

Research Article

# Falls and Hospitalizations Among Persons With Dementia and Associated Caregiver Emotional Difficulties

Amanda N. Leggett, PhD,<sup>1,2,\*</sup> Courtney A. Polenick, PhD,<sup>1,2</sup> Donovan T. Maust, MD, MS,<sup>1,2,3,4</sup> and Helen C. Kales, MD<sup>1,2,3,4</sup>

<sup>1</sup>Program for Positive Aging and <sup>2</sup>Department of Psychiatry, University of Michigan, Ann Arbor. <sup>3</sup>Center for Clinical Management Research, VA Ann Arbor Healthcare System. <sup>4</sup>Institute for Healthcare Policy and Innovation, University of Michigan, Ann Arbor.

\*Address correspondence to: Amanda N. Leggett, PhD, Department of Psychiatry, University of Michigan, Rachel Upjohn Building, 4250 Plymouth Road, Ann Arbor, MI 48109. E-mail: [leggetta@med.umich.edu](mailto:leggetta@med.umich.edu)

Received: August 24, 2017; Editorial Decision Date: November 13, 2017

**Decision Editor:** Rachel Pruchno, PhD

## Abstract

**Background and Objectives:** Falls and hospitalizations are adverse health events commonly experienced by persons with dementia (PWDs). These events often require urgent care from a family caregiver and may increase caregiver stress. We examine falls and hospitalizations among PWDs as predictors of caregivers' reported care-related emotional difficulty, in addition to care-related stressors.

**Research Design and Methods:** Cross-sectional telephone survey of 652 informal caregivers for PWDs. A multinomial logistic regression examined falls (last month) and hospitalizations (prior year) experienced by PWDs as predictors of caregivers' care-related emotional difficulty, accounting for demographic characteristics and primary and secondary caregiving stressors.

**Results:** Over 20% of caregivers reported high levels of care-related emotional difficulty. Controlling for demographic characteristics and primary and secondary caregiving stressors, the PWD's prior month fall was significantly associated with greater care-related emotional difficulty; the PWD's hospitalizations were not associated with care-related emotional difficulty.

**Discussion and Implications:** Approximately 30% of PWDs had experienced a past year hospitalization and prior month fall, and one in five caregivers reported high emotional difficulty related to care. Although secondary strains and resources of caregiving were strong predictors of care-related emotional difficulty, PWDs' falls represent a significant stressor that increases odds of caregiver emotional difficulty over and above other strains. Consequently, a fall experienced by a PWD may represent a key time for clinicians to assess caregiver well-being.

**Keywords:** Falls, Hospitalizations, Caregiving, Care-related stress

Approximately 15 million U.S. adults serve as informal caregivers for a person with dementia (PWD; [Alzheimer's Association, 2017](#)). Although caregiving has many rewards, reports of burden and mental health concerns among caregivers are common ([Adelman, Tmanova, Delgado, Dion, & Lachs, 2014](#); [Cohen, Colantonio, & Vernich, 2002](#)).

A seminal model of caregiver stress, Pearlin's Stress Process Model, posits that mental health outcomes for caregivers stem from both primary stressors directly relating to the care situation (e.g., cognitive status, functional dependencies) and secondary strains, which are ways primary stressors proliferate into the caregiver's life (e.g., family conflict; [Pearlin,](#)

Mullan, Semple, & Skaff, 1990). The model further posits that resources, such as social support and the experience of gains related to the caregiving role, may protect caregivers from negative outcomes. Primary stressors such as functional dependencies and problematic behaviors may also increase the risk for adverse health events experienced by the PWD. For example, adverse health events such as falls and hospitalizations are of great concern for caregivers, and the occurrence of both can lead to a downward spiral in the health and functioning of older adults with dementia which in turn may increase caregiver stress (Bail et al., 2015; Bynum et al., 2004; Cumming, Salkeld, Thomas, & Szonyi, 2000; Kressig et al., 2001; Lin, Adelman, Diamond, & Evans, 2014; Maslow, 2006; Zekry et al., 2009). In this study, we seek to extend the Stress Process Model to include adverse health events commonly experienced by the PWD, specifically falls and hospitalizations, as common stressors and potential predictors of a caregiver's experienced emotional difficulty related to care.

## Falls

The Centers for Disease Control and Prevention estimates that approximately 29% of older adults (aged 65 or older) experienced a fall in 2014 (Bergen, Stevens, & Burns, 2016). Older adults in general are at risk for falls due to balance or gait impairments, medications, environmental hazards, visual impairment, and orthostatic hypotension. However, falls experienced by PWDs are even more common, with PWDs having two to eight times more incident falls than age-matched controls without dementia (Allan, Ballard, Rowan, & Kenny, 2009; Shaw et al., 2003; Tinetti, Speechley, & Ginter, 1988; van Dijk, Meulenberg, van de Sande, & Habbema, 1993). Factors including wandering, perceptual challenges, and agitation may specifically increase the risk of falls for PWDs (Shaw, 2003).

