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2015 Report

Caregiving in the U.S.

Conducted by

AARP
Real Possibilities
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Institute

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National Alliance for Caregiving

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The National Alliance for Caregiving (NAC) and the AARP Public Policy Institute are proud to present *Caregiving in the U.S. 2015.*

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Gail Gibson Hunt, National Alliance for Caregiving
Rick Greene, MSW, National Alliance for Caregiving
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Lynn Friss Feinberg, MSW, AARP Public Policy Institute
Rita Choula, AARP Public Policy Institute
Jordan Green, MS, AARP Public Policy Institute
Ari Houser, PhD, AARP Public Policy Institute

NAC Advisory Panel

Donna Benton, PhD, Family Caregiver Support Program, University of Southern California
Thomas Dudley, MS, RN, Centers for Medicare & Medicaid Services
Marty Ford, JD, the Arc
Cindy Hounsell, JD, WISER
Jed Johnson, Easter Seals
Carol Levine, PhD, United Hospital Fund of New York City
Katie Maslow, MSW, Institute of Medicine
Ruth Stein, MD, Albert Einstein College of Medicine
Catherine Thurston, LCSW, Services and Advocacy for GLBT Elders
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I. Introduction

The purpose of this study is to present a portrait of unpaid family caregivers today. To that end, the National Alliance for Caregiving (NAC) and the AARP Public Policy Institute are proud to present *Caregiving in the U.S. 2015*, based on data collected in late 2014.

A national profile of family caregivers first emerged from the 1997 *Caregiving in the U.S.* study. Related studies were conducted in 2004 and 2009 by the NAC in collaboration with AARP. This study builds on those prior efforts, but was conducted against the backdrop of a societal shift in technology,[2] requiring a shift to online data collection.

Caregiving in the U.S. 2015 should be considered a stand-alone research effort, and should not be compared with prior waves conducted via landline telephone only (1997, 2004, or 2009). *Caregiving in the U.S. 2015* establishes a new baseline for examining changes to caregiving in the future.

The core areas that we examined in this study include the following:

- The prevalence of caregivers in the United States
- Demographic characteristics of caregivers and care recipients
- The caregiver's situation in terms of the nature of caregiving activities, the intensity and duration of care, the health conditions and living situation of the person to whom care is provided, and other unpaid and paid help provided
- How caregiving affects caregiver stress, strain, and health
- Information needs related to caregiving
- Public policy and caregiver support

The unique areas of exploration were the following:

- Medical/nursing tasks
- Hospitalization of care recipients
- Supports provided to and impacts on working caregivers
- Older caregivers ages 65-plus

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[2] Discussed in depth later and in the accompanying appendix B, Detailed Methodology, nearly 60 percent of Americans have no landline telephone or use their cell phone primarily. Blumberg, S. & Luke, J. "Wireless Substitution: Early Release of Estimates From the National Health Interview Survey, January–June 2014." U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, National Health Interview Survey, Early Release Program. December 2014.

Caregivers are as diverse as the United States as a whole: they come from every age, gender, socioeconomic, and racial/ethnic group. They share positive aspects of caregiving. They also share many struggles, but can face different challenges depending on their circumstances. Caregivers may need differing support depending on their loved one's condition and needs, and their own problems, strengths, and resources.

This report outlines all the *Caregiving in the U.S. 2015* study findings, while drawing special attention to some vulnerable groups of caregivers who face complex, high burden care situations, sometimes resulting in higher stress and strain for the caregiver. These vulnerable groups include older caregivers, caregivers who had no choice in taking on their caregiving role, and higher-hour caregivers (those providing greater hours of care weekly).

Because caregivers' circumstances can vary markedly depending on the age of their care recipient, NAC and the AARP Public Policy Institute will be publishing two companion reports in the coming weeks that separately explore the experiences of caregivers whose loved one is 1) age 18 to 49, or 2) age 50 or older.

II. Overview of Methodology

This report is based primarily on quantitative online interviews with 1,248 caregivers ages 18 or older. Caregivers of adults are defined as those who provide unpaid care, as described in the following question:

> *At any time in the last 12 months, has anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? This may include helping with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you.*

Additionally, to estimate the national prevalence of caregiving for someone of any age, the study asked respondents if they had provided care to a child with special needs in the past year, as described in the following question:[3]

> *In the last 12 months, has anyone in your household provided unpaid care to any child under the age of 18 because of a medical, behavioral, or other condition or disability? This kind of unpaid care is more than the normal care required for a child of that age. This could include care for an ongoing medical condition, a serious short-term condition, emotional or behavioral problems, or developmental problems.*

Only caregivers of adults were eligible to complete the full online interview. Results from the screening question about caring for a child with special needs were included in the prevalence estimates only.

