CLINICAL INVESTIGATION

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

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OBJECTIVES: To estimate the number of caregivers providing assistance to community-dwelling older persons with and without dementia and with or without substantial disability; to describe the characteristics of caregivers and care recipients in these groups; to characterize the health-related tasks that caregivers provide; and to 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, who were selected on the basis of having assisted with mobility, self-care, household activities, transportation, or medical tasks.

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

RESULTS: Although much larger proportions of older adults with dementia and disability (98.4%, n = 1.0 million) and dementia but not disability (95.5%, n = 1.3 million) received caregiving assistance, the largest absolute number of individuals receiving assistance were older adults without dementia or disability (4.0 million). Within each caregiver group, caregivers provided assistance with at least one task across domains of activity of daily living and instrumental activity of daily living–related assistance (>98%), health systems logistics (>70%), and health management (>50%). There was a significant linear association between number of tasks provided and risk of burden in virtually all caregiver groups and domains of assistance.

CONCLUSION: 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 or disability, delivered a broad spectrum of health-related tasks and experienced 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. **J Am Geriatr Soc 2017.**

Key words: family caregiving; caregiver burden; dementia; disability

It is estimated that, of the 38.2 million adults aged 65 and older in the United States, 29% receive assistance for health or functioning reasons.[1] Of the 6.6 million older adults who receive assistance in the community, 66% rely exclusively on help from family, friends, or neighbors (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 caregiver health and minimize burden,[9,10] but fewer than 25% of family caregivers use these services[11] because of 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 individuals 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

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burden of caregiving by characterizing caregiving for older individuals with and without dementia and with or without disability and by examining a broader spectrum of caregiving tasks.

The number of caregivers providing assistance to older care recipients with and without dementia and with or without substantial disability is estimated. According to these groups of care recipients, the sociodemographic and health characteristics of caregivers and care recipients are described, the full range of tasks for which caregivers provide assistance is characterized, and associations between the number of caregiving tasks caregivers provide and caregiver burden is examined.

METHODS

Data Sources

Data for the present study were 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 Medicare beneficiaries aged 65 and older.[22] Cases were selected using a stratified three-stage design that 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 aged 65 and 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 had 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. 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 nonrelative who helped with any activity identified during the NHATS interview, including mobility, self-care, and household tasks; transportation; and medical care activities.[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

The study cohort included NHATS participants living in the community and their caregivers who responded to the NSOC. These older persons were characterized 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 based on cognitive test criteria.[26] Also using previously established criteria,[25] participants were classified as having substantial disability if they had received help with two or more self-care or mobility activities in the last month (eating, dressing, bathing, toileting, transferring from bed, indoor mobility). Four mutually exclusive subgroups of older adults were created: 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, the corresponding subgroup of caregivers who provided assistance was identified. In analyses examining the characteristics of care recipients, the study cohort was restricted to individuals with a caregiver in the NSOC.

Measures

Caregiver assistance with 16 health-related tasks was categorized into three domains: activity of daily living (ADL) and instrumental activity of daily living (IADL)-related activities, health system logistics, and health management.[11] The ADL- and 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, managing insurance, 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, and dental care. Caregivers were asked whether they had helped the older person with ADL- and 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. Participant responses to each question (0 = no, 1 = yes) were summed 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. Items that have been used in prior research were selected from this set of measures[11,29,30] and 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 and provided responses on a 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 (visiting friends and family, going out for enjoyment, attending religious services, participating in club meetings or group activities). Caregivers were categorized according to those who reported no restriction and those who reported any restriction.

Descriptive variables included caregiver sociodemographic characteristics (age, sex, education, marital status, relationship to the older adult); health characteristics (self-rated health, depression assessed using the Patient Health Questionnaire (PHQ)-2,[31] anxiety assessed using the Generalized Anxiety Disorder Scale (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 recipient sociodemographic characteristics included age, sex, and race. Health characteristics included self-reported health, number of chronic health conditions (heart attack, heart disease, high blood pressure, arthritis, osteoporosis, diabetes mellitus, lung disease, stroke, cancer), number of hospital stays in the past year, depressive symptoms (assessed using the PHQ-2),[31] and anxiety symptoms (assessed by the GAD-2).[32]

Data Analysis

The numbers and percentages of NHATS participants who required assistance and received caregiver support, required assistance but did not receive caregiver support, and did not require assistance were summarized. Subsequent analyses focus on the subset of NHATS participants who required assistance and received caregiver support and their caregivers. Means, standard deviations, frequencies, and percentages were generated to describe the sociodemographic, health, and psychosocial characteristics of caregivers and care recipients and for the subgroups according to care recipient dementia and disability status. To examine differences between the four groups, chi-square tests of independence (Satterthwaite Rao-Scott) were conducted for categorical variables and *F* tests for continuous variables, accounting for the complex sampling design.

