducted with family members and others providing unpaid care to older adults who participated in the 2011 NHATS. NHATS is a prospective, annual, longitudinal study of a nationally representative sample of Medicare beneficiaries age 65 and older in contiguous US. If participants die, caregivers answer questions about care in the decedents' last month of life. In the linked data, 410 NSOC caregivers completed questions about NHATS participant last month of life. 391 cases had complete information on all caregiver and care recipient variables relevant to analyses (4.6% missing). Complete case numbers used in final analyses varied from 373 to

388, depending on differences in missing data in caregiver responses to each of five EOL care quality outcome measures (Table 1). All analyses used NSOC analytic weights, adjusting for complex survey design.

Measures.

Outcomes: EOL care quality measures.—We analyzed five dichotomous EOL care quality measures for deceased NHATS participants.²⁸ Three outcomes measured patient autonomy and decision making, asking whether: the decedent or family was involved in decisions about his/her care (yes=1), the decedent or family was informed about his/her condition (always=1), and the decedent received any care he/she would not have wanted (no=1). Two outcomes assessed dignified treatment, asking whether: decedent personal care needs were met (always=1), decedent was treated respectfully (always=1). To facilitate interpretation, outcomes associated with higher quality EOL care (i.e. retaining autonomy, personal dignity) were coded 1 for all variables. Consistent with prior NHATS analyses^{4,29} and given low Chronbach's alphas for measures in our sample (autonomy $\alpha=.23$; dignity $\alpha=.55$), we analyze these as five individual measures.

Key predictors: Perceived caregiver burden and benefit.—We measured caregiver burden and benefit with index variables.^{15,30} Burden is a summed agreement score of four statements about caregiving activities: being exhausted at night, having more to do than one can handle, having no time for oneself, and changing routines to meet care recipient needs ($\alpha=.75$). Benefit is a summed agreement score of four statements about caregiving results: increased confidence in abilities, learning to deal with difficult situations, brought caregiver closer to care recipient, satisfaction care recipient is well cared for ($\alpha=.70$). For all eight statements, caregivers indicated whether it described their situation “very much,” “somewhat,” or “not so much.” We coded individual statement responses from 0 to 2 with higher scores indicating greater perceived burden (for burden index) and greater perceived benefit (for benefit index). Final indexes ranged from 0 (no burden or benefit) to 8 (maximum burden or benefit).

Covariates.—We controlled for caregiver and care recipient factors that previous research indicates influence caregiving benefit, burden, and/or EOL care quality, and should therefore be considered in caregiver benefit, burden, or EOL care quality analyses. 1) Care characteristics: caregiving intensity (median number hours of caregiving/month) and duration (caregiving ≤ 5 years); 2) caregiver characteristics: relationship to decedent (spouse/child=1), gender (male=1), self-rated health (excellent/very good=1), mental health (normal, mild, or moderate/severe depressive symptoms using PHQ-4); 3) care recipient characteristics when caregiver data were collected (2011): gender (male=1), race (non-Hispanic white=1), number of five serious chronic illnesses (heart disease, cancer, lung disease, stroke, diabetes), dementia diagnosis, recent hospitalization (1+ in prior year=1), functional impairment (help with ≥ 2 of 6 activities of daily living (ADLs)³¹ (bathing, toileting, dressing, eating, getting out of bed, moving around home)), and hospice care receipt (yes=1); and 4) time in years between caregiving characteristics reports (2011) and care recipient death (2012-2016). Extended caregiving periods (e.g. 5+ years),^{13,17,32,33} more intensive caregiving responsibilities,^{13,16,17,33} being female,^{17,18,33,34} poorer caregiver

health,^{14,33} increased depressive symptoms,^{13,32,33,35} being the care recipient's spouse/child,¹³ greater care recipient health problems,^{13,14,16,34} dementia^{13,31,36} or disability,³¹ and caregiving for a person nearing EOL⁹ are associated with increased caregiver burden. Identifying as African-American is associated with decreased caregiver burden.^{13,37,38} Others' help in caregiving,¹⁴ being the care recipient's spouse, and identifying as African-American^{13,39} or Hispanic¹³ are associated with increased caregiver benefit and satisfaction.¹⁴ Being male,¹⁸ closely related to care recipient (spouse/child),^{25,28} and caring for non-Hispanic white persons²⁸ are associated with more negative EOL care quality perceptions. Being the care recipient's spouse,²⁵ caring for an African-American person,²⁸ and hospice care^{40,41} are associated with more positive EOL care quality and perceptions.

