Published in final edited form as:

J Am Geriatr Soc. 2017 August ; 65(8): 1821–1828. doi:10.1111/jgs.14910.

Family and Other Unpaid Caregivers and Older Adults with and without Dementia and Disability

Catherine Riffin, PhD[1,a], **Peter H. Van Ness, PhD, MPH**[1], **Jennifer L. Wolff, PhD**[2], and **Terri Fried, MD**[1,3]

[1]Department of Internal Medicine, Yale University School of Medicine, New Haven, CT

[2]Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

[3]Veterans Affairs Connecticut Healthcare System, West Haven, CT

Abstract

OBJECTIVES—To estimate the number of caregivers providing assistance to a nationally-representative sample of community-dwelling older persons with and without dementia and/or substantial disability; describe the characteristics of caregivers and care recipients across these groups; characterize the health-related tasks caregivers provide; and estimate associations between the numbers of tasks and caregiver burden.

DESIGN—Nationally-representative surveys of caregivers and older adults 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, selected on the basis of having assisted with mobility, self-care, household activities, transportation, or medical tasks.

MEASUREMENTS—Caregiver burden (comprised of emotional, physical and financial difficulties) and restrictions on social participation.

RESULTS—While much larger proportions of older adults with dementia and disability (98.4%; 1.0 million) and dementia but not disability (95.5%; 1.3 million) received caregiving assistance, the largest absolute number of individuals receiving assistance was older adults without dementia or disability (4.0 million). Within each caregiver group, caregivers provided assistance with at least one task across domains of ADL/IADL-related assistance (>98%), health systems logistics (>70%), and health management (>50%). There was a significant linear association between the number of tasks provided and risk for burden across virtually all caregiver groups and domains of assistance.

CONCLUSIONS—Caregivers of care recipients without dementia or disability accounted for the largest absolute number of helpers. These caregivers, similar to caregivers of care recipients with dementia and/or disability, delivered a broad spectrum of health-related tasks, and experienced

---

[a]To whom correspondence should be addressed: Catherine Riffin, Department of Medicine (Geriatrics), Yale School of Medicine, 333 Cedar Street, PO Box 208239, New Haven, CT, 06520, Telephone: 781-454-6126. catherine.riffin@yale.edu.
DR. CATHERINE RIFFIN (Orcid ID : 0000-0002-2361-3083)

Disclosures and Conflicts of Interest: The authors have no conflicts of interest to report

caregiver burden and restrictions on social participation. Findings support the need for interventions that address the needs of caregivers who have not typically been defined as high-risk.

Keywords

family caregiving; caregiver burden; dementia; disability

INTRODUCTION

It is estimated that, of the 38.2 million adults age 65 and older in the United States, more than a quarter (29%) receive assistance for health or functioning reasons.[1] Among the 6.6 million older adults who receive assistance in the community, two-thirds (66%) rely exclusively on help from family, friends or neighbors (here forward, "family caregivers").[2] These caregivers play a critical role in older adults' health care.[3] Yet, their personal well-being may suffer as a result of the demands they face. The burdens of caregiving include physical, psychological, and financial hardships,[4] and can have serious consequences for caregivers' overall health,[5,6] immune functioning,[7] and longevity.[8] Evidence-based interventions, such as education and skills training, respite care, and psychosocial support have been developed to enhance caregivers' health and minimize burden,[9,10] but less than 25% of family caregivers use these services[11] due to lack of awareness, lack of accessibility,[12] or cultural beliefs about caregiving responsibilities.[13]

The epidemiology and outcomes of caregiving have been most carefully characterized within subsets of caregivers thought to have the highest burden of caregiving, such as those caring for patients with dementia[14–16] or substantial disability,[17,18] and the caregiver role has traditionally been defined in terms of disability-related assistance.[19–21] The present study builds upon this prior work to present an expanded assessment of the extent and burden of caregiving by characterizing caregiving for older individuals both with and without dementia and/or disability and by examining a broader spectrum of caregiving tasks. We first estimate the numbers of caregivers providing assistance to older care recipients with and without dementia and/or substantial disability. Across these groups of care recipients, we describe the sociodemographic and health characteristics of caregivers and the care recipients they assist; characterize the full range of tasks for which caregivers provide assistance; and examine associations between the number of caregiving tasks caregivers provide and caregiver burden.

METHODS

Data Sources

Data for the present study are drawn from two linked population-based surveys, the baseline (2011) National Health and Aging Trends Study (NHATS) and its companion study, the National Study of Caregiving (NSOC). Because the NHATS and NSOC data sources are publicly available and do not contain individual identifiers, studies using these sources are exempt from human subjects review.

