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Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

INFORMAL CAREGIVING FOR OLDER AMERICANS:

AN ANALYSIS OF THE 2011 NATIONAL STUDY OF CAREGIVING

April 2014

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National Study of Caregiving

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ACRONYMS

The following acronyms are mentioned in this report.

ACL	HHS Administration for Community Living
AD8	Alzheimer's Disease 8-Question Interview Tool
ADL	Activity of Daily Living
ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
GAD2	Glutamate Decarboxylase 2 Gene
HHS	U.S. Department of Health and Human Services
IADL	Instrumental Activity of Daily Living
ICS	Informal Caregiving Supplement
IOM	Institute of Medicine
NHATS	National Health and Aging Trends Study
NLTCS	National Long-Term Care Survey
NSOC	National Survey of Caregiving
PHQ	Patient Health Questionnaire

EXECUTIVE SUMMARY

This report examines the role and experiences of informal caregivers for the older population, using a new resource, the National Survey of Caregiving (NSOC). The NSOC is unique in interviewing all informal caregivers for a nationally representative sample of persons age 65 or older receiving assistance with daily activities. NSOC respondents report on types of assistance they provide beyond traditional household (instrumental activities of daily living) and self-care or mobility (activities of daily living) tasks. These tasks range from assisting with transportation to help with health or medical care, including such things as injections or ostomy care. Thus, estimates capture the full range of supports informal caregivers provide and contributions they make in areas other than explicit long-term care. Information collected about positive and negative aspects of caregiving, health, and indicators of subjective well-being allows examination of how gains and burdens differ by caregiver and care-recipient characteristics and by the intensity of care provided.

In 2011, 18 million informal caregivers provided 1.3 billion hours of care monthly to the more than 9 million older adults receiving informal assistance. Consistent with prior studies, family members are the main source of informal care: Spouses are about 20% of caregivers and provide nearly one-third of the aggregate hours, and adult children provide nearly half of aggregate hours. Hours are concentrated among caregivers of high need recipients--the 31% assisting recipients receiving help with at least three self-care or mobility tasks and the 33% assisting persons with probable dementia, account for nearly half and 40% of aggregate hours, respectively. Informal caregivers provide an average 75 hours per month. Average monthly hours provided are significantly more for spouses (110) and other caregivers living with the care-recipient (114) and those assisting higher need recipients with self-care or mobility (84).

Most caregivers (68%) report substantial positive consequences of caregiving and few (10%) report substantial negative consequences. High levels of both positive and negative aspects of caregiving are associated with greater engagement in caregiving. The most common negative aspects are exhaustion, having too much to do, and too little time for themselves. Not surprisingly, substantial negative consequences are most common among caregivers who provide high levels of care, those who assist individuals with probable dementia, and those who have health problems themselves.

Our findings substantiate that beyond supportive care, informal caregivers commonly provide assistance with a range of medically-oriented tasks as well as interacting with providers and helping older recipients navigate the health system. Finding ways to support informal caregivers in their traditional roles as well as their expanded role in providing and managing health care for the older population continues to be an important policy goal, particularly as the locus of care continues to shift from nursing homes to community settings. Both the Administration for Community Living

(ACL) and the National Plan to Address Alzheimer's Disease recognize the need to support informal caregivers as an essential part of the workforce for maintaining the well-being and health of the older population. The NSOC can contribute to the knowledge base for these efforts.

INTRODUCTION

Informal caregiving is the foundation of long-term care for the older population in the United States. At least 90% of persons receiving help with daily activities receive some informal care, and about two-thirds receive only informal care (Freedman et al. 2013; Kaye, Harrington & LaPlante 2010; Spillman 2009; Spillman & Black 2005). Reliance on informal care is even higher among those who have spouses or adult children, who are the most common source of informal care. Previous research has found that collectively, informal caregivers to older Americans living in non-institutional settings provide 75%-80% of total care hours, indicating their paramount importance in the long-term care system and the substantial amount of care that would have to be provided otherwise in their absence (Spillman 2009; Johnson & Wiener 2006).

In recognition of their critical role in care for the older population with disabilities, greater emphasis has been placed in recent years on understanding how best to support informal caregivers' efforts, notably through Administration for Community Living (ACL) initiatives, such as the National Family Caregiving Support Program and Aging and Disability Resource Centers, and more recently through the U.S. Department of Health and Human Services (HHS) National Plan to Address Alzheimer's Disease.

Research has shown that the financial, emotional, and physical demands of caregiving can be high and that the resulting stress or burden can threaten the ability of caregivers to maintain their efforts. Kasper et al. (1994) found that perspectives on caregiving, including stress, were factors in the decision to end caregiving. Spillman & Long (2009) found that having a highly stressed caregiver was associated with a greater risk of long-stay nursing home entry over a two-year follow-up period and that financial and physical strain were important predictors of perceived high stress from caregiving. A substantial literature has examined caregiving-related stress, burden, and their consequences, especially among caregivers to persons with cognitive impairment (Pinquart & Sorensen 2003, 2007).

In this report, we provide new estimates from the National Survey of Caregiving (NSOC), a nationally representative survey of informal caregivers to the older population, supported by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) within HHS. The NSOC was a supplement to the 2011 National Health and Aging Trends Study (NHATS), a new National Institute on Aging-supported annual survey of a nationally representative sample of Medicare beneficiaries age 65 or older. The NHATS is designed to measure both trends and trajectories of health and functioning and the consequences for the older population, their families, and society. The NSOC is particularly innovative in that it attempts to interview all informal caregivers for a well-defined study population of persons receiving informal help with daily activities from family members or friends.

We address the following questions:

- How many informal caregivers provided help with basic and instrumental activities of daily living (IADLs) to elders with disabilities and how many hours of help did they provide on a monthly basis in 2011?

- How does the type and amount of care provided vary by caregiver characteristics (gender, age, relationship to care-recipient, employment status, and health status)?

- What is the distribution and balance of positive and negative aspects of caregiving by caregiver and care-recipient characteristics?

- What roles do different caregivers play, and how do these different roles and caregiver health and participation in valued activities relate to well-being and negative aspects of caregiving?

BACKGROUND

Like the predecessor surveys, the National Long-Term Care Survey (NLTCS) and its companion Informal Caregiving Supplement (ICS), the NHATS and NSOC are unique in providing nationally representative information reported by informal caregivers for a well-characterized population-based sample of older adults. In addition, the baseline NSOC has the distinction of interviewing the entire informal caregiver network, rather than only the “primary caregiver” interviewed in the ICS. These unique characteristics of the combined NHATS and NSOC data allow a more comprehensive understanding of the context, scope of activities, and implications of informal caregiving for the older population than is possible with surveys that rely solely on either care-recipient-reported or caregiver-reported information. The NSOC design draws on a substantial literature on the scope, nature, and consequences of informal caregiving.

Despite variability in the estimated numbers of family caregivers to older adults across national surveys (Giovannetti & Wolff 2010), there is remarkable consistency that informal caregivers of older adults are predominantly middle-aged daughters and spouses (Wolff & Kasper 2006; Johnson & Wiener 2006; Spillman & Black 2005; Spillman & Pezzin 2000; Stone & Kemper 1989). Although there is growing recognition of the unique challenges posed by distance caregiving (Bevan et al. 2012), evidence suggests caregivers and recipients typically live together or within close proximity (Wolff & Kasper 2006; Johnson & Wiener 2006; Spillman & Pezzin 2000). Approximately half of informal caregivers work for pay, but employment rates vary widely by relationship and are generally higher among adult child (versus spouse) caregivers, (Pinquart & Sorensen 2011; Wolff & Kasper 2006) and among caregivers who provide a less intensive level of supportive assistance as part of a larger helping network (Johnson & Wiener 2006; Spillman & Pezzin 2000).