Analysis.

We calculated weighted descriptive statistics for the sample of NSOC respondents providing care in 2011 to an NHATS respondent who died between 2012 and 2016, and had complete information on covariates and outcome measures. We conducted binary logistic regression predicting each of five EOL care quality outcomes listed above, adjusting for covariates. We included an interaction term for caregiver burden and benefit to examine how they jointly shape outcomes. We calculated goodness-of-fit statistics compatible with analyses using weighted data to assess whether interactions improved model fit (McFadden's r^2 , AIC, BIC). In all cases, models with interaction terms better fit the data. We calculated and graphed predicted probabilities of burden-benefit interactions in models with significant interaction terms based on modal (for categorical variables) and mean (for continuous variables) covariates values. We conducted analyses using Stata/MP 15.1.

Results

Table 1 presents analytic sample weighted descriptive statistics. Caregivers often positively assessed their loved one's EOL care: 83-89% endorsed EOL care quality measures. On average, caregivers reported relatively low burden levels ($m=2.7$, $range=0-8$) and high benefits levels ($m=6.0$, $range=0-8$). Although median reported burden level was low and median benefit level was high, there is sufficient variability in each to test interactions. About half of caregivers were providing care for 5+ years (49%); median time spent caregiving monthly was 60 hours (before weighting). Caregivers were predominantly female (69%) and the deceased's spouse/child (81%). Half reported having excellent or very good health (51%) and had no depressive symptoms (53%). Care recipients were predominantly female (66%), non-Hispanic white (79%), received help with 2+ ADLs (82%), and reported 1.5 serious illnesses on average. Half were hospitalized in the year before death, and died an average of 2.6 years after caregiver experiences were recorded.

Table 2 presents adjusted odds ratios, linearized standard errors, 95% confidence intervals, and p-values for caregiver burden, benefit, and burden-benefit interactions. Models adjust for caregiving factors, and for caregiver and care recipient sociodemographic and health characteristics. In three of five instances, burden, benefit, and their interaction were not associated with EOL care assessments (being involved in decisions, avoiding unwanted care, being treated with respect). In two cases—always being informed about one's condition and

always having personal care needs met—both perceived burden and the burden-benefit interaction were significantly associated with EOL care assessments. Perceived burden was associated with lower odds of reporting always being informed about the decedent's condition and the decedent's personal care needs were always met (informed: aOR=0.46, 95% CI=0.25-0.85; personal care: aOR=0.42, 95% CI=0.23-0.76). However, the burden-benefit interaction was associated with higher positive assessment odds of these two EOL care measures (informed: aOR=1.13, 95% CI=1.02-1.26; personal care: aOR=1.14, 95% CI=1.04-1.25), suggesting that perceived benefits may partially buffer the high negative report likelihood associated with perceived burden.

To illustrate interaction at different caregiver burden and benefit levels, figures show predicted probabilities of caregivers reporting being always informed about his/her condition (Figure 1) and care recipient's personal care needs always being met (Figure 2). Although respondents reported various burden and benefit combinations, we focus here on results reflecting the most common experiences: high benefit levels and varying burden. Caregivers with low burden levels (0-1) had a .70 predicted probability of reporting the care recipient or family was always informed about his/her condition, regardless of benefit level (Figure 1). Similarly, when caregivers reported high benefits (6-8), they had a .70 predicted probability of reporting always being informed, regardless of burden. Caregivers with low burden levels (0-2) had a .80 predicted probability of reporting the care recipient's personal care needs were always met, regardless of benefits (Figure 2). Further, caregivers reporting high benefit levels (6-8) had a .80 predicted probability of reporting care needs were always met, regardless of perceived burden.

