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Caregiving Factors as Predictors of Care Recipient Mortality

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ABSTRACT

Objective: Assess a conceptual model linking caregiving factors to care recipient mortality in a large representative sample of older adults with disability. **Design:** Descriptive longitudinal study with 5-year mortality follow-up among older adults with disability. Baseline in person and telephone interviews/assessments of older adults with disability and their family caregivers carried out in 2011. **Setting:** Representative samples of older US population and their family caregivers. **Participants:** US representative samples of older adults with disability aged 65 and over (National Health and Aging Study) and their family caregivers (National Study of Caregiving; www.nbats.org; N = 1,262). **Measurement:** Controlling for known risk factors for mortality in older adults, including age, gender, race, education, socioeconomic status, disability, and cognitive status, we assess the role of three caregiving factors (depression, anxiety, and burden) and three mediating factors (care recipient depression, anxiety, and unmet needs for care) as predictors of care recipient mortality. **Results:** Caregiver burden, care recipient depression, and care recipient unmet needs are independent predictors of care recipient mortality. **Conclusion:** Caregiving factors may play an important role in the survival of their care recipients. This is a relatively unexplored research area that calls for fine-grained studies capturing caregiver—care recipient health-related interactions over time. (Am J Geriatr Psychiatry 2020; ■■■:■■■-■■■)

INTRODUCTION

Much of the family caregiving literature focuses on the impact of caregiving on the care provider, including effects on psychological and physical health, social relationships, and economic

well-being.¹ This literature in turn has generated wide-ranging research programs to identify risk factors for adverse caregiver (CG) outcomes as well as intervention strategies to mitigate the negative effects of caregiving.² To a lesser extent, researchers have documented the impact of caregiving on care recipient (CR) outcomes, including care recipient

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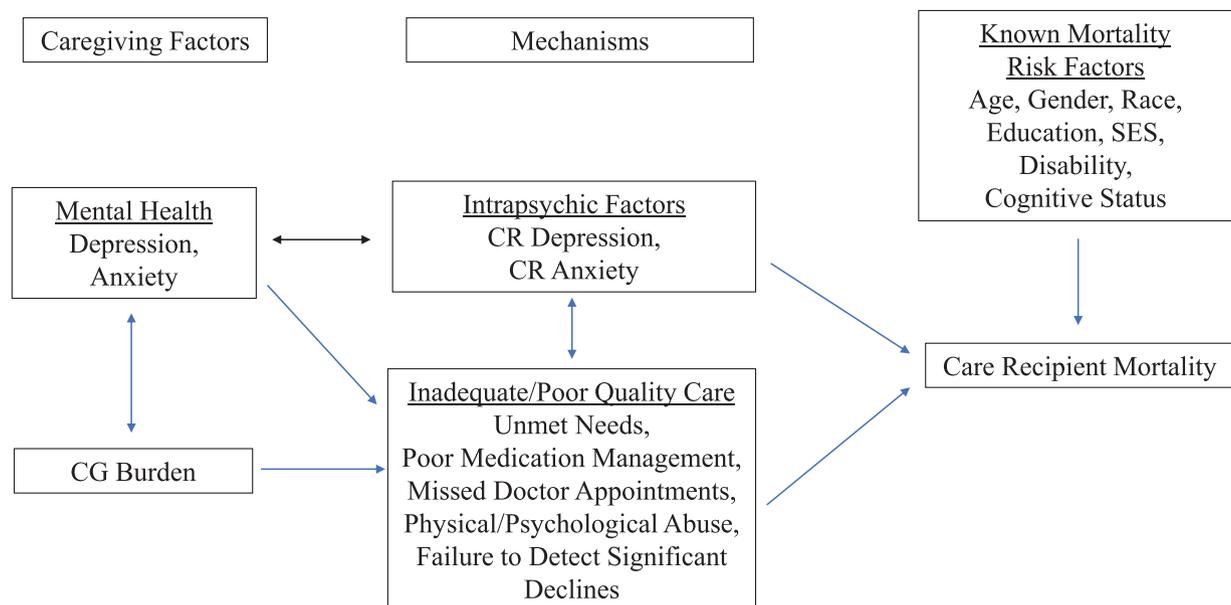
Caregiving Factors as Predictors of Care Recipient

behavior,³ psychological symptoms such as depression,⁴ time to nursing home admission,⁵ and health-care expenditures.⁶

