

## Original Investigation

# A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities

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**IMPORTANCE** Family and unpaid caregivers commonly help older adults who are at high risk for poorly coordinated care.

**OBJECTIVE** To examine how caregivers' involvement in older adults' health care activities relates to caregiving responsibilities, supportive services use, and caregiving-related effects.

**DESIGN, SETTING, AND PARTICIPANTS** A total of 1739 family and unpaid caregivers of 1171 community-dwelling older adults with disabilities who participated in the 2011 National Health and Aging Trends Study (NHATS) and National Study of Caregiving (NSOC).

**MAIN OUTCOMES AND MEASURES** Caregiving-related effects, including emotional, physical, and financial difficulty; participation restrictions in valued activities; and work productivity loss.

**EXPOSURES** Caregivers assisting older adults who provide substantial, some, or no help with health care, defined by coordinating care and managing medications (help with both, either, or neither activity, respectively).

**RESULTS** Based on NHATS and NSOC responses from 1739 family and unpaid caregivers of 1171 older adults with disabilities, weighted estimates were produced that accounted for the sampling designs of each survey. From these weighted estimates, 14.7 million caregivers assisting 7.7 million older adults, 6.5 million (44.1%) provided substantial help, 4.4 million (29.8%) provided some help, and 3.8 million (26.1%) provided no help with health care. Almost half (45.5%) of the caregivers providing substantial help with health care assisted an older adult with dementia. Caregivers providing substantial help with health care provided more hours of assistance per week than caregivers providing some or no help (28.1 vs 15.1 and 8.3 hours,  $P < .001$  for both). The use of supportive services was low but was greater among caregivers providing substantial vs some or no help (26.7% vs 15.5% and 7.6%,  $P < .001$  for both). In multivariable regression models adjusting for older adults' function and caregivers' sociodemographic and health characteristics, caregivers providing substantial help with health care were significantly more likely to experience emotional difficulty (adjusted odds ratio [aOR], 1.79; 95% CI, 1.20-2.66), physical difficulty (aOR, 2.03; 95% CI, 1.39-2.97), and financial difficulty (aOR, 2.21; 95% CI, 1.52-3.22) than caregivers providing no help. Compared with caregivers providing no help with health care activities, caregivers providing substantial help with health care activities were more than 5 times as likely to experience participation restrictions in valued activities (aOR, 5.32; 95% CI, 3.31-8.59) and more than 3 times as likely to experience work productivity loss (aOR, 3.14; 95% CI, 1.40-7.02).

**CONCLUSIONS AND RELEVANCE** Family caregivers providing substantial assistance with health care experience significant emotional difficulty and role-related effects, yet only one-quarter use supportive services.

*JAMA Intern Med.* 2016;176(3):372-379. doi:10.1001/jamainternmed.2015.7664  
Published online February 15, 2016.

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The high costs and poor quality of care delivered to older adults with complex health needs represent a pressing concern for policy makers, clinicians, patients, and society.<sup>1,2</sup> Almost 8 million older adults with significant disabilities live in the community with help from family and unpaid caregivers (family caregivers).<sup>3,4</sup> Older adults' family caregivers not only provide most assistance with everyday activities<sup>3,5</sup> but also help with a range of health care activities, such as physician visits,<sup>6,7</sup> transitions between settings of care,<sup>8,9</sup> medical decisions,<sup>10,11</sup> and medical tasks, such as injections, medication management, and wound care.<sup>12</sup> Because family caregivers are not systematically identified or routinely assessed in health care delivery,<sup>13-15</sup> little is known about the degree to which they assist with health care activities or about the nature of caregiving-related effects they may experience. A better understanding of the "workforce" of family caregivers who assist with health care activities is particularly timely and important given growing attention to the contribution of nonmedical factors to health<sup>16,17</sup> and given reform efforts that are shifting the focus of the health care enterprise toward accountability and value.<sup>17,18</sup>

This study draws on 2 nationally representative, population-based studies that together provide insight regarding older adults and the family caregivers who assist them. We focus on caregivers' assistance with 2 prevalent and clinically important health care activities that pertain to coordinating care with health care professionals and managing medications. A recent companion analysis that exclusively examined older adults found that approximately half of those individuals receiving help with both activities had dementia.<sup>19</sup> Our study extends this line of inquiry by examining family caregivers' perspectives and by focusing on a range of topics that may only be ascertained by speaking to a caregiver. By identifying the characteristics, responsibilities, and caregiving-related effects of family caregivers who navigate health system demands alongside or on behalf of older adults with disabilities, we seek to inform public health and health care delivery initiatives to better support family caregivers.

