IssueBRIEF

PURPOSE

The purpose of this exploratory analysis was to examine which caregiver and care recipient (CR) characteristics predict institutionalization of CRs among the sample of caregiver-care recipient dyads in the National Family Caregiving Support Program (NFCSP) Outcome Evaluation.

KEY FINDINGS

Age-adjusted institutionalization rates were found to be influenced by the care recipient's medical diagnosis and a recent hospitalization. Higher rates were also associated with caregiver factors such as race, caregiving's emotional toll, and the caregiver's self-reported physical health status.

AUTHORS
Duck-Hye Yang
Joanne Campione
Katarzyna Zebrak
Willow Burns

Predictors of Institutionalization of Older Individuals Cared for by an Informal Caregiver

BACKGROUND

Informal caregivers are a key component of long-term care for older adults. Over 40 million informal caregivers in the United States provide unpaid services to older adults with limitations in daily activities.[1] Informal caregiving can help prevent or postpone costly institutionalization of care recipients, many whom are family members. While the care recipients' health status (both physical and mental) is often the main driver of institutionalization, there are caregiver-related factors that may contribute to the decision to place a loved one in a nursing home or other long-term care facility.

The majority of past studies of informal caregiving and the risk of care recipient institutionalization exclusively target caregivers of persons with Alzheimer's disease or related dementia (ADRD), given the high caregiving burden and high risk of institutionalization for the care recipient.[2-6] These studies find that the rates of institutionalization are higher among White families compared with Black, Asian, and Hispanic families.[7,8,9] Buhr et al. (2006) found that caregiver-reported risk factors for nursing home

1

placement of a person with ADRD include the need for more skilled care, a decline in caregiver health, ADRD-related behaviors, and the caregiver's need for more assistance.[9] However, it is unclear whether the findings from these studies are generalizable to caregivers of care recipients with other medical conditions. Luppa and colleagues (2010) performed a systematic review of reasons for care recipient institutionalization that focused on care recipient characteristics and identified several strong predictors, such as increased age, low self-rated health status, functional and cognitive impairment, dementia, prior nursing home stay, and a high number of prescription drugs.[10] Wolinsky and colleagues (1992) found that nursing home placement was greater for older adults who had been in the hospital during the prior year.[11] However, the Wolinsky et al. and Luppa et al. studies did not include caregiver characteristics.

Thus, more studies are needed to examine independent predictors of institutionalization that include both caregiver and care recipient characteristics, and are not restricted to specific care recipient conditions (e.g., ADRD) or populations, such as veterans.

PURPOSE

The purpose of this exploratory analysis was to examine which caregiver and care recipient (CR) characteristics predict institutionalization of CRs among the sample of caregiver-care recipient dyads in the National Family Caregiving Support Program (NFCSP) Outcome Evaluation.[12] The NFCSP is a Federal program that supports informal caregivers of older adults by providing two core services: 1) caregiver education/training; individual counseling; and support groups (i.e., educational services) to help caregivers better manage their responsibilities and cope with the stress of caregiving; and 2) respite care provided either at home or at adult day care facilities, so that caregivers can rest or attend to their own needs.

SAMPLE OF CAREGIVER-CARE RECIPIENT DYADS

The source data for this analysis was survey data from 1,568 informal caregivers in 43 states in the United States interviewed by telephone in December 2016 as part of the baseline data collection for the NFCSP evaluation. The evaluation's sample of caregivers was derived through systematic random sampling of individuals from Area Agencies on Aging (AAA) client lists for caregiver services or home- and community-based services for the CR in 316 sampled AAAs. The evaluation team attempted to interview all baseline caregivers at the 6-month followup.

For caregivers who were still providing care at 6 months, another followup attempt was made at 12 months. The 6-month and 12-month followup interviews began with the question "*Are you still the caregiver for {CR name}?*" When a caregiver said "No" to the *still caregiver* question, they were then asked "*Please tell me why you are no longer providing care for {CR name}.*" When institutionalization or death of the CR occurred, caregivers were asked to provide the year and month of institutionalization or death.