An emergent recent development in the caregiving literature is a focus on care recipient mortality as an outcome. Controlling for known risk factors for mortality in older adults⁷ such as health, functional status, and demographic characteristics, what caregiving-related factors contribute to survival time in the care recipient? Lwi et al.⁸ found that poor caregiver mental health predicted mortality of patients with neurodegenerative diseases. In a small sample of dementia patients and their caregivers (n = 91), Brodaty et al.⁹ also showed that caregiver psychological morbidity was associated with shorter patient survival times. Boele et al.¹⁰ explored depression, anxiety, burden, and mastery as predictors of patient mortality in a sample of caregivers caring for patients with glioblastoma multiform. Only caregiver mastery was found to be a significant predictor of patient mortality. Pristavec and Luth,¹¹ using a large representative sample of older adult care recipients and their caregivers, showed that older adults whose caregiver reported higher levels of burden had a significantly higher mortality risk during the 6-year follow-up period.

The present study advances existing research in this area by exploring the role of caregiving factors and possible mechanisms on care recipient mortality in a large representative sample of older adults with disability and their caregivers. A preliminary conceptual model linking caregiving factors to CR mortality is presented in Figure 1. The existing literature suggests that three caregiver factors (depression, anxiety, and burden) impact CR mortality through two broad categories of mechanisms: (1) intrapsychic factors such as CR depression and anxiety; and (2) inadequate or poor-quality care provided to the CR. Intrapsychic mechanisms linking caregiver status to mortality might occur through contagion of emotions or behavioral mimicry.^{8,12} Individuals in close relationships have reciprocal effects on each other's emotional status, especially when the emotions are negative (e.g., anger, fear, sadness). Thus, depressed caregivers may instigate similar effect in their care recipients, and vice versa. Inadequate or poor-quality care includes failure to meet the functional and mobility needs of the CR (i.e., typically measured as unmet needs), poor medication management, missed doctor appointments, physical/psychological abuse, and failure to detect significant CR declines that require

FIGURE 1. Conceptual model linking caregiving factors to care recipient mortality.



medical intervention. As shown in the model, CG depression/anxiety is thought to impact both CR depression/anxiety and the quality of care provided to the CR. Burden is thought to impact CR mortality primarily through inadequate or poor-quality care.

Controlling for known risk factors for mortality in older adults, we assess the role of the caregiver and mediating factors as predictors of mortality. In our first Cox proportional hazards (CPH) model, we explore the association between the three hypothesized caregiving factors, CG depression/anxiety and burden on CR mortality, and based on the existing literature, we predict statistically significant associations between depression/anxiety, burden, and survival time. In a second Cox model, we test the independent effects of CR depression/anxiety and unmet needs on mortality (note the available data limited our ability to explore other indicators of inadequate/poor-quality indicators), and we predict statistically significant associations between depression/anxiety, unmet needs, and survival time. In a final model, we simultaneously examine the effects of both caregiving factors and mediating factors on CR mortality. We predict that the effects of caregiving factors observed in model 1 will be attenuated such that they are no longer significant predictors of mortality, while the effects of mediating variables will remain significant.

METHODS

Data

The data used in this study are publicly available, do not contain individual identifiers, and are, therefore, exempt from institutional review board review. A detailed description of the data sources for this study was provided in a recent publication,¹³ and much of this section is repeated from this source.

Data are drawn from the 2011 National Health and Aging Trends Study (NHATS) and the National Study of Caregiving (NSOC) (www.nhats.org), two linked national surveys that provide information regarding a well-defined population of older adults and their family caregivers. The NHATS is nationally representative of Americans 65 years and older. The NSOC is a nationally representative survey of family members and other unpaid caregivers who assist

older persons with disabilities. The NSOC participants were identified from the NHATS helper roster on the basis of being a family member or an unpaid helper who provided assistance with mobility, self-care, household activities, transportation, or medically oriented tasks.

Of 7,609 NHATS participants living in the community or in a residential care facility, 2,423 were included in the NSOC sampling frame, and 4,935 helpers met eligibility criteria for the NSOC. In cases where an NHATS care recipient was linked to more than one caregiver, the caregiver who reported providing the most hours of care per month was included in the current analyses. The base sample for this analysis was 1,348 “primary caregivers” of NHATS respondents who reported difficulty or were receiving help with at least one of 12 instrumental activities of daily living (IADL), basic activities of daily living (ADL), or mobility tasks (i.e., 18 NHATS respondents with an NSOC caregiver did not meet this criteria). The final sample consisted of the subset of 1,262 primary caregivers and care recipients who had valid data on variables included in the models (see below). Comparisons between the 86 cases with missing data versus the 1,262 included cases showed no significant differences in any of the outcome, predictor, or socio-demographic control variables.