The NHATS is a nationally representative study of US Medicare beneficiaries ages 65 and older.[22] Cases were selected using a stratified three-stage design, which selected counties or groups of counties from the contiguous United States; ZIP codes or ZIP code fragments within the selected counties; and beneficiaries within the selected ZIP codes who were age 65 or older as of September 30, 2010.[22] In-person interviews were conducted with 7,609 older adults(and proxy respondents) living in the community and in residential care settings[23] (71% response rate).

The NSOC is a telephone survey of caregivers (N=2,007) who assist NHATS participants.[24] Eligibility for the NSOC was determined using a two-step process. NHATS participants were first asked whether and how they performed daily activities in the past month. Proxy respondents provided information for NHATS participants who had dementia or cognitive impairment reported by the proxy, a severe illness, or a speech or hearing impairment. Those 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 and provide contact information for each of their caregivers. Caregivers were eligible for the NSOC if they were a family member or an unpaid, non-relative who helped with any activity identified during the NHATS interview including mobility, self-care, household tasks, transportation, and medical careactivities.[24] As detailed in the NSOC User Guide,[24] there were 4,934 eligible caregivers, 1,573 for whom NHATS participants refused to provide contact information, and an additional 1,355 who could not be located or refused to respond.

Study Cohort

Our study cohort included NHATS participants living in the community and their caregivers who responded to the NSOC. We characterized these older persons according to the presence or absence of dementia and disability.[11,25] As defined in prior research,[11,25–27] a person was classified as having probable dementia on the basis of: a self-reported physician diagnosis of Alzheimer’s disease or dementia; a score indicating likely dementia on a screening instrument administered to proxy respondents;[28] or impairment based on cognitive tests that evaluate memory, orientation, and executive function.[26] High percentages of persons for whom a diagnosis was reported also met criteria for dementia classification based on cognitive test criteria.[26] Also using previously established criteria,[25] participants were classified as having substantial disability if they received help with two or more self-care or mobility activities in the last month (eating, dressing, bathing, toileting, transferring from bed, indoor mobility). We created four mutually-exclusive subgroups of older adults: those with dementia and substantial disability, dementia but not substantial disability, no dementia but substantial disability, and no dementia or substantial disability. For each subgroup of care recipients, we identified the corresponding subgroup of caregivers who provided assistance. In analyses examining the characteristics of care recipients, we restricted our study cohort to those individuals with a caregiver in the NSOC.

Measures

Caregivers’ assistance with 16 health-related tasks was categorized into three domains: activities of daily living (ADL) and instrumental activities of daily living (IADL)-related activities, health systems logistics, and health management.[11] The ADL/IADL-related domain consisted of six tasks: shopping, transportation, housework, mobility, banking, and self-care. The health system logistics domain consisted of five tasks: making appointments, ordering medicines, handling insurance issues, keeping track of medications, and speaking with the older adult's medical provider. The health management domain consisted of five tasks: assistance with diet, foot care, skin care, exercise, dental care. Caregivers were asked whether they helped the older person with ADL/IADL-related activities and health management tasks in the past month. Tasks pertaining to health systems logistics used a 12-month, recall because these tasks are typically undertaken less frequently. We summed participants' responses to each question (0=no; 1=yes) to form a count of the number of tasks for which the caregiver provided assistance within each domain.

The NSOC included a variety of questions designed to assess the positive and negative aspects of caregiving. From this set of measures, we selected items that have been used in prior research.[11,29,30] These items were used to construct a measure of caregiving difficulty and a measure of restrictions on social participation. As defined elsewhere,[11] caregiving difficulty refers to the emotional, physical, and financial difficulties associated with care provision. Caregivers were asked about each type of difficulty with responses on a 0–5 Likert scale (0=no difficulty; 5=very difficult); participants with a score of 1 or more were characterized as experiencing difficulty. Restriction on social participation was assessed by asking respondents whether their caregiving responsibilities interfered with activities (i.e., visiting friends and family, going out for enjoyment, attending religious services, and participating in club meetings or group activities). Caregivers were categorized according to those who reported no restriction versus those who reported any restriction.