OUTCOME MEASURE: CARE RECIPIENT STATUS AT FOLLOWUP

Figure 1 shows the sample and the distribution of responses by caregiving and CR status at followup. From the Evaluation's baseline sample, 466 caregivers were excluded because they could not be contacted past baseline. We also excluded four caregivers with CRs younger than age 60 to focus on CRs aged 60 and older. The 12-month interview was the last followup for 791 caregivers and the 6-month interview was the last followup for 307 caregivers, resulting in a final sample of 1,098 caregivers. At last followup, 811 caregivers (74%) responded that they were still caregiving and 287 caregivers (26%) responded that they were no longer caregiving. The majority of the 287 caregivers provided information as to why they stopped caregiving, but a few caregivers did not. As shown in Figure 1, the most common reason for stopping caregiving was the death of the care recipient (n=148), followed by the response option "care recipient went into a nursing home or other long term care facility" (labeled *institutionalization*; n=90), which is the focal event for this analysis.

Figure 1. Caregiving Status at Last Followup
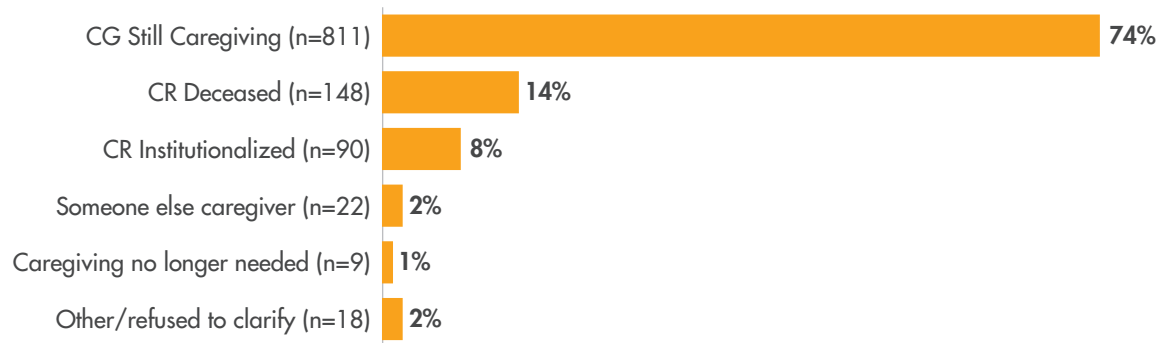
CG=caregiver; CR=care recipient

CARE RECIPIENT AND CAREGIVER CHARACTERISTICS

The characteristics collected from caregivers in the NFCSP Outcome Evaluation fell within four overarching domains: (1) caregiver characteristics that include demographics and the number of years caregiving; (2) caregiving well-being that includes self-reported burden and health,[13,14] caregiving satisfaction, and other perceptions about the impact of caregiving; (3) CR age, behaviors, hospitalizations, and health conditions; and (4) caregiver support including respite care and educational services from any organization, family, or friends.

Sixty-nine characteristics were explored as potential predictors of institutionalization. The amount of missing data for all study variables was less than 1%, with the exception of caregiver annual income which had 5% missing values. We imputed missing data using the most appropriate regression model based on the underlying distribution of each variable: logistic regression to impute missing binary variables and predictive mean matching to impute missing continuous variables. For the annual income category, missing data was imputed using the median household income by ZIP Code of caregivers' residence available from the 2016 American Community Survey.

Caregiving intensity was measured by the number of five activities of daily living (ADLs) with which the caregiver reported providing assistance daily (eating, dressing, toileting, and mobility), or daily/several times a week (bathing). Measures of self-reported caregiver burden and health status were derived from well-known scales. Caregiver burden was measured using the 4-item Zarit

Burden Inventory. Self-reported mental and physical health were scored from the validated Patient-Reported Outcomes Measurement Information System (PROMIS) Short Form for Global Health (version 1.1). For example, the PROMIS Physical health score is the sum of four items assessing different aspects of caregiver's physical health on a scale of 1 to 5 with a score of 20 representing the best reported health possible. The items include general rating of physical health; perceived ability to carry out every day physical activities; a rating of fatigue; and a rating of pain.

Caregivers reported using caregiver supports in the past 6 months. We created an indicator of whether a caregiver received caregiver educational services from any organization in the past 6 months. For respite care, we measured the number of weekly respite hours received from all sources including NFCSP; other organizations (e.g., Medicare, Medicaid, or private home health care); and family and friends. Finally, to measure global support, caregivers were asked if they are receiving all the help that they need.