Measures

This study included measures from both older disabled adults (NHATS) and their linked family caregivers (NSOC). Baseline NHATS and NSOC assessments were conducted in 2011.

Survival time. The primary outcome in the analyses was care recipient 5-year all-cause mortality (i.e., through NHATS Round 5 in 2016). More specifically, months from baseline assessment date to month of death (exact death dates were not available) was modeled in CPH models. For censored cases with complete follow-up, time to event was months between NHATS baseline and wave 5 assessment dates. For censored cases lost to follow-up, time to event was months between NHATS baseline and attrition dates. All predictors and covariates were taken from the 2011 baseline assessment.

Caregiver depression and anxiety. Caregiver depression was measured with the two-item version of the Patient Health Questionnaire (PHQ), and a cutoff

Caregiving Factors as Predictors of Care Recipient

score was used to classify caregivers as at risk for depression versus not (NSOC; www.nhats.org). Similarly, *caregiver anxiety* was measured with the two-item version of the PHQ, and a cutoff score was used to classify caregivers as at risk for anxiety disorder versus not (NSOC; www.nhats.org).

Caregiver burden. This was a six-item index including how often (“very much,” “somewhat,” “not so much”) the caregiver reports “*being exhausted when you go to bed at night*,” “*have more things to do than you can handle*,” “*don’t have time for yourself*,” “*as soon as you get a routine going, care recipient’s needs change*.” Two additional items asked if helping the recipient is emotionally and physically difficult for them (yes/no). The index (range = 0–6) consisted of a count of “very much” responses to the first four items and “yes” responses to the last two items. Three categories were created for analysis: (1) *Low burden* (score of 0 on the index); (2) *Medium burden* (score of 1 or 2); and (3) *high burden* (score of 3 or higher).

Care recipient adverse consequences of unmet needs. NHATS respondents were asked single questions (for each of four ADL/three mobility/five IADL tasks) assessing whether during the past month they experienced a negative consequence because there was no one there to help (for those reporting that they never performed the task without help in a prior question); or it was too difficult to do by themselves without additional help (for those reporting that they performed the task by themselves at least sometimes). Adverse consequences of unmet ADL needs included wet or soiled clothing; went without eating; went without bathing/showering; and went without getting dressed. Adverse consequences of unmet mobility needs included had to stay in bed; had to stay inside; and unable to go places in home/building. Adverse consequences of unmet IADL needs included went without clean laundry; went without groceries; went without a hot meal; went without paying bills; and made a medication mistake. For analyses, separate indicators for *any* ADL/mobility adverse consequences and *any* IADL adverse consequences were created, given that they reflect different levels of disability/needs for care and typically occur at earlier (IADL) and later (ADL/mobility) stages of the caregiving trajectory.

Caregiver sex and caregiver relationship to care recipient were also included (see [Table 1](#) for coding).

Care recipient mortality risk factor covariates. Care recipient sociodemographic covariates included sex, age, race, and education (see [Table 1](#) for coding). An indicator for whether the care recipient was receiving Medicaid was also included as a proxy for low income. We constructed a composite index of care recipient disability level by classifying older adults as having probable dementia only;¹⁴ needing help with two or more self-care (ADL) activities (toileting, eating, bathing, dressing, getting out of bed), but no dementia; having *both* probable dementia and needing help with two or more self-care tasks; or neither probable dementia nor needing help with two or more ADL. Care recipient depression and anxiety were assessed with the same two-item PHQ measures and cutoffs as described for caregivers.

Statistical Analysis

CPH models were used to estimate hazard ratios (HR) for all-cause care recipient mortality over approximately 5 years using baseline care recipient (NHATS) and caregiver (NSOC) variables as predictors. We report HR, 95% confidence interval for HR, Wald statistic, and p value for each model predictor. The Breslow¹⁵ approximation is used to handle ties in the months to event variable. CPH methods assume that the hazard ratio is constant over time. We conducted both visual [log(-log) plots] and formal tests using scaled Schoenfeld residuals.¹⁶ Age, care recipient anxiety, and caregiver depression showed statistically significant violations in the final model. However, visual plots showed essentially parallel log(-log) plots for care recipient anxiety and caregiver depression. This suggests minor proportionality departures due to sample size and the relatively large number of covariates. Therefore, we retained all covariates due to their hypothesized importance for care recipient mortality. We considered adding time-varying covariates to the model but decided against this since only NHATS care recipients were interviewed yearly. Caregivers were only interviewed at baseline in 2011.