Discussion

This study examines the relationship between burden and benefit reports and their EOL care quality perceptions for a sample of caregivers of 2011 Medicare beneficiaries who died between 2012-2016. EOL care quality perceptions are linked to caregiver health and well-being and are the metric used to evaluate hospice care quality. Caregiver burden and benefit are common and potentially modifiable experiences. Insofar as they shape EOL care quality perceptions, they are a mechanism for improving bereaved caregiver outcomes and our understanding of EOL care quality. Overall, caregivers in our analyses reported relatively positive EOL care assessments, low burden levels, and high benefit. Consistent with prior research on EOL care for older adults, caregivers provided mostly positive individual EOL care measure assessments (80%+).^{4,29} These positive assessments may be related to caregiver adaptation to long-term caregiving.⁴² However, two-fifths of caregivers negatively assessed one or more EOL care aspects (Table 1), reinforcing that there is scope for improving EOL care.²⁸ Understanding relationships between caregiver burden and benefits with EOL care perceptions is important, first, because EOL care assessments are associated with bereaved caregiver health; and second, they have implications for our overall EOL care understanding, and for hospice care quality and reimbursement. Measures used in this analysis are similar to those hospices use for quality measurement.³ Here we analyze them in a general deceased older adult population including persons who did not receive hospice care.

On average, caregivers reported low overall burden levels. However, the majority endorsed one or more individual burden aspects, and almost half indicated one or more caregiving aspect was very burdensome. Although multiple interventions targeted at reducing caregiver burden aspects exist,^{33,43} our analysis suggests caregiver burden remains a heterogeneous and common experience requiring a tailored assessment and response approach.^{13,33} Less research attends to positive caregiving aspects¹³. We found that overall, caregivers report high perceived caregiving benefits levels and nearly all reported at least one caregiving benefit. To the extent that perceived caregiving benefits shape EOL care perceptions, interventions enhancing perceived benefit may also protect caregivers from potentially harmful caregiving effects (e.g., poor health/well-being).¹³

Of five EOL care measures examined, two autonomy measures and one dignified care measure showed significant relationships between baseline caregiver burden reports, and their prospective EOL care assessments. Caregiver burden was associated with subsequent negative assessments of receiving care consistent with one's wishes, being informed about one's condition, and having personal care needs met. Providing goal-concordant care is an important component of high-quality EOL care, and key in reducing health care and social costs.¹ Burdened caregivers may feel less able to make emotionally difficult decisions about EOL care or to advocate for goal-concordant care.¹ Communication about the dying individuals' condition and respectful care are key overall EOL care perceptions drivers.^{10,44} As EOL care perceptions are linked to bereaved family members' long-term physical and mental health,^{20,23} addressing caregiver burden while the care recipient is still living may lay groundwork for more positive bereaved caregiver outcomes. Lower burden levels may enable caregivers to more frequently and actively communicate with medical professionals about loved ones' preferences and EOL care, and may facilitate more involvement in better understanding and meeting the dying individual's needs.

The caregiver burden and benefits interaction was significantly and positively associated with being informed about one's condition and personal care needs being met. In both cases, reporting high caregiver burden levels and low benefits was associated with negative EOL care assessments. This relationship reversed for caregivers reporting burden with high benefits. Experiencing high burden alongside high benefit levels was associated with positive EOL care evaluations, consistent with prior research demonstrating benefits may mitigate negative burden effects.⁴⁵ EOL caregiving is typically more demanding than other care provision.⁹ In circumstances where it is not possible to reduce caregivers' objective or perceived burden, interventions may focus on improving their objective and perceived benefits. Involving caregivers in EOL care and decision-making, programs improving care provision skills, and interventions targeting coping abilities may increase caregivers' confidence and give them satisfaction that their dying loved one is well cared-for.⁴⁶ In sum, results suggest that interventions improving caregiver benefits may be beneficial for certain EOL care autonomy and dignity perceptions, and by extension for caregiver well-being,^{20,23} even when caregiver burden is high and cannot be reduced.