STATISTICAL ANALYSIS

We categorized the sample of caregivers into four event-type groups based on their status at last followup: 1) CG still caregiving (n=811), 2) CR deceased (n=148), 2) CR institutionalized (n=90), and 4) Other reason for not caregiving or refusal to clarify (n=49). For each characteristic, we examined the differences in means and frequencies between CR Institutionalized group and the other three groups with an event other than institutionalization ("competing event"). Based on results of these analyses and information from extant literature, we selected 26 characteristics for further analysis.

The longitudinal dataset enabled us to perform a multivariable Cox regression analysis. With this analysis, we could follow caregiver-care recipient dyads for up to 12 months and compare the characteristics between those that were institutionalized with those that were still caregiving or had another event. Since the age effect is much stronger than the time effect for this cohort, we directly incorporated the age effect into the model by using the CR age-based time scale. The approach of using an age-based time scale has been used in numerous studies where directly adjusting for age is important.[15-18] In this manner, the model calculates an age-adjusted ratio of institutionalization rates between caregivers with a given characteristic and those without, holding all other characteristics in the model constant. To determine the characteristics to include in the model, we employed a stepwise method whereby each variable was added to the model one at a time. The entered variables were tested/re-tested at each step, and only the variables that fit the specified stay criterion were retained in the regression model. The enter and stay criterion were 0.2, which means that only the variables with hazard ratios statistically significant at the 0.20 level ($p < 0.2$) were allowed to remain in the final model.

RESULTS

Descriptive Statistics

Table 1 presents the frequencies or mean values of CR age and each of the 26 factors theorized to be associated with institutionalization for the four mutually exclusive groups of caregivers by event: 1) CG still caregiving, 2) CR institutionalized, 3) CR deceased, and 4) Other reason not caregiving or refusal to clarify. Variables that remained in the final regression model are indicated with an asterisk.

Cox Regression Model Results

Table 2 presents the hazard ratios (HRs) and 95% confidence intervals from the multivariable Cox regression model of the 11 variables that met the model inclusion criterion. An HR below 1 represents a decrease in risk and an HR above 1 represents an increase in risk. The HR for each variable reported is adjusted for CR's age and all other variables in the model.

The risk of institutionalization was 2.3 times higher when a CR had ADRD than when a CR did not have ADRD (adjusted hazard ratio [AHR] = 2.30; p=.004). The risk of institutionalization was 1.7 times higher among CRs hospitalized in the past 6 months than for those who were not (AHR = 1.70; p=0.020). The risk of institutionalization was lower when CR had arthritis than when CR did not (AHR=0.61; p=0.030). Compared to White caregivers, the risk of institutionalization was lower for Black caregivers (AHR = 0.37; p=0.038) and for caregivers who were Hispanic or Other race (AHR = 0.13; p=0.005). The risk of institutionalization

was higher when caregivers reported that caregiving was very emotionally difficult (AHR=1.68; p=0.040). Lastly, the risk of institutionalization was lower for caregivers with better self-reported physical health (AHR=0.92; p=0.027).

As shown in Table 2, the following five variables in the model were not significant factors for predicting institutionalization: 1) Caregiver enjoys being with CR, 2) Caregiver lives with CR, 3) Caregiver has high school education or higher, 4) CR wanders or gets lost, and 5) Caregiver agreed that they were receiving all help needed.

DISCUSSION

Using a longitudinal sample of 1,098 caregiver-care recipient dyads, we found that CR with ADRD was the strongest independent predictor of institutionalization. This finding is not surprising, given that multiple other studies have shown that caring for an individual with ADRD has been linked to greater emotional stress, more caregiver burden, and higher physical demands on caregivers.[19,20,21] Several other CR health conditions were tested for inclusion in the model, including cancer and heart disease, but did not meet criterion. (These health condition indicators were not mutually exclusive, meaning a CR could have more than one condition.) The CRs that had arthritis had a decreased risk of institutionalization suggesting that this condition alone (without co-morbidities) is more manageable at home.

