

Research Article

# Family Caregivers of Older Adults, 1999–2015: Trends in Characteristics, Circumstances, and Role-Related Appraisal

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## Abstract

**Purpose of Study:** To assess trends in family caregiving between 1999 and 2015.

**Design and Methods:** We construct nationally representative profiles of community-dwelling older adults receiving help with self-care or indoor mobility and their “primary” family or unpaid caregiver using the 1999 and 2004 National Long Term Care Survey, 2011 and 2015 National Health and Aging Trends Study, and linked caregiver surveys. Trends are examined.

**Results:** Older adults receiving help were incrementally younger, more racially diverse, and better educated in 2015. Primary caregivers overwhelmingly continued to be spouses and adult children. Arrangements were increasingly 4 years or longer in duration (shifting from 44.8% in 1999 to 60.5% by 2015). On average, primary caregivers provided about or in excess of 30 hr per week at all four time points. Spouses provided fewer hours of care, were twice as likely to work, and half as likely to report substantial emotional, physical, and financial difficulty due to caregiving in 2015 than 1999. Adult children provided comparable hours of care to a more impaired population; a similar proportion reported substantial caregiving-related difficulty at each time. Use of respite care nearly doubled from 8.5% in 1999 to 15.7% in 2015. Dementia caregivers were less likely to report substantial physical and financial difficulty and more likely to use respite care in 2015 than 1999.

**Implications:** Family caregivers’ circumstances generally improved during the 16-year period. Results diverge from prevailing concerns regarding the state of family caregiving and demonstrate the importance of longitudinally monitoring trends in late-life family caregiving.

**Keywords:** Long-term care, Family caregivers, Disability

Although it has been long established that the majority of older adults’ care needs are met by family and unpaid caregivers, a recent report by the National Academies of Sciences, Engineering, and Medicine raises concern about the future state of family caregiving (NASSEM, 2016). Greater longevity, declining fertility, and increasing female labor force participation pose potential threats to continued

availability of family and unpaid caregivers for growing numbers of older adults. More individuals are living to very old ages at which there is heightened risk of dementia. The care delivery and payment landscape are undergoing a period of rapid change and transformation. Efforts to deliver higher quality, more efficient care and expand the possibilities of “aging in place” could have unintended

consequences that place increasing demands on family caregivers (Coleman, 2016; Levine et al., 2014).

Although the importance of understanding the changing context and experiences of family caregivers has never been greater, it is challenging to assess. The scientific literature has primarily relied on national surveys that are cross-sectional and reflect a single perspective of older adults receiving assistance (e.g., the Health and Retirement Survey), or family caregivers providing assistance (e.g., the Behavioral Risk Factor and Surveillance Survey). However, family caregiving arises from the impaired function of another person, and persons with disabilities may employ a range of alternative strategies to compensate for disability, such as using assistive devices or services, modifying the home environment, performing activities less often or in a different way, or relying on paid or unpaid help. Studies from nationally representative surveys demonstrate that reliance on these strategies has shifted over time (Freedman, Agree, Martin, and Cornman, 2006). Factors relating to availability of help, such as family structure, geographic proximity, and economic resources affect entry into family caregiving (Roth, Haley, Wadley, Clay, & Howard, 2007), and these factors are also subject to change (Spillman & Pezzin, 2000). Because family caregiving arises from complex, interrelated factors that affect both older adults and family caregivers, assessing trends in caregiving requires comprehensive information about consistently defined population-based estimates of older adults *receiving* help, as well as family caregivers *providing* help. For this reason, little is known about trends in the context, composition, and experiences of family and other unpaid caregivers over time.

Two nationally representative surveys of older adults have administered ancillary surveys to family caregivers at multiple time points, and afford the possibility to examine caregiving trends. The National Long Term Care Survey (NLTC) was conducted in 1982, 1984, and every 5 years thereafter until its final wave of data collection in 2004. The first national profile of family and unpaid caregivers was constructed from these data using the 1982 NLTC and Informal Caregiver Survey (ICS) (Stone, Cafferata, & Sangl, 1987). This profile was subsequently updated to examine change in the composition and experience of family and unpaid caregivers between 1989 and 1999 (Wolff & Kasper, 2006). In 2011, a new national survey, the National Health and Aging Trends Study (NHATS) and its linked National Survey of Caregivers (NSOC) were launched. The NLTC and NHATS have been used to examine trends in disability and life expectancy among older adults (Freedman & Spillman, 2016; Freedman, Wolf, & Spillman, 2016), but no studies to date have relied on both data sources and their linked caregiver surveys to examine family caregiving at multiple points in time.

This study draws from the final two waves of the NLTC/ICS (in 1999 and 2004), and the first two waves of linked NHATS/NSOC (in 2011 and 2015) to examine

trends in family and unpaid caregiving over a 16-year period for a selected population of older adults living in the community and receiving help for self-care or indoor mobility disability. We address three research questions. First, we ask whether characteristics of this selected population of older adults changed between 1999 and 2015. We hypothesized that characteristics of this selected population shifted in parallel with broader sociodemographic trends with respect to greater educational attainment, growing racial and ethnic diversity, and improving economic status (IOM, 2007; Schoeni, Freedman, & Martin, 2008). Second, we examine trends in family and unpaid caregivers' sociodemographic characteristics, caregiving circumstances, and caregiving experiences across the 16-year period for the selected care recipient population. We expected that caregiving arrangements would continue to primarily draw on spousal and adult child relationships and to involve transfers of assistance of similarly high intensity (Shanas, 1979; Wolff & Kasper, 2006). Third, we ask whether the composition and experiences of family and unpaid caregiver shifted within notable older adult-family caregiver subgroups. We expected that trends in the composition and experience of caregiving would differ by type of caregiving relationship and older adults' dementia status. In particular, we hypothesized that the effects of greater longevity among older adults would be more pronounced among adult child and other caregivers, who would be increasingly likely to care for an incrementally more functionally and cognitively impaired population in 2015 relative to earlier time periods (Kasper, Freedman, Spillman, & Wolff, 2015; Pinquart & Sorensen, 2011; Wolff & Kasper, 2006).

