



Published in final edited form as:

*J Am Geriatr Soc.* 2019 February ; 67(2): 277–283. doi:10.1111/jgs.15664.

## A Multifactorial Examination of Caregiver Burden in a National Sample of Family and Unpaid Caregivers

Catherine Riffin, PhD<sup>1,a</sup>, Peter H. Van Ness, PhD, MPH<sup>2</sup>, Jennifer L. Wolff, PhD<sup>3</sup>, and Terri Fried, MD<sup>2,4</sup>

<sup>1</sup>Department of Internal Medicine, Weill Cornell Medicine, New York, NY

<sup>2</sup>Department of Internal Medicine, Yale University School of Medicine, New Haven, CT

<sup>3</sup>Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

<sup>4</sup>Veterans Affairs Connecticut Healthcare System, West Haven, CT

### Abstract

**OBJECTIVES:** To examine the factors associated with caregiver burden from a multifactorial perspective by including caregiver and care recipient characteristics and a full range of caregiving tasks.

**DESIGN:** Nationally-representative surveys of community-dwelling older adults and their family caregivers residing in the United States.

**SETTING:** 2011 National Health and Aging Trends Study and National Study of Caregiving.

**PARTICIPANTS:** Community-dwelling older adults and their family caregivers

**MEASUREMENTS:** Caregiver burden, comprised of emotional, physical, and financial difficulties associated with caregiving.

**RESULTS:** An estimated 14.9 million caregivers provided assistance to 7.6 million care recipients. More than half of caregivers reported burden related to caregiving. In a multivariable regression model, caregivers who provided assistance with a greater number of ADL/IADL activities, health management tasks, and health systems logistics were more likely to experience burden, as were female caregivers, adult child caregivers, caregivers with poor health, anxiety symptoms, and those using respite care. Dementia was the only care recipient characteristic associated with burden.

**CONCLUSION:** Results suggest that caregiver burden is determined more by the characteristics of the caregiver and the provision of caregiving tasks than by characteristics of the care recipient.

<sup>a</sup>To whom correspondence should be addressed: Catherine Riffin, Division of Geriatrics and Palliative Medicine, Weill Cornell Medicine, 525 East 68<sup>th</sup> Street, Box 39, New York City, NY 10066, Telephone: 781-454-6126. acr2213@med.cornell.edu.

**Author Contributions:** Riffin: study concept and design; data analysis and interpretation; drafting and preparing the manuscript. VanNess: interpretation of data; editing of manuscript. Wolff: statistical advice on data analysis and weighting procedures; editing of manuscript. Fried: study supervision; interpretation of data; editing of manuscript. All authors: revision of manuscript for important intellectual content.

**Conflict of Interest:** The authors have no financial, personal, or potential conflicts of interest to disclose.

**Sponsor's Role.** No sponsor placed any restriction on this work or had any role in the design of the study; data collection, analysis, or interpretation; or preparation of this manuscript.

The absence of an association between the type of care recipients' chronic conditions and burden, except for dementia, suggests that the experience of caregiving is shaped by the tasks undertaken by caregivers who assist older adults with a variety of health conditions.

## Keywords

Informal caregiver; caregiver burden; caregiving

## INTRODUCTION

Strong evidence indicates that the burdens of caregiving, defined as its physical, emotional, and financial hardships,<sup>1</sup> are prevalent among family and other unpaid helpers.<sup>2-4</sup> Numerous studies examining disease-specific cohorts have identified a higher risk of adverse outcomes, including diminished physical and emotional health, among female caregivers and caregivers who are assisting care recipients with high levels of cognitive or physical impairment.<sup>5,6,7,8</sup> Research has also provided consistent evidence for the links between the provision of ADL and IADL assistance with caregiver burden.<sup>9,10</sup>

Recently, there has been growing appreciation of family and other unpaid caregivers' involvement in health care tasks beyond ADLs and IADLs.<sup>11-13</sup> Several studies have demonstrated significant relationships of the provision of other types of assistance (e.g. health systems logistics, nursing tasks) with burden and adverse outcomes, including restrictions on social participation, work productivity loss, and poor health,<sup>13-15</sup> but these associations have not been fully evaluated in a multifactorial context. In the absence of multivariable regression modeling, the interrelationships among these factors are less clear, especially given prior research showing associations between the provision of assistance (ADLs/IADLs) and patient (i.e. cancer and dementia)<sup>16</sup> and caregiver characteristics (i.e. female gender).<sup>17</sup>

While prior studies have demonstrated multiple determinants of caregiver burden, there are two important gaps in the literature. First, no study has simultaneously examined the various types of assistance that caregivers provide while also considering other potential determinants of burden, namely caregiver and care recipient characteristics. Second, most studies examining the risk factors for burden have focused on selected cohorts defined by care recipient disease diagnosis,<sup>10,18,19</sup> thus limiting our understanding of the caregiving experience to certain subsets of the broader caregiver population.