Informal caregivers provide assistance with diverse health-related activities that span daily personal care activities such as eating and bathing, household management activities such as shopping and meal preparation, self-management activities such as managing prescribed medications, navigating health system demands such as attending medical encounters, and financial activities such as handling insurance and bills (IOM 2008). The emphasis on informal caregiving historically has focused on assistance with personal care and household activities (Katz et al. 1963; Lawton & Brody 1969; Stone, Cafferata & Sangl 1987). However, recent emerging evidence demonstrates that family members also are often involved in managing complex health care activities at home (Reinhard, Levine & Samis 2012; IOM 2008; Donelan et al. 2002), as well as in directly navigating the demands of health care system and transitions between settings of care (Levine et al. 2010; Wolff & Roter 2008).

The caregiving experience is shaped by multiple diverse factors that may affect reactions, such as perception of burden or rewards from caregiving. The balance of positive and negative aspects may affect the likelihood of adverse outcomes such as cessation of caregiving or institutionalization of the care-recipient. Factors affecting the experience of caregivers include the nature and severity of older adults' underlying disability and specific health conditions (Pinquart & Sorensen 2007; Roth et al. 2009), the types of caregiving tasks, the intensity of caregiving (Pearlin et al. 1990; Zarit et al. 2010), the nature of the relationship between the informal caregiver and the care-recipient (Pearlin et al. 1990; Pinquart & Sorensen 2011), and competing work and child care responsibilities (Pearlin et al. 1990; Spillman & Pezzin 2000). Informal caregivers who regularly provide “high intensity” help in terms of greater hours of care and assistance with activities of daily living (ADLs) are more likely to experience burden and strain (Chappell & Reid 2002). Other family caregivers experience elevated stress (Kiecolt-Glaser et al. 2003; Vitaliano, Zhang & Scanlan 2003), physical or psychological illness (Emanuel et al. 2000; Pinquart & Sorensen 2003; Roth et al. 2009), or economic impacts, including cessation of work (Schulz et al. 2003; Covinsky et al. 2001). On the other hand, many informal caregivers cope well and derive personal reward from their role (Freedman et al. 2014; Beach et al. 2000; Kramer 1997; Stuckey, Neundorfer & Smyth 1996).

DATA, MEASURES, AND METHODS

The first round of NHATS took place in May 2011 through October 2011 with a national sample of Medicare beneficiaries drawn from the Medicare enrollment file (Montaquila et al. 2012a). The NHATS represents the full Medicare population age 65 or older. Facility interviews are conducted with staff for persons living in nursing homes. For persons living outside of nursing homes, sample person interviews covering a wide range of information on functioning, health, and other characteristics are conducted, and facility interviews also are conducted for those living in other supportive care settings, broadly defined.

NHATS collects self-reported information on functioning using a validated protocol (Freedman et al. 2011) that ascertains whether and how activities were performed in the month prior to interview. Activities include self-care and mobility, household tasks, and other common tasks, such as transportation assistance or being accompanied to doctor appointments. Respondents reporting assistance were asked to identify all persons providing help with each activity, and those eligible for the NSOC also were asked to provide contact information for eligible caregivers.

NSOC eligibility was a two-stage process. First, NHATS respondents were eligible if they reported help with mobility or self-care, help with household activities specifically for health/functioning-related reasons, or lived in residential care settings. Second, caregivers were eligible if they were a family member or were an unpaid caregiver who was not a relative and helped with any activity identified during the NHATS interview including not only mobility, self-care, and household activities but also transportation and medical care activities (e.g., going to the doctor, helping with medications). NSOC interviews took place between May 2011 and November 2011.

Sample

The NSOC sample was drawn from 4935 eligible informal caregivers to 2423 eligible NHATS respondents. (For a small number of NHATS respondents identifying more than five eligible caregivers, five caregivers were selected randomly.) Eligible NHATS respondents refused to provide contact information for 1573 eligible caregivers, and of the remaining 3362 caregivers with contact information, 1355 could not be located or refused to respond. The first stage (NHATS) response rate was 68%, and the second stage (caregiver) response rate was 60% (Kasper, Freedman & Spillman 2013). For a “primary caregiver” defined by the number of hours of care provided, the corresponding rates were 73% and 67%. The final NSOC sample consists of 2007 responding caregivers to 1369 NHATS respondents. Sample weights developed for the NSOC take into account differential probabilities of selection and non-response at both the NHATS sample person and caregiver level (Kasper et al. 2013a). We excluded 11 caregivers who had helped within the year prior to interview, but not within the last month, for a final analysis sample of 1996 caregivers.

Analysis Measures

Measures used in this report include both care-recipient characteristics drawn from the NHATS and caregiver characteristics and experience drawn from the NSOC.

Care-Recipient Measures

The care-recipient measures used are a hierarchical assistance level measure developed and further described in Freedman & Spillman (2013), a dementia measure developed and described in Kasper et al. (2013b, 2014), and an indicator that the NHATS respondent is living in a supportive care setting other than a nursing home.

As noted, only NHATS respondents reporting assistance in the last month with self-care or mobility activities, help with household activities for reasons related to health or functioning, or living in supportive care settings are eligible to have informal caregivers selected for the NSOC. Self-care activities include bathing, dressing, eating, and toileting. Mobility-related activities include getting out of bed, getting around inside one's home or building, and leaving one's home or building. Taken together, self-care and mobility activities correspond to ADLs. Household activities include laundry, hot meals, shopping for personal items, paying bills/banking, handling medications, corresponding to IADLs. These activities were grouped into a three-category hierarchical measure identifying NHATS respondents as receiving assistance only with household activities, receiving assistance with 1-2 self-care or mobility activities, or receiving assistance with 3+ self-care or mobility activities.

The dementia measure used also is a three-category measure classifying NHATS respondents as having probable dementia, possible dementia, or no dementia based on: (1) a report that a doctor told the sample person he/she had dementia or Alzheimer's disease; (2) a score indicating probable dementia on a screening instrument (the AD8; Galvin 2005, 2006) administered to all proxy respondents; and (3) results from cognitive tests that evaluate memory, orientation and executive function (Kasper et al. 2013).

Informal Caregiver Measures

NSOC gathered detailed information about each informal caregiver's caregiving experience, caregiving support, and demographic, socioeconomic, and family characteristics. In this report, we focus primarily on the type and amount of help provided in the last month, work and family situation, positive and negative aspects of caregiving (i.e., gains from and burdens of caregiving activities), physical and mental health (including symptoms and impairments that limited their activities), participation in valued activities and whether caregiving limited participation, and subjective well-being.

Type and Amount of Help. Each NSOC respondent reported the total hours of care they provided in the month prior to interview and the proportion devoted to self-care or mobility assistance. In this report, we focus only on the total hours of care each caregiver-reported. NSOC respondents reported whether they helped with activities in **five domains** of care:

- self-care and mobility activities;
- household activities;
- transportation;
- health or medical care activities; and
- interactions relating to the health care system and providers.

In addition to examining whether each caregiver assisted with individual tasks, we constructed indicators of whether each caregiver assisted with any task in each domain, measures of engagement and specialization, and a hierarchical measure of the intensity of caregiving.

We used two measures to characterize the engagement of each caregiver in the recipient's care. The first measure of engagement and the most common in the literature is whether the caregiver assisted with activities in the first domain, self-care or mobility activities, which are associated both with greater personal contact and with greater dependency. This measure is used throughout the report. The second measure differentiates caregivers who help with tasks in all domains in which the recipient receives help from those who specialize in a subset of activities. To construct this measure, we compared the specific tasks with which each caregiver helped and the full array of tasks with which the recipient received help from any network member. Using this information, we constructed an indicator of whether each caregiver provided assistance across all domains in which the care-recipient received help (not specializing), or only a subset of domains (specializing).

Finally, we used the monthly hours of care provided as a measure of caregiving intensity, to examine the relationship between caregiving intensity and subjective well-being and burden.

Work and Family. We examine each caregiver's age, relationship to the care-recipient, gender, and whether they worked for pay. For employed caregivers, we also examine hours worked in the last week. For those who were employed but did not work in the last week, hours were assessed for the most recent week when they did work. For caregivers other than spouses, we also examined whether the caregiver lived with the care-recipient, marital status, whether the caregiver had children under age 18, and employment and hours worked.