## Methods

### Data Sources

We examined linked surveys that provide information regarding older adults with disability (from the 1999 and 2004 NLTC and the 2011 and 2015 NHATS), and caregivers (from 1999 and 2004 ICS and the 2011 and 2015 NSOC). The NLTC and NHATS are nationally representative of adults ages 65 and older. Both surveys rely on Medicare enrollment files for their sampling frame. Both surveys conduct in-person interviews to collect information about a broad range of characteristics relating to health and function. With sampling weights, both studies were designed to produce nationally representative estimates of late-life disability.

The ICS and NSOC were administered to relatives and unpaid helpers of older adults receiving assistance with self-care, mobility, or household activities for health or function. The ICS was administered using a combination of telephone and in-person surveys whereas the NSOC was administered by telephone. Core domains of ICS and NSOC are similar, but differences exist in sampling design. Most notably, the ICS interviewed *primary caregivers* whereas the NSOC interviewed all caregivers (up to five) for each

participant. The strategy to identify primary caregivers varied in the 1999 and 2004 ICS. In 1999, the primary caregiver was defined as the helper the NLTCS participant identified as providing the most hours of care whereas in 2004 the primary caregiver was defined as the helper identified by the NLTCS participant “who helps the most.” Because all caregivers identified in NHATS are eligible for NSOC and hours of help are reported by both NHATS and NSOC participants, two data sources are available from which a primary caregiver may be identified. Most often, the same caregiver was identified by both sources. In some cases, the caregiver who reported providing the most hours was not the caregiver identified by the older adult as helping the most, or no NSOC interview was completed with the caregiver identified as providing the most hours by the older adult, although interviews were completed with other caregivers. In these cases, we defined the “primary” caregiver from hours reported in the NSOC (see [Table 1](#), footnote f, for more detail).

### Study Participants: Identifying Older Adults With Disability and Their Caregivers

As we sought to maximize comparability of the study sample at each point in time, we paid particular attention to survey design issues that have been identified as being important to measurement of disability ([Freedman et al., 2004](#)), and by extension, family caregivers ([Giovannetti & Wolff, 2010](#)). We restricted our focus to older adults who were receiving help with self-care (eating, dressing, bathing, toileting) or indoor mobility (transferring, getting around inside), for whom question wording was comparable in both the NLTCS and NHATS. We excluded older adults who were living in nursing homes or residential care facilities as the nature of family help in such settings is likely to differ from help provided in the community. Eligible caregivers were relatives or unpaid nonrelatives of older adults with self-care or indoor mobility disability.

[Table 1](#) presents unweighted sample and weighted estimates of the older adult population at each time point. Older adults living in the community increased from 33.6 million in 1999 to 42.2 million in 2015. Community-dwelling older adults who were receiving help with self-care or indoor mobility activities were estimated to increase in number from 2.7 million in 1999 to 5.6 million in 2015 (see Supplementary Appendix A for additional detail regarding age distribution of this selected population in relation to the broader population ages 65+). Interviews were completed with 791 of 1,266 (62.5%) eligible caregivers in 1999, 1,149 of 1,400 (82.1%) eligible caregivers in 2004, 736 of 1,194 (61.6%) eligible caregivers in 2011, and 746 of 1,151 (64.8%) eligible caregivers in 2015.

### Measurement

Older adults' sociodemographic and health characteristics included age, gender, race, Hispanic ethnicity, educational

attainment, marital status, living arrangement, Medicaid enrollment, and summary measures of cognitive and physical function. Receipt of help with self-care (eating, dressing, bathing, toileting) or indoor mobility (transferring, getting around inside) was measured by the number of self-care and indoor mobility activities for which older adults reported receiving help. Question wording was comparable but the reference period varied in the NLTCS (1 week) and NHATS (1 month; [Freedman et al., 2004](#); [Freedman & Spillman, 2014](#)).

Available measures of cognitive function varied by survey wave in the NLTCS and NHATS (see Supplementary Appendix B). A composite measure of cognitive impairment has been developed for NHATS from information reported by self- and proxy-respondents and cognitive tests. Participants are classified as having “probable dementia” on the basis of a report of a doctor's diagnosis of dementia or Alzheimer's disease; a score indicating likely dementia on the AD8, a dementia screening instrument administered to proxy respondents ([Galvin et al., 2005](#); [Galvin, Roe, Xiong, & Morris, 2006](#)), or impairment based on cognitive tests that evaluate memory, orientation, and executive function (with a score of  $\geq 1.5$  SDs below the mean in at least two of three domains; [Kasper, Freedman, & Spillman, 2013](#)).