The present study builds on the existing literature by examining caregiver burden from a multifactorial perspective in a nationally representative cohort of older persons and their caregivers.<sup>20,21</sup> In this secondary data analysis, we comprehensively examine risk factors for caregiver burden, including characteristics of the caregiver, characteristics of the care recipient, as well as a broad range of caregiving tasks.

## METHODS

### Data Source

The data for this study come from the 2011 National Health and Aging Trends Study (NHATS) and its linked National Study of Caregiving (NSOC). The NHATS is a longitudinal panel study of US Medicare beneficiaries (aged 65 and older) living in the community and in residential care settings.<sup>22</sup> In round 1 (2011), in-person interviews were conducted with 7,609 older persons or proxy respondents if the participant was unable to respond (71% response rate of the total approached).<sup>20</sup> Proxy respondents provided information for NHATS participants who had a severe illness, a speech or hearing impairment, a language barrier, or dementia or cognitive impairment reported by the proxy.

The NSOC is a telephone survey of family and other unpaid caregivers who assist NHATS participants. NHATS participants who received assistance with at least one mobility, self-care, or household task for health and functioning reasons (n=2,423) were asked to identify each of their caregivers. Of the 4,935 identified caregivers, there were 1,573 caregivers for whom NHATS participants refused to provide contact information. Of the remaining 3,362 caregivers, 1,355 could not be located or refused to respond. In total, 2,007 caregivers participated in the NSOC. Because the nature of caregiving is likely to differ for older adults living in residential care facilities due to the availability of supportive services, we limited our analysis to older adults living in community settings, leaving a final sample of 1,742 family and other unpaid caregivers who assisted 1,171 community-dwelling older care recipients.

Observations from the NHATS and NSOC are weighted to produce nationally representative estimates and to account for the complex sampling strategy of each survey. As in other household surveys (e.g., Medical Expenditure Panel Survey, National Health Interview Survey), special design variables associated with the NSOC account for the non-independence among multiple caregivers for a given care recipient.

## MEASURES

### Types of Assistance

Caregivers were asked whether they provided assistance with each of 16 tasks. Following the categorization set forth in prior studies using NSOC data,<sup>13,15</sup> specific tasks were grouped into three types of assistance: ADL/IADL-related, health management, and health systems logistics. ADL/IADL-related assistance was comprised of: help with shopping, transportation, housework, mobility, banking, and self-care. Health management was comprised of: help with diet, foot care, skin care, exercise, dental care. Health systems logistics was comprised of: making appointments, ordering medicines, handling insurance issues, keeping track of medications, and speaking with the care recipient's medical provider. Within each type of assistance, the number of tasks for which help was provided was summed to form a composite measure.<sup>15</sup> Caregivers were asked whether they assisted with ADL/IADL-related activities and health management tasks in the past month; the reference period for health system logistics was in the past year because these tasks are typically undertaken less frequently.

## Characteristics of Caregivers and Care Recipients

Caregiver and care recipient characteristics included sociodemographic and health variables, as well as measures pertaining to caregivers' use of supportive services and availability of help from others.

Caregiver sociodemographic variables included age, gender, education, marital status, and relationship to the care recipient. Health variables included caregiver's self-reported health, depressive symptoms (assessed by the PHQ-2; a score of 3 is indicative of probable depression)<sup>23</sup> and anxiety symptoms (assessed by the GAD-2; a score of 3 is indicative of probable anxiety).<sup>24</sup> Caregiver's use of support services was characterized as receipt of training for caregiving, use of respite care, and attendance at a caregiver support group in the past year. Additional variables included the average number of hours they provided care for the NHATS participant per week, and the availability of family or friends to help with caregiving.

Care recipient sociodemographic variables included age, gender, and race. Health variables included self-reported health, number of specific chronic health conditions (cancer, stroke, lung disease, heart attack, heart disease, high blood pressure, arthritis, osteoporosis, diabetes), depressive symptoms (assessed by the PHQ-2)<sup>23</sup> and anxiety symptoms (assessed by the GAD-2).<sup>24</sup> Four health conditions (cancer, stroke, lung disease, heart attack) were examined individually because they have received the greatest attention in the caregiving literature as imposing caregiving-related burden.<sup>3</sup> A composite measure of care recipients' dementia/disability status was constructed by using previously established algorithms for defining dementia and disability in the NHATS cohort.<sup>25–29</sup> These characterizations have been used in prior research to define meaningful subgroups by dementia status and disability.<sup>3,15,25,29</sup> Probable dementia was defined on the basis of: a self-reported physician diagnosis of dementia or Alzheimer's disease; a score of 2 on the AD8 screening instrument administered to proxy respondents; or a score of 1.5 Standard Deviations below the mean on a battery of cognitive tests.<sup>27</sup> Substantial disability was defined as the receipt of assistance with two or more self-care or mobility activities in the last month (i.e., eating, dressing, bathing, toileting, transferring, and getting around inside one's home). Based on these criteria, care recipients were categorized into four mutually exclusive groups: those with dementia and substantial disability, dementia but not substantial disability, no dementia but substantial disability, and no dementia or substantial disability.