## Methods

### Data

The data that were examined in this study are publicly available, do not contain individual identifiers, and are therefore exempt from institutional review board review. Data for this study are drawn from the 2011 National Health and Aging Trends Study (NHATS) and the National Study of Caregiving (NSOC), 2 linked national surveys that provide information regarding a well-defined population of older adults and their family caregivers. The NHATS is nationally representative of Americans 65 years and older. In-person interviews are conducted with study participants or with proxy respondents if the participant is unable to respond. Study participants are asked whether and how they performed daily activities in the month before the interview. Among older adults who receive assistance, a detailed helper roster lists the relationship and specific activities for each person providing assistance.

The NSOC is a nationally representative survey of family members (>95% of whom are unpaid) and other unpaid caregivers who assist older persons with disabilities. Caregivers of the NHATS participants who lived in the community and received help with mobility, self-care, or household activities for health and functioning reasons or who lived in a residential care facility with supportive services were eligible for the NSOC. The NSOC participants were identified from the NHATS helper roster on the basis of being a family member or an unpaid helper who provided assistance with mobility, self-care, household activities, transportation, or medically oriented tasks. A telephone interview was conducted with up to 5 eligible helpers for each older adult. For older adults with more than 5 eligible helpers, 5 helpers were selected at random, and the remaining helpers were considered ineligible for the NSOC.

The NSOC participants are drawn from a well-defined population of older adults and the helpers they identify (from the NHATS Other Person file). Of 7609 NHATS participants living in the community or in a residential care facility, 2423 were included in the NSOC sampling frame, and 4935 helpers met eligibility criteria for the NSOC. An NSOC nonresponse can arise from the NHATS participant (who may refuse to provide contact information for helpers) or his or her caregivers (who may refuse to participate). The NHATS participants did not provide contact information for 1573 eligible family caregivers, and 1355 of the remaining 3362 eligible family caregivers could not be located or refused to respond, yielding 68.1% and 59.7% first-stage and second-stage response rates, respectively. In total, 2007 family caregivers of 1369 older adults responded in 2011 to the NSOC.<sup>20</sup> Because the nature of caregiving is likely to vary for older adults who live in residential care facilities owing to the availability of supportive services, we limited this study to older adults living in traditional community settings, leaving a final sample of 1739 family and unpaid caregivers of 1171 older adults with disabilities.

### Measures

We examined caregivers' sociodemographic and health characteristics, the nature and intensity of care they provide, their use of supportive services, and caregiving-related effects. Caregivers' sociodemographic and health characteristics included age, sex, educational attainment, relationship to the older adult, presence of a child younger than 18 years in the household, and self-rated health status. We constructed a composite measure of older adults' cognitive and physical function. Dementia refers to probable dementia, from self-reported physician diagnosis of Alzheimer disease or dementia, the AD8 dementia screening interview (administered to proxy respondents),<sup>21</sup> and cognitive tests to evaluate memory, orientation, and executive function.<sup>22</sup> Severe disability refers to receipt of help with 3 or more self-care or mobility activities. Using these measures, older adults' function was categorized as no dementia or severe disability, dementia but not severe disability, no dementia but severe disability, or both dementia and severe disability.