Online Data Collection

Caregiving in the U.S. 2015 utilized GfK's national, probability-based, online KnowledgePanel® in lieu of the traditional random digit dial landline-only telephone study used in prior waves (1997, 2004, and 2009). This change was necessitated by the ever-changing technological shift occurring in the United States away from landline ownership and toward cell phone use. A majority of adults in the United States now use only their cell phone (43%) or primarily use their cell phone (16.6%) for phone calls.[4]

Due to the shift in data collection, *Caregiving in the U.S. 2015* should be considered a stand-alone research effort, and should not be compared with prior waves conducted via landline telephone only (1997, 2004, or 2009). *Caregiving in the U.S. 2015* establishes a new baseline for examining changes to unpaid family caregiving in the future.

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[3] These two questions used to identify caregivers are the same questions used in *Caregiving in the U.S. 2009*, with minor wording edits to make them suitable for online self-administration.

[4] Blumberg, S. & Luke, J. "Wireless Substitution: Early Release of Estimates From the National Health Interview Survey, January–June 2014." U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, National Health Interview Survey, Early Release Program. December 2014.

GfK's KnowledgePanel® is the only probability-based online panel, designed to be representative of the U.S. population. Initially, participants were chosen scientifically by a random selection of telephone numbers and residential addresses. People in selected households were then invited by telephone or by mail to participate in the web-enabled KnowledgePanel®. For those who agreed to participate, but did not already have Internet access, GfK provided at no cost a laptop and internet service provider connection.

Online interviews were conducted with a random sample of 1,015 adult caregivers. To supplement the sample of ethnic adult caregivers, 233 additional online interviews were conducted via targeted sampling of racial/ethnic groups, yielding the total 1,248 base study, full online interviews with caregivers of adults[5] (by race/ethnicity: 698 white non-Hispanic caregivers, 206 non-Hispanic African American caregivers, 208 Hispanic caregivers, 95 Asian American caregivers,[6] and 41 caregivers of another race).

Oversamples and Questionnaire

In addition to the 1,248 caregiver interviews in the base study, the study included an oversample of older caregivers. Specifically, an additional 209 online interviews were conducted with caregivers ages 65 or older, yielding a total of 213 caregivers ages 65 to 74 and 269 caregivers ages 75 or older. Further, 106 Asian American caregivers were interviewed via telephone (65 landline and 41 cell phone) to bring the total among this caregiving subset to 201 caregivers. The landline sample was targeted by surname and geographic density, while the cell phone sample was targeted by surname. The oversamples were weighted according to the weighted distribution of caregivers in the base sample by individual respondent's age, sex, and race/ethnicity. See appendix B, Detailed Methodology, for additional details about these targeted oversamples, which are not included in the base study.

The questionnaire was designed to replicate many of the questions posed in the 1997, 2004, and 2009 NAC/AARP *Caregiving in the U.S.* studies, as well as to explore new areas. It was designed by a team from NAC, the AARP Public Policy Institute, and Greenwald & Associates. It has two main sections: 1) a screener, used to identify the presence of a caregiver of someone—adult or child—within the household, and 2) the substantive questions about caregiving, administered to only caregivers of adults. The full questionnaires, for both web and phone administration, are presented in appendix A to this report.

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[5] For additional details about sampling, including oversamples, see appendix B, Detailed Methodology.

[6] Asian American is inclusive of those caregivers who are of Asian origin, background, or descent, including the regions of the Indian subcontinent, Far East, Southeast Asia, or Pacific Islands.

Prevalence Estimation and Fielding

All of the data gathered from the screener were used to estimate prevalence—the proportion of caregiving individuals and households in the United States (shown in appendix B).

Online respondents were given the option of conducting the interview in Spanish or English, and 45% of Hispanic respondents chose the Spanish version. The average length of the interview was 23.8 minutes online and 24.7 minutes via telephone. The interviews were conducted between September 11 and November 5, 2014.

Weighting and Margin of Error

All fully screened respondents—regardless of caregiver status—were weighted by the individual's age, sex, and race/ethnicity to population estimates from the IPUMS public-use data file of the March 2014 Current Population Survey, conducted by the U.S. Census Bureau.