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 were examined according to the older adults' dementia and disability status. Associations between each task and older adults' dementia and 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 and different probabilities of selection and nonresponse at 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., Cary, NC).

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%, n = 1.0 million) and those with substantial disability but not dementia (95.5%, n = 1.3 million) required assistance and received help from a caregiver (Table 1). More than half of individuals with dementia but not substantial disability also needed help and received caregiving assistance (57.4%, n = 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 assistance are reported in Table 2. Although the four groups of caregivers did not vary significantly with respect to sociodemographic characteristics (caregivers had a mean age of 59, most were female, and adult children were the largest group providing assistance), they differed 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% of caregivers of persons without dementia or disability to almost 19% of 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; although 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 between the groups were also observed with respect to the time demand of caregiving, which ranged from 12 hours per week for caregivers of persons without dementia or disability to nearly 30 hours per week for caregivers of persons with dementia and disability. A minority of caregivers used supportive services. On average, fewer 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 dementia and disability.

Caregiving Tasks Provided within Each Domain of Assistance

Large proportions of caregivers assisted with multiple ADLs and IADLs (Table 3). More than two-thirds of caregivers helped with four or more tasks in this domain. Although the proportions helping with shopping and

Table 1. Community-Dwelling Older Adults' Need for Activity of Daily Living– and Instrumental Activity of Daily Living–Related Assistance and Receipt of Family Caregiver Support

Group	Dementia and Substantial Disability[b]	Dementia but No Substantial Disability	Substantial Disability but No Dementia	No Dementia or Substantial Disability
	N (%)			
Weighted estimate[a]	1,048,000	1,795,000	1,348,000	28,275,000
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] Weighted estimates represent the number of older adults (aged ≥65) residing in the United States in 2011, as specified by the row and column headings. Weighted estimates were rounded to the nearest thousand and based on an unweighted sample of National Health and Aging Trends Study (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 5,767 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 the 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 and substantial disability who did not need assistance; n = 2 for older adults with disability but not dementia who did not need assistance) were too small to obtain valid estimates.

housework did not differ, larger proportions of caregivers of persons with disability helped with self-care and mobility tasks.

Many caregivers also helped with health systems and health management tasks. From 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 managing insurance.

The highest proportion of caregivers providing assistance with health management tasks was generally those caring for individuals with dementia. From 20% to 40% of caregivers provided assistance with skin care, foot care, and diet.

Association Between Assistance Provided and Caregiving Difficulty

The prevalence of caregiving difficulty varied across the four groups, with the highest prevalence observed for 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 more tasks within each domain of assistance was associated with higher risk of caregiving difficulty.

Associations Between Assistance Provided and Restrictions in Social Participation

The prevalence of restrictions on social participation varied across the four groups (Table 5). The highest prevalence was observed for 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 more tasks in each domain of assistance was associated with higher risk of restrictions on social participation.

DISCUSSION

This study drew on a nationally representative sample to characterize the scope of assistance that family caregivers provide 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. Although 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 with or without disability, caregivers of these persons accounted for the largest absolute number of helpers, exceeding the combined number of caregivers for the other groups of care recipients. Caregivers in all the groups shared similar sociodemographic characteristics. Caregivers of care recipients with dementia and substantial disability, not surprisingly, experienced the greatest burden. Large proportions assisted with multiple ADLs and 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

Table 2. Family Caregiver and Care Recipient Characteristics

Characteristic	Dementia and Substantial Disability	Dementia but No Substantial Disability	Substantial Disability but No Dementia	No Dementia or Substantial Disability	*P*-Value
Caregiver					
Weighted estimate, n[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	<.001
Anxiety symptoms[d]	16.3	18.7	12.8	9.6	<.001
Relationship to older adult, %					
Spouse, husband, wife	17.1	16.2	24.9	26.1	.11
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)	<.001
Has family or 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	<.001
Used respite care, %	22.8	9.9	13.0	5.1	<.001
Attends caregiving support group, %	8.9	4.1	4.8	2.4	.15
Care recipient					
Weighted estimate, n[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)	<.001
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	<.001
Depressive symptoms[c]	47.7	31.9	35.7	24.7	<.001
Anxiety symptoms[d]	34.1	25.5	37.1	19.8	<.001
Number of comorbidities, mean (SE)	4.6 (0.1)	4.1 (0.1)	5.0 (0.1)	4.5 (0.1)	<.001
Number of hospital stays in past year, mean (SE)	1.5 (0.0)	1.7 (0.0)	1.5 (0.0)	1.8 (0.0)	.001

[a] Caregiver characteristics weighted according to National Study of Caregiving (NSOC) analytical weight. Estimates rounded to the nearest thousand.

[b] Older adult characteristics weighted according to National Health and Aging Trends Study (NHATS) analytical weight. Estimates rounded to the nearest thousand. Data based on reports of older adults in NHATS with caregivers surveyed in NSOC.