Information regarding the nature and intensity of care provision included travel time to older adults' residence, duration of caregiving, intensity of help (measured by hours of care

in the previous week), and assistance with specific tasks in domains of disability-related activities, health system logistics, and health management. Because of missing information, hours of care could not be computed using responses to the NSOC for 104 caregivers. For these caregivers, we used a hot-deck approach to impute hours of care based on older adults' function and caregivers' relationship, sex, and age (B. C. S. written communication to J.L.W., June 27, 2015). Measures of physical, financial, and emotional difficulties associated with providing care were constructed based on reported levels of difficulty in each domain (ratings of none, 1-2, and 3-5, respectively, were categorized as little or none, some, and substantial).<sup>4</sup> Participation restrictions refer to activities reported as being very or somewhat important to the caregiver that were limited in the prior month because of caregiving. Missed work refers to caregivers' reports of any missed time from work because of caregiving in the prior month among caregivers who were working for pay. In addition, we constructed a summary measure of work productivity loss that incorporated absenteeism (missed hours of work because of caregiving in relation to typical hours worked) and presenteeism (effect of caregiving on productivity when at work).<sup>23</sup> Caregivers' use of supportive services was examined using a 1-year reference period.

Involvement in health care activities refers to care coordination and medication management. Care coordination was defined by direct interactions with health care professionals. Caregivers who were identified by older adults as "sitting in

with them" at physician visits (from the NHATS) or who reported that they spoke to or emailed medical professionals about older adults' care (from the NSOC) were categorized as helping with care coordination. Medication management refers to caregivers from the NSOC who reported that they helped older adults "keep track of medications" or "take shots or injections." Using these data elements, we constructed mutually exclusive categories to summarize involvement in health care activities as follows: (1) no help (neither care coordination nor medications) (n = 364), (2) some help (care coordination but not medication management [n = 338] or medication management but not care coordination [n = 162]), or (3) substantial help (assisting with both care coordination and medication management) (n = 875).

**Data Analysis and Estimation**

We first present the numbers and characteristics of family and unpaid caregivers who assist older adults. We then describe the nature and intensity of care provided by caregivers as expressed by hours of care per week and types of activities for which help is provided across domains of disability-related activities, health system interactions, and health management tasks. We next evaluate caregiving-related emotional, physical, and financial difficulty; participation effects in valued activities; work productivity loss; and the use of supportive services, stratified by the degree of caregiver assistance with health care activities. Finally, we use multivariable regression models to examine how involvement in older adults'

**Table 1. Characteristics of Older Adults' Family and Unpaid Caregivers**

Caregiver Characteristic	Help With Health Care Activities					
	Substantial Help		Some Help		No Help	
	% [Reference]	%	P Value	%	P Value	
No. of caregivers (row %), millions <sup>a</sup>	6.5 (44.1)	4.4 (29.8)	NA	3.8 (26.1)	NA	
Age, mean (SE), y	57.2 (0.7)	55.3 (1.2)	.16	53.4 (1.4)	<.01	
Female sex	69.3	56.6	<.001	56.8	<.001	
Educational attainment <sup>b</sup>						
≤High school	40.5	43.3		48.1		
Some college	35.5	31.4	.43	31.0	.17	
≥College	24.0	25.4		20.9		
Self-rated health status						
Excellent or very good	44.5	56.1		53.5		
Good	31.1	24.4	<.01	28.5	.11	
Fair or poor	24.5	19.5		18.0		
Presence of a child <18 y old in the household	18.3	16.4	.49	13.8	.13	
Relationship to the older adult						
Spouse	26.2	25.9		15.3		
Daughter or son	54.2	45.6		34.7		
Other relative	16.7	23.9	.03	31.6	<.001	
Nonrelative	3.0	4.6		18.4		
Older adults' function <sup>c</sup>						
No dementia or severe disability	41.5	63.3		70.3		
Dementia but not severe disability	24.3	14.3		13.1		
No dementia but severe disability	13.1	12.9	<.001	9.1	<.001	
Both dementia and severe disability	21.2	9.4		7.5		

Abbreviation: NA, not applicable.

<sup>a</sup> Unweighted sample, with 875 providing substantial help, 500 providing some help, and 364 providing no help.