Summary descriptive statistics for the entire sample are presented first, followed by simple bivariate comparisons on all predictors between care recipients who died before wave 5 and those surviving until wave 5 ([Table 1](#)). We use χ^2 and *t*-tests for bivariate comparisons. We also report unadjusted hazard ratios for all predictors ([Table 2](#)). Three multivariate CPH

TABLE 1. Sample Descriptive Statistics (n = 1,262; Unweighted); and Bivariate Associations Between CR Risk Factors, CG Factors, CR Mechanisms, and CR Mortality by Wave 5 (n = 1,262; Weighted)

Predictor	Unweighted		CR Died Before Wave 5 (Weighted)		χ^2 (df)	p
	N	%	% No	% Yes		
CR died before wave 5						
No	762	60.4				
Yes	500	39.6				
Months to death (deceased CRs only)						
25th percentile	10.0					
50th percentile	22.0					
75th percentile	34.0					
Mean and standard deviation	23.3	14.1				
CR sex						
Male	396	31.4	30.9	38.0	6.55(1)	0.028
Female	866	68.6	69.1	62.0		
CR age (mean)	81.6		77.4	82.7	72.13 ^a	<0.001
CR race						
White (non-Hispanic)	790	62.6	74.6	82.9	12.24(3)	0.017
Black (non-Hispanic)	356	28.2	12.7	9.7		
Hispanic	88	7.0	9.7	5.8		
Other	28	2.2	3.1	1.6		
CR education						
High school or less	815	64.6	58.8	62.6	1.88(2)	0.500
Some college	283	22.4	26.4	23.5		
Bachelor's degree or higher	164	13.0	14.9	13.9		
CR Medicaid recipient						
No	961	76.2	78.5	82.5	2.93(1)	0.119
Yes	301	23.9	21.5	17.5		
CR disability status						
Probable dementia (only)	239	18.9	13.8	20.7	102.38(3)	<0.001
2+ ADLs (only)	188	14.9	14.2	17.1		
Both probable dementia and 2+ ADLs	219	17.4	8.4	24.9		
Neither probable dementia nor 2+ ADLs	616	48.8	63.6	37.3		
CG sex						
Male	414	32.8	41.8	30.4	16.04(1)	<0.001
Female	848	67.2	58.2	69.6		
CG relationship to CR						
Spouse	340	26.9	39.7	27.1	28.66(3)	<0.001
Daughter/daughter-in-law/step-daughter	490	38.8	28.7	41.7		
Son/son-in-law/step-son	204	16.2	15.7	16.9		
Other	228	18.1	16.0	14.2		
CG depressed						
No	1084	85.9	86.4	84.7	0.67(1)	0.479
Yes	178	14.1	13.6	15.3		
CG anxious						
No	1087	86.1	86.8	83.1	3.15(1)	0.127
Yes	175	13.9	13.2	16.9		
CG burden						
Low	434	34.4	38.0	25.6	36.40(2)	<0.001
Medium	574	45.5	47.2	47.2		
High	254	20.1	14.8	27.2		
CR depressed						
No	887	70.3	71.4	64.1	7.23(1)	0.022
Yes	375	29.7	28.6	35.9		
CR anxious						
No	954	75.6	75.8	71.9	2.33(1)	0.192
Yes	308	24.4	24.2	28.1		
CR suffered adverse consequence of unmet IADL need						
No	1073	85.0	86.6	81.7	5.50(1)	0.044
Yes	189	15.0	13.4	18.3		
CR suffered adverse consequence of unmet ADL/mobility need						
No	767	60.8	65.9	53.0	20.35(1)	<0.001
Yes	495	39.2	34.1	47.0		

^a F(1, 1,206)

Caregiving Factors as Predictors of Care Recipient

TABLE 2. Cox Proportional Hazards Models Testing Mortality Risk of CR Risk Factors, CG Factors, and CR Mechanisms (n = 1,262; Weighted)