The margin of error for the overall 2015 results is plus or minus approximately 2.8 percentage points at the 95% confidence level. This means that 95 times out of 100, a difference of greater than roughly 3 percentage points would not have occurred by chance. For subgroups of caregivers, the margin of error is larger.

All details of the methodology are included in appendix B to this report.

Reading This Report

The main figures in this report present results for all 1,248 base study caregivers, who completed a full online interview. A focused look at caregivers' hours of care is shown in mini-tables to the right of each graphic. We define "higher-hour" caregivers as those who provide at least 21 hours of care each week, while "lower-hour" caregivers are those who provide 20 or fewer hours of care weekly. The n sizes shown in the mini-tables may not always net to the full n size shown in the main figure, as a few caregivers did not provide their care hours.

All numbers have been weighted and rounded. In addition, "don't know" or "refused" responses are not always presented in figures. For these reasons, data in some figures will not add to 100 percent. The results for multiple response questions may also add to greater than 100 percent.

The n sizes shown in each table or graphic represent the unweighted number of respondents who answered each question.

To signal key differences between subgroup findings, the report uses an asterisk to highlight any numerical result that is significantly higher than the comparison group. When there are more than two columns or groups being compared, a superscript letter next to a numerical result indicates that it is significantly higher than the numerical result in the column designated by that letter.

All demographic information about the caregivers is in reference to their current situation if currently caregiving, or their situation at the time they last provided care if not a current caregiver.

When presenting differences between different racial/ethnic groups, any mention of whites or African Americans refers solely to non-Hispanic individuals. When discussing marital status of the caregiver, married refers to any caregiver who was married or living with a partner at the time of caregiving. Unmarried refers to any caregiver who was single, separated, divorced, or widowed at the time of caregiving. Unemployed refers to caregivers who were not working at any time in the past year while they were also providing care (could include retired, disabled, homemaker, student, not looking for work, and not working but looking for work).

III. Key Findings

Prevalence of Caregiving

An estimated 43.5 million adults in the United States have provided unpaid care to an adult or a child in the prior 12 months.[7] About 18.2% of the respondents interviewed reported being caregivers. The estimated prevalence of caring for an adult is 16.6%, or 39.8 million Americans.[8] Approximately 34.2 million Americans have provided unpaid care to an adult age 50 or older in the prior 12 months.

Basics of the Caregiving Situation

The majority of caregivers are female (60%), but 40 percent are male. Eight in 10 are taking care of one person (82%). They are 49 years of age, on average. A large majority of caregivers provide care for a relative (85%), with 49 percent caring for a parent or parent-in-law. One in 10 provides care for a spouse. Higher-hour caregivers[9] are almost four times as likely to be caring for a spouse/partner.

Nearly 1 in 10 caregivers is 75 years of age or older (7%). *Caregiving in the U.S. 2015* provides an in-depth glimpse into this older group of caregivers, to see how they differ from younger caregivers. While the oldest caregivers in the study are not experiencing significantly more stress or strain than younger caregivers, they are more likely to be

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[7] As with prior *Caregiving in the U.S.* studies, prevalence estimates are inclusive of those having provided in the 12 months before the time they were surveyed, whether they were currently a caregiver at the time of survey or had been a caregiver in the prior 12 months but no longer were.

[8] Add the estimated 13.9% caring for an adult *only* plus the 2.7% caring for *both* a child and adult to get the total prevalence estimate of caring for an adult.

[9] Higher-hour caregivers are those providing 21 or more hours of care weekly, while lower-hour caregivers are those providing 0–20 hours of care.

caregiving without other unpaid help. They are communicating with care professionals and advocating for their recipient, making them an important part of the care team. They are less likely to be employed, more likely to be caring for their own spouse, and more likely to be managing finances for their recipient. This means that at a time of life when income may be fixed, they are performing the difficult task of managing household finances, for both themselves and their spouse. Further research is needed to understand this transition and some of the challenges these older caregivers are facing, relative to financial management and fixed income.

How long have all caregivers of adults been in their role? On average, they have been in their role for 4 years, with a quarter having provided care for 5 years or more (24%). Higher-hour caregivers are twice as likely to have been in their caregiving role for 10 or more years.

The typical care recipient is female (65%) and averages 69.4 years of age. Nearly half of caregivers provide care to someone 75 years old or older (47%). Roughly half of care recipients live in their own home (48%). However, as hours of care increase, so do the chances that the care recipient co-resides with the caregiver.