Falls are of great concern for PWDs and their caregivers given their potentially severe consequences. More than a third of persons who fall require some form of medical treatment or restricted activity (Bergen et al., 2016). Among older adults, falls are the leading cause of nonfatal and fatal injuries (Bergen et al., 2016), and fall-related injuries are a leading cause of emergency department visits and hospitalizations (Benner, Steiner, & Pierce, 2016). PWDs are at a threefold increased risk of hip fracture and a twofold increased risk of death following a fall compared to same-aged peers without dementia (Baker, Cook, Arrighi, & Bullock, 2011). Falls may lead to functional decline, reduced ability for self-care, and also a fear of falling which could reduce independence and activity (Cumming et al., 2000; Kressig et al., 2001). Injury, functional decline, and reduced confidence in PWDs may lead to increased need for and physical demand of caregiving, an unanticipated stressor that requires an immediate response from caregivers (Allan et al., 2009; Cumming et al., 2000; Kressig et al., 2001).

Although it is known that falls may have significant adverse impact for a PWD, less is understood about the

indirect impact on caregivers of older adults with dementia (Kuzuya et al., 2006). One of the few studies on this topic found that care recipient fall history was a significant predictor of caregiver burden after controlling for activities of daily living disability, dementia status, and caregiver and care recipient depression (Kuzuya et al., 2006). Similarly, among caregivers of care recipients with Parkinson's disease, care receiver falls have been associated with greater caregiver burden, poorer quality of life, and higher depressive symptoms (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006). These studies suggest that falls are highly stressful for the caregiver, with one fall leading to fear of another (Kuzuya et al., 2006). This stress may be evidenced by a fall increasing risk for institutionalization of the PWD by threefold (a fall with serious injury increasing risk of placement by 10-fold), even after controlling for other psychological and medical factors (Tinetti & Williams, 1997).

## Hospitalizations

Hospitalizations are another common adverse health event experienced by PWDs that may result in caregiver emotional difficulty. PWDs are hospitalized at two to four times the rate of same-aged peers without dementia, with urinary tract infections, delirium, falls, behavioral issues, and pressure ulcers being frequent reasons for admission among PWDs (Benner et al., 2016; Bynum et al., 2004; Feng, Coots, Kaganova, & Wiener, 2014; Phelan, Borson, Grothaus, Balch, & Larson, 2012; Rudolph et al., 2010). Furthermore, PWDs tend to have longer and more expensive stays, higher rates of readmission, worse complications and outcomes (such as functional decline), and higher rates of institutionalization following discharge (Bail et al., 2015; Bynum et al., 2004; Lin et al., 2014; Maslow, 2006; Zekry et al., 2009).

Similar to falls, hospitalizations may exacerbate caregiver stress and leave caregivers with a sense of inability to assist in their loved one's recovery (Borbasi, Jones, Lockwood, & Emden, 2006). Boltz, Chippendale, Resnick, and Galvin (2015) interviewed caregivers for PWDs within 48 hr of hospital admission and found that 20%–30% of caregivers expressed symptoms of depression and/or anxiety at the time of interview. These caregivers described hospitalization as intensifying the existing stress of care, disrupting their routine, and leading to worry about their relative's care (Boltz et al., 2015). A similar qualitative study of caregivers for PWDs who had been recently hospitalized found that caregivers felt stress from not being able to provide the necessary care for the care recipient due to personal limitations of the caregiver (e.g., not having informal support or knowing how to manage behaviors) and that hospitalization posed a crisis leading to disrupted self-care, sleep problems, and emotional strain (Sadak, Foster Zdon, Ishado, Zaslavsky, & Borson, 2017). Adverse health events would thus be anticipated to increase caregivers' care-related distress, yet a quantitative analysis controlling

for other stressors from the Stress Process Model known to be associated with the caregiver stress process is needed.

### Care-Related Emotional Difficulties

We consider falls and hospitalizations experienced by the care recipient as key predictors of caregivers' reported care-related emotional difficulty. Stress related to dementia care has been linked with decreased well-being, anger, guilt, a sense of being trapped, a feeling of loss, vulnerability to disease, irregular levels of stress hormones/increased allostatic load, and even higher mortality (Alzheimer's Association, 2017; Aneshensel, 1995; Fonareva & Oken, 2014; Hinrichsen & Zweig, 1994; Perkins et al., 2013; Schulz & Beach, 1999; von Känel et al., 2006; Zarit, 2008). Recent work has also found that PWDs who had caregivers reporting high levels of distress used more acute care services such as emergency department visits (Maust et al., 2017). Finally, care-related distress may affect care provision for individuals with dementia because caregivers with higher levels of distress and anger have been found to report more potentially harmful behaviors toward the care recipient (MacNeil et al., 2010). Thus, if adverse health events such as falls and hospitalizations are associated with increased care-related emotional difficulty, these events may represent a key time to intervene with caregivers to improve well-being for both the caregiver and care receiver.

### Current Study

Adverse medical events such as falls and hospitalizations may increase strain on caregivers by increasing demands during the crisis and depleting their emotional and physical reserves (Bloomer, Digby, Tan, Crawford, & Williams, 2016). These situations may require caregivers to make immediate and urgent decisions regarding medical care for a PWD, often amidst confusing circumstances, which may disrupt routines and increase care-related emotional difficulty (Boltz et al., 2015). Using data from the 2015 National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC), we examine informal caregiver demographics, primary and secondary stressors of the care context, and care recipients' prior falls and hospitalizations as predictors of caregivers' care-related emotional difficulties among caregivers for a PWD. We hypothesize that care recipient falls and hospitalizations will be independent predictors of caregivers' emotional difficulties, over and above primary and secondary stressors and resources of the care situation.