Descriptive variables included caregivers' sociodemographic (age, gender, education, marital status, and relationship to the older adult), health characteristics (self-rated health, depression assessed by the PHQ-2,[31] and anxiety assessed by the GAD-2),[32] and use of support services in the past year, defined as having received training for caregiving, having used respite care, having attended a caregiver support group, and the average number of hours they provided care to the NHATS participant per week. Care recipients' sociodemographic characteristics included age, gender, and race. Health characteristics included self-reported health, number of chronic health conditions (heart attack, heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, cancer), number of hospital stays in the past year, depressive symptoms (assessed by the PHQ-2)[31] and anxiety symptoms (assessed by the GAD-2).[32]

Data Analysis

We first summarized the numbers and percentages of NHATS participants who (a) required assistance and received caregiver support, (b) required assistance but did not receive caregiver support, and (c) did not require assistance. Subsequent analyses focus on the subset of NHATS participants who required assistance and received caregiver support, and their caregivers. We generated means, standard deviations, frequencies and percentages to describe the sociodemographic, health and psychosocial characteristics of caregivers and care recipients, and for the subgroups according to care recipients' dementia and disability status. To examine differences across the four groups, chi-square tests of independence

(Satterthwaite Rao-Scott) were conducted for categorical variables and F tests were used for continuous variables while accounting for the complex sampling design.

We examined the frequencies and percentages of the specific tasks and number of tasks caregivers provided within each domain of assistance, and caregiving-related difficulty and restrictions on social participation, according to older adults' dementia/disability status. Associations between each task and older adults' dementia/disability status were examined using chi-square tests. The Satterthwaite Rao-Scott chi-square test was used to examine the significance of the association between number of tasks for which assistance was provided within each domain of assistance and the outcome variables, caregiving-related difficulty and restrictions on social participation.

All analyses of older adults incorporated NHATS survey weights that take into account the complex sampling strategy of NHATS, and provide nationally representative estimates of Medicare beneficiaries aged 65 and older.[33] NSOC weights were used in all in analyses in which the caregiver was the unit of analysis. NSOC weights adjust for the complex sampling strategy of NHATS as well as differential probabilities of selection and non-response at both the NHATS sample person and caregiver levels,[24] and produce nationally representative estimates of family caregivers. All analyses were conducted using SAS, version 9.4; SAS Institute Inc.

RESULTS

NHATS Participants' Need for Assistance and Receipt of Caregiver Support

Weighted estimates indicate that virtually all older persons with dementia and substantial disability (98.4%; 1.0 million) and those with substantial disability but not dementia required assistance and received help from a caregiver (95.5%; 1.3 million) (Table 1). More than half of individuals with dementia but not substantial disability also needed help and received caregiving assistance (57.4%; 1.0 million). Although only 14.1% of older adults without dementia or substantial disability required assistance and received help from a caregiver, these individuals (approximately 4.0 million individuals) accounted for the largest absolute number of individuals receiving caregiver assistance.

Caregiver and Care Recipient Characteristics

Characteristics of caregivers and older adults who received caregiving assistance are reported in Table 2. While the four groups of caregivers did not vary significantly with respect to sociodemographic characteristics (caregivers were 59 years of age, most were women, and adult children were the largest group providing assistance), they did differ in terms of their physical and emotional health. Overall, approximately 13% of caregivers had symptoms of depression or anxiety; this ranged from close to 10% among caregivers of persons without dementia or disability to almost 19% among caregivers of persons with dementia but no disability. Nearly 19% of caregivers of persons without dementia or disability rated their health as fair or poor; while this proportion was the same for caregivers of persons with dementia and disability, more than 27% of caregivers of persons with dementia but no disability reported themselves to be in poor or fair health.

Significant differences across the groups were also observed with respect to the time demand of caregiving, which ranged from 12 hours per week among caregivers of persons without dementia or disability to nearly 30 hours per week among caregivers of persons with dementia and disability. A minority of caregivers across the four group used supportive services. On average, less than 5% of caregivers attended support groups; slightly larger proportions received training for caregiving (6.3%) or used respite care (12.7%). The highest proportions of caregivers using any of these services were those of older persons with both dementia and disability.

Caregiving Tasks Provided within Each Domain of Assistance

Large proportions of caregivers assisted with multiple ADLs and IADLs (Table 3). Greater than two-thirds of caregivers across the four groups helped with four or more tasks within this domain. While the proportions helping with shopping and housework did not differ; larger proportions of caregivers for persons with disability helped with self-care and mobility tasks.

Many caregivers also helped with health systems and health management tasks. A range from approximately 40% to over 70% of caregivers provided assistance with medications, making appointments, and speaking with medical providers. Approximately one quarter of caregivers were involved in handling insurance issues.

The highest proportion of caregivers providing assistance with health management tasks was generally among caregivers of individuals with dementia. Between about 20% and 40% of caregivers across the four groups provided assistance with skin care, foot care, and diet.