No standard approach to measurement of cognitive function in the NLTCS exists. Prior studies have defined cognitive impairment on the basis of performance tests ([Manton, Gu, & Ukraintseva, 2005](#)), proxy reports of Alzheimer's disease ([Spillman & Long, 2009](#)), or combining information from performance tests and proxy responses and categorizing as missing those with neither source of information ([Depalma et al., 2013](#); [Xu, Covinsky, Stallard, Thomas, & Sands, 2012](#)). In this study, proxy-report of Alzheimer's disease/dementia was considered an indicator of cognitive impairment. For NLTCS participants who were administered cognitive performance tests, a cut-point of  $\leq 1.5$  SDs below the community mean was used to distinguish cognitive impairment, in keeping with prior literature ([Kasper, Freedman, & Spillman, 2013](#); [Morris, 2012](#)). For participants who were missing information from performance tests (18.1% in 1999 and 2.6% in 2004) or for whom the proxy did not report the presence of Alzheimer's disease/dementia, we constructed measures from behaviors or symptoms of memory impairment that were significantly correlated with proxy reports of Alzheimer's disease/dementia or low scores on cognitive performance measures (see Supplementary Appendix B). As our measures reflect significant cognitive impairment, we use the term “dementia” throughout.

Caregiver characteristics included age, gender, marital status, self-rated health, relationship to the older adult, and travel time to older adults' place of residence. The ICS asked caregivers to rate their health in relation to “other people your age” (excellent, good, fair, poor) whereas the NSOC asked caregivers to rate their own health (excellent, very good, good, fair, poor). Given differences in question wording and response categories, self-rated health was

**Table 1.** National Estimates of Older Adults in the Community Receiving Help with Self-Care or Indoor Mobility from a Family or Unpaid Caregiver

	1999 NLTCS			2004 NLTCS			2011 NHATS			2015 NHATS		
	N	Weighted		N	Weighted		N	Weighted		N	Weighted	
		Million	%		Million	%		Million	%		Million	%
Older adults ages 65 <sup>a</sup>	6,183	35.2	100.0	6,171	36.2	100.0	8,077	39.7	100.0	7,859	45.3	100.0
Nursing facility	1,036	1.5	4.3	976	1.6	4.5	468	1.1	2.8	360	1.1	2.5
Residential care facility <sup>b</sup>	—	—	—	—	—	—	412	2.0	5.1	429	2.0	4.4
Community	5,147	33.6	95.7	5,195	34.6	95.5	7,197	36.5	92.1	7,070	42.2	93.1
Living in the community, receiving help with self-care or indoor mobility <sup>c,d,e</sup>	1,491	2.7	7.5	1,540	2.9	7.9	1,235	4.7	11.9	1,224	5.6	12.4
Living in the community, receiving help with self-care or indoor mobility from 1+ family or unpaid caregiver <sup>e,d,e,f</sup>	1,266	2.3	6.5	1,400	2.6	7.3	1,194	4.6	11.5	1,151	5.2	11.5

Notes: NHATS = National Health and Aging Trends Study; NLTCS = National Long Term Care Survey; NSOC = National Survey of Caregivers.

<sup>a</sup>Estimates from the NLTCS and NHATS have been standardized to the United States Census Bureau frame using the approach described by Freedman and Spillman (2016). See Supplementary Appendix A for further detail. Numbers may not sum exactly due to rounding. <sup>b</sup>Residential care facility was not differentiated as a distinct setting in the NLTCS. <sup>c</sup>NLTCS uses a reference period of the past week and NHATS uses a reference period of the past month. <sup>d</sup>Self-care includes: eating, dressing, bathing, and toileting. Indoor mobility includes transferring and getting around inside. <sup>e</sup>Determination of receiving self-care and mobility help was based on older adults' self- or proxy report. Reliance on proxy respondents varied by wave ( $n = 361$  in 1999,  $n = 423$  in 2004,  $n = 234$  of 1,235 in 2011,  $n = 183$  of 1,224 in 2015). <sup>f</sup>This study focuses on a "primary" caregiver. The NLTCS only interviewed a "primary" family or unpaid caregiver ( $n = 791$  of 1,266 in 1999;  $n = 1,149$  of 1,400 in 2004). All caregivers identified in NHATS are eligible for NSOC and hours of help are reported by both NHATS and NSOC participants. Therefore, two data sources are available from which a "primary" caregiver may be identified. Most often, the same caregiver was identified by both NHATS and NSOC participants ( $n = 533$  of 736 in 2011 and  $n = 517$  of 746 in 2015). In some cases, the caregiver who reported providing the most hours was not the caregiver identified by the older adult ( $n = 73$  in 2011 and  $n = 74$  in 2015) or no NSOC interview was completed with the caregiver identified as providing the most hours by the older adult although interviews were completed with other caregivers ( $n = 91$  in 2011 and  $n = 90$  in 2015). In these cases, we defined the "primary" caregiver from hours reported in the NSOC.

dichotomized using a cut-point of “fair or poor” versus all other. Information regarding the nature and intensity of care provision included duration of caregiving in years and hours of care per week. Competing responsibilities included the presence of a co-residing child less than 18 years of age and being employed. Measures of caregiver experience included caregiving-related physical, financial, and emotional difficulty. The NLTCs asked participants to rate physical, financial, and emotional difficulty on a scale of 1 to 5, with 1 meaning “not difficult at all” and 5 meaning “very difficult.” The NSOC first asked participants whether helping was difficult (yes/no). Those who responded “yes” were then asked to rate the level of difficulty on a scale of 1 to 5, with 1 meaning “a little difficult” and 5 meaning “very difficult.” Caregiving-related difficulty was dichotomized: ratings of <4 were categorized as “none or some” difficulty and 4–5 as “substantial” difficulty. Caregivers’ use of respite care and support groups was examined: the ICS asked whether services were “ever” used whereas the NSOC asks about service use for a 1-year reference period.