Predictor	Unadjusted HR [CI]Wald; p	Model 1 HR [CI]Wald; p	Model 2 HR [CI]Wald; p	Model 1 HR [CI]Wald; p
CR is female	0.77 [0.62, 0.95] 5.63; 0.018	0.65 [0.51, 0.83] 12.01; <0.001	0.66 [0.51, 0.84] 11.25; <0.001	0.66 [0.52, 0.85] 10.61; 0.001
CR age	1.06 [1.05, 1.08] 71.86; <0.001	1.05 [1.03, 1.07] 30.79; <0.001	1.06 [1.04, 1.08] 38.95; <0.001	1.06 [1.04, 1.08] 38.03; <0.001
CR race—Black (non-Hispanic) ^a	0.74 [0.58, 0.92] 6.97; 0.008	0.79 [0.62, 1.01] 3.68; 0.055	0.77 [0.60, 0.99] 4.26; 0.039	0.78 [0.61, 1.00] 3.83; 0.051
CR race—Hispanic ^a	0.67 [0.42, 1.08] 2.70; 0.101	0.69 [0.43, 1.10] 2.46; 0.117	0.68 [0.43, 1.08] 2.67; 0.102	0.68 [0.43, 1.08] 2.63; 0.105
CR education—some college ^b	0.83 [0.64, 1.07] 2.03; 0.154	0.98 [0.76, 1.28] 0.01; 0.909	0.95 [0.73, 1.23] 0.16; 0.692	0.96 [0.74, 1.25] 0.08; 0.781
CR education—bachelor's degree or higher ^b	0.85 [0.63, 1.17] 0.98; 0.321	0.70 [0.50, 0.98] 4.39; 0.036	0.70 [0.51, 0.97] 4.70; 0.030	0.71 [0.51, 0.98] 4.27; 0.039
CR on Medicaid	0.83 [0.63, 1.09] 1.90; 0.169	0.81 [0.62, 1.07] 2.23; 0.136	0.76 [0.58, 1.02] 3.45; 0.063	0.78 [0.59, 1.03] 3.09; 0.079
CR disability—probable dementia only ^c	2.17 [1.64, 2.88] 29.46; <0.001	1.69 [1.27, 2.23] 13.25; <0.001	1.68 [1.26, 2.23] 12.50; <0.001	1.65 [1.24, 2.20] 11.74; <0.001
CR disability—2+ ADLs (only) ^c	1.83 [1.34, 2.50] 14.45; <0.001	1.73 [1.27, 2.35] 12.17; <0.001	1.61 [1.18, 2.20] 9.05; 0.003	1.56 [1.14, 2.14] 7.71; 0.006
CR disability—both probable dementia and 2+ ADLs ^c	3.67 [2.78, 4.84] 84.95; <0.001	2.76 [2.07, 3.67] 48.35; <0.001	2.49 [1.85, 3.36] 35.87; <0.001	2.37 [1.75, 3.20] 31.77; <0.001
CG relationship—spouse	0.65 [0.51, 0.83] 11.71; 0.001	0.81 [0.60, 1.08] 2.10; 0.147	0.84 [0.63, 1.12] 1.39; 0.238	0.84 [0.63, 1.13] 1.34; 0.247
CG depressed	1.08 [0.80, 1.46] 0.27; 0.604	0.89 [0.64, 1.23] 0.52; 0.472	—	0.82 [0.59, 1.15] 1.30; 0.254
CG anxious	1.20 [0.90, 1.60] 1.61; 0.205	0.98 [0.72, 1.33] 0.02; 0.895	—	0.98 [0.72, 1.34] 0.01; 0.914
CG burden—medium level ^d	1.39 [1.08, 1.79] 6.36; 0.012	1.20 [0.94, 1.54] 2.13; 0.144	—	1.14 [0.89, 1.47] 1.11; 0.292
CG burden—high level ^d	2.12 [1.59, 2.82] 26.71; <0.001	1.51 [1.13, 2.02] 7.79; 0.005	—	1.39 [1.03, 1.88] 4.72; 0.030
CR depressed	1.37 [1.10, 1.72] 7.73; 0.006	—	1.34 [1.05, 1.71] 5.63; 0.018	1.34 [1.05, 1.72] 5.46; 0.020
CR anxious	1.18 [0.93, 1.51] 1.85; 0.175	—	1.03 [0.79, 1.33] 0.04; 0.834	1.03 [0.79, 1.34] 0.05; 0.825
CR suffered adverse consequence of unmet IADL need	1.21 [0.91, 1.60] 1.72; 0.191	—	1.21 [0.91, 1.61] 1.79; 0.181	1.18 [0.88, 1.57] 1.21; 0.271
CR suffered adverse consequence of unmet ADL need	1.59 [1.29, 1.98] 18.11; <0.001	—	1.29 [1.03, 1.62] 4.76; 0.029	1.27 [1.01, 1.60] 4.27; 0.039

Notes: Wald Statistic Degrees of freedom = (1, 1,206) for all cells. HR: hazard ratio; CI: 95% confidence interval.

Reference groups:

^a Non-Hispanic White.

^b High school or less.

^c Neither probable dementia nor 2+ ADLs.