Positive and Negative Aspects of Caregiving. The primary measures used to characterize positive and negative aspects of caregiving draw on four items assessing perceived gains from caregiving and four items assessing perceived negative aspects of caregiving (Pearlin et al. 1990, Lawton et al. 1989). Each item has three response categories: very much, somewhat, or not so much. Both sets of questions were preceded by a neutral introduction in which the interviewer asked the respondent to listen to the statements and "answer whether this describes your situation…". Values were rescaled so that each item was valued from 0 (not so much) to 2 (very much). Factor analysis indicated that the two sets of items represented two factors, one positive with loadings of 0.52 or higher (alpha=0.70) and the other negative with loadings of 0.58 or higher (alpha=0.75). Each set of items was then combined to create positive and negative scales valued 0-8. We also examined three items in which respondents were asked where they experienced financial, emotional, and physical "difficulty," and if so, to rate the level of difficulty of each type on a scale of 1-5. Only 94 (<5%) of the 1996 respondents in the analysis sample was missing any of the 11 items. Missing values were imputed separately for positive, negative, and difficulty items using a vector approach that matched donors and recipients by residential setting, the reported values for the vector of positive (negative, or difficulty) items, relationship to care-recipient, gender, and age. Donors were respondents with the respective vectors fully reported.

Physical and Mental Health. To characterize the health of informal caregivers, we drew on self-reported health; two scales measuring depression and anxiety, respectively; sleep problems; and severity of symptoms or impairments. Depression and anxiety scales were created by combining two questions about the frequency of current symptoms of depression and two about generalized anxiety and rescaling the result from 2-8 to 0-6. For each scale, a cut point of 3 was used (Kroenke et al. 2009; Lowe et al. 2009). Sleep problems were assessed as the frequency of difficulty of falling back to sleep. Severity of symptoms or impairments were assessed as the frequency with which pain, upper or lower body weakness, low energy or exhaustion, or breathing problems limited activities.

Participation and Well-Being. We also constructed measures of restricted participation in valued activities because of caregiving and subjective well-being. We measured participation restriction using four items about visiting in person with friends or family; attending religious services; participating in clubs, classes, or other organized activities; and going out for enjoyment in the month prior to interview. We constructed a count of the number of activity restrictions, based on the caregiver's rating the activity as somewhat or very important and reporting that caregiving ever prevented participation in the activity in the last month. For subjective well-being, we created a score for each caregiver from four items reflecting positive and negative emotions (frequency from every day to never in the last month of feeling cheerful, bored, full of life, upset) and three reflecting self-realization (extent of disagreement with statements about purpose in life, self-acceptance, and environmental mastery). Factor analysis confirmed that these items formed one factor with loadings 0.74 or higher (alpha=0.92). Only 62 respondents (3% of the analysis sample) were missing any of the seven items. Values were imputed using the vector approach described above.

Methods

For all estimates, we use the analytic weights that take into account differential probabilities of selection and non-response at the NHATS sample person and caregiver level (Kasper et al. 2013a) and statistical software that adjusts standard errors for survey design.

PROFILE OF INFORMAL CAREGIVERS AND HOURS OF CARE PROVIDED

In 2011, about 18 million informal caregivers provided 1.3 billion hours of care on a monthly basis (Table 1) to more than 9 million recipients age 65 or older (Freedman & Spillman 2013). About one in five informal caregivers were spouses of care-recipients, 29.3% were daughters, 18.3% were sons, and 22.3% were other relatives, about half of whom were sons-in-law or daughters-in-law or grandchildren. Fewer than 10% were non-relatives. Spouses provided a disproportionately high 31.1% of aggregate hours, reflecting in part that nearly half of spouses were the sole informal caregiver (not shown). Daughters provided about 30% of aggregate monthly hours, while sons provided about half that proportion, a somewhat smaller proportion of hours than provided by other relatives. Nearly 20% of daughters and about 12% of sons, other relatives, and non-relatives were the only informal caregiver (not shown).

TABLE 1. Number of Informal Caregivers and Hours of Help Provided in the Last Month to Recipients Age 65 or Older Living Outside Nursing Homes, 2011

	Number of Caregivers (000s)	Percent of Caregivers	Aggregate Monthly Hours Provided (000s)	Percent of Aggregate Hours of Health
All caregivers	17,949	100.0	1,342,520	100.0
Relationship to recipient				
Spouse	3,802	21.2	417,018	31.1
Daughter	5,263	29.3	411,138	30.6
Son	3,287	18.3	213,530	15.9
Other relative	4,011	22.3	245,508	18.3
Other non-relative	1,586	8.8	55,326	4.1
Help reported by recipient				
Household/other activities only[a]	5,581	31.1	284,530	21.2
Self-care or mobility	12,368	68.9	1,057,990	78.8
1-2 self-care/mobility tasks	6,823	38.0	434,406	32.4
3+ self-care/mobility tasks	5,545	30.9	623,584	46.4
Recipient dementia status				
No dementia	9,369	52.2	608,435	45.3
Possible dementia	2,741	15.3	197,236	14.7
Probable dementia	5,838	32.5	536,849	40.0

SOURCES: Data from the baseline 2011 NHATS and the companion NSOC. Care-recipient characteristics are from NHATS. Hours of care and caregiver relationship to NHATS respondent are from the NSOC. N=1996 NSOC respondents who provided care in the month prior to interview.

NOTE:

a. Includes 35 caregivers assisting 28 NHATs respondents who live in residential care settings and report no self-care or mobility help and no household activity help for health or functioning reasons, although all have NSOC eligible caregivers who report providing these types of assistance.

The care-recipient's physical and cognitive status, as expected, are related to both the distribution of caregivers and the hours of care provided. Caregivers helping recipients who report self-care or mobility assistance represent more than two-thirds of informal caregivers and provide nearly 80% of hours. The 31% of caregivers who assist recipients reporting 3+ self-care or mobility activities account for nearly half of hours. Even more striking is that although care-recipients with probable dementia represent only 11% of the older population (Kasper et al. 2014), their caregivers are nearly a third of informal caregivers and provide 40% of aggregate monthly hours. There is substantial overlap between the highest level of physical and cognitive impairment. Persons with probable dementia represent half the population receiving assistance with 3+ self-care or mobility activities (Kasper et al. 2014).

As a group, informal caregivers provided an average 75 hours per month (top panel of Table 2). Although only 69% of caregivers were helping recipients who reported assistance with self-care or mobility activities (see Table 1), more than three-quarters of caregivers reported that they assisted with these activities, and they provided an average 84 hours per month. Because self-care and mobility assistance is so prevalent, sample sizes for those not providing such assistance do not support separate estimates for those not assisting with self-care or mobility, but as a group, they provided an average 44 monthly hours (not shown).

Spouses provided 110 hours per month as a group and 127 hours if assisting with self-care or mobility activities. These monthly hours translate to 25-30 hours per week and 3.5-4.0 hours per day, far higher than for other caregivers. Daughters provided 78 hours of care overall (91 hours if they were assisting with self-care or mobility), and sons provided 65(69) hours of care, similar to the 61(67) hours per month provided by other relatives. The youngest (under age 45) and the oldest (age 75 or older) caregivers provided the most hours on average. Not surprisingly, 85% of the oldest caregivers were spouses (not shown). The youngest group was predominantly adult children (46%) and grandchildren (42%) (not shown). As expected, women comprised a larger proportion of caregivers and provided 15-20 more hours of care than men, depending on the level of assistance. Interestingly, about 44% of all caregivers were employed, and workers and non-workers were equally likely to be helping with self-care or mobility activities. Average hours of care provided by workers were substantially lower, however, and were lowest for those working the greatest number of hours per week.