## Caregiver Burden

While caregiver burden has been measured in a variety of ways,<sup>30–32</sup> these measures frequently encompass a combination of objective (physical demands, financial consequences) and subjective (emotional) hardships. Drawing upon the available measures in the NSOC, we selected items that have been used in prior research to capture objective and subjective burdens,<sup>21,25</sup> including the emotional, physical and financial difficulties associated with care provision. Participants were asked three questions about whether caregiving was emotionally, physically, or financially difficult (0=no, 1=yes). Responses to these questions were summed, and caregivers were categorized into those who experienced

“no burden,” defined as a score of 0 versus those who experienced “any burden,” defined as a score of 1 or greater.

## Statistical Analysis

National estimates of caregivers and care recipients were produced using NSOC and NHATS weights, respectively. Descriptive statistics, including means, standard errors, and percentages were used to summarize the sociodemographic, health and psychosocial characteristics of caregivers and care recipients. Associations between caregiver and care recipient characteristics and caregiver burden were examined in bivariate analyses using chi-square tests of independence for categorical variables and t-test for continuous variables. Relationships among the three assistance variables (ADL/IADL-related, health management, and health systems logistics) and caregiver burden were examined using t-tests.

All caregiver and care recipient characteristics were screened for possible inclusion in a multivariable logistic regression model using the criteria of  $p < .20$  in bivariate analyses. Multicollinearity among the three assistance variables was examined using Pearson correlations ( $r < .50$ ) and variance inflation factors ( $VIF < 10$ ). Collinearity was not sufficiently high to preclude entering all three variables into one model: ADL/IADL-related assistance was modestly correlated with health management ( $r = .38$ ,  $p < .001$ ) and with health systems logistics ( $r = .32$ ,  $p < .001$ ); health management and health systems logistics were also modestly correlated ( $r = .41$ ,  $p < .001$ ). No VIFs were problematic. We therefore constructed a model in which all three variables were entered simultaneously. Residuals and model fit statistics were examined. The adjusted (maximum-rescaled)  $R^2$  is reported for the multivariable logistic regression model as an indicator of the overall model fit. Odds ratios with 95% confidence intervals are reported.

The descriptions of care recipients' characteristics incorporate NHATS weights that take into account the complex sampling strategy of NHATS and produce nationally representative estimates.<sup>33</sup> The descriptions of caregivers' characteristics incorporate NSOC weights, which are also used in multivariable modeling because the unit of analysis is the caregiver.<sup>34</sup> All analyses use survey commands that incorporate the strata and clustering elements of the sample design and were conducted using SAS, version 9.4 (SAS Institute Inc.). The extent and nature of missing data were examined. Item non-response was generally low, and missing values were imputed using single imputation.

## RESULTS

### Description of study cohort

Caregivers' and care recipients' characteristics are provided in Tables 1 and 2. An estimated 15.0 million caregivers provided assistance to 7.6 million older care recipients. On average, caregivers were 57.1 years of age ( $SE = 0.7$ ). The majority were female (62.2%) and most were not married (63.4%); 46.2% were adult children, 22.9% were spouses, and 31.0% were other relatives or friends. One-fifth (21.1%) of caregivers self-reported poor physical health; approximately 13% reported symptoms of depression (12.7%) or anxiety (12.8%). Few caregivers used supportive services, including caregiver training (7.0%), respite care

(10.4%), or support groups (4.4%). Caregivers spent an average of 18.3 hours per week (SE=0.8) assisting the care recipients. More than two-thirds (70.4%) reported having family or friends who could help with caregiving. More than one half experienced caregiver burden (56.1%). On average, caregivers provided 4.0 IADL- and ADL-related tasks (SE=0.1), 1.3 health management tasks (SE=0.0), and 2.5 health systems tasks (SE=0.1).

Care recipients had a mean age of 78.3 years (SE=0.2). The majority were white (82.1%) and female (67.5%). One-half reported themselves to be in fair or poor health (54.1%); nearly one-third experienced depressive (30.3%) and/or anxiety symptoms (26.6%). Care recipients reported a mean of 4.5 comorbid health conditions (SE=0.0). More than half of care recipients had neither dementia nor substantial disability (54.1%); 17.6% had substantial disability but not dementia; 14.2% had dementia but not substantial disability; the remaining 14.1% had dementia and substantial disability.

### **Associations of Types of Assistance and Caregiver and Care Recipient Characteristics with Caregiver Burden**

Table 3 shows the candidate variables that were associated with burden at a significance level of  $p < .20$  and were included the multivariable model. Additional caregiver and care recipient characteristics examined in bivariate analyses were not associated with burden and were therefore excluded from multivariable modeling: caregiver age, level of education, marital status, having family/friends to help with caregiving; care recipient age, race, number of comorbidities, cancer, lung disease, heart attack, and anxiety symptoms.