Item nonresponse was generally low, and missing values were coded to the modal response category for the study sample. Item nonresponse was higher for hours of care (varying from 3.4% in 2011 to 4.5% in 2004) and caregiver age (varying from 1.8% in 1999 to 12.1% in 2004), and missing values for these measures were recoded to the mean by caregiver relationship (spouse, adult child, other). Item nonresponse for distance between caregiver and recipient residence was higher in 2015 (6.5%) and recoded based on older adults place of residence (see Table 3, footnote d).

### Design Variables and Caregiver Weights

The NLTCs and NHATS employ a complex multistage sample design with stratification, clustering, and oversampling of specific population subgroups. Observations from surveys must be weighted to produce nationally representative estimates, and design variables must be used to account for the survey design. Public use design variables released with the NHATS (Montaquila, Freedman, Edwards, & Kasper, 2012) and NLTCs design variables developed by the Center for Demographic Studies at Duke (Ash, 2006) were integrated for pooled analyses. The stratum variable in the NLTCs (PSEUDOSTRAT) ranges in value from 1 to 108 and the stratum variable in the NHATS (W1VARSTRAT) ranges in value from 1 to 56. In our pooled dataset a new variable was constructed in which NLTCs stratum values retained original values and NHATS stratum values were recoded to 109–164. Primary Sampling Unit variables for variance estimation (HALFSAMP in the NLTCs and W1VARUNIT in the NHATS) have values of 1 or 2 in both surveys, and these variables were pooled without recoding.

Because of cross-wave differences in the availability and approach for weighting caregiver estimates, we

constructed new weights in each wave. We followed a previously described approach (Wolff & Kasper, 2006) using the NLTCs or NHATS study participant weights as the starting point for developing primary caregiver weights in each wave. A nonresponse adjustment was applied to the weights of study participants with a completed caregiver survey, stratified by age, gender, and physical function (1–2, 3–4, or 5–6 self-care or mobility activities). Using this approach, the available observations in each wave were weighted to the eligible population of primary caregivers who met study criteria, yielding weighted estimates of 2.3 million in 1999, 2.6 million in 2004, 4.6 million in 2011, and 5.2 million in 2015 (Table 1).

### Data Analysis and Estimation

The overarching focus of this analysis was to examine stability and change in the characteristics and experiences of primary caregivers to older adults with self-care or indoor mobility disability over a 16-year period. We first compare demographic, health, and functioning characteristics of older adults receiving self-care or indoor mobility assistance from family or unpaid caregivers. We then examine the composition, circumstances, and experience of their primary family or unpaid caregivers. Given the recognized importance of relationship to caregiving dynamics (Shanas, 1979; Stone, Cafferata, & Sangl, 1987; Wolff & Kasper, 2006), these analyses are stratified by caregiver relationship to recipient (spouse, child, other). Finally, because dementia affects disability as well as the nature, intensity, and experience of caregiving (Kasper et al., 2015; Pinquart & Sorensen, 2007) we examine change in the composition and experiences of caregivers assisting older adults with and without dementia.

The primary objective of this study was directed at understanding stability and change in the circumstances and experiences of family and unpaid caregivers. Therefore, tests of statistical significance focus on differences in estimates across the four survey waves for the entire sample. We additionally compare differences in estimates between 1999 and 2015 for two subgroups of interest: (a) by caregiver relationship to older adult, and (b) by older adults’ dementia status. We used SAS Proc SurveyLogistic to examine cross-wave differences using logistic regression models in which older adult or caregiver characteristics were the outcome variable and survey wave was included as an independent categorical variable with 2015 as the reference period. For categorical variables with more than two levels, differences were examined by dichotomizing each measure and comparing the statistical significance of difference for each group in relation to all other categories. For continuous measures (e.g., hours of care), SAS Proc SurveyMeans was used to examine the statistical significance of cross-wave differences in group means using domain analyses. All analyses were conducted in SAS 9.4 using survey sampling weights and procedures that account for the complex sampling strategy.

## Results

### Characteristics of Older Adults Receiving Help

The majority of community-dwelling older adults with self-care/indoor mobility disability who were receiving help from a family or unpaid caregiver was consistently female, white, and widowed or married (Table 2). About one in three older adults were characterized as having dementia and one in five were enrolled in Medicaid. The sociodemographic profile shifted over the 16-year period toward younger ages (from 28.3% 65–74 years in 1999 to 41.7% in 2015), greater racial diversity (from 86.7% white in 1999 to 80.1% in 2015), higher levels of education (from 45.4% with high school or more in 1999 to 74.7% in 2015). Older adults receiving help were more likely to be married and less likely to be widowed or live alone in 2015 relative to 1999. No evident trend was observed with respect to changes in dementia status or level of disability. About

85% of older adults' primary caregivers were spouses or adult children and less than one in five were caregivers of "other" relationships at each of the four time points. Older adults with adult child caregivers were more functionally impaired in 2015 than in 1999: the proportion receiving help with 3–4 self-care or mobility activities increased from 18.1% in 1999 to 26.0% in 2015.