The lower panel of Table 2 examines caregivers other than spouses. Thirty percent of non-spouse caregivers lived with the care-recipient, and these coresident caregivers were more likely to be providing self-care or mobility assistance than non-resident caregivers (85% vs. 75%). They also provided more than twice the hours of care--114 hours per month overall and 120 if assisting with self-care or mobility--representing 27-28 hours per week. The majority of non-spouse caregivers were married (58%), and they provided fewer hours of care on average than unmarried caregivers. One in five non-spouse caregivers were parents of children less than 18 years of age. Caregivers with and without minor children provided similar hours of care. Those with children were more likely to be providing assistance with self-care or mobility activities (84% vs. 76%). About half of non-spouse caregivers are employed. Care patterns are similar to those for seen for all caregivers, with workers providing fewer hours of care than non-workers (50-55 vs. 81-93), and lower average hours of care if working more hours per week.

TABLE 2. Characteristics of Informal Caregivers and Mean Hours of Care Provided in the Last Month to Recipients Age 65 or Older Living Outside of Nursing Homes, 2011

	All Informal Caregivers			Caregivers Helping with Self-Care or Mobility			
	Number (000s)	**Percent**	**Mean Hours of Help**	**Number (000s)**	**Percent of All**	**Percent**	**Mean Hours of Help**
Percent of caregivers	17,949	100.0	75	13,784	76.8	100.0	84
Distribution by Characteristics, All Caregivers							
Relationship to recipient							
Spouse	3,802	21.2	110	2,740	72.1	19.9	127
Daughter	5,263	29.3	78	4,066	77.3	29.5	91
Son	3,287	18.3	65	2,684	81.7	19.5	69
Other relative	4,011	22.3	61	3,178	79.2	23.1	67
Other non-relative	1,586	8.8	35	1,116	70.4	8.1	41
Caregiver age							
<45	2,948	16.8	85	2,480	84.1	18.4	87
45-54	4,191	23.9	71	3,202	76.4	23.8	81
55-64	4,760	27.1	67	3,790	79.6	28.2	77
65-74	3,292	18.7	68	2,347	71.3	17.4	84
75+	2,373	13.5	97	1,635	68.9	12.2	111
Caregiver gender							
Male	6,853	38.2	65	5,471	79.8	39.7	72
Female	11,096	61.8	81	8,313	74.9	60.3	92
Caregiver works for pay							
No	9,793	55.8	93	7,607	77.7	55.8	105
Yes	7,838	44.2	53	6,032	77.0	44.2	58
Hours worked per week							
20 or fewer	1,707	22.2	70	1,237	72.5	20.9	72
21-39	1,830	23.8	54	1,404	76.7	23.7	63
40+	4,157	54.0	45	3,289	79.1	55.5	50
Non-Spouse Caregivers							
Lives with recipient							
No	9,918	70.1	45	7,465	75.3	67.6	51
Yes	4,229	29.9	114	3,579	84.6	32.4	120
Marital status							
Married/partnered	8,003	57.7	48	6,236	77.9	57.6	56
Separated/ divorced	2,062	14.9	94	1,682	81.6	15.5	103
Widowed	1,044	7.5	75	709	67.9	6.6	99
Never married	2,771	20.0	92	2,191	79.1	20.3	96
Children under 18							
None	11,127	80.1	66	8,498	76.4	78.6	74
Any	2,768	19.9	65	2,315	83.7	21.4	73
Caregiver works for pay							
No	6,778	49.1	81	5,389	79.5	49.3	93
Yes	7,140	50.9	50	5,553	77.8	50.7	55
Hours worked per week							
20 or fewer	1,472	20.9	74	1,130	76.7	20.7	74
21-39	1,610	22.9	49	1,214	75.4	22.2	57
40+	3,949	56.2	42	3,124	79.1	57.1	46

SOURCE: Data from the baseline 2011 NHATS and the companion NSOC. NHATS functional level is taken from the NHATS. Hours of care and caregiver characteristics are taken from the NSOC. N=1996 NSOC respondents who provided care in the month prior to interview.

TYPES OF ASSISTANCE AND HOURS OF CARE

Table 3 provides detail on breadth of assistance informal caregivers provide, grouped into five domains: more traditionally examined self-care or mobility (ADLs) and household activities (IADLs), transportation, assistance with medical system interactions, and health or medical care activities, ordered from most to least common. A somewhat larger proportion of self-care or mobility helpers reported assisting with each activity, indicating the broad scope of activities they typically undertake.

TABLE 3. Types of Help Provided in the Last Month to Recipients Age 65 or Older Living Outside of Nursing Homes, 2011

	All Caregivers		**Caregivers Helping with Self-Care or Mobility**	
	Number (000s)	**Percent**	**Number (000s)**	**Percent**
Self-care or mobility	13,768	76.8	13,784	100.0
Mobility	12,826	71.6	12,826	93.2
Self-care	8,806	49.2	8,806	63.9
Household activities	17,319	96.5	13,496	97.9
Shopping	16,023	89.5	12,622	91.9
Laundry, housework, meals	14,212	79.2	11,613	84.3
Help with bills, managing money	10,471	58.3	8,413	61.1
Keep track of medicines	8,726	48.7	7,477	54.3
Transportation	15,503	86.4	12,284	89.1
Health system interactions	13,848	77.2	10,987	79.7
Make appointments[a]	10,859	60.5	9,009	65.4
Speak to doctor[a]	9,859	55.0	8,150	59.2
Order medicine	8,653	48.4	7,074	51.5
Other insurance issues[a]	6,033	33.7	5,045	36.6
Add or change insurance[a]	4,523	25.2	3,721	27.0
Health/medical care	10,243	57.1	8,997	65.5
Diet	4,916	27.4	4,257	31.0
Foot care	4,857	27.1	4,456	32.4
Skin care	4,158	23.2	3,823	27.7
Exercises	3,808	21.2	3,602	26.1
Dental care	2,675	14.9	2,515	18.2
Manage medical tasks	1,899	10.6	1,723	12.5
Shots or injections	1,391	7.8	1,251	9.1

SOURCE: Data from the baseline 2011 NHATS and the companion NSOC. NHATS functional level is taken from the NHATS. Hours of care and caregiver characteristics are taken from the NSOC. Of the full sample of 2007 information caregivers, 11 who reported helping in the last year, but not the last month are excluded.

NOTE:

a. The reference period is "in the last year" for these activities, which may be performed less frequently.

Mobility assistance is provided by 71.6% of all informal caregivers, and more than 90% of those assisting with any self-care or mobility activity, while nearly half of all caregivers and almost two-thirds of those helping with self-care or mobility are providing some self-care help. Nearly all caregivers are helping with at least one household activity (96.5%). About 90% of caregivers assist with shopping, the most common household activity for which help is received, and about half assist with keeping track of medications, which is the least common among the activities traditionally included in this domain.

Nearly 90% of caregivers assist with transportation, more than three in four were assisting with at least one health system interaction task. Just under 60% of all caregivers and nearly two-thirds of those assisting with self-care or mobility were helping with at least one health or medical care task. The most common health system interactions were helping with appointments and communications with health care providers, and the least common were helping with insurance issues. Not surprisingly, the proportion of caregivers assisting with ordering medications is very similar to the proportion helping keeping track of medications, which is included in household activities, following the traditional IADL grouping. The most common health or medical care tasks were assistance with diet and foot care, and the least common were giving injections and managing medical tasks, such as ostomy care, IV therapy assistance, or blood tests. To give a sense of the extent to which help with activities in these last two domains is concentrated among caregivers who help with self-care or mobility, among those not assisting with self-care or mobility, 69% helped with any health system interaction task and only 30% helped with any health or medical care activity (not shown).

To explore the dispersion of tasks across caregivers, Table 4 examines the proportion of informal caregivers helping with at least one activity in each of the five domains of care (self-care or mobility, household activities, transportation, health system interactions, and health or medical care) by recipient-reported assistance level, dementia status, and residential setting. The number of domains with which caregivers assist depends both on the individual needs of the care-recipient and on how labor is divided among members of the care network--whether there is specialization. The far right columns provide the proportion and mean hours provided by caregivers who help in all domains of activities and by specialized caregivers helping with activities in a subset of domains.