### Design and Methods

#### Procedures and Sample

Data for this cross-sectional study were drawn from the 2015 NHATS (care-receiver data) and NSOC (caregiver

data). NHATS is a nationally representative sample of Medicare beneficiaries aged 65 years or older. NHATS participants were sampled from a Medicare enrollment file with African Americans and older individuals oversampled. The sample for this study included NHATS participants with "probable dementia" who had caregivers that participated in the companion NSOC study. In NHATS, a probable dementia classification was based on one of the following criteria: (1) a reported diagnosis by the participant or proxy, (2) meeting criteria for diagnosis based on the AD8 score, or (3) scoring at least 1.5 SD below the mean in at least two domains on cognitive testing including memory, executive function, and orientation (described in full detail in a technical paper by Kasper, Freedman, & Spillman, 2013a).

NHATS participants (or their proxy respondents) were asked to provide the names of all unpaid family or nonfamily helpers who assisted them with household chores, mobility tasks, or self-care activities. If more than five caregivers were listed, five were randomly selected for NSOC participation and interviewed via telephone. Out of 5,212 eligible caregivers, interviews were conducted with 2,204. Of 725 caregivers for 474 PWDs, our analytic sample included 652 caregivers for 430 PWDs with no missing data on key variables. The majority (60%) had only one caregiver in the study. Only publicly available secondary data with no individual identifiers were used, and thus, ethical approval for this study was not required per University of Michigan policies.

### Measures

#### Outcome

Emotional care-related difficulty. Caregivers' emotional care-related difficulty was measured using a combination of two NSOC items. First, caregivers were asked whether or not they experienced emotional difficulty related to caring for the PWD (yes/no). If caregivers responded affirmatively, then they were asked to rate the level of emotional difficulty on a scale of 1 (a little difficult) to 5 (very difficult). We combined these terms so the full sample would be included and the scale ranged from 0 (no difficulty) to 5 (high difficulty).

#### Demographics

Caregiver age, gender, level of education, chronic medical conditions, and relation to the PWD were included as background characteristics. Caregivers' count of chronic medical conditions was based on 10 self-reported physician diagnoses of medical conditions including heart attack, other heart condition (e.g., heart disease), high blood pressure, arthritis, osteoporosis, diabetes, lung disease, cancer, serious difficulty seeing, and serious difficulty hearing.

#### Primary Stressors

We also included those NSOC items that would capture caregiver primary stressors, which are directly related to the

care situation. First, we considered the level of caregiving provided in terms of *self-care activities*, *household chores*, and *mobility tasks*. Self-care activities provision was a sum of the number of activities a caregiver helped with including eating, bathing, toileting, and dressing. Household chores provision was a count of help with laundry, shopping, meal preparation, banking assistance, and medication management. Finally, support with mobility was a count of assistance with getting around outside, getting around inside, and getting out of bed. A caregiver's *level of role overload* (Pearlin et al., 1990) was measured with the following three items on a scale of 0 (not so much) to 2 (very much): "you have more things to do than you can handle," "are exhausted when you go to bed at night," and "don't have time for yourself." The overload items were averaged for each NSOC respondent so that higher scores represented greater overload ( $\alpha = .74$ ).

### Secondary Strains and Resources

Next secondary strains, or ways the care situation proliferated into other areas of the caregiver's life, were captured with additional NSOC measures. Caregivers were asked about the level of *family disagreement over care* for the care recipient and reported disagreement on a scale of 0 (not so much) to 3 (very much), which we dichotomized as no family and not so much disagreement versus somewhat or very much disagreement. Resources included whether they had *friends or family who help* the caregiver care for their care recipient (yes/no). In addition to the experience of stresses and strains associated with caregiving for a loved one with dementia, caregivers often report gains or areas of growth related to caregiving (de Labra et al., 2015; Sánchez-Izquierdo, Prieto-Ursúa, & Caperos, 2015). The experience of *caregiving gains* was included as a resource and was measured with a scale of four items. Participants were asked if helping the care recipient: "made you more confident in your abilities," "taught you to deal with difficult situations," "brought you closer to the care recipient," and "gives you satisfaction that the care recipient is well-cared for". Participants responded on a scale of 0 (not so much) to 2 (very much), and items were summed with a higher score indicating a greater experience of gains ( $\alpha = .71$ ).

### Adverse Health Events

Two adverse health events of the PWD were considered as predictors of caregivers' emotional difficulty: *past month falls* and *past year hospitalizations*. Both items were drawn from the care recipient data file (NHATS) and asked whether the care recipient had experienced a fall in the past month, and the number of times the care recipient had been hospitalized in the past year. As most care recipients had experienced no hospitalization or only one, hospitalizations were categorized into three levels: no past year hospitalization, one hospitalization, or two or more hospitalizations (range: 2–10).

### Statistical Analysis

Descriptive statistics were estimated for all study variables in preliminary analyses. Next, to examine adverse health events as predictors of caregivers' reports of emotional difficulty of care, we used a multinomial logistic regression with the SAS 9.4 (SAS Institute, Inc., Cary, NC) survey logistic procedure (Hardin & Hilbe, 2003) and report the adjusted odds ratios (ORs) and 95% confidence intervals (CIs). All predictors were entered together in Model 1 (Table 2). The NSOC caregiver sampling analytic weight was applied to the models to account for differential probabilities of sample selection and survey design (Kasper, Freedman, & Spillman, 2013b). In addition, we accounted for the clustering and stratification of the sample design in the model so that standard errors would be computed properly. Goodness of fit of the model is described using the Wald *F* test.