### Characteristics of Family and Other Unpaid Caregivers

Primary caregiver age, marital status, and distance to older adults' place of residence was generally stable across the 16-year period (Table 3). We observed a nonstatistically significant shift toward greater representation of men (from 31.8% in 1999 and 36.3% in 2015). More than 95% of caregivers lived within 30 min, and about three in four

**Table 2.** Community-Dwelling Older Adults Receiving Help with Self-Care or Indoor Mobility, Stratified by Primary Caregiver Relationship

	All				Spouse		Child		Other	
	1999	2004	2011	2015 <sup>a</sup>	1999	2015 <sup>a</sup>	1999	2015 <sup>a</sup>	1999	2015 <sup>a</sup>
Weighted (000s); Row %	2,270	2,635	4,581	5,222	42.7	48.9	38.7	36.1	18.6	15.0
Age in years (%) <sup>a</sup>										
65–74	28.3*	26.6*	36.1	41.7	43.1*	54.6	13.9*	28.8	24.5	30.9
75–84	41.6*	42.0*	37.9	35.5	45.9*	35.4	38.6	33.8	38.0	39.7
85+	30.1*	31.4*	26.0	22.8	11.1	10.0	47.5*	37.4	37.5	29.4
Female gender (%)	63.9	66.3	64.0	60.8	42.7	46.4	84.3	77.7	69.9	67.2
Race (%) <sup>a</sup>										
White	86.7*	83.8	83.2	80.1	91.8	88.2	86.3*	73.9	75.7	68.6
Black	10.4	10.3*	13.7	13.8	5.7	6.9	10.5*	19.5	20.8	22.7
Other	2.9	5.9	3.2*	6.1	2.4	4.9	3.2	6.5	3.5	8.7
Hispanic ethnicity (%) <sup>b</sup>	—	7.2	9.1	6.5	—	3.1	—	10.5	—	7.8
12+ years education (%)	45.4*	51.8*	65.0*	74.7	55.3*	83.8	37.8*	66.0	38.7*	66.1
Marital status (%) <sup>a</sup>										
Married	49.7*	46.2*	56.0*	61.7			12.4*	25.1	12.1*	24.8
Widowed	43.4*	44.5*	33.7	29.2			80.9*	58.5	65.0	53.9
Other	6.9	9.2	10.3	7.4			6.7*	16.4	22.9	21.3
Medicaid (%)	23.1	24.3	21.4	20.7	12.2	11.2	28.5	31.8	36.9*	24.7
Living arrangement (%) <sup>a</sup>										
Alone	16.2*	19.2*	12.2	10.4			29.4*	18.9	23.8	23.8
Spouse only	38.3*	35.4*	41.6	46.9	81.4	81.8	6.0	10.9	6.4*	19.5
Adult child	33.3	34.8	36.7	33.6	12.5	13.4	60.0	63.5	25.5	27.7
Other	12.3	10.6	9.5	9.1	5.2	4.8	4.6	6.7	44.4*	29.0
Dementia (%) <sup>b</sup>	29.7	28.7	35.0*	26.8	22.9	16.9	35.4	40.2	33.2	27.0
Degree of self-care, indoor mobility help (%) <sup>a,c</sup>										
Standby only or 1–2 activities	65.3	68.3	61.8*	66.8	68.5	76.8	63.0	55.6	63.0	61.0
3–4 activities	18.0	15.2	21.9	19.2	18.2	14.4	18.1*	26.0	17.3	18.2
5–6 activities	16.7	16.5	16.3	14.1	13.4	8.8	18.9	18.4	19.7	20.8

Notes: NHATS = National Health and Aging Trends Study; NLTCS = National Long Term Care Survey.

<sup>a</sup>Tests of statistical significance using reference period of 2015 and each category in comparison with all others. <sup>b</sup>Hispanic ethnicity was not available in 1999. Additional details regarding dementia measurement are included in Supplementary Appendix B. <sup>c</sup>Self-care activities include: eating, dressing, bathing, and toileting. Indoor mobility refers to transferring and getting around inside. Standby help refers to NLTCS only and is combined with 1–2 self-care/ mobility activities to maximize comparability with the NHATS.

\*Denotes statistical significance at  $p < .05$ .

**Table 3.** Characteristics of Primary Family and Unpaid Caregivers, by Relationship to Older Adults Receiving Self-Care or Mobility Help

	All				Spouse		Child		Other	
	1999	2004	2011	2015 <sup>a</sup>	1999	2015 <sup>a</sup>	1999	2015 <sup>a</sup>	1999	2015 <sup>a</sup>
Age (%) <sup>a</sup>										
<65 years	51.1	53.2	53.8	47.0	12.1	15.6	84.1	84.7	72.0	58.6
65–74 years	24.2*	21.9*	27.1	31.6	38.1	44.5	13.8	14.7	13.8	30.0
75+ years	24.7	24.9	19.1	21.5	49.8	39.9	2.2*	0.6	14.3	11.4
Mean age in years	63.5	63.1	61.8	63.3	73.8	72.1	55.2	54.2	57.0	56.5
Gender (%)										
Male	31.8	34.8	38.0	36.3	42.6	45.3	25.3	28.6	20.7	25.5
Female	68.2	65.2	62.0	63.7	57.4	54.7	74.7	71.4	79.3	74.4
Marital status (%) <sup>a,b</sup>										
Married	72.4		70.7	72.4			52.8	46.9	50.3	43.7
Widowed	6.4		6.1	4.8			9.4	6.2	15.4	17.1
Divorced/ separated	11.0		10.7	11.8			21.2	24.3	14.4	20.1
Never married	10.2		12.6	11.0			16.6	22.7	19.9	19.0
Fair or poor health (%) <sup>c</sup>	32.8*	31.6*	25.1	21.7	35.9*	20.3	30.0	25.6	31.8*	16.5
Distance to older adults' residence (%) <sup>a,d</sup>										
Live together	76.1	73.7	75.4	77.4			58.0	61.2	63.4*	43.0
≤10 min	15.7	13.6	12.7	16.1			28.7	25.5	23.0*	45.8
11–30 min	6.2	9.0*	8.8*	4.0			10.1	7.5	12.5	8.4
>30 min	2.0	3.6	3.0	2.5			3.2	5.8	1.1	2.8

Note: ICS = Informal Caregiver Survey; NHATS = National Health and Aging Trends Study; NLTCS = National Long Term Care Survey; NSOC = National Survey of Caregivers.