Generally similar proportions of caregivers provided assistance with household activities (95% or more) and transportation (81%-88%) across recipient-reported assistance level, dementia status, and residential setting. More variation is evident in the proportion of caregivers providing self-care or mobility assistance (59%-92%), help with health system interactions (68%-86%), and health or medical care assistance (37%-72%). These differences may be explained in part by recipient need and in part by greater sharing or delegation of responsibilities across caregivers. The proportion of caregivers helping with self-care or mobility is significantly higher with higher recipient-reported assistance levels and also is significantly higher for those with probable dementia. A similar pattern is evident for assistance with health system interactions and health or medical care, with higher proportions of caregivers helping as the level of recipient-reported assistance increases and for care-recipients with possible or probable dementia.

Overall, 74% of caregivers assist with activities in all domains, with little variation across recipient-reported assistance level and dementia status. However, 81.2% of caregivers to those living in a supportive setting assist with all activities, compared with 72.7% of those helping recipients in traditional community residence.

Informal caregivers who performed all tasks provided substantially greater hours of care in the last month, generally at least twice the hours provided by caregivers specializing in a subset of activities. For example, among caregivers assisting recipients reporting help with 3+ self-care/mobility activities, those helping with all tasks provided an average of 131 hours in the last month compared with 50 hours for those not helping with all tasks; for caregivers assisting recipients with probable dementia, the difference was 110 hours versus 44 hours.

TABLE 4. Types of Help Provided by Informal Caregivers in the Last Month by Characteristics of Recipients Age 65 or Older Living Outside of Nursing Homes and Care Network Size, 2011

	Number of Caregivers (000s)	Domains of Assistance					Caregivers Helping with All Activities[a]		Specialized Caregivers	
		Self-Care or Mobility	Household Activities	Transportation	Health System Interactions	Health or Medical Care	Percent	Mean Hours Provided	Percent	Mean Hours Provided
All	17,949	13,768	17,319	15,503	13,848	10,243	74.0	87	26.0	39
Percent of all caregivers	100.0	76.7	96.5	86.4	77.2	57.1				
Recipient-reported assistance level										
Household/other activities only	5,581	59.1	95.8	88.3	70.3	39.4	73.0	58	27.0	32
1-2 self-care/ mobility activities	6,823	78.7	96.9	88.9	77.1	59.8	72.3	74	27.7	37
3+ self-care/ mobility activities	5,545	92.3	96.7	81.3	84.2	71.6	77.1	131	22.9	50
Recipient dementia status										
No dementia	9,369	70.7	96.5	88.5	71.8	52.1	74.9	74	25.1	37
Possible dementia	2,741	81.2	96.3	87.4	77.4	62.6	73.5	86	26.5	33
Probable dementia	5,838	84.5	96.6	82.4	85.7	62.5	72.9	110	27.1	44
Residential setting										
Community	15,129	77.5	96.7	87.3	76.2	60.8	72.7	97	27.3	41
Supportive care setting	2,820	73.0	95.6	81.6	82.4	37.0	81.2	44	18.8	20

SOURCE: Data from the baseline 2011 NHATS and the companion NSOC. NHATS functional level is take from the NHATS. Hours of care and caregiver characteristics are taken from the NSOC. Of the full sample of 2007 informal caregivers, 11 who reported helping in the last year, but not the last month are excluded.

NOTE:

a. Percent of caregivers providing at least one type of help in the last month in all five domains (self-care/mobility, household activities, transportation, medical care, or health system interactions) with which the care recipient receives assistance.

BALANCE OF POSITIVE AND NEGATIVE ASPECTS OF CAREGIVING

Table 5 provides an overview of individual items measuring caregiver perceptions of positive and negative aspects of caregiving, as well as difficulties arising from caregiving, for all caregivers (top panel) and for caregivers helping with self-care or mobility (lower panel). Scales constructed by summing individual items also are shown for positive and negative aspects of caregiving.

Overall, most caregivers report substantial positive aspects (67%) and little or no negative aspects (62.5%). More than two in three report that caregiving brought them closer to the care-recipient, and 86.3% report caregiving provides satisfaction that the recipient is well cared for. Only about one in ten caregivers report substantial negative aspects of caregiving, the most common being having more to do than they can handle (17%), feeling exhausted (16%), and not having time for themselves (15%). Most caregivers also reported no difficulty with caregiving, and only about 14% reported substantial financial or physical difficulties. Slightly more than one in four, however, reported emotional difficulty as a result of their caregiving. Patterns were similar for caregivers helping with self-care or mobility, although they appear to be slightly less likely to report few gains and more likely to report substantial negative aspects of caregiving and difficulties with caregiving. The apparent differences are not statistically significant, however, although self-care and mobility helpers were significantly less likely to report no financial, emotional, or physical difficulties.

Daughters, caregivers age 45-54, and those who worked for pay 20 or fewer hours per week or 40 hours per week, were most likely to report substantial negative aspects of caregiving (Table 6). Generally, for all caregivers and among non-spouse caregivers, those providing self-care or mobility assistance appeared to be marginally more likely to report substantial negative aspects and marginally less likely to report few gains, although differences were not statistically significant. This pattern may suggest, however, that both rewards and burdens are associated with greater engagement in caregiving. Relationship to care-recipient also appears to be important in the balance of gains and burdens. Non-relative caregivers, who, as seen in Table 2, provided the lowest hours of care on average, were more likely than related caregivers to report little or no gains from caregiving but also less likely to report substantial negative aspects, even when they were providing self-care or mobility assistance.

TABLE 5. Gains from and Negative Aspects of Caregiving Reported by Informal Caregivers to Recipients Age 65 or Older Living Outside of Nursing Homes, 2011

	Little or None	Some	Substantial
All Caregivers			
Gains from caregiving[a]	6.1	26.4	67.5
More confident about your abilities	19.7	34.8	45.5
Taught you to deal with difficult situations	14.1	33.8	52.1
Brought you closer to care recipient	10.1	21.2	68.7
Gives you satisfaction that recipient is well cared for	1.2	12.5	86.3
Negative aspects of caregiving[a]	62.5	27.4	10.1
Exhausted when you go to bed at night	57.4	26.7	15.9
Have more things to do than you can handle	56.8	26.3	17.0
Don't have time for yourself	58.5	26.4	15.1
When you get a routine going, recipient's needs change	70.0	20.4	9.6
Difficulties with caregiving[b]			
Financial	77.5	8.0	14.5
Emotional	55.6	18.0	26.4
Physical	77.1	9.3	13.6
Caregivers Helping with Self-Care or Mobility			
Gains from caregiving[a]	5.8	25.1	69.1
More confident about your abilities	19.4	35.0	45.6
Taught you to deal with difficult situations	12.2	32.5	55.3
Brought you closer to care recipient	9.2	21.2	69.7
Gives you satisfaction that recipient is well cared for	1.0	12.5	86.5
Negative aspects of caregiving[a]	59.0	29.0	12.0
Exhausted when you go to bed at night	53.9	28.2	17.9
Have more things to do than you can handle	54.1	27.1	18.8
Don't have time for yourself	54.8	28.0	17.2
When you get a routine going, recipient's needs change	66.5	22.1	11.3
Difficulties with caregiving[b]			
Financial	74.9*	8.7	16.4
Emotional	51.7*	19.6	28.7
Physical	73.7**	10.5	15.8

SOURCE: Data from the baseline 2011 NHATS and the companion NSOC. Of the full sample of 2007 informal caregivers, 11 who reported helping in the last year, but not the last month are excluded.

NOTES:

a. Scale from 0-8 summing individual gains or negative aspects after recoding each item to 0-2, with 0 representing the lowest and 2 the highest. Factor analysis indicated that gains and negative aspects of caregiving represented 2 factors: alpha=0.70 for gains from caregiving and alpha=0.75 for negative aspects. Categories for scales are 0-2: little or none; 3-5: some; 6-8: substantial.

b. For difficulty items, respondents are asked whether they have any difficulty and, if yes, to provide a level from 1-5 with 1 being a little difficulty and 5 being a lot of difficulty. Categories in the table are defined as 0: none; 1-2: some, and 3-5: substantial.