Burden and the burden and benefit interaction were not significantly associated with the remaining autonomy (involved in decisions, avoiding unwanted care) and dignified care measures (respectfully treated). Caregiver burden and benefit could operate differently with

respect to these EOL care facets. However, the associations for burden and the burden-benefit interaction in receiving goal-concordant care and always being treated respectfully are marginally significant with associations in the same direction as significant outcomes. It is possible we cannot detect significant effects due to limited sample size in currently available NSOC waves. Future research using a larger longitudinal NSOC caregiver sample may be able to establish whether burden and benefit matter for these EOL care aspects.

Limitations.

NHATS does not capture objective EOL treatment or care quality measures. We do not have Medicare Claims data access linked to NHATS and were unable to examine other EOL care measures, such as treatment intensity. Collecting EOL care information from caregivers familiar with EOL is standard practice given recognized difficulties in conducting research with vulnerable, dying individuals.^{7,47} Further, there are limitations in data included in NHATS and NSOC. NHATS does not contain death cause information, which may influence the dying trajectory and care an individual receives. We account for illness chronicity and acuity, controlling for serious diagnosis number and recent hospitalizations. Caregiver personality traits may be associated with burden and benefit reporting. However, NSOC does not contain caregiver personality information. Third, NHATS captures caregiving burden and benefit cross-sectionally (2011), and we cannot account for caregiving experience change over time. Future research may employ longitudinal NSOC data waves as they become available. However, the relationship we observed persists over time, even when controlling for years passed between caregiver burden and benefit measurement and care recipient death. Additionally, although caregivers reported varied burden and benefit combinations, a small proportion reported high burden with low benefits. Predicted probabilities for these individuals should be interpreted cautiously. Future research should examine the characteristics and needs of these caregivers who are heavily burdened and perceive few benefits. Finally, additional caregiver and care recipient factors may influence EOL care quality perceptions. We control for characteristics established as key in prior studies; there may be others not captured in NHATS or NSOC.

Conclusion.

This study underscores the importance of attending to caregiver benefit and burden perceptions, as they shape EOL care evaluations. EOL care evaluations matter for bereaved caregiver health and wellbeing, and for our understanding of the overall state of EOL care quality. Positive EOL care perceptions are most likely among caregivers reporting low burden levels and high benefits. Therefore, interventions reducing burden and increasing perceived benefit simultaneously may result in more positive EOL care assessments. Positive EOL care evaluations are also likely among caregivers who perceive benefits to caregiving at any burden level. In situations where it is not possible to reduce objective caregiver burden, interventions to increase benefits perceptions may be helpful. Our findings suggest caregivers with high burden levels and low benefits assess EOL care negatively. Further research should investigate the needs of this smaller, potentially vulnerable group. Research is also needed to examine pathways between caregiving experiences and EOL assessments, and to determine whether and how caregiver burden and benefit jointly operate through EOL care perceptions to influence bereaved individuals' outcomes.

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Key Message: This article examines how caregiver burden and benefit operate jointly with respect to end-of-life care perceptions. The results indicate perceived caregiving benefits are associated with positive end-of-life care perceptions, regardless of burden level.

Figure 1. Predicted probability of always being informed about dying person's care by caregiver burden and benefits.

Source: 2011 NSOC, 2011-2016 NHATS.

Note: Figure depicts predicted probabilities for variables at their modal or mean values. In this case, values are shown a female caregiver who was a close family member of the care recipient, in good, fair, or poor health, with no depressive symptoms, who provided more than 60 hours of caregiving a month and had been caregiving for five or fewer years in 2011. She provided care to a non-Hispanic white female with serious disability, 1.5 medical diagnoses, no dementia, with one or more recent hospitalization, and who did not receive hospice care.

Figure 2. Predicted probability of dying person's care needs always being met by caregiver burden and benefits

Source: 2011 NSOC, 2011-2016 NHATS.