<sup>a</sup>Tests of statistical significance using reference period of 2015 and each category in comparison with all others. <sup>b</sup>Marital status was not asked of caregivers in 2004. Marital status and living arrangement are not presented for spousal caregivers. <sup>c</sup>NLTCS/ICS asked about self-rated health “compared to other people your age” and provided four response categories, excluding “very good,” whereas NHATS/NSOC asked the question directly and provided 5 response categories, including “very good”. <sup>d</sup>Distance not reported by 77 caregivers in 2015 and recoded based on older adults' reported living arrangement and caregiver relationship. Older adults who did not live with a caregiver ( $n = 52$ ) were recoded to ≤ 10 min.

\*Denotes statistical significance at  $p < .05$ .

caregivers lived in the same household as the older adult they assisted. Caregivers were incrementally less likely to rate their health as fair or poor throughout the 16-year observation period (decreasing from 32.8% in 1999 to 21.7% in 2015); this shift was more notable for spouses and other caregivers than adult children.

### Caregiver Duration and Hours of Assistance

Caregiving arrangements were intense and increasingly longstanding (Table 4). This trend was evident across all relationship types but was most pronounced among spousal caregivers, for whom the percentage providing assistance for 4 or more years increased from 45.5% in 1999 to 64.1% by 2015. Average weekly hours of assistance was about or exceeded 30 hr at all four points in time but varied by relationship over time. Mean hours per week were comparable in 1999 and 2004 (37.1 and 36.2 hr) and lower in 2011 and 2015 (30.7 and 29.9 hr). The reduction in hours was most striking for spousal caregivers for whom average weekly hours of assistance decreased from 44.2 in 1999 to 27.5 in 2015. Adult children provided about 35 hr of care per week at both points in time.

### Competing Responsibilities

Trends in the prevalence of competing responsibilities differed by relationship. A greater proportion of adult child caregivers lived in a household with a child less than 18 years of age in 2015 than in 1999 (26.0% vs. 12.6%). About one in three caregivers were employed at all four points in time. Shifts in employment were most notable among spouses: spousal caregivers were twice as likely to be employed in 2015 as in 1999 (increasing to 15.3% from 7.3%).

### Caregiver Experience and Use of Supportive Services

The percentage of primary caregivers who experienced substantial caregiving-related emotional, physical, and financial difficulty declined over the observation period. This trend was most pronounced for spousal caregivers, for whom the proportion reporting substantial caregiving-related difficulties declined by more than half between 1999 and 2015. The proportion of adult child caregivers who reported substantial caregiving-related difficulty was comparable in 1999 and 2015. Approximately 5% of

**Table 4.** Aspects of Caregiving and Caregiver Experience, Stratified Primary Caregiver Relationship to Older Adult Receiving Self-Care/Mobility Help

	All				Spouse		Child		Other	
	1999	2004	2011	2015 <sup>a</sup>	1999	2015 <sup>a</sup>	1999	2015 <sup>a</sup>	1999	2015 <sup>a</sup>
Duration and hours										
Duration of caregiving, in years (%) <sup>a</sup>										
<1 year	20.8*	15.1*	8.0	9.2	20.1*	8.7	18.6*	10.6	27.0*	7.6
1–3 years	34.4	37.1*	39.0*	30.3	34.4	27.2	34.8	31.2	33.5	38.0
4+ years	44.8*	47.8*	53.1*	60.5	45.5*	64.1	46.6*	58.2	39.5*	54.4
Mean hours per week	37.1*	36.2*	30.7	29.9	44.2*	27.5	32.2	35.0	30.9	25.5
Hours of care provided per week (%) <sup>a</sup>										
≤10 hr	26.9*	31.1	31.2	35.0	19.1*	40.2	30.8	24.0	36.8	44.8
11–20 hr	14.9*	14.6*	20.0	22.2	15.4	21.5	15.9*	23.7	12.0	20.6
21–40 hr	29.7*	28.1*	22.8*	18.0	28.7*	15.7	30.3	23.3	30.9*	12.6
>40 hr	28.4	26.3	26.0	24.8	36.9*	22.6	23.0	29.0	20.4	22.1
Competing responsibilities										
Co-residing child < 18 years (%) <sup>b</sup>	8.7	11.9	10.8	12.2			12.6*	26.0	15.1	18.5
Employed (%)	28.3	31.5	29.5	27.5	7.3*	15.3	47.6	40.4	36.4	36.2
Experience of providing help										
Substantial emotional difficulty (%) <sup>c</sup>	22.2*	22.8*	18.2	14.9	23.0*	11.4	23.9	22.1	16.6	9.1
Substantial physical difficulty (%) <sup>c</sup>	16.5*	14.6*	10.9	9.7	20.1*	8.9	15.4	11.6	10.7	8.1
Substantial financial difficulty (%) <sup>c</sup>	14.2*	11.7	10.2	8.6	18.6*	6.9	11.2	12.4	10.1	5.3
Help from others (%)										
Support group use <sup>d</sup>	5.3	5.8	3.7	4.5	3.8	3.8	6.1	4.5	7.4	6.5
Respite care use <sup>d</sup>	8.5*	11.2*	15.9	15.7	5.0*	10.2	12.1*	23.0	9.0	15.9

Note: ICS = Informal Caregiver Survey; NSOC = National Survey of Caregivers.