^d Low CG burden.

models were estimated (Table 2). All models included covariates assessing traditional risk factors for mortality in older adults, including a caregiver-care recipient spouse dyad indicator. First, we tested a model containing available known caregiver mortality risk factors (depression, anxiety, and burden). Then, we tested a model with mechanisms thought to mediate the relation between caregiver factors and care recipient mortality (CR depression and anxiety, CR unmet needs). Finally, we tested a model

entering *all variables simultaneously* to estimate the best predictors of care recipient mortality and the proposed mediating mechanisms. Cases where the care recipient survived to wave 5 and those who were lost to follow-up for reasons other than death were considered censored for the CPH models. Given that several previous mortality analyses have been conducted in Alzheimer's/dementia patients, we conducted *supplemental CPH analyses* (testing the same models) on the subset of cases with *probable*

dementia (n = 458). All analyses use the final NHATS analytic weight (given the focus on care recipient mortality). All analyses were conducted with statistical software¹⁷ using survey sampling weights and procedures that account for the complex sampling strategy. Standard errors were computed using a linearized variance estimator based on a first-order Taylor series linear approximation.¹⁷

RESULTS

Descriptive Statistics

Summary descriptive statistics for the entire sample (n = 1,262) are reported in Table 1. By the wave 5 assessment, 500 (39.6%) care recipients had died (mean time to death = 23.3 months; mdn = 22.0 months); 499 (39.5%) continued to be enrolled in the study; and 263 (20.9%) were lost to follow-up for reasons other than death. The care recipients were predominantly female (68.6%) with a mean age of 81.6 years at baseline (sd = 8.3), and were predominantly white non-Hispanic (62.6%), with 28.2% African American, and 7% Hispanic. Nearly two-thirds reported a high school education or less, with 13% earning a bachelor's degree or higher. A little less than one-fourth (23.9%) of the care recipients were enrolled in Medicaid. The disability level grouping showed that while almost half the sample had neither probable dementia nor needed help with multiple ADL tasks (48.8%), 18.9% had probable dementia, 14.9% needed help with multiple ADLs, and 17.4% had *both* probable dementia and multiple ADL needs. Most caregivers were also female (67.2%); the majority (55.0%) were adult children taking care of a parent; and 26.9% were taking care of a spouse. Looking at other caregiving factors, 14.1% of the caregivers met the PHQ cutoff for risk for depression, while 13.9% met the PHQ anxiety cutoff score. Approximately one in five caregivers scored high on the caregiver burden index, while a little more than one-third scored zero. In terms of possible mediating mechanisms, 29.7% of care recipients met depression risk criteria, and 24.4% met anxiety risk criteria. While only 15% of care recipients reported adverse consequences of unmet IADL needs, 39.2% said they had experienced such negative consequences from unmet ADL or mobility needs.

Bivariate Tests

Bivariate baseline comparisons between subsamples among whom the care recipients died (versus not) before wave 5 are also shown in Table 1. Looking at care recipient sociodemographic and health covariates, males, older, non-Hispanic white, and care recipients with higher disability levels (especially those with *both* probable dementia and multiple ADL needs) had higher mortality rates. Female caregivers and those who were daughters had recipients with higher mortality rates. While there were no mortality differences for caregiver depression and anxiety, higher caregiver burden was significantly related to subsequent care recipient mortality. Among those who died, about a quarter (27.2%) had "high burden" caregivers, versus 14.8% for those who did not die. Care recipients at risk for depression, and those reporting adverse consequences of unmet IADL and ADL/mobility needs, had higher subsequent mortality, though the ADL/mobility effect was stronger than IADL.

Multivariate Cox Proportional Hazards Models

The unadjusted CPH ratio results reported in column 1 of Table 2 are quite similar to the bivariate results just described from Table 1. Note that the only exception is that the effect for adverse consequences of unmet needs for IADL is not significant (though the ADL/mobility effect remains).

The multivariate CPH models are reported in columns 2, 3, and 4 of Table 2. Model 1 (column 2) replicates previous mortality analyses for known risk factors. Being male, older, having probable dementia, needing help with two or more self-care ADLs, and the combination of needing help and having probable dementia, were risk factors for higher mortality. Also, those with a bachelor's degree or higher had lower mortality hazard ratios. Looking at caregiving factors, those reporting high levels of caregiver burden had care recipients with higher mortality hazard ratios. Caregiver depression and anxiety were not related to recipient mortality. Model 2 (column 3) shows partial support for the proposed care recipient mechanisms. Care recipients at risk for depression and those reporting unmet ADL/mobility needs were at higher risk for mortality. Neither care recipient anxiety nor unmet IADL needs were related to mortality. Model 3 (column 4) included all variables simultaneously and

Caregiving Factors as Predictors of Care Recipient

shows that care recipient depression and unmet ADL/mobility needs effects remain significant. The effect of high caregiver burden on care recipient mortality, while still significant, is slightly attenuated.