### Results

Full descriptive statistics of sample characteristics can be found in Table 1. Caregivers were in their late 50s on average (range: 18–96), 71% were female, and over half were a child of the PWD. Approximately 20% of caregivers reported the emotional difficulty they experienced related to care provision to be very difficult, although on average, emotional difficulty was moderately low ( $M = 1.7$ ,  $SE = 0.1$ ). Approximately 24% of PWDs had fallen in the last month and 16% had two or more hospitalizations in the past year.

We next estimated a multinomial logistic regression to consider demographic characteristics, primary stressors, secondary strains, and adverse health events as predictors of emotional difficulty of care (complete model results in Table 2). Demographic characteristics and primary stressors were largely not significantly associated with caregiver emotional difficulty. Being an adult child caregiver (OR: 1.94, CI: 1.17–3.22,  $p < .05$ ) and experiencing overload (OR: 2.32, CI: 1.65–3.25,  $p < .001$ ) were associated with increased emotional difficulty. Among the secondary strains and resources, however, there were more significant covariates in the model. Experiencing more caregiving gains was associated with reduced reports of experiencing emotional difficulty (OR: 0.79, CI: 0.69–0.90,  $p < .001$ ), whereas experiencing family disagreement surrounding care for the PWD was associated with increased emotional difficulty (OR: 1.70, CI: 1.03–2.81,  $p < .05$ ). Whereas a past month fall by the PWD was associated with increased care-related emotional difficulty (OR: 1.65, CI: 1.09–2.48,  $p < .05$ ), hospitalizations in the past year were not. As a post hoc test to examine the stability of findings, we did consider a dichotomous indicator of hospitalization (past year hospitalization vs. no past year hospitalization) and hospitalization remained insignificant. As an additional post hoc test, controls for caregiver employment, other individuals living

**Table 1.** Sample Characteristics for Persons With Dementia and Their Caregivers, National Study of Caregiving and National Health and Aging Trends Study, 2015 (PWD  $N = 430$ , Caregiver  $N = 652$ )

Variable	Mean or %, $n$	Standard error	Range
Caregiver variables ( $N = 652$ )			
Emotional difficulty of care	1.7	0.1	0–5
Age	59.8	0.5	18–96
Female	71.0%, 463/652		
Education			
Less than high school	11.0%, 72		
High school	59.4%, 387		
College	29.6%, 193		
Relation to PWD			
Spouse	14.0%, 94		
Adult child	55.0%, 373		
Other	28.4%, 185		
Chronic medical conditions	1.7	0.1	0–7
Assistance with mobility tasks	0.9	0.0	0–3
Assistance with household chores	2.6	0.1	0–5
Assistance with self-care tasks	0.9	0.1	0–4
Role overload	0.8	0.0	0–2
Has care help from family or friends	75.2%, 490/652		
Caregiving gains	6.4	0.1	0–8
Family disagreement about care	21.3%, 139/652		
PWD variables ( $N = 430$ )			
Fall in the last month	23.5%, 101/430		
Hospitalizations in the last year			
None	64.9%, 279		
1	19.1%, 82		
2 or more	16.0%, 69		

Note: PWD = person with dementia.

in the caregiver's household, and caregiver use of a formal service to support care provision were included; however, these were not significantly associated with care-related emotional difficulty and did not affect the significance of the adverse health events. Thus, they were removed to maintain parsimony of the final model.

## Discussion and Implications

Informal caregiving by a relative or friend is critical to the well-being of many individuals with dementia, yet can be detrimental to the mental health of the caregiver. In our national U.S. sample of caregivers for individuals with

dementia, one in five reported high emotional difficulty related to care. The Stress Process Model posits that contextual characteristics, primary stressors, secondary strains and resources all impact caregiver emotional and physical health. Emotional care-related difficulty is a key outcome of concern because prior work has identified a host of negative outcomes for both the caregiver (e.g., depression) and the caregiver's care provision (e.g., potentially harmful care behaviors) associated with increased caregiving stress (Alzheimer's Association, 2017; Fonareva & Oken, 2014; MacNeil et al., 2010; Perkins et al., 2013; Schulz & Beach, 1999; von Känel et al., 2006). We sought to examine whether adverse health events among PWDs contribute to caregiver emotional difficulty beyond these key factors.

In support of our primary research question, the PWD's prior month fall was associated with increased odds of caregivers' care-related emotional difficulty even controlling for demographic characteristics and primary and secondary strains. Although hospitalization within the past year was relatively common for NHATS participants, the number of hospitalizations was not significantly associated with care-related emotional difficulty. Falls signify an adverse health event that may be related to the primary stressors of dementia such as functional impairment and problematic behaviors and are highly associated with an outcome of the stress process, care-related emotional difficulty, over and above these primary stressors.