<sup>a</sup>Tests of statistical significance using reference period of 2015 and each category in comparison with all others. <sup>b</sup>Not asked of spousal caregivers in 2011 and 2015.

<sup>c</sup>Refers to ratings of “4” or “5” on a 5-point scale, 1 as “not difficult at all” (in the ICS) or “a little difficult” (in NSOC) and 5 is “very difficult”. <sup>d</sup>Reference period of ever (in the ICS) and the last year (in the NSOC).

\*Denotes statistical significance at  $p < .05$ .

caregivers reported attending a support group at all three points in time. Use of respite care increased from 8.5% in 1999 to 15.7% in 2015 and was highest among adult children (increasing from 12.1% in 1999 to 23.0% in 2015).

### Caregivers Assisting Older Adults With and Without Dementia

Trends in caregiving to older adults with and without dementia were generally similar over the 16-year period, although the magnitude of observed changes differed by dementia status (Table 5). We observed notable shifts toward greater representation of men and spouses among non-dementia caregivers. Mean weekly hours of care provided by primary caregivers of persons without dementia decreased significantly from 33.8 in 1999 to 23.5 in 2015, whereas changes in hours of care among dementia caregivers were smaller in magnitude and increased from 44.8 hr in 1999 to 47.5 hr in 2015. Primary caregivers of older adults with dementia were significantly less likely over time to report substantial caregiving-related physical difficulty (decreasing from 30.3% in 1999 to 17.0%

in 2015) and financial difficulty (decreasing from 22.2% in 1999 to 8.9% in 2015); the proportion who reported substantial emotional difficulty also decreased but was not statistically significant. Reductions in the proportion of caregivers who reported substantial caregiving-related physical difficulty (from 10.7% to 7.1%) and emotional difficulty (from 16.8% to 11.2%) were observed among non-dementia caregivers. Use of respite care by dementia caregivers was twice that of non-dementia caregivers and nearly doubled for both groups between 1999 and 2015, from 13.4% to 26.9% for dementia caregivers and 6.4% to 11.5% for non-dementia caregivers.

### Discussion

This study draws on linked national surveys of older adults and family caregivers to examine trends in caregiving to older adults receiving help with self-care or indoor mobility across a 16-year period. Study findings are generally consistent with stated hypotheses. As expected, community-dwelling care recipients were incrementally better educated and more racially diverse in 2015 relative to the



**Table 5.** Characteristics of Primary Family and Unpaid Caregivers, Stratified by Dementia Status of Older Adult Receiving Self-Care or Mobility Help

Primary caregiver characteristics	Older adult without dementia		Older adult with dementia	
	1999	2015 <sup>b</sup>	1999	2015 <sup>b</sup>
Percent of total (row %) <sup>a</sup>	70.3%	73.2%	29.7%	26.8%
Age (%) <sup>b</sup>				
< 65 years	49.0	42.5	56.1	59.1
65–74 years	24.5*	34.2	23.5	24.4
75+ years	26.6	23.3	20.4	16.5
Mean age in years	63.7	64.0	63.0	61.4
Gender (%)				
Male	33.6*	41.8	27.6	21.4
Female	66.4*	58.2	72.4	78.6
Relationship <sup>b</sup>				
Spouse	46.8*	55.6	32.9	30.7
Child	35.5	29.5	46.2	54.2
Other	17.7	15.0	20.9	15.1
Duration of caregiving, in years (%) <sup>b</sup>				
< 1 year	21.5*	9.5	19.1*	8.6
1–3 years	34.7	29.5	33.7	31.9
4+ years	43.8*	60.9	47.3	59.5
Mean hours per week	33.8*	23.5	44.8	47.5
Hours of care provided per week (%) <sup>b</sup>				
≤ 10 hr	29.5*	41.8	20.7	16.4
11–20 hr	15.9*	23.2	12.7	19.4
21–40 hr	29.9*	15.9	29.4	23.7
> 40 hr	24.7	19.1	37.2	40.4
Competing responsibilities				
Co-residing child < 18 years (%)	8.5	11.6	9.1	13.5
Employed (%)	27.8	26.8	29.4	29.4
Experience of providing help				
Substantial emotional difficulty (%) <sup>c</sup>	16.8*	11.2	34.8	24.9
Substantial physical difficulty (%) <sup>c</sup>	10.7*	7.1	30.3*	17.0
Substantial financial difficulty (%) <sup>c</sup>	10.8	8.6	22.2*	8.9
Help from others (%)				
Support group use	4.3	4.4	7.8	4.8
Respite care use	6.4*	11.5	13.4*	26.9

Notes: ICS = Informal Caregiver Survey; NSOC = National Survey of Caregivers.

<sup>a</sup>Unweighted  $n = 529, 790, 413, 472$  without dementia and  $n = 262, 361, 323, 274$  with dementia in 1999, 2004, 2011, and 2015, respectively. <sup>b</sup>Tests of statistical significance using reference period of 2015 and each category in comparison with all others. <sup>c</sup>Refers to rating of “4” or “5” on a 5-point scale where 1 is “not difficult at all” (in the ICS) or “a little difficult” (in NSOC) and 5 is “very difficult”. <sup>d</sup>Refers to “a lot” (in the ICS) or “very much” (in the NSOC).