**(*) Significantly different from value for all caregivers at the 5%(10%) level in a two-tailed test.

The balance of positive and negative aspects of caregiving differs across groups in interesting ways. For example, those ages 45-54 were most likely to report substantial negative aspects of caregiving, but they also were least likely to report little or no gains. Among non-spouse working caregivers, those working 20 or fewer hours per week also had a higher than average likelihood of reporting substantial negative aspects of caregiving but were less likely than average to report little or no gains, even if they were providing self-care or mobility assistance.

TABLE 6. Percent Reporting Little or Substantial Negative Aspects of Caregiving by Characteristics of Informal Caregivers to Recipients Age 65 or Older Living Outside of Nursing Home, 2011

	All Caregivers		Self-Care or Mobility Caregivers	
	Little or No Gains	Substantial Negative Aspects	Little or No Gains	Substantial Negative Aspects
All	6.1	10.1	5.8	12.0
All Informal Caregivers				
Relationship to recipient				
Spouse	7.1	7.6	5.8	9.8
Daughter	6.1	15.4	5.3	17.8
Son	5.0	8.8	4.7	10.4
Other relative	5.1	8.0	5.5	9.5
Other non-relative	8.9	6.3	10.6	7.1
Caregiver age				
<45	8.0	8.5	8.3	9.6
45-54	2.6	13.3	2.6	15.8
55-64	5.8	11.7	4.5	13.9
65-74	8.0	7.1	7.1	9.1
75+	7.6	6.0	7.9	6.3
Caregiver gender				
Male	6.7	7.2	6.6	8.5
Female	5.7	11.9	5.2	14.3
Caregiver works for pay				
No	5.4	8.8	4.9	10.8
Yes	6.8	11.4	6.6	13.9
Hours per week				
20 or fewer	5.0	12.5	5.2	15.8
21-39	7.0	8.7	5.9	11.3
40+	7.7	12.1	7.6	14.0
Non-Spouse Caregivers				
All	5.9	10.7	5.8	12.5
Lives with recipient				
No	5.9	10.0	5.8	11.6
Yes	5.7	12.5	5.7	14.6
Marital status				
Married/partnered	5.6	10.3	5.6	12.2
Separated/ divorced	5.8	12.1	5.2	12.2
Widowed	6.1	8.9	8.6	10.1
Never married	5.1	11.2	4.7	13.9
Children under 18				
None	5.6	10.8	5.4	12.8
Any	6.2	10.1	6.2	11.0
Caregiver works for pay				
No	4.7	9.5	5.2	11.4
Yes	6.7	11.6	6.4	13.9
Hours per week				
20 or fewer	2.8	13.7	3.1	16.3
21-39	7.2	8.8	5.9	11.7
40+	8.1	11.8	8.0	13.6

SOURCE: Data from the baseline 2011 NHATS and the companion NSOC. NHATS functional level is taken from the NHATS. Hours of care and caregiver characteristics are taken from the NSOC. N=1996 NSOC respondents who provided care in the month prior to interview.

Care-recipient characteristics appear to be far more important than informal caregiver characteristics in whether caregivers perceive substantial negative aspects of caregiving (Table 7). Among all caregivers, caregivers to recipients who report assistance with 3+ self-care or mobility tasks are more than twice as likely to report substantial negative aspects as those helping recipients who report receiving assistance with only household activities (14.4% vs. 5.9%). Nearly one in five caregivers assisting recipients who have probable dementia report substantial negative aspects, about three times the proportion among caregivers assisting recipients with no dementia. Among caregivers assisting with self-care or mobility activities, those caring for recipients with dementia also are twice as likely to report little or no gains from caregiving (8% vs. 4%). Among self-care or mobility caregivers, those assisting recipients in supportive care settings are half as likely as others to report little or no gains from caregiving.

TABLE 7. Percent of Informal Caregivers Reporting Little or No Gains and Substantial Negative Aspects of Caregiving by Characteristics of Recipients Age 65 or Older Living Outside of Nursing Homes, 2011

	All Caregivers		Self-Care or Mobility Caregivers	
	Little or No Gains	Substantial Negative Aspects	Little or No Gains	Substantial Negative Aspects
Help reported by recipient				
Household or other activities only	6.1	5.9	5.7	6.3
1-2 self-care or mobility activities	5.9	10.0**	5.2	12.4**
3+ self-care or mobility activities	6.4	14.4**	6.4	15.2‡
Recipient dementia status				
No dementia	5.7	6.3	4.1	7.5
Possible dementia	5.7	6.5	5.4	7.8
Probable dementia	7.0	17.8**	8.1†	19.9**
Residential setting				
Community	6.5	10.1	6.2	11.8
Supportive care setting	4.1	9.7	3.0**	13.3

SOURCE: Data from the baseline 2011 NHATS and the companion NSOC. NHATS functional level is taken from the NHATS. Hours of care and caregiver characteristics are taken from the NSOC. Of the full sample of 2007 informal caregivers, 11 who reported helping in the last year, but not the last month are excluded.

**(*) Significantly different from previous value at the 5%(10%) level in a two-tailed test.
††(†) Significantly different from the value for no dementia at the 5%(10%) level in a two-tailed test.
‡‡(‡) Significantly different from the value for no self-care or mobility at the 5%(10%) level in a two-tailed test.

Health of the informal caregiver also is very important in perception of substantial negative effects of caregiving (Table 8), although it is not possible in cross-sectional analysis to parse the inter-relationships between the two. As was seen for other caregiver characteristics in Table 6, the proportion reporting little or no gains from caregiving is relatively invariant by health. One in five caregivers report fair or poor health, and another nearly three in ten report good health. These caregivers are four times and three times as likely, respectively, as those in excellent health to report experiencing substantial negative aspects of caregiving.

TABLE 8. Percent of Caregivers and Percent Reporting Little or No Gains and Substantial Negative Aspects of Caregiving by Health and Physical Symptoms of Informal Caregivers to Recipients Age 65 or Older Living Outside of Nursing Homes, 2011

	All Caregivers			Self-Care or Mobility Caregivers		
	Percent	Little or No Gains	Substantial Negative Aspects	Percent	Little or No Gains	Substantial Negative Aspects
All	100.0	6.1	10.1	100.0	5.8	12.0
Self-reported health status						
Excellent	18.3	6.1	3.7	17.3	5.7	5.1
Very good	33.0	6.0	7.4**	32.7	6.1	9.4*
Good	28.3	5.6	13.1**	29.3	5.4	15.1**
Fair/poor	20.4	7.5	16.7	20.7	6.3	18.4
Depression (PHQ2)						
No	86.8	6.2	7.7	84.9	6.0	9.0
Yes	13.2	5.2	25.8**	15.1	3.6	28.6**
Anxiety (GAD2)						
No	86.6	5.7	7.3	85.3	5.0	8.8
Yes	13.4	7.5	27.5**	14.7	7.8	30.3**
Sleep problems						
Rarely/never	56.8	6.3	6.4	54.7	7.1	8.1
Yes	43.2	5.8	14.8**	45.3	3.8	16.7**
Pain limits activities						
Rarely/never	70.7	6.3	6.2	68.9	6.2	7.6
Yes	29.3	5.6	19.5**	31.1	4.8	21.7**
Weakness limits activities						
Rarely/never	72.0	6.3	8.3	70.6	6.1	10.3
Yes	28.0	5.7	14.6**	29.4	4.8	16.0**
Low energy/exhaustion limits activities						
Rarely/never	73.2	6.0	4.6	70.5	5.7	5.4
Yes	26.8	6.5	24.8**	29.5	6.0	27.9**
Breathing problem limits activities						
Rarely/never	92.9	6.0	9.2	92.2	5.9	11.2
Yes	7.1	7.3	21.1**	7.8	4.3	21.8**

SOURCE: Data from the baseline 2011 NHATS and the companion NSOC. Of the full sample of 2007 informal caregivers, 11 who reported helping in the last year, but not the last month are excluded.