<sup>b</sup> Educational attainment is from the National Study of Caregiving for nonspousal caregivers (n = 1332) and from the National Health and Aging Trends Study Other Person file for spouses (n = 393). Information regarding educational attainment was missing for 14 caregivers.

<sup>c</sup> Dementia refers to possible dementia from a summary measure. Severe disability refers to receiving help with 3 or more self-care or mobility activities, including bathing, eating, dressing, toileting, transferring, and indoor mobility.

health care activities is associated with caregiving-related effects after adjusting for older adults' function and caregivers' sociodemographic and health characteristics.

Observations from the NHATS and NSOC are weighted to produce nationally representative estimates and to account for the complex sampling designs of each survey. Detailed weights released with the NSOC and used to generate population estimates in this study use information from the NHATS to adjust for differential probabilities of selection at both the NHATS sample person and caregiver levels.<sup>20</sup> All analyses were conducted with statistical software (SAS, version 9.3; SAS Institute Inc) using survey sampling weights and procedures that account for the complex sampling strategy.

## Results

Drawing on weighted estimates from linked nationally representative disability and family caregiver surveys, we find that 14.7 million family and unpaid caregivers assisted 7.7 million community-dwelling older adults with daily activities for health and functioning reasons in 2011. Of these caregivers, 6.5 million (44.1%) provided substantial help, 4.4 million (29.8%) provided some help, and 3.8 million (26.1%) provided no help with health care activities (Table 1). Caregivers who provided substantial help with health care activities were comparatively more likely to be female and adult children than caregivers who provided some or no help, respectively. Caregivers providing substantial help with health care activities were older than caregivers who provided no health care help and were less likely to rate their health as excellent or very good than caregivers who provided some help. Caregivers providing substantial help with health care activities were significantly more likely than caregivers providing no or some health care help to assist an older adult with both dementia and severe disability (21.2% vs 9.4% and 7.5%,  $P < .001$  for both) or with dementia only (24.3% vs 14.3% and 13.1%), while the proportion assisting an older adult with severe disability was comparable across the 3 groups (13.1% vs 12.9% and 9.1%, respectively). Among older adults receiving substantial help with health care activities, 45.5% (24.3% plus 21.2%) had dementia, and 34.3% (13.1% plus 21.2%) had severe disability.

Caregivers who provided substantial help with health care were comparatively more likely to live with older adults (61.1% vs 49.4% and 37.6%,  $P < .01$  and  $P < .001$ , respectively) (Table 2) and to provide care of greater intensity (28.1 vs 15.1 and 8.3 hours per week,  $P < .001$  for both) than caregivers who provided some or no help with these activities. Caregivers providing substantial (vs no) help with health care were half as likely to have assisted for less than 1 year (5.4% vs 11.0%,  $P = .02$ ). Caregivers providing substantial help with health care were more likely to assist with each of the specified activities that pertain to help for disability-related activities, health system logistics, and health management than caregivers providing some or no help.

Caregivers who provided substantial assistance with health care were more likely to report caregiving-related difficulties than their counterparts providing some or no help across do-

**Table 2. Caregiving Circumstances and the Nature of Assistance Provided**

Caregiving Circumstance	Help With Health Care Activities				
	Substantial Help % [Reference]	Some Help %	<i>P</i> Value	No Help %	<i>P</i> Value
Hours of care per week, mean (SE)	28.1 (1.5)	15.1 (1.3)	<.001	8.3 (0.7)	<.001
Travel time to older adults' residence					
Coreside	61.1	49.4		37.6	
≤10 min	21.4	22.0		27.8	
11-30 min	15.6	25.7	<.01	30.8	<.001
≥31 min	1.9	2.9		3.8	
Duration of caregiving, y					
<1	5.4	7.0		11.0	
1-4	44.1	48.1	.22	38.0	.02
>4	50.4	44.9		50.9	
<b>Nature of Assistance Provided</b>					
Disability-related activity					
Shopping	96.3	89.3	<.001	82.3	<.001
Transportation	92.4	86.2	<.001	80.4	<.001
Housework	95.6	82.0	<.001	72.1	<.001
Mobility	80.6	69.0	<.001	60.6	<.001
Banking	78.1	55.7	<.001	30.2	<.001
Self-care	70.4	43.0	<.001	31.2	<.001
Health system logistics					
Make appointments	90.8	53.1	<.001	14.8	<.001
Order medicines	83.6	36.7	<.001	16.6	<.001
Handle insurance issues	38.0	21.5	<.001	7.3	<.001
Health management					
Diet	45.1	24.1	<.001	15.2	<.001
Foot care	44.1	23.9	<.001	14.1	<.001
Skin care	38.8	23.1	<.001	7.9	<.001
Exercise	33.0	19.6	<.001	10.1	<.001
Dental care	28.2	9.2	<.001	3.6	<.001