Association between Assistance Provided and Caregiving Difficulty

The prevalence of caregiving difficulty existed on a continuum across the four groups, with the highest prevalence observed among caregivers assisting older persons with dementia and disability (70.9%), followed by caregivers of older adults with dementia but not disability (65.3%), caregivers of older adults with disability but not dementia (58.2%), and caregivers of older adults without dementia or disability (47.4%) (Table 4). Providing help with a greater number of tasks within each domain of assistance was associated with a higher risk of caregiving-related difficulty across the four groups.

Associations between Assistance Provided and Restrictions in Social Participation

The prevalence of restrictions on social participation also existed on a continuum across the four groups (Table 5). The highest prevalence was observed among caregivers assisting older adults with dementia and disability (39.9%), followed by caregivers of older adults with dementia but not disability (30.2%), caregivers of older adults with disability but not dementia (28.5%), and caregivers of older adults with neither dementia nor disability (16.2%). Providing help with a greater number of tasks within each domain of assistance was associated with a higher risk for restrictions on social participation across all groups of caregivers.

DISCUSSION

This study draws on a nationally-representative sample to characterize the scope of assistance provided by family caregivers to community-dwelling care recipients and its association with caregiver burden, defined in terms of the emotional, physical and financial difficulties associated with caregiving, and restrictions on social participation. While the proportion of older persons without dementia and substantial disability who required and received caregiving assistance was much smaller than the proportions of persons with dementia and/or disability, caregivers for these persons accounted for the largest absolute number of helpers, exceeding the combined number of caregivers for the other groups of care recipients. Caregivers across all the groups shared similar sociodemographic characteristics. Caregivers of care recipients with dementia and substantial disability, not surprisingly, experienced the greatest impacts. Large proportions assisted with multiple ADLs, IADLs and with a range of health management and health systems activities and reported caregiving difficulty and restrictions on social participation. Nonetheless, caregivers assisting older persons with neither dementia nor substantial disability also faced considerable demands associated with caregiving. Sizeable proportions of these caregivers also provided a range of tasks and experienced burden. There was a significant linear association between the number of tasks provided within each domain of assistance (ADL/IADL-related, health systems logistics, health management) and risk for caregiving difficulty and restrictions on social participation for all caregiver groups.

Our findings add to the small, but growing body of literature examining caregivers' varied involvement in older adults' health care.[3,11,34,35] Prior qualitative research has shown that caregivers are often involved in managing health care activities at home and in conjunction with community services.[34] Other studies have found that caregivers frequently accompany older persons to their physician visits[36] and undertake complex medical and nursing tasks, including injections and wound care.[3,35] Our study corroborates and extends this work by showing that, across a nationally-representative sample of older persons, sizeable proportions of caregivers deliver multiple health-related activities that span domains of ADLs/IADLs, health systems logistics, and health management. Such findings have important implications for caregiver training as they suggest the need for strategies that respond to the varied tasks caregivers provide beyond assistance with daily activities. Also critical will be the development of practical tools that assess caregiver's preparedness to deliver the requisite activities in order to identify caregivers in need of specialized training.

While our results are consistent with prior research emphasizing the burdens experienced by caregivers assisting older persons with dementia,[27,37] they also suggest that a broader spectrum of caregivers warrant attention. Within this population-based sample, the greatest absolute number of caregivers (7.3 million individuals) provided assistance to care recipients without dementia and substantial disability. This group represented the largest number of caregivers experiencing caregiver burden and participation restrictions, and sizeable proportions experienced depressive and anxiety symptoms, and poor physical health. Yet, only a small minority accessed supportive services, including caregiver training, respite care, or support groups. These findings demonstrate the need for studies that move beyond selected samples as well as support strategies and interventions that extend to caregivers who have not typically been defined as high-risk. Especially important will be an expanded evaluation of caregiver burden, health, and knowledge regarding support services among caregivers of all older persons.

Our study is subject to several limitations. Because the purpose of this study was to present a broad summary of the types of assistance caregivers provided to four groups of older care recipients, it does not report adjusted analyses. Future research should include clinically-relevant covariates, such as caregiver and older adult sociodemographic and health characteristics, in multivariable analyses. Our analysis was subject to the constraints of the NSOC eligibility criteria: that older persons were included in the NSOC sampling frame if they received assistance with at least one mobility, self-care or household activity, and caregivers were eligible if they provided assistance with at least one task pertaining to mobility, self-care, household activities, transportation, or medical care. Given these criteria, our analyses regarding the type of assistance provided pertained only to those caregivers who assisted with at least one of the aforementioned tasks.