\*Denotes statistical significance at  $p < .05$ .

earlier time periods. Family caregivers were predominantly spouses and adult children whose involvement continued to be longstanding and intense: on average they provided about or in excess of 30 hr of help per week at each point in time. Caregivers provided fewer hours of care and were less likely to report substantial emotional, physical, and financial difficulty in 2015 than in 1999; these trends were most pronounced among spousal caregivers. Adult children were incrementally more likely to assist older adults with greater impairment, provided comparable hours of assistance per week, and were about equally likely to report substantial caregiving-related difficulty in 2015 as in 1999.

Several findings in this study diverge from prevailing concerns regarding the current state of family caregiving. We found no evidence to suggest reduced availability of family caregivers to older adults with mobility or self-care disability between 1999 and 2015. We also did not find evidence suggesting that the caregiving experience has become more challenging. In fact, study findings suggest that family caregivers' circumstances generally improved during the 16-year observation period: caregivers on average provided fewer hours of weekly assistance, were less likely to report their health to be fair or poor, and were less likely to report substantial emotional, physical, and financial difficulty due to caregiving. Our findings that the use of respite

care essentially doubled between 1999 and 2015 and that a lower proportion of dementia caregivers reported substantial difficulty due to caregiving are particularly encouraging. However, it is important to note that the trends presented in this paper reflect the very early stages of the baby boom. Continued population aging will undoubtedly affect the prevalence and nature of family caregiving in coming years. That the proportion of the population ages 85 and older is projected to double from 2.5% to 5.0% between 2030 and 2050 (Colby & Ortman, 2014) portends increasing age-related care needs and suggests greater caregiving-related challenges for families in the decades to come.

Our study reinforces the value of monitoring longitudinal trends in family caregiving. Although some aspects of caregiving remained largely unchanged (reliance on spouses and children), shifts in the composition and experiences of caregivers were observed. Study findings are in line with recent studies questioning traditional assumptions regarding who serves as a caregiver, the health effects of caregiving, and the interplay between caregiving and employment with respect to caregiver emotional and financial well-being (Bakker & Geurts, 2004; Roth, Fredman, & Haley, 2015; Roth et al., 2007). The shift toward increasing representation of male caregivers was more notable among non-dementia caregivers, and is consistent with observed trends between 1989 and 1999 from the prior NLTC/ICS analysis (Wolff & Kasper, 2006). Understanding the experiences of male caregivers is an emerging area of research with sparse empirical information (Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014), highlighting the need for a stronger understanding of the changing composition of late-life family caregivers. Taken together, study findings substantiate the recent NASEM recommendation to strengthen data collection infrastructure to facilitate improvements in the ability to assess the experience of family caregivers and the effects of policy efforts to better meet their needs (NASEM, 2016).

The approach to this study varies from others in several important ways. First, we focus on a care recipient population of community-dwelling older adults receiving help with self-care or indoor mobility. The composition and experience of caregivers would differ for individuals of younger ages, with less significant disability, or living in a range of residential settings that offer help with a wide spectrum of tasks. Second, our study focuses on “primary” caregivers to a selected population of older adults as opposed to all family and unpaid caregivers within older adults’ helping network. For these two reasons, the numbers of caregivers identified as providing assistance are lower than has been reported elsewhere (Spillman, Wolff, Freedman, & Kasper, 2014). Although we were able to optimize comparability in study samples across waves, not all methodological differences could be fully reconciled. Differences in recall period, survey design, and question wording may have affected the number and composition of family caregivers who were identified. Future waves of the NHATS/NSOC will afford

further opportunity to examine observed trends using consistent measures and survey design for a broader set of family caregivers assisting older adults with a more comprehensive set of activities.

Assessing trends in the composition and experience of family and unpaid caregivers has considerable relevance to long-term services and supports policy. The future lifetime costs of long-term services and supports among those turning 65 in 2016 was estimated to be \$138,000 on average (Favreault & Dey, 2015), but exclude the economic value of family caregivers’ time and effort. As most older adults’ care needs are met by family caregivers (Freedman & Spillman, 2014) these cost estimates understate the economic implications of older adults’ projected long-term services and supports care needs. Other countries have moved to explicitly recognize and reward family care as part of the long-term care continuum (Doty, Nadash, & Racco, 2015; Geraedts, Heller, & Harrington, 2000). There is some momentum in this country toward adopting consumer-directed models that afford flexibility in directing payments to family caregivers, though efforts are largely concentrated within the Medicaid program (Newcomer, Kang, & Doty, 2012). The National Family Caregiver Support Program is the only broad-based federal program that is specifically devoted to addressing the needs of family caregivers, and despite growing demand for services, its budget has remained flat since its inception in 2001.

There is strong evidence and consensus regarding the important individual and societal benefits that result from the efforts of family and unpaid caregivers (NASEM, 2016). Study findings indicate that the sociodemographic and health profile of older adults receiving care and the composition and experience of their family and unpaid caregivers are far from static. As the Congress and states deliberate and act on policies and programs to better support family and unpaid caregivers (Congress, 2015), it is equally important to attend to developing surveillance strategies that afford the ability to monitor family caregivers, including their characteristics, the circumstances under which they provide care, and the effects of care provision.

## Supplementary Material

Supplementary data is available at *The Gerontologist* online.

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## Conflict of Interest

The authors declare that they do not have a conflict of interest.

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