Supplemental CPH Models for the Dementia Subsample

Given prior analyses of dementia patient mortality, we ran the same three CPH models on the subsample of cases where the care recipient had probable dementia at baseline ($n = 458$). Results of the final model were similar to those for the full sample with one exception. Adverse consequences of unmet needs (neither ADL/mobility nor IADL) were *not related to mortality* among dementia care recipients.

DISCUSSION

Mortality of older adult CRs is driven primarily by demographic and health-related variables. Being male, older, having less education, being disabled, cognitively impaired, and depressed are all risk factors for increased mortality. These findings are consistent with the existing literature on predictors of mortality in older adults. In support of our model, both CR depression and unmet needs were associated with increased mortality. We also hypothesized that the effects of CG mental health and burden would be mediated through CR mental health and behaviors reflecting inadequate or poor-quality care resulting in more unmet needs of the care recipient. These predictions were not supported. Instead, caregiver mental health had no impact on mortality, and burden had a direct effect on mortality. Of course, this does not rule out the possibility that emotional status and burden might contribute to other behavioral mediators, such as poor medication regimen, missed doctor appointments, or failure to detect significant care recipient declines. Caregiver burden and unmet care recipient needs may both be indicators of a “poor-quality care” syndrome, additional aspects of which were not measured in this study. Caregiver depression has also been associated with potentially harmful caregiver behaviors (verbal abuse, threatening with physical force, threatening to institutionalize or abandon), which in turn may affect CR mental health and mortality.¹⁸ Our failure to find CG mental health effects on mortality

was not consistent with the study by Lwi et al.⁸ and may be due to unique sample of CRs with neurodegenerative disease included in their study.

A replication of these analyses with the subsample of care recipients with probable dementia yielded a similar pattern of results, although unmet needs did not predict mortality. This is consistent with research showing that unmet needs have low prevalence in persons with dementia unless they also have ADL or mobility limitations.¹⁹ The criteria used to classify individuals with “probable dementia” in NHATS include individuals with moderate cognitive impairment who do not yet have ADL limitations.

The clinical implications of these findings are two-fold. First, interventions that reduce caregiver burden and address CR unmet needs may also impact CR mortality. We know of three studies^{9,20,21} that show that multicomponent interventions reduced mortality among community residing CRs, although these effects are relatively small. Comprehensive multicomponent approaches to treatment may impact survival time because they reduce burden and improve the quality of care provided to the CR. Second, interventions that address CR depression may enhance both the quality and duration of life. Depression is a known risk factor for mortality in older adults^{22,23} and is likely due to complex feedback loops involving functional disability, health behaviors,²³ and motivational depletion.²²

LIMITATIONS

This paper has a number of limitations. Although our sample is relatively large and generally representative of white CRs over the age of 65, minority populations such as Hispanics are underrepresented. Caregiver data are based on a one-time baseline assessment and do not include possible changes in caregiver status that might have occurred between baseline assessment and CR death. Data limitations also prevented us from assessing more complex predictive mortality models. Clearly, we are in the early stages of understanding how caregiving context, processes, and individual differences might affect care recipient outcomes such as mortality. Future research should expand the range of variables examined with a greater emphasis on macro- and micro-level behavioral interactions between CG and CR. How and to what extent do caregivers regulate CR health

behaviors and encounters with the healthcare system? What factors contribute to exemplary as opposed to inadequate or harmful care provided to the CR? What role does the emotional bond play between CG and CR in care processes and health outcomes for both members of the dyad? Answers to these questions will shape our understanding of CR health, functioning, and survival.

AUTHOR CONTRIBUTIONS

Each of the three authors—Richard Schulz, Scott Beach, Esther Friedman—contributed to the

conceptualization of the questions, analysis of the data, and the writing of the manuscript.

DISCLOSURE

The authors report no conflicts with any product mentioned or concept discussed in this article.