Conclusion

Our study advances knowledge regarding the range of tasks caregivers provide and associated consequences among caregivers assisting community-dwelling care recipients with and without dementia and substantial disability. Within this nationally-representative sample of caregivers, caregiving difficulty and restrictions on social participation were common; providing a greater number of tasks within domains of ADL/IADL-related assistance, health systems logistics, and health management was associated with caregiving difficulty and restrictions on social participation. Additional research using multivariable analyses and longitudinal study designs will be necessary to confirm these findings, and inform strategies for identifying at-risk caregivers and designing health care delivery models that take into account the role of caregivers in maintaining the health and well-being of the older population.

Acknowledgments

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.

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

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.

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.

Funding: Terri Fried and Peter H. VanNess are supported by the Claude D. Pepper Older Americans Independence Center at Yale University School of Medicine (P30AG021342 National Institute on Aging). Catherine Riffin is supported by training grant T32AG1934 from the National Institute on Aging.

References

1. Families Caring for an Aging America. Washington, DC: National Academies of Sciences Engineering Medicine; 2016.
2. Freedman VA, Spillman BC. Disability and care needs among older Americans. Milbank Quarterly. 2014; 92:509–541. [PubMed: 25199898]
3. Reinhard, S., Levine, C., Samis, S. Home alone: Family caregivers providing complex chronic care. Washington, DC: AARP and United Hospital Fund; 2012.
4. George L, Gwyther L. Caregiver well-being: A multidimensional examination of family caregivers of demented adults. Gerontologist. 1986; 26:253–259. [PubMed: 3721232]
5. Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. Psych Aging. 2003; 18:250–267.
6. Pinquart M, Sorensen S. Correlates of physical health of informal caregivers: A meta-analysis. J Gerontol B Psychol Sci Soc Sci. 2007; 62:P126–137. [PubMed: 17379673]
7. Kiecolt-Glaser JK, Dura JR, Speicher CE, et al. Spousal caregivers of dementia victims: Longitudinal changes in immunity and health. Psychosom Med. 1991; 53:345–362. [PubMed: 1656478]
8. Schulz R, Beach SR. Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. JAMA. 1999; 282:S223–229.
9. Revenson, TA., Griva, K., Luszczynska, A., et al. Caregiving in the illness context. Basingstoke: Palgrave Macmillan; 2016. Interventions to support caregivers.
10. Chen YM. Differences in outcomes of caregiver support services for male and female caregivers. SAGE Open. 2014; 4:1–10.
11. 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 Int Med. 2016; 176:372–379.
12. Macleod A, Tatangelo G, McCabe M, et al. “There isn’t an easy way of finding the help that’s available.” Barriers and facilitators of service use among dementia family caregivers: A qualitative study. Int Psychogeriatrics. 2017:1–12.
13. Brandão D, Ribeiro O, Martín I. Underuse and unawareness of residential respite care services in dementia caregiving: Constraining the need for relief. Health Soc Work. 2016; 41:254–262.
14. Schulz R, Martire LM. Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. Am J Geriatr Psychiatry. 2004; 12:240–249. [PubMed: 15126224]
15. Kim H, Chang M, Rose K, et al. Predictors of caregiver burden in caregivers of individuals with dementia. J Adv Nurs. 2012; 68:846–855. [PubMed: 21793872]
16. Razani J, Kakos B, Orieta-Barbalace C, et al. Predicting caregiver burden from daily functional abilities of patients with mild dementia. JAGS. 2007; 55:1415–1420.
17. Dankner R, Bachner YG, Ginsberg G, et al. Correlates of well-being among caregivers of long-term community-dwelling stroke survivors. Int J Rehab Res. 2016; 39:326–330.
18. Byun E, Riegel B, Sommers M, et al. Caregiving immediately after stroke: A study of uncertainty in caregivers of older adults. J Neurosci Nurs. 2016; 48:343–351. [PubMed: 27824803]
19. Giovannetti ER, Wolff JL. Cross-survey differences in national estimates of numbers of caregivers of disabled older adults. Milbank Quarterly. 2010; 88:310–349. [PubMed: 20860574]
20. Feldman PH, Kane RL. Strengthening research to improve the practice and management of long-term care. Milbank Quarterly. 2003; 81:179–220. [PubMed: 12841048]
21. Reinhard, SC. The work of caregiving: What do ADLs and IADLs tell us?. In: Levine, C., editor. Family caregivers on the job: Moving beyond ADLs and IADLs. New York: United Hospital Fund; 2004. p. 37-65.
22. Montaquila, J., Freedman, VA., Edwards, B., et al. Technical Paper #1. Baltimore: Johns Hopkins University School of Public Health; 2012. National Health and Aging Trends Study Round 1 Sample Design and Selection.
23. Kasper JD, Freedman VA. Findings from the 1st Round of the National Health and Aging Trends Study (NHATS): Introduction to a Special Issue. J Gerontol B Psychol Sci Soc Sci. 2014; 69:S1–7.