**(*) Significantly different from previous value at the 5%(10%) level in a two-tailed test.

Sleep problems affect more than four in ten caregivers and are associated with a three-fold higher likelihood of reporting substantial negative aspects of caregiving. Depression and anxiety affect about 13% of all caregivers and 15% of those assisting with self-care or mobility and are associated with the highest reported rates of substantial negative aspects of caregiving (25.8%-28.6% and 27.5%-30.3%, respectively). The most prevalent symptoms and impairments are pain, weakness in upper or lower extremities, and low energy or exhaustion to the point of limiting activities, all of which are associated with significantly elevated rates of experiencing substantial negative aspects of caregiving. Activity limitation because of breathing problems is uncommon, but about one in five caregivers experiencing limitation from this impairment report substantial negative aspects of caregiving.

CAREGIVING, HEALTH, PARTICIPATION AND WELL-BEING

Interest in informal caregivers often focuses more on their contributions to care-recipients and society than on the well-being of caregivers themselves. This final section considers how subjective well-being and perceived negative aspects of caregiving relate to intensity, as measured by the number of hours of care provided, to caregiver health status, and to the ability to participate in valued activities. Figure 1, Figure 2 and Figure 3 plot mean well-being scores (left axis scale) and mean score for negative aspects of caregiving (right axis scale) against the mean monthly hours of care provided, self-reported health, and the number of activities for which caregivers reported limited participation in the last month because of caregiving. Positive aspects of caregiving are not shown because they were essentially invariant, with mean scores very close to six out of the maximum eight across all measures and categories. Again, this suggests that gains from caregiving may in some sense balance burdens, but that high levels of perceived gains often accompany high perceived levels of burdens.

FIGURE 1. Well-Being and Negative Aspects of Caregiving by Hours of Care Provided

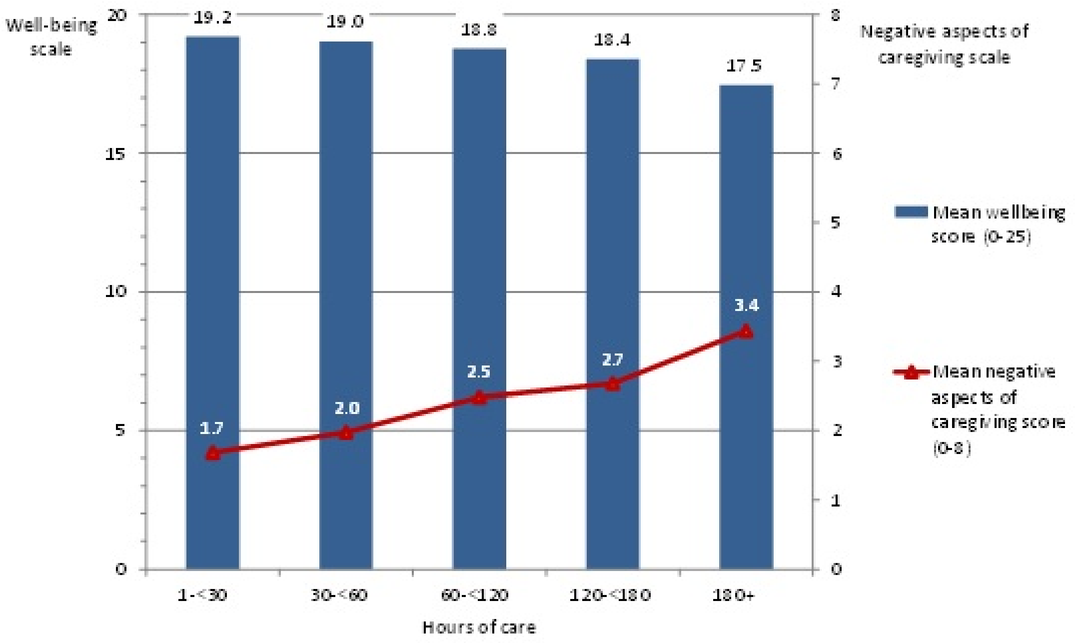


Figure 1 suggests a straightforward association of caregiving intensity, as measured by greater hours of care, with reduced well-being and higher perceived burden (Figure 1). As hours of care rise, average well-being scores decline monotonically, and perceived negative aspects of caregiving increase monotonically.

FIGURE 2. Well-being and Negative Aspects of Caregiving by Self-Reported Health Status

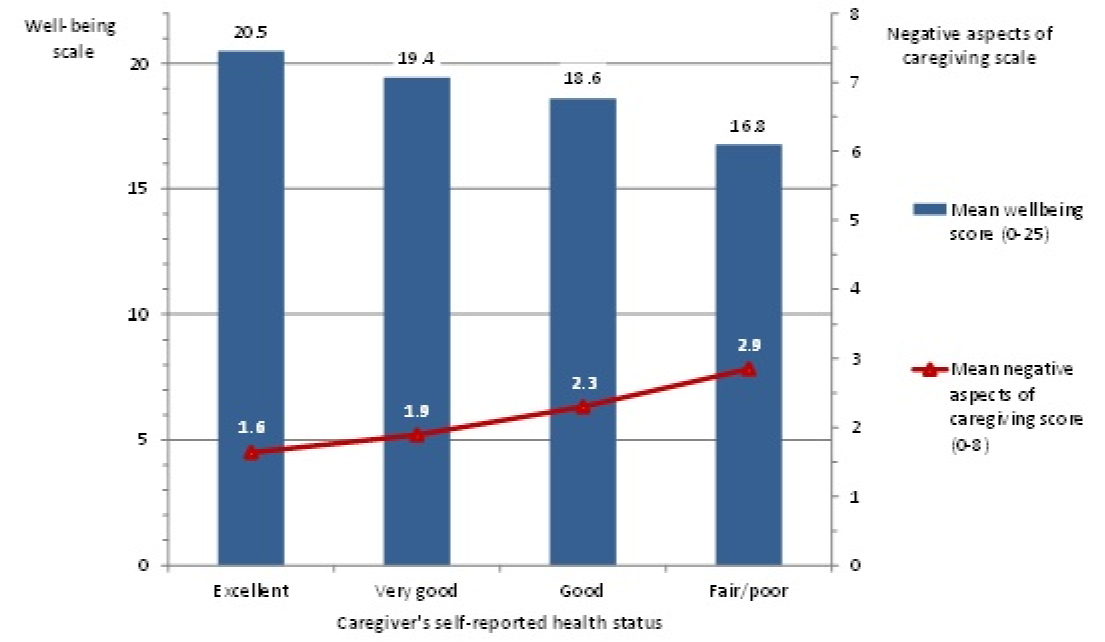
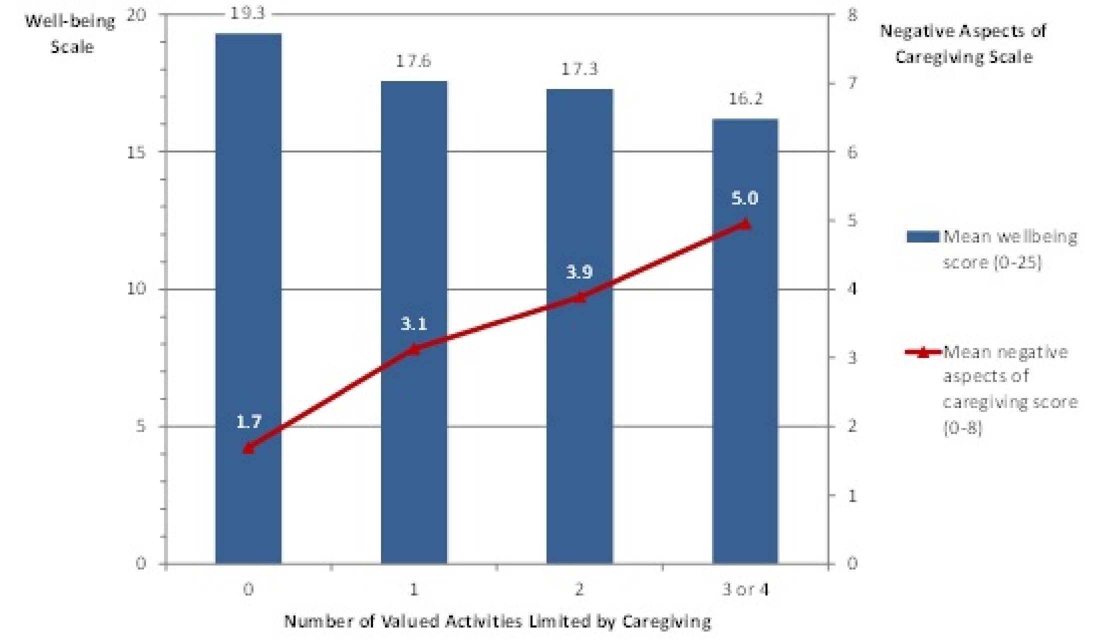