Although falls have been recognized as an adverse outcome for older adults, there has been less focus on its impact on the caregiver. A fall by PWD may increase caregivers' emotional care-related difficulty through several mechanisms: the need for urgent decisions and medical care; adjusted routines; a decline in the PWD's abilities for self-care and participation in social activities; and fear of another fall and the challenges such a crisis can bring (Boltz et al., 2015; Gill, Desai, Gahbauer, Holford, & Williams, 2001; Tinetti & Williams, 1998). A fall may represent a key intervention point for caregivers to ensure they have the appropriate supports and services to aid them in handling a crisis, in addition to the regular activities of care. Intervention is particularly important as caregiver distress and burden has been associated with such negative outcomes as higher caregiver mortality, as well as potentially harmful behaviors (e.g., yelling, hitting) toward the care recipient (Beach et al., 2005; Schulz & Beach, 1999). Furthermore, distressed caregivers are more likely to place their care recipient in a long-term care facility, suggesting that the caregiver may have depleted his or her emotional and/or physical capacity to provide care independently (Coehlo, Hooker, & Bowman, 2007).

Hospitalizations were not significantly associated with caregiver emotional difficulties. Perhaps this is in part because the type of hospitalization may vary dramatically across PWDs. For example, hospitalizations for a routine procedure or scheduled surgery may have a different impact on a caregiver than hospitalization for an

**Table 2.** Predictors of Care-Related Emotional Difficulties Among Caregivers for a Person With Dementia (National Health and Aging Trends Study and National Study of Caregiving, 2015; *N* = 652)

Variable	Adjusted odds ratio	Confidence limits
Age	0.98	0.96–1.00
Female	1.34	0.84–2.13
Less than high school	0.47	0.21–1.06
High school	0.70	0.43–1.04
Spouse caregiver	1.45	0.80–2.60
Adult child caregiver	1.94*	1.17–3.22
Chronic medical conditions	0.96	0.86–1.07
Mobility support	1.05	0.84–1.30
IADL support	1.03	0.92–1.15
ADL support	1.09	0.90–1.33
Role overload	2.32***	1.65–3.25
Care support from family/friends	0.75	0.48–1.16
Caregiving gains	0.79***	0.69–0.90
Family disagreement	1.70*	1.03–2.81
PWDs' last month fall	1.65*	1.09–2.48
PWDs' last year hospitalization	1.11	0.84–1.47
Wald test	4.96 (16, 56)***	

Note: ADL = activities of daily living; IADL = instrumental activities of daily living; PWD = person with dementia. The multinomial logistic regression model is weighted to account for sample selection and adjusted for the complex survey design.

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

unexpected medical emergency (Sadak et al., 2017), yet they were not distinguished by the NHATS item. In addition, regardless of the type of hospitalization, the question assessed hospitalizations within the past 12 months with no specific hospitalization date ascertained. In contrast, asking about past month hospitalization may have yielded a different caregiver response. As a post hoc test, we considered a dichotomous indicator of hospitalization (past year hospitalization vs. no past year hospitalization) and the results did not change (analysis not shown), implying that hospitalization alone is not associated with stress and more contextual information about the hospitalization is needed. Future work may consider how the type and timing of a hospitalization is associated with caregiver stress.

Of note in our study, emotional care-related difficulty was largely not associated with demographic characteristics of the caregiver or primary stressors of the care context such as care provision for self-care activities, mobility tasks, and household chores. Furthermore, we also considered controls for caregiver employment, other individuals living in the caregiver's household, and whether or not the caregiver used a formal service to support care provision; however, these were not significantly associated with emotional difficulty of care and did not affect the significance of

the adverse health events and thus were removed to maintain parsimony of the final model. The secondary strains and resources, however, were especially strong predictors of care-related emotional difficulty, supporting the Stress Process Model that suggests that how the primary stressors associated with dementia proliferate into other areas of the caregiver's life is of key importance to the emotional difficulty reported. Experiencing family disagreements surrounding the care of the PWD was associated with increased risk of emotional care-related difficulty, whereas the experience of caregiving gains, or positive aspects of care, protected caregivers from such emotional difficulty.

There are several implications from our findings that sudden, potentially unanticipated events such as a fall among PWDs can increase a caregiver's care-related emotional difficulty over and above the declining functional and cognitive capabilities of their relative with dementia. First, a fall by a PWD may be an indicator for a clinician to inquire about the mental health and well-being of caregivers and offer additional supports. For example, if a PWD were to present to an emergency room following a fall, a social worker might assess accompanying caregivers for burden and offer information on home and community-based resources. The CDC has developed a tool kit specifically designed for health care providers to include a fall risk assessment and intervention in their practice for older adults (Stevens & Phelan, 2013). Furthermore, there are a number of preventive actions caregivers may take to help prevent a PWD from falling including working to correct vision impairments, modifying the physical environment of the home such as incorporating railings or adding an automated stair chair lift, checking for any medications that may be increasing risk, and improving management of behavioral disturbances and activities of daily living (Härlein, Dassen, Halfens, & Heinze, 2009; Shaw, 2007). A recent meta-analysis also suggests that exercise interventions and even calcium supplements may have a significant impact on reducing falls (Tricco et al., 2017). Ultimately, it is important to consider that sudden adverse events such as an acute medical illness or fall may be dramatically increasing caregiver stress, yet often go unaccounted in modeling the stress process.