main of emotional difficulty (34.3% vs 27.2% and 14.6%), physical difficulty (21.6% vs 12.0% and 5.7%), and financial difficulty (23.0% vs 12.3% and 6.7%) ( $P < .001$  for all) (Table 3). Compared with caregivers providing some or no help with health care, caregivers providing substantial help were more likely to experience reduced participation in 1 or more valued activities because of caregiving (35.3% vs 18.8% and 6.4%,  $P < .001$  for both), as well as each of the following specific activities: visiting friends and family, going out for enjoyment, attending religious services, and participating in club meetings or group activities. Although caregiver employment did not differ by involvement in health care, working caregivers providing substantial assistance with health care were more likely to have missed work because of caregiving in the past month than working caregivers who provided some or no help (20.0% vs 7.0% and 3.5%,  $P < .001$  for both). Work

Table 3. Caregiving-Related Difficulties, Participation Effects, and Supportive Services Use

Variable	Help With Health Care Activities				
	Substantial Help	Some Help		No Help	
	% [Reference]	%	P Value	%	P Value
Emotional difficulty related to providing care <sup>a</sup>					
Little or none	45.1	56.5		70.5	
Some	20.7	16.4	<.01	14.9	<.001
Substantial	34.3	27.2		14.6	
Physical difficulty related to providing care <sup>a</sup>					
Little or none	66.9	77.7		87.6	
Some	11.5	10.3	<.001	6.7	<.001
Substantial	21.6	12.0		5.7	
Financial difficulty related to providing care <sup>a</sup>					
Little or none	67.2	79.9		86.7	
Some	9.9	7.8	<.001	6.6	<.001
Substantial	23.0	12.3		6.7	
Caregiving effects on valued activities <sup>b</sup>					
Visiting friends and family	28.1	12.6	<.001	5.3	<.001
Going out for enjoyment	20.1	9.0	<.001	2.3	<.001
Attending religious services	14.9	4.7	<.01	0.8	<.001
Participating in club meetings or group activities	12.9	6.0	<.001	0.5	<.001
Caregiving effects on participation in ≥1 valued activities					
Works for pay <sup>c</sup>	38.8	41.0	.61	41.3	.57
Caregiving effects on work, of those who work					
Missed work because of caregiving in the past month <sup>d</sup>	20.0	7.0	<.001	3.5	<.001
Absenteeism, missed hours because of caregiving <sup>e</sup>	2.1	0.7	.01	0.2	<.001
Presenteeism, reduced productivity because of caregiving	7.9	2.6	<.01	2.7	<.01
Caregiving-related work productivity loss	9.6	3.3	<.01	2.9	<.001
Supportive services or assistance directed to caregiver					
Respite care	16.6	8.4	<.001	2.8	<.001
Received training regarding how to assist older adult	9.5	6.3	.11	2.8	<.001
Support group participation	6.5	3.0	.03	2.7	.04
Use of ≥1 supportive services	26.7	15.5	<.001	7.6	<.001

<sup>a</sup> Responses of no difficulty are categorized as little or none, rated levels of difficulty of 1 to 2 are categorized as some, and rated levels of difficulty of 3 to 5 are categorized as substantial.

<sup>b</sup> Reduced participation in the past month because of caregiving for activities identified as being somewhat or very important.