[c] Based on a score of ≥3 on the Patient Health Questionnaire-2.

[d] Based on a score of ≥3 on the Generalized Anxiety Disorder Scale-2.

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

SE = standard error.

caregivers also provided a range of tasks and experienced burden. There was a significant linear association between number of tasks provided in each domain of assistance (ADL- and IADL-related, health systems logistics, health management) and risk of caregiving difficulty and restrictions on social participation for all caregiver groups.

These 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 healthcare 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] The current study corroborates and extends this work by showing that, in a nationally representative sample of older persons, sizeable proportions of caregivers deliver health-related assistance that span domains of ADLs, IADLs, health systems logistics, and health management. Such findings have important implications for caregiver training because 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 caregivers' preparedness to deliver the requisite activities to identify caregivers in need of specialized training.

Although these results are consistent with prior research emphasizing the burdens that caregivers assisting older persons with dementia experience,[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 had 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, and support groups. These findings demonstrate the need for studies that move beyond selected samples and support strategies and interventions that extend to caregivers who have not typically been defined as high risk. Especially important

Table 3. Types of Assistance That Family Caregivers Provide to Older Adults According to Disability and Dementia Status

Type of Assistance	Dementia and Substantial Disability	Dementia but No Substantial Disability	Substantial Disability but No Dementia	No Dementia or Substantial Disability	*P*-Value
Weighted estimate, n[a]	2,447,000	2,920,000	2,302,000	7,314,000	
Type of assistance provided, %					
Activities of daily living and instrumental activities of daily living					
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
Assisted with ≥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
Manage insurance	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
Assisted with ≥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
Assisted with ≥2 tasks	54.8	29.9	46.0	23.1	<.001

[a] Weighted using the National Study of Caregiving caregiver analytical weight. Estimates are rounded to the nearest thousand.

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

Table 4. Prevalence of and Bivariate Associations Between Assistance Provided and Caregiving Difficulty, Stratified According to Older Adults' Dementia and Disability Status

	Caregivers Reporting Difficulty[a]							
	Dementia and Substantial Disability		Dementia but No Substantial Disability		Substantial Disability but No Dementia		No Dementia or Substantial Disability	
Weighted estimate, n (%)[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
Activities of daily living and instrumental activities of daily living[c]								
0–3 disabilities	48.0	.02	38.3	.002	46.4	.02	34.7	<.001
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]								
0–1 tasks	42.1	<.001	51.9	<.001	37.6	<.001	40.5	.003
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]								
0 tasks	52.8	.01	57.4	.01	45.7	.03	38.1	<.001
1 task	71.8		66.3		58.2		53.1	
≥2 tasks	79.2		76.4		66.5		61.5	

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

[b] Weighted using the National Study of Caregiving caregiver analytical weight. Estimates refer to caregivers who report caregiving difficulty, and are rounded to the nearest thousand.

[c] Shopping, transportation, housework, mobility, banking, self-care.

[d] Making appointments, ordering and keeping track of medications, managing insurance, speaking with the provider.

[e] Diet, foot care, skin care, exercise, 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 According to Older Adults' Dementia and Disability Status

	Caregivers Reporting Restrictions on Social Participation[a]							
	Dementia and Substantial Disability		Dementia but No Substantial Disability		Substantial Disability but No Dementia		No Dementia or Substantial Disability	
Weighted estimate, n (%)[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
Activities of daily living and instrumental activities of daily living–related[c]								
0–3 disabilities	11.8	<.001	22.8	.004	18.7	.03	6.4	<.001
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]								
0–1 tasks	18.0	<.001	15.0	.01	11.3	<.001	7.8	<.001
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]								
0 tasks	21.0	<.001	22.4	.01	8.9	<.001	9.8	<.001
1 task	31.3		35.1		29.1		19.1	
≥2 tasks	52.3		37.7		41.1		26.8	

[a] Four binary-response questions asking whether caregiving 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 National Study of Caregiving caregiver analytical weight. Estimates refer to caregivers who report restrictions on social participation and are rounded to the nearest thousand.

[c] Shopping, transportation, housework, mobility, banking, self-care.

[d] Making appointments, ordering and keeping track of medications, handling insurance, speaking with the provider.

[e] Diet, foot care, skin care, exercise, dental care.

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

will be an expanded evaluation of caregiver burden, health, and knowledge regarding support services for caregivers of all older persons.

This study is subject to several limitations. Because its purpose was to present a broad summary of the types of assistance caregivers provide 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. This 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 that 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, the analyses regarding the type of assistance provided pertained only to caregivers who assisted with at least one of the aforementioned tasks.

Conclusion

This study advances knowledge regarding the range of tasks caregivers provide and associated consequences for 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; assisting with a greater number of ADL- and IADL-related tasks, health systems logistics, and health management tasks 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 healthcare delivery models that take into account the role of caregivers in maintaining the health and well-being of older adults.

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