### Limitations

In this study, we were not able to determine the type of hospitalization and/or whether it was considered preventable, both factors that may affect resulting emotional caregiving difficulties. In addition, the hospitalization may have been up to 12 months before the caregiver was interviewed, so the caregiver may have provided different responses than had they been interviewed closer to the admission. Although falls were ascertained during a more recent time period, the seriousness of a fall was not ascertained (e.g., whether it required a visit to the emergency department or resulted in serious injury). History was assessed for both

adverse events; thus, survival bias could lead to a sample of PWDs who survived these events thereby representing a healthier sample. However, this would be more of a limitation in analyzing longitudinal outcomes in NHATS rather than our cross-sectional analysis. As caregivers in the study are not necessarily the “primary” caregiver responsible for the majority of care, it is also possible that impact from a fall or hospitalization was directly experienced by another caregiver who did not participate in NSOC (furthermore, 40% of PWDs had more than one caregiver and it is possible that only one dealt with the adverse event). In addition, as the NSOC study was not specific to caregivers of PWDs but of older adults with functional disability, primary stressors specific to dementia such as behavioral and psychological symptoms (e.g., agitation, aggression) were not ascertained. Dementia-specific stressors might give a more sensitive measure of the severity of dementia-specific caregiving and be more strongly associated with emotional care-related difficulty. Finally, due to the cross-sectional nature of the study, we cannot imply causation. Despite these limitations, we are able to extend Pearlin’s Stress Process Model to include adverse health events in a large and diverse sample of caregivers for PWDs in the United States.

In conclusion, falls among PWDs are a significant stressor that challenges caregiver well-being over and above other aspects of the care situation such as provision of care for a PWD’s functional decline and mobility challenges. Although a hospitalization may also cause significant stress, stress may vary by the urgent nature or length and seriousness of the hospitalization as to the ultimate toll it takes on a caregiver’s emotional distress. Thus, it may be important to consider a caregiver’s own fear of the PWD’s falls, and how this fear may affect their care provision. Caregivers can take preventative measures in aims of avoiding a fall, but should also be prepared with a plan for handling such a crisis when it occurs. Furthermore, clinicians should keep in mind that in addition to addressing any injury or medical emergency on behalf of a PWD, caregivers may themselves be in need of support and care during the adverse event. Interventions at this critical time may reduce caregivers’ reported emotional difficulty related to care and subsequently improve the care provided to PWDs.

## Funding

This study was supported by the University of Michigan Program for Positive Aging. C. A. Polenick was supported by training grant T32 MH 073553-11 from the National Institute of Mental Health (Stephen J. Bartels, Principal Investigator).

## Conflict of Interest

None reported.

## References

- Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *JAMA*, *311*, 1052–1060. doi:10.1001/jama.2014.304
- Allan, L. M., Ballard, C. G., Rowan, E. N., & Kenny, R. A. (2009). Incidence and prediction of falls in dementia: A prospective study in older people. *PLoS One*, *4*, e5521. doi:10.1371/journal.pone.0005521
- Alzheimer’s Association. (2017). Alzheimer’s disease facts and figures. *Alzheimer’s and Dementia*, *13*, 325–373. doi:10.1016/j.jalz.2017.02.001
- Aneshensel, C. S. (1995). *Profiles in caregiving: The unexpected career*. San Diego, CA: Academic Press.
- Bail, K., Goss, J., Draper, B., Berry, H., Karmel, R., & Gibson, D. (2015). The cost of hospital-acquired complications for older people with and without dementia: A retrospective cohort study. *BMC Health Services Research*, *15*, 91. doi:10.1186/s12913-015-0743-1
- Baker, N. L., Cook, M. N., Arrighi, H. M., & Bullock, R. (2011). Hip fracture risk and subsequent mortality among Alzheimer’s disease patients in the United Kingdom, 1988-2007. *Age and Ageing*, *40*, 49–54. doi:10.1093/ageing/afq146
- Beach, S. R., Schulz, R., Williamson, G. M., Miller, L. S., Weiner, M. F., & Lance, C. E. (2005). Risk factors for potentially harmful informal caregiver behavior. *Journal of the American Geriatrics Society*, *53*, 255–261. doi:10.1111/j.1532-5415.2005.53111.x
- Benner, M., Steiner, V., & Pierce, L. L. (2016). Family caregivers’ reports of hospitalizations and emergency department visits in community-dwelling individuals with dementia. *Dementia*. Advance online publication. doi:10.1177/1471301216653537
- Bergen, G., Stevens, M. R., & Burns, E. R. (2016). Falls and fall injuries among adults aged ≥65 years – United States, 2014. *MMWR. Morbidity and Mortality Weekly Report*, *65*, 993–998. doi:10.15585/mmwr.mm6537a2
- Bloomer, M., Digby, R., Tan, H., Crawford, K., & Williams, A. (2016). The experience of family carers of people with dementia who are hospitalised. *Dementia*, *15*, 1234–1245. doi:10.1177/1471301214558308
- Boltz, M., Chippendale, T., Resnick, B., & Galvin, J. E. (2015). Anxiety in family caregivers of hospitalized persons with dementia: Contributing factors and responses. *Alzheimer Disease and Associated Disorders*, *29*, 236–241. doi:10.1097/WAD.0000000000000072
- Borbasi, S., Jones, J., Lockwood, C., & Emden, C. (2006). Health professionals’ perspectives of providing care to people with dementia in the acute setting: Toward better practice. *Geriatric Nursing*, *27*, 300–308. doi:10.1016/j.gerinurse.2006.08.013
- Bynum, J. P., Rabins, P. V., Weller, W., Niefeld, M., Anderson, G. F., & Wu, A. W. (2004). The relationship between a dementia diagnosis, chronic illness, Medicare expenditures, and hospital use. *Journal of the American Geriatrics Society*, *52*, 187–194. doi:10.1111/j.1532-5415.2004.52054.x
- Coehlo, D. P., Hooker, K., & Bowman, S. (2007). Institutional placement of persons with dementia: What predicts occurrence and timing? *Journal of Family Nursing*, *13*, 253–277. doi:10.1177/1074840707300947
- Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience.