<sup>c</sup> Sample includes 656 working family caregivers providing substantial help (n = 327), some help (n = 181), or no help (n = 148) with health care activities.

<sup>d</sup> Missed work refers to any missed time from work in the past month because of caregiving.

<sup>e</sup> Absenteeism reflects hours of work missed because of caregiving in relation to all hours typically worked.

productivity loss was 3 times higher for caregivers who provided substantial assistance with health care compared with caregivers who provided some or no help (9.6% vs 3.3% and 2.9%,  $P < .01$  and  $P < .001$ , respectively). Finally, caregivers who provided substantial assistance with health care were more likely to use supportive services than caregivers who provided some or no help (26.7% vs 15.5% and 7.6%,  $P < .001$  for both).

Caregivers' involvement in older adults' health care activities was highly associated with each of the caregiving-related effects after adjusting for older adults' function and caregivers' sociodemographic and health characteristics (Table 4). In multivariable models, caregivers who provided substantial help with health care were 1.8 times more likely to experience emotional difficulty (aOR, 1.79; 95% CI, 1.20-2.66) and more than twice as likely to experience physical difficulty (aOR, 2.03; 95% CI, 1.39-2.97) and financial difficulty (aOR, 2.21; 95% CI, 1.52-3.22) than caregivers who provided no help with health care. Caregivers who provided substantial help with health care were 5.3 times as likely to experience participation restrictions in valued activities (aOR, 5.32; 95% CI, 3.31-8.59) and, among working caregivers, were 3 times as likely

to experience work productivity loss (aOR, 3.14; 95% CI, 1.40-7.02) than caregivers who provided no help with health care activities.

## Discussion

We found that 6.5 million family and unpaid caregivers of community-dwelling older adults provide substantial help with health care activities. Relative to caregivers who provide some or no help, caregivers providing substantial help with health care activities assist with greater intensity (as measured by hours of care) and are significantly more likely to experience caregiving-related effects across dimensions that include physical, emotional, and financial difficulty, as well as participation restrictions and work productivity loss. Approximately 1 in 4 caregivers receives supportive services. To our knowledge, this investigation is the first nationally representative study to comprehensively examine differential caregiving-related effects for family caregivers who assist with health care activities, and the results collectively raise important ques-



Table 4. Multivariable Logistic Regression Results for Correlates of Caregiving-Related Effects