24. Kasper, JD., Freedman, VA., Spillman, BC. National Study of Caregiving User Guide. Baltimore: Johns Hopkins University School of Public Health; 2013.
25. Beach SR, Schulz R. Family caregiver factors associated with unmet needs for care of older adults. JAGS. 2016 epub ahead of print.
26. 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.
27. Kasper JD, Freedman VA, Spillman BC, et al. The disproportionate impact of dementia on family and unpaid caregiving to older adults. Health Affairs. 2015; 34:1642–1649. [PubMed: 26438739]
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. Cohen SA, Cook S, Kelley L, et al. Psychosocial factors of caregiver burden in child caregivers: Results from the new national study of caregiving. Health Qual Life Outcomes. 2015; 13:120. [PubMed: 26246132]
30. Spillman, BC., Wolff, JL., Freedman, VA., et al. Informal caregiving for older Americans: An analysis of the 2011 National Health and Aging Trends Study. Washington DC: Department of Health and Human Services, Office of the Assistance Secretary for Planning and Evaluation; 2014.
31. 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]
32. 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; 122:86–95. [PubMed: 19616305]
33. Montaquila, J., Freedban, VA., Spillman, BC., et al. NHATS Technical Paper #2. Baltimore: Johns Hopkins University School of Public Health; 2012. National Health and Aging Trends Study Development of Round 1 Survey Weights.
34. Bookman A, Harrington M. Family caregivers: A shadow workforce in the geriatric health care system. J Health Polit Polic. 2007; 32:1005–1041.
35. Donelan K, Hill CA, Hoffman C, et al. Challenged to care: Informal caregivers in a changing health system. Health Affairs. 2002; 21:222–231. [PubMed: 12117133]
36. Wolff JL, Spillman BC. Older adults receiving assistance with physician visits and prescribed medications and their family caregivers: prevalence, characteristics, and hours of care. J Gerontol B Psychol Sci Soc Sci. 2014; 69:S650–672.
37. Chien LY, Chu H, Guo JL, et al. Caregiver support groups in patients with dementia: A meta-analysis. Int J Geriat Psych. 2011; 26:1089–1098.

Table 1

Community-Dwelling Older Adults' Need for ADL/IADL-Related Assistance and Receipt of Family Caregiver Support

	Dementia and Substantial Disability [b]	**Dementia but not Substantial Disability**	**Substantial Disability but not Dementia**	**No Dementia or Substantial Disability**
Weighted estimate[a]	1,048,000	1,795,000	1,348,000	28,275,000
	Weighted n (column %)	*Weighted n (column %)*	*Weighted n (column %)*	*Weighted n (column %)*
Older adults living in the community who needed assistance and received caregiver support [c]	1,019,000 (98.4)	1,029,000 (57.4)	1,287,000 (95.5)	3,989,000 (14.1)
Older adults living in the community who needed assistance, but did not receive caregiver support	16,000 (1.6)	306,000 (17.0)	49,000 (3.6)	2,268,000 (8.1)
Older adults living in the community who did not need assistance	Not reportable[d]	460,000 (25.6)	Not reportable[c]	22,008,000 (77.8)

[a] The weighted estimates represent the number of older adults (age 65 and older) residing in the United States in 2011, as specified by the row and column headings. Weighted estimates rounded to the nearest thousandth, and based on an unweighted sample of NHATS participants living in the community: 350 older persons with dementia and disability, 517 with dementia but not substantial disability, 359 with substantial disability but not dementia, and 5767 with no dementia or disability. NHATS participants residing in nursing homes or other residential care facilities were excluded from this analysis (n=578). Data were missing for 38 individuals.

[b] Care recipient dementia is based on a summary measure of self- and proxy-report and performance-based testing from NHATS. Substantial disability is defined on the basis of needing assistance with two or more self-care or mobility tasks.

[c] Need for assistance was defined on the basis of older adult's inability to perform one or more mobility, self-care or household tasks without help. Caregiving support was defined on the basis of receiving help with any mobility, self-care or household tasks.

[d] Data not reportable because unweighted cell sizes (n=0 for older adults with dementia/disability who did not need assistance; n=2 for older adults with disability but not dementia who did not need assistance) were too small for obtaining valid estimates.

ADL= activities of daily living; IADL=instrumental activities of daily living.