In the multivariable model (Table 4), female gender (aOR=1.40; 95% CI, 1.04–1.89), being an adult child (aOR=1.54; 95% CI, 1.06–2.24), having fair or poor self-reported health (aOR=2.16; 95% CI, 1.45–3.20), symptoms of anxiety (aOR=1.60; 95% CI, 1.09–2.35), and respite care use (aOR=1.95; 95% CI, 1.16–3.29) were significantly associated with burden. Caregivers assisting care recipients with dementia but not substantial disability (aOR=1.62; 95% CI, 1.10–2.39) or dementia and substantial disability (aOR=1.67; 95% CI, 1.07–2.60) were more likely to experience burden than caregivers assisting care recipients with neither dementia nor substantial disability. However, no statistically significant difference was observed for caregivers assisting care recipients with substantial disability but not dementia (aOR=1.11 95% CI, 0.75–1.65). Providing assistance with a greater number of ADL/IADL activities (adjusted odds ratio (aOR)=1.14; 95% CI, 1.01–1.29), health management tasks (aOR=1.15; 95% CI, 1.02–1.28), and health systems logistics (aOR=1.16; 95% CI, 1.06–1.26) were significantly associated with caregiver burden ( $p < .05$ ). Several factors failed to retain significance in the multivariable model: caregiver spousal relationship, depressive symptoms, receipt of training, support group attendance, hours per week spent caregiving, care recipient poor health, stroke, and care recipient depressive symptoms.

## **DISCUSSION**

In this sample of family and other unpaid caregivers assisting a nationally representative sample of older care recipients, more than one half reported caregiver burden. In a multivariable model examining caregiver and care recipient characteristics and different types of assistance, caregivers who provided assistance with a greater number of ADL/



IADL-related activities, health management tasks, and health systems logistics were more likely to experience burden, as were female caregivers, adult child caregivers, caregivers with self-reported poor health, anxiety symptoms, and caregivers using respite services. Dementia was the only care recipient characteristic that was associated with burden in our multivariable analysis.

A handful of studies have examined associations between the provision of assistance with tasks other than ADLs or IADLs and adverse outcomes for family caregivers. In a recent national study that controlled for patient and caregiver characteristics but not other types of assistance, Wolff and colleagues found that caregivers who assisted with care coordination and medication management were more likely to experience emotional, physical, and financial difficulties; work productivity loss; and participation restrictions in valued activities than caregivers who assisted with neither task.<sup>25</sup> Using unadjusted analyses, another large-scale study showed that caregivers who perform medical and nursing tasks, such as monitoring medical equipment and preparing food for special diets, report taking time off from work, poor physical health, and feelings of worry and hopelessness.<sup>14</sup> Results from the present study add to this literature by using multivariable analyses to demonstrate significant, independent associations of multiple types of assistance—ADL/IADL-related assistance, health management tasks, and health systems logistics—with caregiver burden, while also taking into account caregiver and care recipient characteristics.

A number of factors that were strongly associated with burden in bivariate analyses failed to retain significance when examined in a multivariable context. This finding underscores the value of examining caregiver burden from a multifactorial perspective and further clarifies the interrelationships among these factors. In particular, hours spent caregiving was no longer associated with burden after accounting for the number of caregiving tasks, suggesting that the provision of additional caregiving responsibilities may be more taxing for caregivers than the sheer time demand of providing assistance. Spousal relationship also became non-significant in the multivariable model. It may be that because spouses are more likely to live with the care recipient, they have more opportunities to assume additional caregiving tasks.<sup>35</sup>

Our findings are consistent with prior research indicating that female caregivers are prone to greater distress and burden as a result of caregiving.<sup>8,26,36</sup> Caregivers' physical<sup>37</sup> and emotional health<sup>38,39</sup> were also associated with burden, though the directionality of these relationships remains unclear given the cross-sectional nature of our study design. Research in other caregiving contexts suggests that caregiver burden and health are interrelated, with some studies showing that burden is an antecedent of poor physical and emotional health,<sup>40</sup> and others showing the reverse.<sup>41</sup> Prospective longitudinal investigations will be necessary for determining whether the association between burden and poor health is bidirectional, or whether one of these variables is a cause of the other. Given the relationship between burden and health, it may be appropriate for clinicians to inquire about their patients' caregiving responsibilities and evaluate whether these responsibilities may be related to the patient's physical or emotional well-being.