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References

- Schulz R, Eden J, eds. Families Caring for an Aging America, Washington, DC: The National Academies Press, 2016; doi:10.17226/23606
- Schulz R, Beach SR, Czaja SJ, et al: Family caregiving for older adults. *Annu Rev Psychol* 2020; 71:635–659;doi:10.1146/annurev-psych-010419-050754
- Vernon E, Cooley B, Rozum W, et al: Caregiver-care recipient relationships are associated with neuropsychiatric symptoms in dementia. *Innov Aging* 2017; 1:572, doi.org/10.1093/geroni/igx004.2011
- Ejem D, Bauldry S, Bakita M, et al: Caregiver burden, care recipient depressive symptomology, and social exchange: does race matter? *J Palliat Care* 2018; 33:100–108, doi.org/10.1177/0825859718758120
- Betini RSD, Hirdes JP, Lero DS, et al: A longitudinal study looking at and beyond care recipient health as a predictor of long-term care home admission. *BMC Health Serv Res* 2017; 17:709, doi.org/10.1186/s12913-017-2671-8
- Ankuda CK, Maust DT, Kabeto MU, et al: Association between spousal caregiver well-being and care recipient healthcare expenditures. *J Am Geriatr Soc* 2017; 65:2220–2226; doi:10.1111/jgs.15039
- Carey EC, Covinsky KE, Lui LY, et al: Prediction of mortality in community-living frail elderly people with long-term care needs. *J Am Geriatr Soc* 2008; 56:68–75;doi:10.1111/j.1532-5415.2007.01496.x
- Lwi SJ, Ford BQ, Casey JJ, et al: Caregiver mental health predicts patient mortality. *Proc Natl Acad Sci* 2017; 114:7319–7324; doi:10.1073/pnas.1701597114
- Brodsky H, McGilchrist C, Harris L, et al: Time until institutionalization and death in patients with dementia: role of caregiver training and risk factors. *Arch Neurol* 1993; 50:643–650; doi:10.1001/archneur.1993.00540060073021
- Boele FW, Given CW, Given BA, et al: Family caregivers' level of mastery predicts survival of glioblastoma patients: a preliminary report. *Cancer* 2017; 123:832–840;doi:10.1002/cncr.30428
- Pristavec T, Luth E: The effect of caregiving experience on care recipient older adults' mortality: a survival analysis. *Innov Aging* 2019; 3:S217., doi.org/10.1093/geroni/igz038.796
- Monin JK, Schulz R: Interpersonal effects of suffering in older adult caregiving relationships. *Psychol Aging* 2009; 24:681–695; doi:10.1037/a0016355
- Wolff A, Gooch D, Cavero Montaner JJ, et al: Creating an understanding of data literacy for a data-driven society. *J Community Inf* 2016; 12:9–26
- Kasper JD, Freedman VA, Spillman B: Classification of Persons by Dementia Status in the National Health and Aging Trends Study. Baltimore, MD: Johns Hopkins University School of Public Health, 2013. Technical Paper #5. Available at www.NHATS.org
- Breslow N: Covariance analysis of censored survival data. *Biometrics* 1974; 30:89–99, doi.org/10.2307/2529620
- Grambsch PM, Therneau TM: Proportional hazards tests and diagnostics based on weighted residuals. *Biometrika* 1994; 81:515–526, doi.org/10.1093/biomet/81.3.515
- StataCorp: Stata Statistical Software: Release 15. College Station, TX: StataCorp LLC, 2017
- Beach SR, Schulz R, Williamson GM: Risk factors for potentially harmful caregiver behavior. *J Am Geriatr Soc* 2005; 53:255–261, 10.1111/j.1532-5415.2005.53111.x
- Beach SR, Schulz R: Family caregiver factors associated with unmet needs for care of older adults. *J Am Geriatr Soc* 2017; 65:560–566;doi:10.1111/jgs.14547
- Schulz R, Zdaniuk B, Belle SH, et al: Baseline differences and trajectories of change for deceased, placed, and community residing Alzheimer's disease patients. *Alzheimer Dis Assoc Disord* 2010; 24:143–150;doi:10.1097/WAD.0b013e3181b795b7
- Gitlin L, Hauck W, Winter L, et al: Effect of an in-home occupational and physical therapy intervention on reducing mortality in functionally vulnerable elders: preliminary findings. *J Am Geriatr Soc* 2006; 54:950–955;doi:10.1111/j.1532-5415.2006.00733.x
- Schulz R, Beach SR, Ives DG, et al: Association between depression and mortality in older adults: the Cardiovascular Health Study. *Arch Intern Med* 2000; 160:1761–1768;doi:10.1001/archinte.160.12.1761
- Blazer DG, Hybels CF, Pieper CF: The association of depression and mortality in elderly persons: a case for multiple, independent pathways. *J Gerontol A Biol Sci Med Sci* 2001; 56:M505–M509, doi.org/10.1093/gerona/56.8.M505