Table 2

Description of Family Caregivers and Care Recipients

	Dementia and Substantial Disability	Dementia but not Substantial Disability	Substantial Disability but not Dementia	No Dementia or Substantial Disability	P Value
Caregiver Characteristic					
Weighted estimate[a]	2,447,000	2,920,000	2,302,000	7,314,000	
Age, mean (SE)	59.4 (0.9)	59.4 (1.3)	57.4 (1.2)	58.5 (0.7)	.45
Education, college graduate, %	31.1	32.4	33.2	39.6	.26
Female, %	65.9	65.8	59.8	60.7	.29
Married, %	38.8	42.5	32.8	35.4	.37
Self-rated health, fair or poor, %	18.7	27.2	24.6	18.7	.05
Depressive symptoms[c]	13.8	18.5	14.4	9.9	<.01
Anxiety symptoms[d]	16.3	18.7	12.8	9.6	<.01
Relationship to older adult, %					.11
Spouse, husband, wife	17.1	16.2	24.9	26.1	
Child, daughter, son	50.4	52.8	43.5	43.7	
Other, relative, friend	32.5	31.0	31.6	30.2	
Hours of care per week, mean (SE)	27.9(2.4)	17.7(1.5)	24.9(2.2)	12.3(0.9)	<.01
Has family/friends to help with care, %	78.4	73.3	69.2	66.3	.03
Received training for caregiving, %	13.9	5.9	9.0	4.1	<.01
Used respite care, %	22.8	9.9	13.0	5.1	<.01
Attended caregiving support group, %	8.9	4.1	4.8	2.4	.15
Care Recipient Characteristic					
Weighted estimate[b]	643,000	596,000	788,000	2,091,000	
Age, mean (SE)	87.6 (0.5)	87.2 (0.4)	82.8 (0.4)	82.2 (0.4)	<.01
White, %	81.2	74.7	82.4	84.8	.02
Female, %	61.1	66.1	66.1	64.8	.79
Self-reported health fair or poor, %	68.1	40.4	58.8	45.5	<.01
Depressive symptoms[c]	47.7	31.9	35.7	24.7	<.01
Anxiety symptoms[d]	34.1	25.5	37.1	19.8	<.01
Number of comorbidities, mean (SE)	4.6 (0.1)	4.1 (0.1)	5.0 (0.1)	4.5 (0.1)	<.01

	Dementia and Substantial Disability	Dementia but not Substantial Disability	Substantial Disability but not Dementia	No Dementia or Substantial Disability	P Value
Number of hospital stays in the last year, mean (SE)	1.5 (0.0)	1.7 (0.0)	1.5 (0.0)	1.8 (0.0)	.01

[a] Caregiver characteristics weighted according to NSOC analytical weight. Estimates rounded to the nearest thousandth.

[b] Older adult characteristics weighted according to NHATS analytical weight. Estimates rounded to the nearest thousandth. Data are based on reports of older adults in NHATS with caregivers surveyed in NSOC.

[c] Based on a cut-off score of ≥3 on the PHQ-2.

[d] Based on a cut-off score of ≥3 on the GAD-2.

P-values were obtained using chi-square tests of independence, and account for the complex sampling design.

Table 3

Family Caregivers who Provide Different Types of Assistance to Older Adults According to Disability and Dementia Status

	Dementia and Substantial Disability	**Dementia but not Substantial Disability**	**Substantial Disability but not Dementia**	**No Dementia or Substantial Disability**	
Weighted estimate[a]	2,447,000	2,920,000	2,302,000	7,314,000	
Type of Assistance	Column %	Column %	Column %	Column %	P Value
ADL/IADL-related assistance					
Shopping	88.6	88.7	89.1	90.1	.56
Transportation	74.6	82.6	77.5	83.6	.01
Housework	86.9	86.4	87.3	80.5	.14
Mobility	86.3	65.8	84.8	61.6	<.001
Banking	60.5	65.2	60.5	53.0	.04
Self-care	81.1	45.5	66.6	34.4	<.001
Provided 4+ tasks	84.6	76.9	82.5	68.1	<.001
Health system logistics					
Make appointments	73.3	71.9	57.8	51.0	<.001
Order medicines	62.3	63.6	54.7	42.1	<.001
Handle insurance issues	26.9	28.6	27.0	21.3	.12
Speak with medical provider	67.5	62.1	48.9	44.7	<.001
Keep track of medications	72.5	63.6	57.9	36.8	<.001
Provided 3+ tasks	68.7	65.0	54.0	37.5	<.001
Health management					
Diet	34.7	27.4	41.0	25.0	<.001
Foot care	41.1	25.7	40.5	21.5	<.001
Skin care	39.7	18.9	31.7	19.3	<.001
Exercise	34.3	24.7	27.4	16.1	<.001
Dental care	39.2	13.1	14.7	7.3	<.001
Provided 2+ tasks	54.8	29.9	46.0	23.1	<.001

[a] Weighted using the NSOC caregiver analytical weight. Estimates are rounded to the nearest thousandth.