The findings from our study have implications for advancing the development of interventions to ameliorate burden. Investigators have taken a number of different approaches to addressing caregiver burden.<sup>42,43</sup> Among these approaches, task-specific education and training programs have evidence to suggest their effectiveness. Randomized controlled trials conducted with specific patient populations – namely, cancer<sup>44</sup> and stroke<sup>45</sup> – have demonstrated significant reductions in caregiver burden by providing education and training that is tailored to the tasks that caregivers provide. In the current study, it was the type of assistance, rather than the care recipients' health conditions or disability that was associated with burden, suggesting a common caregiving experience based on the type of assistance provided rather than the diagnosis for which the assistance is needed. These results raise the possibility that training programs designed for selected caregiver samples could be adapted and implemented more broadly among other groups of caregivers, provided that they address the specific tasks that are relevant to the caregiver's situation. The one exception to this was the independent association of care recipient dementia status with caregiver burden. It has been argued that the behavioral disturbances of individuals with dementia increase the burden placed on their caregivers,<sup>46</sup> and the current study confirms the need for interventions that are tailored to the unique needs of dementia caregivers.<sup>47–49</sup>

Several limitations merit comment. Within the NSOC, caregivers were selected on the basis of having provided help with daily tasks, transportation, and medically oriented activities; therefore, results may not be generalizable to caregivers providing assistance with other tasks. The standard errors in our multivariable model may have been underestimated due to decreased variability associated with single imputation, the approach we used to handle missing data. A substantial amount of the variance in caregiver burden remains unexplained by our multivariable analysis; though, the  $R^2$  in our model (.19) is comparable to those reported in a meta-analysis of prior studies examining multivariable associations with caregiver burden.<sup>8</sup> Factors that were not included in this study may account for an additional proportion of the variance in caregiver burden; for example, a recent hospitalization or emergency department visit by the care recipient.<sup>50</sup> Future research may benefit from examining the relationship of these events with the types of assistance that caregivers provide and the overall impact on burden.

## Conclusion

Within this nationally representative cohort of older persons and their caregivers, caregiver burden was associated with the provision of a greater number of ADL/IADL-related, health management, and health systems tasks, with a number of sociodemographic and health characteristics of caregivers, and with provision of assistance to persons with dementia. These results support a multifactorial approach to understanding caregiver burden, encompassing the individual characteristics of the caregiver and care recipient as well as the various types of assistance that caregivers provide.

## ACKNOWLEDGEMENTS

**Funding Source:** Supported in part by the Claude D. Pepper Older Americans Independence Center at the Yale University School of Medicine P30AG021342, and by National Institute on Aging training grant T32AG1934.



NHATS is sponsored by National Institute on Aging Grant NIA U01AG032947 through a cooperative agreement with the Johns Hopkins Bloomberg School of Public Health.

Funding: This work is supported in part by the Claude D. Pepper Older Americans Independence Center at the Yale University School of Medicine (grant number P30AG021342), and by National Institute on Aging training grant (grant number T32AG1934). NHATS is sponsored by National Institute on Aging Grant (grant number U01 AG032947) through a cooperative agreement with the Johns Hopkins Bloomberg School of Public Health.

## REFERENCES

1. George LK, Gwyther LP. Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *Gerontologist*. 1986;26:253–259. [PubMed: 3721232]
2. National Alliance for Caregiving. Caregiving in the U.S Washington DC: AARP Public Policy Institute, 2009.
3. Committee on Family Caregiving for Older Adults, Board on Health Care Services, Health and Medicine Division, & National Academies of Sciences Engineering and Medicine Families Caring for an Aging America. Washington, DC: National Academies of Sciences Engineering Medicine, 2016.
4. Reinhard SC, Feinberg LF, Choula A et al. Valuing the invaluable: 2015 Update. Washington DC: AARP Public Policy Institute, 2015.
5. Sherwood PR, Given C, Given B et al. Caregiver burden and depressive symptoms analysis of common outcomes in caregivers of elderly patients. *J Aging Health*. 2005;17(2):125–147. [PubMed: 15750048]
6. Kim H, Chang M, Rose K et al. Predictors of caregiver burden in caregivers of individuals with dementia. *J Advance Nurs*. 2012;68(4):846–855.
7. Goldstein NE, Concato J, Fried TR et al. Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *J Pall Care*. 2004;20(1):38–43.
8. Pinquart M, Sörensen S. Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *J Gerontol B: Psychol Sci Soc Sci*. 2006;61(1):33–45.
9. Giovannetti ER, Wolff JL, Xue QL et al. Difficulty assisting with health care tasks among caregivers of multimorbid older adults. *J Gen Intern Med*. 2007;22(1):37–44. [PubMed: 17187438]
10. Pinquart M, Sörensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *J Gerontol B: Psychol Sci Soc Sci*. 2003;58(2):112–128.
11. Bookman A, Harrington M. Family caregivers: A shadow workforce in the geriatric health care system. *Health Polit Polic Law*. 2007;32(6):1005–1041.
12. Levine C, Reinhard S, Feinberg L et al. Family caregivers on the job: Moving beyond ADLs and IADLs. *Generations*. 2003;27(4):17–23.
13. Wolff JL, Spillman BC, Freedman VA et al. A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA IM*. 2016;176(3):372–379.
14. Reinhard S, Levine C, Samis S. Home alone: Family caregivers providing complex chronic care. Washington, DC: AARP Public Policy Institute and the United Hospital Fund, 2012.
15. Riffin C, Van Ness PH, Wolff JL et al. Family and other unpaid caregivers and older adults with and without dementia and disability. *J Am Geriatr Soc*. 2017.
16. Kim Y, Schulz R. Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *J Aging Health*. 2008;20(5):483–503. [PubMed: 18420838]
17. Navaie-Waliser M, Feldman PH, Gould DA et al. When the caregiver needs care: The plight of vulnerable caregivers. *Am J Public Health*. 2002;92(3):409–413. [PubMed: 11867321]
18. Chiao CY, Wu HS, Hsiao CY. Caregiver burden for informal caregivers of patients with dementia: a systematic review. *In Nurs Review*. 2015;63(3):340–350.
19. Rigby H, Gubitz G, Phillips S. A systematic review of caregiver burden following stroke. *Int J Stroke*. 2009;4(4):285–292. [PubMed: 19689757]