Caregiver Characteristic	Adjusted Odds Ratio (95% CI) <sup>a</sup>				
	Emotional Difficulty <sup>b</sup>	Physical Difficulty <sup>b</sup>	Financial Difficulty <sup>b</sup>	Participation Restrictions <sup>c</sup>	Work Productivity Loss <sup>d</sup>
Age	0.99 (0.98-1.00)	1.01 (1.00-1.02)	0.98 (0.97-0.99)	0.99 (0.98-1.00)	1.00 (0.99-1.02)
Female sex	1.45 (1.10-1.92)	1.92 (1.41-2.62)	1.02 (0.72-1.43)	1.23 (0.85-1.78)	1.36 (0.75-2.47)
Educational attainment					
≤High school	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Some college	1.76 (1.34-2.31)	1.44 (1.02-2.01)	1.30 (0.86-1.96)	1.50 (1.05-2.14)	1.32 (0.71-2.45)
≥College	1.94 (1.43-2.64)	1.36 (0.90-2.04)	1.16 (0.67-1.98)	2.21 (1.51-3.24)	2.26 (1.09-4.70)
Self-rated health status					
Excellent or very good	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Good	1.47 (1.11-1.93)	1.94 (1.38-2.72)	2.49 (1.77-3.49)	1.79 (1.28-2.50)	1.91 (1.07-3.41)
Fair or poor	1.86 (1.30-2.67)	4.91 (3.43-7.03)	2.74 (1.90-3.96)	2.13 (1.51-3.01)	2.13 (0.98-4.60)
Presence of a child <18 y old in the household	0.79 (0.50-1.25)	1.17 (0.67-2.06)	1.06 (0.63-1.79)	0.56 (0.33-0.93)	0.68 (0.35-1.34)
Works for pay	0.93 (0.73-1.19)	0.68 (0.49-0.94)	0.98 (0.70-1.37)	0.93 (0.67-1.29)	Not Applicable
Relationship to the older adult					
Spouse	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Daughter or son	1.28 (0.83-1.97)	0.76 (0.56-1.04)	0.75 (0.46-1.22)	0.93 (0.64-1.36)	1.16 (0.60-2.24)
Other relative	0.58 (0.35-0.97)	0.73 (0.47-1.11)	0.56 (0.35-0.89)	0.92 (0.57-1.47)	0.61 (0.26-1.46)
Nonrelative	0.36 (0.17-0.76)	0.52 (0.23-1.16)	0.25 (0.09-0.72)	0.37 (0.15-0.88)	0.32 (0.05-2.22)
Older adults' function <sup>e</sup>					
No dementia or severe disability	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Dementia but not severe disability	1.19 (0.83-1.69)	1.29 (0.91-1.84)	1.68 (1.09-2.59)	1.67 (1.14-2.43)	1.21 (0.70-2.11)
No dementia but severe disability	1.51 (1.02-2.25)	2.56 (1.59-4.11)	1.59 (1.08-2.35)	1.92 (1.27-2.92)	1.56 (0.75-3.25)
Both dementia and severe disability	1.78 (1.10-2.87)	3.12 (2.12-4.59)	1.83 (1.17-2.86)	3.02 (2.02-4.51)	1.16 (0.49-2.74)
Help with health care activities					
No help	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Some help	1.43 (0.96-2.13)	1.71 (1.11-2.63)	1.37 (0.87-2.17)	2.72 (1.69-4.39)	0.85 (0.39-1.84)
Substantial help	1.79 (1.20-2.66)	2.03 (1.39-2.97)	2.21 (1.52-3.22)	5.32 (3.31-8.59)	3.14 (1.40-7.02)

<sup>a</sup> Adjusted for caregiver age, sex, educational attainment, self-rated health status, presence of a child younger than 18 years in the household, work responsibilities, and relationship to the older adult.

<sup>b</sup> Difficulty related to providing care, with contrast between caregivers who rated the level of difficulty of 1 to 5 (some or substantial in Table 3) vs caregivers who indicated little or no difficulty because of caregiving.

<sup>c</sup> Reduced participation in any of 4 valued activities (visiting friends and family,

going out for enjoyment, attending religious services, and participating in club meetings or group activities) because of caregiving.

<sup>d</sup> Refers to any work productivity loss using a composite measure encompassing absenteeism and presenteeism among caregivers working for pay (n = 656).

<sup>e</sup> Dementia refers to probable dementia using a summary measure. Severe disability refers to receiving help with 3 or more self-care or mobility activities, including bathing, eating, dressing, toileting, transferring and indoor activity.

tions regarding the role of caregivers within a rapidly evolving health system that seeks quality, value, and accountability in care.

Our findings contribute important insight regarding the “invisible work” of managing complex care by documenting the significant caregiving-related effects that are experienced by family and unpaid caregivers who actively manage older adults' health care. Prior studies have established the time and effort associated with managing care for persons with complex health needs for health care professionals<sup>24,25</sup> and for patients.<sup>26,27</sup> Our study extends existing evidence that has established the special challenges encountered by caregivers of persons with dementia.<sup>15,28,29</sup> We found that almost half of the caregivers providing substantial help with health care activities assist an older adult with dementia. For the first time to date, we also quantify the emotional, financial, physical, participation, and work-related effects of caregiving experienced by family caregivers who interact with health care pro-

fessionals and manage health care activities on behalf of or alongside older adults. Study findings indicate that the health system is well poised to serve as a point for the identification of higher-intensity caregivers, who are largely unrecognized in systems of care.<sup>13,30</sup>