Note: Figure depicts predicted probabilities for variables at their modal or mean values. In this case, values are shown a female caregiver who was a close family member of the care recipient, in good, fair, or poor health, with no depressive symptoms, who provided more than 60 hours of caregiving a month and had been caregiving for five or fewer years in 2011. She provided care to a non-Hispanic white female with serious disability, 1.5 medical diagnoses, no dementia, with one or more recent hospitalization and who did not receive hospice care.

Table 1.

Weighted descriptive statistics for 2011 NSOC respondent and 2011–2016 NHATS respondent characteristics.

	Unweighted N	Proportion or means (SD)
Outcomes		
Involved in decisions	373	0.89
Always informed about condition	381	0.87
No unwanted care	373	0.89
Personal care needs always met	386	0.83
Always treated with respect	388	0.88
Negative assessment of any outcome	391	0.40
Key Independent Variables		
Caregiver Experience		
Burden	391	2.71 (2.28)
Any burden reported	391	0.77
“Very much” for any burden item	391	0.42
Benefit	391	6.02 (1.87)
Any benefit reported	391	0.997
“Very much” for any benefit item	391	0.91
Caregiver Characteristics		
Caregiver Activities		
5 years providing caregiving	391	0.49
> 60 hours of caregiving a month	391	0.41
Caregiver Demographics		
Male	391	0.31
Close family member	391	0.81
Very good/Excellent self-rated health	391	0.51
PHQ4	391	
No depressive symptoms		0.53
Mild depressive symptoms		0.37
Moderate/severe depressive symptoms		0.10
Care Recipient Controls		
Male	391	0.34
Non-Hispanic white	391	0.79
Seriously disabled (help with 2+ of 6 ADLs)	391	0.82
Number of serious diagnoses (r: 0-5)	391	1.45 (1.08)
Probable dementia	391	0.47
Recent hospitalization	391	0.50
Received hospice care	391	0.45
Survey Control: years until CR death	391	2.55 (1.32)

Note: NSOC=National Study of Caregiving. NHATS=National Health and Aging Trends Study. SD=Standard deviation.

Table 2.

Adjusted odds ratios and 95% confidence intervals for logistic regression of caregiver burden and benefit on end-of-life care.

	AOR	LSE	95% CI		p value
Involved in decisions (yes=1)					
CG burden	0.84	0.22	0.50	1.43	0.52
CG benefit	1.14	0.19	0.82	1.59	0.44
CG burden*benefit	1.04	0.05	0.94	1.16	0.46
N=373 / McFadden's $r^2=0.243$					
Informed about condition (always=1)					
CG burden	0.46	0.14	0.25	0.85	0.01
CG benefit	0.84	0.13	0.62	1.14	0.26
CG burden*benefit	1.13	0.06	1.02	1.26	0.03
N=381 / McFadden's $r^2=0.182$					
No unwanted care (none=1)					
CG burden	0.57	0.15	0.33	0.98	0.04
CG benefit	0.84	0.14	0.60	1.16	0.28
CG burden*benefit	1.09	0.05	1.00	1.19	0.06
N=373 / McFadden's $r^2=0.101$					
Personal care needs met (always=1)					
CG burden	0.42	0.12	0.23	0.76	0.01
CG benefit	0.78	0.14	0.55	1.12	0.18
CG burden*benefit	1.14	0.05	1.04	1.25	0.01
N=386 / McFadden's $r^2=0.130$					
Treated with respect (always=1)					
CG burden	0.57	0.18	0.30	1.06	0.07
CG benefit	0.89	0.21	0.55	1.44	0.62
CG burden*benefit	1.11	0.06	0.99	1.23	0.07
N=388 / McFadden's $r^2=0.116$					

Source: 2011 NSOC, 2011-2016 NHATS. CG=Caregiver. AOR=Adjusted odds ratio. LSE=Linearized standard error. CI=Confidence interval. Models adjust for caregiving factors (duration and intensity), caregiver factors (gender, relationship to decedent, self-rated health, PHQ4), care recipient factors (gender, race, disability, number of serious diagnoses, dementia, recent hospitalization, hospice care), and time from report of caregiver burden and benefit until care recipient death.