We also found that CRs who experienced a recent hospitalization had additional risk of institutionalization. This may be because the CR has experienced a rapid decline in health or because the caregiver has been tasked with more complex medical care. In recognition of medical care complexity, over 75% of states in the Nation have implemented the Caregiver Advise, Record, Enable (CARE) Act that directs hospitals to better incorporate caregivers into the discharge planning process and to provide education to family caregivers on the care they need to provide at home.[22,23] While the goal of the CARE Act was to decrease readmissions and improve patient outcomes, future studies should evaluate if the CARE Act helps prevent institutionalization after CR hospitalization.

Consistent with previous findings, we found that caregiver race was an independent predictor: the risk of institutionalization was higher for White caregivers, compared to Black caregivers and Other race caregivers including Hispanic caregivers. Researchers who have explored the reasons for these differences explain that Asian, Hispanic, and Black caregivers often have a stronger sense of familism than Whites. Familism emphasizes multigenerational family caretaking and views caregiving as a fulfillment of cultural values.[7]

Two caregiver well-being characteristics – self-reported physical health and emotional toll of caregiving – were strong independent predictors of institutionalization. Our results show that for each unit increase in the PROMIS physical health score, the risk of institutionalization decreased by 8%. Reversely stated, worse caregiver physical health was associated with more risk of CR institutionalization. These findings are troubling because caregiver support programs are designed more to address caregiver confidence and burden, and less to address caregiver physical health.[24,25,26] For emotional toll, we found that the risk of institutionalization was 68% higher for the caregivers who reported that caregiving was very emotionally difficult. Further examination of the 31 caregivers who reported that caregiving was very emotionally difficult and that their CR was institutionalized showed that these caregivers, on average, were less likely to report receiving all the help needed and less likely to enjoy their time with the CR. They were also more likely to have

better health scores and more likely to be caring for a CR with ADRD. Nevertheless, *very emotionally difficult* was a significant factor for institutionalization even after controlling for CR with ADRD, suggesting that the caregivers experiencing severe emotional difficulty were not just among the group of caregivers caring for a CR with ADRD.

Our analysis found no significant association (p < 0.05) between institutionalization and the use of caregiver educational services, the number of respite care hours received weekly, or the caregiver's perception of receiving all the help needed. We should note that, at baseline, the caregivers in this analysis (n=1,089) had a mean of 7 years of caregiving and mean age of 67, which is an older group of caregivers than the nationally reported mean age of 59 among caregivers of Medicare recipients.[27] The caregivers were older, on average, because the NFCSP evaluation only included informal caregivers of CRs who were either age 60+ or diagnosed with ADRD. Additionally, the mean age of the CRs in this sample was 81 years with 14% deceased between baseline and followup. Therefore, without knowing the CR's health trajectory and needs immediately before institutionalization, we can only speculate that the majority of the caregivers in our study had already delayed their CR's institutionalization.

Several study limitations should be considered when interpreting the results. First, this analysis was not designed to measure the effectiveness of caregiver support programs. Studies that measure program effectiveness should include control groups and/or random assignment

of service use. This is because the caregiver's level of need or the propensity for the service confounds the relationship between the treatment and the caregiver outcome. Second, our followup duration was only up to 1 year, relatively shorter than the

majority of survival analysis-type studies. Furthermore, the interview instrument did not collect information on the family's financial situation, living situations, treatment decisions, long-term care planning, end-of-life expectations, or a clinical assessment of the CR's health status and clinical care needs. These are all factors that can influence the decision for institutionalization, and, due to the complexity of this event and end-of-life care, supplemental qualitative research might be needed to best understand institutionalization.[28] Lastly, because CR age was used for time scale in this study, our HRs should not be compared to those derived from time scale-based institutionalization studies.

CONCLUSION

For older adults being cared for at home by an informal caregiver, several caregiver characteristics were independent predictors of institutionalization including race, CR with ADRD, caregiver-reported physical health, and the emotional toll of caregiving. Caregiving daily assistance with ADLs and caregiver burden were not predictors of institutionalization, suggesting that non-clinical functional challenges for the caregiver are less of a risk for institutionalization than the emotional toll of caregiving and the challenges of providing complex medical care associated with post-hospitalization. Physical health of the caregiver should remain a priority

for continued caregiving. For this purpose, respite care is very important when the caregiver needs to tend to their own health care needs and to get rest.