P-values were obtained using chi-square tests of independence, and account for the complex sampling design.

ADL= activities of daily living; IADL=instrumental activities of daily living.

Table 4

Prevalence of and Bivariate Associations between Assistance Provided and Caregiving Difficulty, Stratified by Older Adults' Dementia and Disability Status

	Dementia and Substantial Disability		**Dementia but not Substantial Disability**		**Substantial Disability but not Dementia**		**No Dementia or Substantial Disability**	
	Caregivers Reporting Difficulty[a]							
Weighted estimate (%)[b]	1,735,000 (70.9)		1,498,000 (65.3)		1,702,000 (58.3)		3,463,000 (47.4)	
Type of Assistance Provided	Row%	P Value	Row %	P Value	Row %	P Value	Row %	P Value
ADL/IADL-related[c]		.02		.002		.02		<.001
0–3 disabilities	48.0		38.3		46.4		34.7	
4 disabilities	61.3		64.1		39.5		42.6	
5 disabilities	73.2		78.9		67.0		55.6	
6 disabilities	80.9		78.7		67.4		68.2	
Health system logistics[d]		<.001		<.001		<.001		.003
0–1 tasks	42.1		51.9		37.6		40.5	
2–3 tasks	73.0		55.1		62.0		47.9	
4–5 tasks	83.8		78.5		75.9		60.1	
Health management[e]		.01		.01		.03		<.001
0 tasks	52.8		57.4		45.7		38.1	
1 task	71.8		66.3		58.2		53.1	
2+ tasks	79.2		76.4		66.5		61.5	

[a] Comprised of three variables pertaining to the emotional, physical and financial difficulties associated with care provision.

[b] Weighted using the NSOC caregiver analytical weight. Estimates refer to caregivers who report caregiving difficulty, and are rounded to the nearest thousandth.

[c] Tasks include shopping, transportation, housework, mobility, banking, and self-care.

[d] Tasks include making appointments; ordering and keeping track of medications; handling insurance; speaking with the provider.

[e] Tasks include diet, foot care, skin care, exercise, and dental care.

P-values were obtained using the Satterthwaite Rao-Scott chi-square test.

Table 5

Prevalence of and Bivariate Associations between Assistance Provided and Restrictions on Social Participation, Stratified by Older Adults' Dementia and Disability Status

	Dementia and Substantial Disability		**Dementia but not Substantial Disability**		**Substantial Disability but not Dementia**		**No Dementia or Substantial Disability**	
	Caregivers Reporting Restrictions on Social Participation[a]							
Weighted estimate (%)[b]	962,000 (39.9)		686,000 (30.2)		826,000 (28.5)		1,167,000 (16.2)	
Type of Assistance Provided	Row %	P Value	Row %	P Value	Row %	P Value	Row %	P Value
ADL/IADL-related[c]		<.001		.004		.03		<.001
0–3 disabilities	11.8		22.8		18.7		6.4	
4 disabilities	16.6		14.9		10.5		11.0	
5 disabilities	44.0		31.8		35.8		23.6	
6 disabilities	55.5		54.0		36.4		33.4	
Health system logistics[d]		<.001		.01		<.001		<.001
0–1 tasks	18.0		15.0		11.3		7.8	
2–3 tasks	24.1		26.1		31.7		15.3	
4–5 tasks	57.7		41.1		43.2		32.0	
Health management[e]		<.001		.01		<.001		<.001
0 tasks	21.0		22.4		8.9		9.8	
1 task	31.3		35.1		29.1		19.1	
2+ tasks	52.3		37.7		41.1		26.8	

[a] Comprised of four binary-response questions asking whether cargiving limited participation in visiting friends and family, going out for enjoyment, attending religious services, and participating in club meetings or group activities.

[b] Weighted using the NSOC caregiver analytical weight. Estimates refer to caregivers who report restrictions on social participation, and are rounded to the nearest thousandth.

[c] Tasks include shopping, transportation, housework, mobility, banking, and self-care.

[d] Tasks include making appointments; ordering and keeping track of medications; handling insurance; speaking with the provider.

[e] Tasks include diet, foot care, skin care, exercise, and dental care.

P-values were obtained using the Satterthwaite Rao-Scott chi-square test.