Few family and unpaid caregivers used supportive services. The significant consequences associated with caregiving reported herein and in other studies<sup>15,28,30,31</sup> underscore the need to identify and promulgate strategies that address the needs of caregivers within systems of care delivery. Effective psychosocial and coping interventions have been developed to support family caregivers,<sup>32-34</sup> but they are largely disconnected from routine health care delivery. The lack of systematic identification and support of caregivers in mainstream care means that their information and support needs are not well understood and often remain unmet.<sup>15</sup> Available evidence (largely setting specific and anecdotal) indicates that caregivers may be poorly informed about patients' health or treat-

ment plans<sup>10,35,36</sup> and may experience challenges in accessing such information.<sup>37-39</sup>

To our knowledge, this study provides the first national estimates of work productivity loss due to providing care to an older adult with disability, and our estimates are substantially lower than previously reported.<sup>23,40,41</sup> Although 1 in 5 working family and unpaid caregivers who provided substantial help with health care activities missed work because of caregiving in the previous month, hours of work that were missed were few. In the aggregate, work productivity loss was largely the result of reductions in productivity when working rather than time missed from work. Work productivity loss was 3 times higher among working caregivers who provided substantial help with health care activities compared with working caregivers who provided no help or some health care help. These findings are notable in quantifying the extent to which caregiving effects extend to employers and the importance of workplace strategies and policies to better support working family caregivers such as paid family leave.<sup>42,43</sup>

As in any survey, the results herein are subject to the constraints of sample design, participant response, and questions asked. The methodological challenges of collecting information from family caregivers are not inconsequential. National surveys report wide variation in prevalence estimates and characteristics.<sup>44</sup> The linked data sets used in this study afford several strengths in this regard because family and unpaid caregivers were identified from in-person interviews, with a well-characterized sample of older adults from a survey that was specifically designed to yield national estimates of disability.<sup>3,45</sup> In addition, the NSOC surveyed and there-

fore generalizes to all family and unpaid caregivers rather than a single primary caregiver as in prior surveys.<sup>46</sup> Although our measure of caregivers' involvement in health care activities was limited to coordination of care and management of medications, these activities are common, broadly applicable to a wide range of conditions, and of great clinical importance. Because analyses are cross-sectional, we are unable to comment on the causal processes that underlie observed caregiving-related effects or supportive services use.

## Conclusions

Our study results pertain directly to calls that family members should be included as members of patients' interdisciplinary care teams<sup>47,48</sup> and to consensus statements from professional organizations that endorse more explicit and robust partnerships with patients' family caregivers.<sup>49-52</sup> Although care is safer, more efficient, and of higher quality when delivered by a coordinated health care team,<sup>1,53,54</sup> little attention has been directed at understanding the extent or consequences of coordination between health care professionals and family caregivers. Because the magnitude and scope of assistance provided to disabled older adults by family and unpaid caregivers far exceed those of paid caregivers<sup>3,55</sup> and because their involvement persists across both time<sup>56</sup> and settings of care,<sup>8,57</sup> devising organizational strategies and health care practices to identify and more purposefully engage and support family caregivers merits greater attention by health system stakeholders seeking high-value care.

### ARTICLE INFORMATION

**Accepted for Publication:** November 11, 2015.

**Published Online:** February 15, 2016.  
doi:10.1001/jamainternmed.2015.7664.

**Author Contributions:** Dr Wolff had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Study concept and design:** Wolff, Spillman, Kasper.  
**Acquisition, analysis, or interpretation of data:** All authors.

**Drafting of the manuscript:** Wolff, Kasper.

**Critical revision of the manuscript for important intellectual content:** All authors.

**Statistical analysis:** Wolff, Spillman.

**Obtained funding:** Wolff, Freedman, Kasper.

**Administrative, technical, or material support:** Wolff, Spillman.

**Conflict of Interest Disclosures:** None reported.

**Funding/Support:** This study was supported by grant KO1MH082885 from the National Institute of Mental Health (Dr Wolff), by grant U01AG032947 from the National Institute on Aging, and by grant 12-233-SOL-00434 from the Assistant Secretary for Planning and Evaluation.

**Role of the Funder/Sponsor:** These sponsors were not involved in the design and conduct of the study; management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; or decision to submit the manuscript for publication.

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