To help informal caregivers maintain caregiving capacity and avert institutionalization of their CR, the findings from this analysis suggest the importance of continuous assessment of caregivers' emotions, their satisfaction with caregiving, and their needs;[29,30] the provision of psychosocial support for the caregiver;[31] and an increase in education and support after hospitalization of the CR.[23]

Table 1. Key Variables/Factors Tested in the Prediction Model

Factor	Group Frequency (%) or Mean			
	CG still Caregiver (n=811)	CR Institutionalized (n=90)	CR Deceased (n=148)	Other Reason Not Caregiving or Refusal (n=49)
Caregiver Characteristics				
Race/Ethnicity*				
Black race	14.7%	5.6%	11.5%	20.4%
White race	69.9%	92.2%	76.4%	57.1%
All other race	15.4%	2.2%	12.2%	22.4%
Relationship to CR				
Spouse to CR	48.6%	58.9%	39.2%	22.4%
Child to CR	41.6%	34.4%	51.4%	38.8%
Other relationship to CR	9.9%	6.7%	9.5%	38.8%
Caregiver age, mean	66.7	69.3	67.5	62.7
High school graduation or above*	62.8%	61.1%	64.9%	51.0%
# of years caregiving, mean	6.9	6.6	6.1	7.3
Caregiving intensity, daily ADLs	1.7	1.8	2.4	1.1
Live with CR*	82.4%	82.2%	81.1%	51.0%
Caregiver Well-Being				
Perception of receiving all the help needed*	16.3%	15.6%	16.2%	26.5%
Caregiving is very emotionally difficult*	13.9%	34.4%	18.2%	14.3%
Reported poor mental health	3.0%	10.0%	2.0%	0%
Zarit Burden score, mean (lower is better)	2.7	3.1	2.7	2.3
Enjoy being with CR*	71.8%	52.2%	75.0%	69.4%
PROMIS mental health score (higher is better)	12.5	11.5	12.8	13.5
PROMIS physical health score* (higher is better)	14.1	13.4	14.1	14.4
Care Recipient Characteristics and "Ever Diagnosed" Health Conditions				
CR age, mean	80.3	80.4	84.8	81.5
Wanders or gets lost*	16.4%	34.4%	20.3%	14.3%
Hospitalized recently*	25.6%	37.8%	31.1%	26.5%
Alzheimer's disease or related dementia*	51.0%	76.7%	63.5%	40.8%
Arthritis*	67.2%	54.4%	64.9%	65.3%
Diabetes	31.9%	31.1%	27.7%	36.7%
Difficulty seeing	34.0%	40.0%	37.2%	30.6%
Lung disease	24.0%	23.3%	25.7%	22.4%
Osteoporosis	34.4%	28.9%	29.1%	34.7%
Cancer	27.1%	32.2%	28.4%	28.6%
Difficulty hearing	37.9%	43.3%	47.3%	36.7%
Caregiver's Use of Support in the Past 6 Months				
Respite hours from all resources per week	8.1	11.2	10.4	4.5
Received educational services	26.9%	36.7%	18.2%	22.4%

CG=caregiver; CR=care recipient; PROMIS= Patient Reported Outcomes Measurement Information System; ADLs=activities of daily living

* Indicates the variable was included in the final Cox regression prediction model.

** Adjustment factor.

Table 2. Cox Regression Model Results for Predicting Care Recipient Institutionalization

Factors	Hazard Ratio	95% Confidence Interval	p-value
CR ADRD	2.30	1.31-4.01	0.004
Caregiver Race Category (Ref=White)			
Black	0.37	0.15-0.95	0.038
Hispanic and All Other	0.13	0.03-0.53	0.005
CR hospitalized during past 6 months	1.70	1.09-2.66	0.020
CG self-reported physical health	0.92	0.85-0.99	0.027
CR arthritis	0.61	0.39-0.95	0.030
Caregiving is very emotionally difficult	1.68	1.02-2.76	0.040
CR wanders or gets lost	1.58	0.97-2.56	0.067
CG enjoys being with CR	0.66	0.42-1.04	0.074
CG lives with CR	0.59	0.32-1.10	0.096
CG education high school or higher	0.69	0.44-1.09	0.115
CG perception receiving all help needed	1.57	0.83-2.95	0.164

Note: CG = Caregiver; CR = care recipient; ADRD = Alzheimer's disease or related dementias; N = 1,098 caregivers.
Note: Two key variables are needed for running a cox regression: (1) duration between baseline and last followup status; and (2) indicator of institutionalization (1 if institutionalization occurred at last followup; 0 otherwise). For this analysis, duration is the difference in the CR's age between baseline and the last followup status.