FIGURE 3. Well-Being and Negative Aspects of Caregiving by Participation Restriction



Both lower health status (Figure 2) and a larger number of participation restrictions because of caregiving (Figure 3) are associated with far larger declines in subjective well-being than seen for intensity of caregiving in Figure 1. However, although those in fair or poor health were more likely than others to report substantial negative aspects

(Table 8), on average increased perception of burden with poorer health status is modest relative to that seen for intensity of caregiving. Conversely, mean scores for negative effects of caregiving increase dramatically as the number of participation restrictions increases, from an average 1.7 out of eight for those with no participation restrictions to an average of five for those with restrictions in 3-4 valued activities.

SUMMARY AND IMPLICATIONS

This report profiles the role and experiences of informal caregivers for the older population, using a new resource that provides a more complete picture of informal caregiving than possible with surveys that rely solely on either care-recipient-reported or caregiver-reported information. NSOC, a supplement to the 2011 NHATS, is unique in interviewing all informal caregivers for a well-defined population of persons age 65 or older receiving assistance with daily activities.

NSOC respondents are asked about a broad set of types of assistance beyond the traditional household (IADL) and self-care or mobility (ADL) tasks, ranging from transportation assistance to help with health or medical tasks. This breadth allows a better understanding of the full range of supports informal caregivers provide and areas other than explicit long-term supportive care where they are making contributions. Information collected about positive and negative aspects of caregiving, health, and indicators of subjective well-being allows exploration of how gains and burdens differ by caregiver and care-recipient characteristics and by the intensity of care provided.

We find in all, 18 million informal caregivers provided 1.3 billion hours of care on a monthly basis in 2011 to the more than 9 million older adults receiving informal assistance (Freedman & Spillman 2013). Five key findings about caregivers and the care they provide are especially noteworthy:

- Consistent with prior studies, family members are the main source of informal care: one in five caregivers are spouses who provide nearly one-third of the aggregate hours, and about half are daughters or sons, who together provide nearly half of aggregate hours.

- Hours are concentrated among caregivers of high need recipients: nearly half of aggregate hours are provided by a minority (31%) of caregivers who assist recipients receiving help with at least three self-care or mobility tasks and 40% of aggregate hours are provided by the 33% of caregivers who assist persons with probable dementia

- On average, informal caregivers provided 75 hours of care per month, but average hours of care provided varies widely by the number and types of tasks for which assistance is given, caregivers' relationship to care-recipient, their age, as well as the caregiver's work and family status. For example, spouses and other caregivers who lived with the care-recipient provided the highest hours of care--110 and 114, respectively, per month.

- The most common domains of assistance were household activities (95%), transportation (nine in ten), health system interactions (eight in ten), self-care and mobility activities (three-quarters) and health care-related tasks (almost 60%). The latter includes a variety of activities including giving injections or helping with ostomy care.

- Regardless of recipient level of assistance, those assisting recipients with tasks in all domains of care in which they receive help provide twice the hours of those who specialize in a subset of activities (on average 87 hours vs. 39 hours); among caregivers to recipients reporting help with 3+ self-care/mobility activities, those helping with all tasks provided an average of 131 hours in the last month compared with 50 hours for those not helping with all tasks.

This reported also highlighted both positive and negative aspects of caregiving.

- Two-thirds of caregivers report substantial gains from caregiving, most commonly confidence that the recipient is well cared for (86%) and feeling closer to the recipient (69%). Conversely, only 10% report substantial negative aspects of caregiving overall, but larger proportions reported having more to do than they can handle (17%), being exhausted by the end of the day (16%), and lacking time for themselves (15%); 63% reported little or no negative aspects.

- The proportion of caregivers perceiving substantial negative aspects varied relatively modestly across caregiver characteristics but substantially by care-recipient characteristics, intensity of care, and caregiver health. While the direction of effects cannot be measured in a cross-sectional analysis, it is of note, that caregivers reporting depression, anxiety, and greater severity of physical symptoms and impairments were dramatically more likely to report substantial negative aspects of caregiving.

There are a number of ways in which these estimates differ from--and in some ways improve upon--the existing literature. In particular, estimates are not comparable to prior estimates from the NLTCS and ICS, the only previous nationally representative survey of the older population to conduct interviews with caregivers to a well-defined population of older adults with disabilities. The most obvious differences are that NHATS/NSOC uses a broader definition than NLTCS/ICS to capture both older persons with care needs and their care providers (Freedman et al. 2013). In particular, the focus of the NLTCS/ICS on “primary” informal caregivers, rather than all informal caregivers, leads to exclusive attention on the experience of the informal caregiver who was most involved. NSOC’s design also differs from the Health and Retirement Study, which allows estimates of ADL and IADL care reported by sample members ages 65 and older (and care provided to parents of sample members ages 51 and older), but does not include a follow-up study to interview caregivers about the care they provide, the caregiving experience, and their health and well-being.

Despite NSOC’s unique design, key findings are consistent with those previously reported in the literature (Johnson & Wiener 2006; Spillman 2009; Spillman & Black 2005). In particular, we find that family members, particularly spouses and daughters are playing a substantial role in providing uncompensated care to older adults, and that for some groups the demands of caregiving are large, especially for those who live with the care-recipient or have health problems of their own. Moreover, NSOC's estimate of an average 75 hours of care in the past month, implying an about 17 hours per week, is on par with (albeit on the lower end of) previous findings, which suggest a range from 17 hours to 25 hours per week, depending on the source (Gibson & Houser 2007). Such findings reinforce that NSOC captures a broader pool of caregivers providing a wider range of levels of care than typically captured by national surveys of older adults.

This report adds to the literature in important ways. Our findings substantiate recent reports indicating that informal caregivers commonly provide assistance with a wide range of medically-oriented tasks as well as interacting with providers and helping the older population navigate the broader health system. Most caregivers do not view their care responsibilities as burdensome. The majority of caregivers report positive consequences and few report substantial negative consequences. Higher levels of both positive and negative aspects of caregiving were associated with greater engagement in caregiving. Negative reports are, however, more likely to be observed for caregivers who provide high levels of care, who assist individuals with probable dementia, and who have worse health status and physical symptoms themselves. As is true for all cross-sectional estimates, the associations we find cannot be interpreted as causal relationships. This is particularly true because of the complex inter-relationships between the hours of care provided, caregiver health, participation restrictions, and perception of caregiving burden. Cross-sectional estimates also cannot reveal, for example, whether informal caregivers working less than full-time provide more hours of care than others workers because they have more hours available or because their caregiving necessitated a reduced work schedule.

Finding ways to support informal caregivers in their traditional roles as well as their expanded role in providing and managing health care for the older population continues to be an important policy goal, as the older population increases and the shift in the locus of care from nursing homes to community and other alternative supportive settings continues (Freedman et al. 2013; Spillman 2011). Both the ACL and national plan developed under the National Alzheimer's Project Act of 2012 recognize the need to support informal caregivers as an essential part of the workforce for maintaining the well-being and health of the older population (HHS 2013). The NSOC can contribute to the knowledge base for these efforts by providing a baseline for further studies examining the dynamics of caregiving and care networks as the NHATS cohort is followed through subsequent annual waves.

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