- International Journal of Geriatric Psychiatry*, 17, 184–188. doi:10.1002/gps.561
- Cumming, R. G., Salkeld, G., Thomas, M., & Szonyi, G. (2000). Prospective study of the impact of fear of falling on activities of daily living, SF-36 scores, and nursing home admission. *The Journals of Gerontology, Series A: Biological Sciences and Medical Sciences*, 55, M299–M305. doi:10.1093/gerona/55.5.M299
- de Labra, C., Millán-Calenti, J. C., Buján, A., Núñez-Naveira, L., Jensen, A. M., Peersen, M. C.,...Maseda, A. (2015). Predictors of caregiving satisfaction in informal caregivers of people with dementia. *Archives of Gerontology and Geriatrics*, 60, 380–388. doi:10.1016/j.archger.2015.03.002
- Feng, Z., Coats, L. A., Kaganova, Y., & Wiener, J. M. (2014). Hospital and ED use among Medicare beneficiaries with dementia varies by setting and proximity to death. *Health Affairs*, 33, 683–690. doi:10.1377/hlthaff.2013.1179
- Fonareva, I., & Oken, B. S. (2014). Physiological and functional consequences of caregiving for relatives with dementia. *International Psychogeriatrics*, 26, 725–747. doi:10.1017/S1041610214000039
- Gill, T. M., Desai, M. M., Gahbauer, E. A., Holford, T. R., & Williams, C. S. (2001). Restricted activity among community-living older persons: Incidence, precipitants, and health care utilization. *Annals of Internal Medicine*, 135, 313–321. doi:10.7326/0003-4819-135-5-200109040-00007
- Hardin, J. W., & Hilbe, J. M. (2003). *Generalized estimating equations*. New York: Chapman & Hall/CRC.
- Härlein, J., Dassen, T., Halfens, R. J., & Heinze, C. (2009). Fall risk factors in older people with dementia or cognitive impairment: A systematic review. *Journal of Advanced Nursing*, 65, 922–933. doi:10.1111/j.1365-2648.2008.04950.x
- Hinrichsen, G. A., & Zweig, R. (1994). Family issues in late-life depression. *Journal of Long Term Home Health Care: The PRIDE Institute Journal*, 13, 4–15.
- Kasper, J. D., Freedman, V. A., & Spillman, B. C. (2013a). *Classification of persons by dementia status in the National Health and Aging Trends Study*. Technical Paper #5. Retrieved from [www.NHATS.org](http://www.NHATS.org)
- Kasper, J. D., Freedman, V. A., & Spillman, B. C. (2013b). *National study of caregiving user guide*. Retrieved from [https://www.nhats.org/scripts/documents%5CNSOC\\_Round\\_1\\_User\\_Guide.pdf](https://www.nhats.org/scripts/documents%5CNSOC_Round_1_User_Guide.pdf)
- Kressig, R. W., Wolf, S. L., Sattin, R. W., O'Grady, M., Greenspan, A., Curns, A., & Kutner, M. (2001). Associations of demographic, functional, and behavioral characteristics with activity-related fear of falling among older adults transitioning to frailty. *Journal of the American Geriatrics Society*, 49, 1456–1462. doi:10.1046/j.1532-5415.2001.4911237.x
- Kuzuya, M., Masuda, Y., Hirakawa, Y., Iwata, M., Enoki, H., Hasegawa, J.,...Iguchi, A. (2006). Falls of the elderly are associated with burden of caregivers in the community. *International Journal of Geriatric Psychiatry*, 21, 740–745. doi:10.1002/gps.1554
- Lin, R. J., Adelman, R. D., Diamond, R. R., & Evans, A. T. (2014). The sentinel hospitalization and the role of palliative care. *Journal of Hospital Medicine*, 9, 320–323. doi:10.1002/jhm.2160
- MacNeil, G., Kosberg, J. I., Durkin, D. W., Dooley, W. K., Decoster, J., & Williamson, G. M. (2010). Caregiver mental health and potentially harmful caregiving behavior: The central role of caregiver anger. *The Gerontologist*, 50, 76–86. doi:10.1093/geront/gnp099
- Maslow, K. (2006). How many people with dementia are hospitalized? In N. Silverstein & K. Maslow (Eds.), *Improving hospital care for persons with dementia* (pp. 3–22). New York: Springer Publishing Company.
- Maust, D. T., Kales, H. C., McCammon, R. J., Blow, F. C., Leggett, A., & Langa, K. M. (2017). Distress associated with dementia-related psychosis and agitation in relation to healthcare utilization and costs. *The American Journal of Geriatric Psychiatry*, 25, 1074–1082. doi:10.1016/j.jagp.2017.02.025
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583–594. doi:10.1093/geront/30.5.583
- Perkins, M., Howard, V. J., Wadley, V. G., Crowe, M., Safford, M. M., Haley, W. E.,...Roth, D. L. (2013). Caregiving strain and all-cause mortality: Evidence from the REGARDS study. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 68, 504–512. doi:10.1093/geronb/gbs084
- Phelan, E. A., Borson, S., Grothaus, L., Balch, S., & Larson, E. B. (2012). Association of incident dementia with hospitalizations. *JAMA*, 307, 165–172. doi:10.1001/jama.2011.1964
- Rudolph, J. L., Zanin, N. M., Jones, R. N., Marcantonio, E. R., Fong, T. G., Yang, F. M.,...Inouye, S. K. (2010). Hospitalization in community-dwelling persons with Alzheimer's disease: Frequency and causes. *Journal of the American Geriatrics Society*, 58, 1542–1548. doi:10.1111/j.1532-5415.2010.02924.x
- Sadak, T., Foster Zdon, S., Ishado, E., Zaslavsky, O., & Borson, S. (2017). Potentially preventable hospitalizations in dementia: Family caregiver experiences. *International Psychogeriatrics*, 29, 1201–1211. doi:10.1017/S1041610217000217
- Sánchez-Izquierdo, M., Prieto-Ursúa, M., & Caperos, J. M. (2015). Positive aspects of family caregiving of dependent elderly. *Educational Gerontology*, 41, 745–756. doi:10.1080/03601277.2015.1033227
- Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshahi, M. (2006). Caregiver-burden in Parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. *Parkinsonism & Related Disorders*, 12, 35–41. doi:10.1016/j.parkreldis.2005.06.011
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *JAMA*, 282, 2215–2219. doi:10.1001/jama.282.23.2215
- Shaw, F. E. (2003). Falls in older people with dementia. *Geriatrics & Aging*, 6, 699–704.
- Shaw, F. E. (2007). Prevention of falls in older people with dementia. *Journal of Neural Transmission (Vienna, Austria: 1996)*, 114, 1259–1264. doi:10.1007/s00702-007-0741-5
- Shaw, F. E., Bond, J., Richardson, D. A., Dawson, P., Steen, I. N., McKeith, I. G., & Kenny, R. A. (2003). Multifactorial intervention after a fall in older people with cognitive impairment and dementia presenting to the accident and emergency department: Randomised controlled trial. *BMJ*, 326, 73. doi:10.1136/bmj.326.7380.73
- Stevens, J. A., & Phelan, E. A. (2013). Development of STEADI: A fall prevention resource for health care providers. *Health Promotion Practice*, 14, 706–714. doi:10.1177/1524839912463576