REFERENCES

1. Reinhard, S. C., Feinberg, L., Choula, R., and Houser, A. (2015). Valuing the invaluable: 2015 Update. Washington, DC: AARP Public Policy Institute. Retrieved from https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf.

2. Bakker, C., de Vugt, M. E., van Vliet, D., Verhey, F. R., Pijnenburg, Y. A., Vernooij-Dassen, M. J., and Koopmans, R. T. (2013). Predictors of the time to institutionalization in young- versus late-onset dementia: results from the Needs in Young Onset Dementia (NeedYD) study. *Journal of the American Medical Directors Association, 14*(4), 248-253.

3. Dufournet, M., Dauphinot, V., Moutet, C., Verdurand, M., Delphin-Combe, F., Krolak-Salmon, P. (2019). Impact of cognitive, functional, behavioral disorders, and caregiver burden on the risk of nursing home placement. *Journal of the American Medical Directors Association.* pii: S1525-8610(19)30322-6. doi:10.1016/j.jamda.2019.03.027. [Epub ahead of print].

4. Eska, K., Graessel, E., Donath, C., Schwarzkopf, L., Lauterberg, J., and Holle, R. (2013). Predictors of institutionalization of dementia patients in mild and moderate stages: a 4-year prospective analysis. *Dementia and Geriatric Cognitive Disorders Extra, 3*(1), 426-445.

5. Gaugler, J. E., Yu, F., Krichbaum, K., and Wyman, J. F. (2009). Predictors of nursing home admission for persons with dementia. *Medical Care, 47*(2), 191-198.

6. Yaffe, K., Fox, P., Newcomer, R., Sands, L., Lindquist, K., Dane, K., and Covinsky, K. E. (2002). Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA, 287*(16), 2090-2097.

7. *Mausbach*, B. T., Coon, D. W., Depp, C. Rabinowitz, Y. G., Wilson-Arias, E., Karaemer, H. C., Thompson, L. W., Lane, G., Gallagher-Thompson, D. (2004). Ethnicity and time to institutionalization of dementia patients: a comparison of Latina and Caucasian female family caregivers. *Journal of the American Geriatrics Society, 52*(7), 1077-1084.

8. Schulz, R., Belle, S. H., Czaja, S. J., McGinnis, K. A., Stevens, A., and Zhang, S. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association, 292*, 961–967.

9. Buhr, G .T., Kuchibhatla, M., and Clipp E. C. (2006). Caregivers' reasons for nursing home placement: clues for improving discussions with families prior to the transition. *The Gerontologist, 46*(1), 52-61.

10. Luppa, M., Luck, T., Weyerer, S., Konig, H. H., Brahler, E., and Riedel-Heller, S. G. (2010). Prediction of institutionalization in the elderly. A systematic review. *Age and Ageing*, 39, 31–38.

11. Wolinsky, F. D., Callahan, C. M., Fitzgerald, J. F., and Johnson, R. J. (1992). The risk of nursing home placement and subsequent death among older adults. *Journal of Gerontology, 47*(4), S173-82.

12. Westat. (2018). *Outcome Evaluation of the National Family Caregiver Support Program.* Report to the Administration for Community Living. Rockville, MD: Author. Retrieved from https://acl.gov/sites/default/files/programs/2018-12/Caregiver_Outcome_Evaluation_Final_Report.pdf.

13. Bedard, M., Molloy, D .W., Squire, L., Dubois, S., Lever, J. A., and O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist*, 41, 652-657. doi:10.1093/geront/41.5.652.

14. Hays, R. D., Bjorner, J. B., Revicki, D. A., Spritzer, K. L., and Cella, D. (2009). Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. *Quality of Life Research, 18*(7), 873-880.