20. Kasper JD, Freedman VA, Spillman BC. Disability and care needs of older Americans by dementia Status: An analysis of the 2011 National Health and Aging Trends Study: US Department of Health and Human Services, 2014.
21. Spillman B, Wolff J, Freedman V et al. Informal Caregiving for Older Americans: An Analysis of the 2011 National Survey of Caregiving Report to the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy. Washington, DC: U.S. Department of Health and Human Services, 2014.
22. Montaquila J, Freedman VA, Edwards B et al. National Health and Aging Trends Study Round 1 Sample Design and Selection Technical Paper #1. Baltimore: Johns Hopkins University School of Public Health, 2012 Retrieved from: [www.NHATS.org](http://www.NHATS.org)
23. Kroenke K, Spitzer RL, Williams JB. The Patient Health Questionnaire-2: Validity of a two-item depression screener. *Medical Care*. 2003;41:1284–1292. [PubMed: 14583691]
24. Löwe B, Wahl I, Rose M et al. A 4-item measure of depression and anxiety: validation and standardization of the Patient Health Questionnaire-4 (PHQ-4) in the general population. *J Affect Disorders*. 2010;122(1):86–95. [PubMed: 19616305]
25. Wolff JL, Spillman BC, Freedman VA et al. A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA IM*. 2016;176(3):372–379.
26. Kasper JD, Freedban VA, Spillman BC et al. The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Affairs*. 2015;34(10):1642–1649. [PubMed: 26438739]
27. Kasper JD, Freedman VA, Spillman BC. Classification of persons by dementia status in the National Health and Aging Trends Study Baltimore, MD: Johns Hopkins University School of Public Health, 2013 Retrieved from: [www.NHATS.org](http://www.NHATS.org)
28. Galvin JE, Roe CM, Xiong C et al. Validity and reliability of the AD8 informant interview in dementia. *Neurology*. 2006;67:1942–1948. [PubMed: 17159098]
29. Beach SR, Schulz R. Family caregiver factors associated with unmet needs for care of older adults. *JAGS*. 2016;65:560–566.
30. van Exel NJA, op Reimer WJS, Brouwer WB et al. Instruments for assessing the burden of informal caregiving for stroke patients in clinical practice: a comparison of CSI, CRA, SCQ and self-rated burden. *Clinical Rehab*. 2004;18(2):203–214.
31. Vitaliano PP, Young HM, Russo J. Burden: A review of measures used among caregivers of individuals with dementia. *Gerontologist*. 1991;31(1):67–75. [PubMed: 2007476]
32. Schulze B, Rössler W. Caregiver burden in mental illness: review of measurement, findings and interventions in 2004–2005. *Curr Opin Psychiatry*. 2005;8(6):684–691.
33. Montaquila J, Freedban VA, Spillman BC et al. National Health and Aging Trends Study Development of Round 1 Survey Weights NHATS Technical Paper #2. Baltimore: Johns Hopkins University School of Public Health, 2012 Retrieved from: [www.NHATS.org](http://www.NHATS.org)
34. Kasper JD, Freedman VA, Spillman BC. National Study of Caregiving User Guide Baltimore: Johns Hopkins University School of Public Health; 2013.
35. Tennstedt SL, Crawford S, McKinlay JB. Determining the pattern of community care: Is coresidence more important than caregiver relationship? *J Gerontol*. 1993;48(2):S74–S83. [PubMed: 8473708]
36. Given B, Wyatt G, Given C et al. Burden and depression among caregivers of patients with cancer at the end-of-life. *Oncol Nurs Forum*. 2005;31(6):1105–1117.
37. Limpawattana P, Theeranut A, Chindaprasirt J et al. Caregivers burden of older adults with chronic illnesses in the community: A cross-sectional study. *J Comm Health*. 2013;38(1):40–45.
38. Crespo M, López J, Zarit SH. Depression and anxiety in primary caregivers: a comparative study of caregivers of demented and nondemented older persons. *International journal of geriatric psychiatry*, 20(6), 591–592. *Int J Geriatr Psych*. 2005;20(6):591–592. [PubMed: 15962352]
39. Cooper C, Balamurali TBS, Livingston G. A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. *Int Psychogeriatrics*. 2007;19(2):175–195.
40. Perlick D, Berk L, Kaczynski R et al. Caregiver burden as a predictor of depression among family and friends who provide care for persons with bipolar disorder. *Bipol disord*. 2016;18(2):183–191.

41. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psych Bull.* 2003;129:946–972.
42. Revenson TA, Griva K, Luszczynska A et al. *Interventions to support caregivers Caregiving in the illness context.* Basingstoke, UK: Palgrave Macmillan, 2016.
43. Sörensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist.* 2002;43(3):356–372.
44. Belgacem B, Auclair C, Fedor MC et al. A caregiver educational program improves quality of life and burden for cancer patients and their caregivers: A randomised clinical trial. *Eur J Oncol Nurs.* 2013;17(6):870–876. [PubMed: 23759361]
45. Kalra L, Evans A, Perez I et al. Training carers of stroke patients: randomised controlled trial. *BMJ.* 2004;328(7448):1099–1103. [PubMed: 15130977]
46. van der Lee J, Bakker TJ, Duivenvoorden HJ et al. Multivariate models of subjective caregiver burden in dementia: A systematic review. *Ageing Res Rev.* 2014;15:76–93. [PubMed: 24675045]
47. Mittelman MS, Haley WE, Clay OJ et al. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology.* 2006;67(9):1592–1599. [PubMed: 17101889]
48. Gitlin LN, Burgio LD, Mahoney D et al. Effect of multicomponent interventions on caregiver burden and depression: the REACH multisite initiative at 6-month follow-up. *Psychol aging.* 2003;18(3):361–374. [PubMed: 14518800]
49. Johnson DK, Niedens M, Wilson JR et al. Treatment outcomes of a crisis intervention program for dementia with severe psychiatric complications: The Kansas bridge project. *Gerontologist.* 2013;52(1):102–112.
50. Miller EA, Rosenheck RA, Schneider LS. Caregiver burden, health utilities, and institutional service use in Alzheimer's disease. *Int J Geriatr Psychiatry.* 2012;27(4):382–393. [PubMed: 21560160]

**Table 1.**

Descriptive Characteristics of Family and Other Unpaid Caregivers and the Types of Assistance they Provide

Characteristic	Weighted Mean (SE) or %
Total sample, weighted n <sup>a</sup>	14,977,000
<b>Caregiver characteristics</b>	
Age	57.1 (0.7)
Female	62.2
Education, college graduate (n=1728)	26.1
Married	36.6
Relationship to care recipient	
Spouse, husband, wife	22.9
Child, daughter, son	46.2
Other, relative, friend	31.0
Self-rated health, fair or poor (n=1718)	21.1
Depressive symptoms, score of ≥ 3 on PHQ-2 <sup>b</sup> (n=1712)	12.7
Anxiety symptoms, score of ≥ 3 on GAD-2 <sup>c</sup> (n=1691)	12.8
Received training for caregiving (n=1730)	7.0
Used respite care (n=1726)	10.4
Attended caregiving support group (n=1726)	4.4
Hours per week spent caregiving (n=1638)	18.3 (0.8)
Has family/friends to help with caregiving (n=1731)	70.4
Caregiver burden <sup>d</sup>	56.1
<b>Type of assistance</b>	
Instrumental/activity of daily living-related	4.0 (0.1)
Health management	1.3 (0.0)
Health systems logistics	2.5 (0.1)

Note. Data weighted using NSOC analytic weights. All variables without a sample size reported have no missing data.

<sup>a</sup>Based on an unweighted sample of 1742 caregivers.

<sup>b</sup>A score of ≥ 3 on the PHQ-2 is the suggested threshold for distinguishing normal ranges from probable cases of depression.

<sup>c</sup>A score of ≥ 3 on the GAD-2 is the suggested threshold for distinguishing normal ranges from probable cases of anxiety.

<sup>d</sup>Caregiver burden is a composite measure of caregivers' emotional, physical and financial difficulties (dichotomized into any vs. no burden).

**Table 2.****Descriptive Characteristics of Community-dwelling Care Recipients**

Characteristic	Weighted Mean (SE) or %
Total sample, weighted n <sup>a</sup>	7,635,000
Age	78.3 (0.2)
Female	67.5
White	82.1
Self-reported health fair or poor	54.1
Number of comorbidities	4.6 (0.0)
Health conditions	
Cancer	27.2
Stroke	20.4
Lung disease	22.9
Heart attack	20.9
Depressive symptoms, score of ≥ 3 on PHQ-2 <sup>b</sup> (n=1165)	30.3
Anxiety symptoms, score of ≥ 3 on GAD-2 <sup>c</sup> (n=1165)	26.6
Dementia/disability status	
No dementia or substantial disability	54.1
No dementia but substantial disability	17.6
Dementia but not substantial disability	14.2
Dementia and substantial disability	14.1

*Note.* Data weighted using NHATS analytic weights. All variables without a sample size reported have no missing data.