- Tinetti, M. E., Speechley, M., & Ginter, S. F. (1988). Risk factors for falls among elderly persons living in the community. *The New England Journal of Medicine*, *319*, 1701–1707. doi:10.1056/NEJM198812293192604
- Tinetti, M. E., & Williams, C. S. (1997). Falls, injuries due to falls, and the risk of admission to a nursing home. *The New England Journal of Medicine*, *337*, 1279–1284. doi:10.1056/NEJM199710303371806
- Tinetti, M. E., & Williams, C. S. (1998). The effect of falls and fall injuries on functioning in community-dwelling older persons. *The Journals of Gerontology, Series A: Biological Sciences and Medical Sciences*, *53*, M112–M119. doi:10.1093/gerona/53A.2.M112
- Tricco, A. C., Thomas, S. M., Veroniki, A. A., Hamid, J. S., Cogo, E., Striffler, L.,...Straus, S. E. (2017). Comparisons of interventions for preventing falls in older adults: A systematic review and meta-analysis. *JAMA*, *318*, 1687–1699. doi:10.1001/jama.2017.15006
- van Dijk, P. T. M., Meulenberg, O. G. R. M., van de Sande, H. J., & Habbema, J. D. F. (1993). Falls in dementia patients. *The Gerontologist*, *33*, 200–204. doi:10.1093/geront/33.2.200
- von Känel, R., Dimsdale, J. E., Mills, P. J., Ancoli-Israel, S., Patterson, T. L., Mausbach, B. T., & Grant, I. (2006). Effect of Alzheimer caregiving stress and age on frailty markers interleukin-6, C-reactive protein, and D-dimer. *The Journals of Gerontology, Series A: Biological Sciences and Medical Sciences*, *61*, 963–969. doi:10.1093/gerona/61.9.963
- Zarit, S. H. (2008). Diagnosis and management of caregiver burden in dementia. In Dementias. C. Duyckaerts, I. Litvan, (Eds.). *Handbook of clinical neurology* (Vol. 89, pp. 101–106). Amsterdam, The Netherlands: Elsevier.
- Zekry, D., Herrmann, F. R., Grandjean, R., Vitale, A. M., De Pinho, M. F., Michel, J. P.,...Krause, K. H. (2009). Does dementia predict adverse hospitalization outcomes? A prospective study in aged inpatients. *International Journal of Geriatric Psychiatry*, *24*, 283–291. doi:10.1002/gps.2104