15. Griffin, B. A., Anderson, G. L., Shih, R. A., and Whitsel, E. A. (2002). Use of alternative time scales in Cox proportional hazard models: Implications for time-varying environmental exposures. *Statistics in Medicine, 31*(27), 3320-3327.

16. Lamarca, R., Alonso, J., Gomez, G., and Munoz, A. (1998). Left-truncated data with age as time scale: an alternative for survival analysis in the elderly population. *The Journals of Gerontology Series A, Biological Sciences and Medical Sciences, 53*(5), M337-343.

17. Lee, M., Gouskova, N. A., Feuer, E. J., and Fine, J. P. (2017). On the choice of time scales in competing risks predictions. *Biostatistics* (Oxford, England), *18*(1), 15-31.

18. Thiebaut, A. C., and Benichou, J. (2004). Choice of time-scale in Cox's model analysis of epidemiologic cohort data: a simulation study. *Statistics in Medicine, 23*(24), 3803-3820.

19. Schulz, R., and Sherwood P. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing, 108*(9 Suppl), 23-27. doi: 10.1097/01.NAJ.0000336406.45248.4c.

20. Li, H. (2012). Unmet service needs: A comparison between dementia and non-dementia caregivers. *Home Health Care Services Quarterly,* 31, 41-59. doi:10.1080/01621424.2011.641921.

21. Pinquart, M., and Sörensen, S. (2003) Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging, 18*(2), 250–67.

22. Reinhard, S., Young, H. M., Ryan, E., and Choula, R. B. (2019). The CARE act implementation: Progress and promise. Washington, DC: AARP Public Policy Institute. Retrieved from https://www.aarp.org/content/dam/aarp/ppi/2019/03/the-care-act-implementation-progress-and-promise.pdf.

23. James, E., and Hughes, M. (2016). Embracing the role of family caregivers in the U.S. health system. *Health Affairs Blog.* doi: 10.1377/hblog20160908.056387.

24. Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Faes, K., and Annemans, L. (2016). Effectiveness of respite care in supporting informal caregivers of persons with dementia: A systematic review. *International Journal of Geriatric Psychiatry,* 31, 1277-1288.

25. Polenick, C. A., Leggett, A. N., Webster, N. J., Han, B. H., Zarit, S. H., and Piette, J. D. (2017). Multiple chronic conditions in spousal caregivers of older adults with functional disability: Associations with caregiving difficulties and gains. *Journals of Gerontology. Series B, Psychological Sciences and Social Sciences.* doi: 10.1093/geronb/gbx118. [Epub ahead of print].

26. Chi, N. C., Demiris, G., Lewis, F. M., Walker, A. J., and Langer, S. L. (2016). Behavioral and educational interventions to support family caregivers in end-of-life care: A systematic review. *American Journal of Hospice & Palliative Medicine, 33*(9), 894-908.

27. Riffin, C., Van Ness, P. H., Wolff, J. L., and Fried, T. (2017). Family and other unpaid caregivers and older adults with and without dementia and disability. *Journal of the American Geriatrics Society,* 65, 1821-1828.

28. Ornstein, K. A., Kelley, A. S., Bollens-Lund, E., and Wolff, J. L. (2017). A national profile of end-of-life caregiving in the United States. *Health Affairs, 36*(7), 1184-1192.

29. Bangerter, L. R., Griffin, J. M., Zarit, S. H., and Havyer, R. (2017) Measuring the needs of family caregivers of people with dementia: An assessment of current methodological strategies and key recommendations. *Journal of Applied Gerontology.* [Epub ahead of print]

30. Hughes, T. B., Black, B. S., Albert, M., Gitlin, L. N., Johnson, D. M., Lyketsos, C. G., and Samus, Q. M. (2014). Correlates of objective and subjective measures of caregiver burden among dementia caregivers: influence of unmet patient and caregiver dementia-related care needs. *International Psychogeriatrics, 26*(11),1875-1883.

31. Gaugler, J. E., Reese, M., and Mittelman, M. S. (2013). Effects of the NYU caregiver intervention-adult child on residential care placement. *Gerontologist, 53*(6), 985-97. doi: 10.1093/geront/gns193. Epub 2013 Jan 20.