<sup>a</sup>Based on an unweighted sample of 1171 care recipients in NHATS who were living in the community and received assistance from a caregiver in the NSOC.

<sup>b</sup>A score of ≥ 3 on the PHQ-2 is the suggested threshold for distinguishing normal ranges from probable cases of depression.

<sup>c</sup>A score of ≥ 3 on the GAD-2 is the suggested threshold for distinguishing normal ranges from probable cases of anxiety.

**Table 3.**

Variables Included in Multivariable Logistic Regression Analysis of a Binary Caregiver Burden Outcome

Characteristic	Caregiver Burden Present Unadjusted OR (95% CI)	P-value <sup>a</sup>
<b>Caregiver</b>		
Female gender	1.52 (1.19, 1.94)	.001
Relationship to care recipient		
Other, relative, friend	1 [Reference]	
Adult child, daughter, son	1.92 (1.42, 2.60)	<.001
Spouse, husband, wife	1.45 (1.05, 2.01)	0.03
Self-rated health, fair or poor	2.40 (1.83, 3.16)	<.001
Depressive symptoms, score of 3 on PHQ-2	2.36 (1.64, 3.39)	<.001
Anxiety symptoms, score of 3 on GAD-2	2.79 (1.93, 4.04)	<.001
Received training for caregiving	2.31 (1.44, 3.70)	<.001
Used respite care	3.37 (2.05, 5.54)	<.001
Attended support group	1.38 (1.12, 1.70)	.003
Hours per week spent caregiving	1.01 (1.01, 1.02)	<.001
<b>Care recipient</b>		
Female gender	1.20 (0.91, 1.58)	.19
Self-reported health, fair or poor	1.50 (1.17, 1.94)	.002
Had stroke	1.45 (1.13, 1.88)	.01
Depressive symptoms, score of 3 on PHQ-2	1.53 (1.14, 2.04)	.004
Dementia/disability status		
No dementia or substantial disability	1 [Reference]	--
No dementia but substantial disability	1.55 (1.13, 2.13)	.007
Dementia but not substantial disability	2.09 (1.50, 2.91)	<.001
Dementia and substantial disability	2.71 (1.94, 3.78)	<.001
<b>Types of assistance <sup>b</sup></b>		
Instrumental/activities of daily living-related	1.31 (1.17, 1.46)	<.001
Health management	1.44 (1.31, 1.59)	<.001
Health systems logistics	1.39 (1.28, 1.50)	<.001

Note. Data weighted according to the NSOC weight. Variables presented in this table reached a significance value of  $p < .20$  in bivariate analyses and were used in the multivariable model.

<sup>a</sup>P-values obtained using unadjusted logistic regression.

<sup>b</sup>Instrumental/activities of daily living-related is comprised of six tasks; health management is comprised of five tasks; health systems logistics is comprised of five tasks.

OR = odds ratio. CI = confidence interval.



**Table 4.**

Multivariable Logistic Regression Analysis of Associations of Caregiver and Care Recipient Characteristics and Types of Assistance Provided with Caregiver Burden

	aOR (95% CI)	P-value
<b>Caregiver characteristics</b>		
Female gender	1.40 (1.04, 1.89)	.03
Relationship to care recipient		
Other relative, friend	1 [Reference]	
Adult child, daughter, son	1.54 (1.06, 2.24)	.02
Spouse, husband, wife	1.20 (0.77, 1.86)	.41
Self-rated health, fair or poor	2.16 (1.45, 3.20)	<.001
Depressive symptoms	1.49 (0.98, 2.28)	.06
Anxiety symptoms	1.60 (1.09, 2.35)	.02
Received training for caregiving	1.28 (0.67, 2.44)	.45
Used respite care	1.95 (1.16, 3.29)	.01
Attended caregiving support group	1.26 (0.47, 3.35)	.64
Hours per week spent caregiving	1.00 (0.99, 1.01)	.95
<b>Care recipient characteristics</b>		
Self-rated health, fair or poor	1.15 (0.82, 1.60)	.42
Had stroke	0.80 (0.61, 1.06)	.12
Depressive symptoms	1.12 (0.80, 1.60)	.52
Dementia/disability status		
No dementia or substantial disability	1 [Reference]	
No dementia but substantial disability	1.11 (0.75, 1.65)	.61
Dementia but not substantial disability	1.62 (1.10, 2.39)	.01
Dementia and substantial disability	1.67 (1.07, 2.60)	.02
<b>Type of assistance provided</b>		
Instrumental/activities of daily living-related	1.14 (1.01, 1.29)	.03
Health management	1.15 (1.02, 1.28)	.02
Health systems logistics	1.16 (1.06, 1.26)	<.001
Adjusted R <sup>2</sup>	.19	

Note. Data weighted using NSOC analytical weights. aOR = adjusted odds ratio. CI = confidence interval.