Care Recipient Condition

Three in five care recipients have a long-term physical condition (59%), more than a third have a short-term physical condition (35%), and a quarter have a memory problem (26%). Many care recipients have more than one ongoing problem or illness (37%).[10]

When caregivers are asked what they perceive to be the main reason their recipient needs care, the top three problems reported are “old age” (14%), Alzheimer's or dementia (8%), or surgery/wounds (8%). Some other common conditions include: cancer (7%), mobility (7%), and mental/emotional health issues (5%).

Although Alzheimer’s or dementia is cited by only 8 percent of caregivers as the main condition for which the care recipient needs help, a total of 22% report their loved one does suffer from this type of condition.[11]

More than half of care recipients have been hospitalized in the past 12 months (53%).

Caregiving Activities and Burden of Care

On average, caregivers spend 24.4 hours a week providing care to their loved one. Nearly one-quarter provide 41 or more hours of care a week (23%). Caregiving is particularly time-intensive for those caring for a spouse/partner (44.6 hours a week).

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[10] Those who did not report the presence of any of the six selected conditions reported their loved one’s main condition was “old age.”

[11] This includes anyone indicating the presence of Alzheimer’s disease, dementia, or other mental confusion either as the main condition or in a direct follow-up asking about the presence of these conditions.

How is caregivers' time spent? A majority of caregivers help their loved one with at least one Activity of Daily Living (ADL; 59%), most commonly helping their care recipient get in and out of beds and chairs (43%). Higher-hour caregivers more often perform each ADL.

Among those performing ADLs, one in four finds it difficult. Caregivers who perform more ADLs are more likely to report having difficulty providing them. Just 10 percent of those performing only one ADL have difficulty doing so, while half of those providing all six ADLs find it difficult (48%). The most difficult individual ADLs involve personal care activities, like dealing with incontinence or diapers (40% difficult), helping the recipient to and from the toilet (33%), and bathing/showering assistance (31%).

Caregivers help, on average, with 4.2 out of 7 Instrumental Activities of Daily Living (IADLs), including transportation (78%), grocery or other shopping (76%), or housework (72%). Higher-hour caregivers are more likely to help with each of the seven IADLs.

Caregivers' responsibilities often extend beyond the traditional ADLs and IADLs, to interacting with various providers, agencies, and professionals on their care recipient's behalf. Two out of three monitor their care recipient's condition to adjust care (66%), 63 percent communicate with health care professionals, and 50 percent advocate for their recipient. Higher-hour caregivers are more likely to report doing each of these tasks, suggesting that these activities are not without their own additive effect on caregivers' time.

All of these activities add up to a burden of care that varies widely for caregivers: 40 percent of caregivers report high burden, 18 percent report moderate burden, and 41 percent report a relatively low burden.[12]

Medical/Nursing Tasks

Recent research revealed that, in addition to ADLs and IADLs, family caregivers are increasingly performing tasks that nurses typically perform.[13] Known now as "medical/nursing tasks," these skilled activities include injections, tube feedings, catheter and colostomy care, and many other complex care responsibilities. About 6 in 10 caregivers assist with medical/nursing tasks (57%), and higher-hour caregivers are more often performing these tasks.

Fourteen percent of those caregivers who assist with medical/nursing tasks find it difficult. Higher-hour caregivers are more likely to feel that performing medical/nursing tasks is difficult, as are those caring for someone with Alzheimer's or dementia (22%) and those who have been providing care for 5 years or more (21%).

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[12] The "burden" of care is a simplified version of the Level of Care Index, the construction of which is detailed in appendix B, Detailed Methodology.

[13] Reinhard, S.C., Levine, C., & Samis, S. *Home Alone: Family Caregivers Providing Complex Chronic Care*. AARP Public Policy Institute & United Hospital Fund, 2012.

The intersection of feeling prepared to provide medical/nursing tasks with actually performing these tasks reveals some important gaps in caregiver preparation. Most commonly, caregivers are doing medical/nursing tasks without any preparation (42%). Just 14 percent of caregivers who assist with medical/nursing tasks report having received some preparation or training.

More than 6 in 10 higher-hour caregivers are performing medical/nursing tasks without any prior preparation. Caregivers in the most complex care situations are the ones most likely to be performing medical/nursing tasks without any preparation—62 percent of high-burden caregivers are performing medical/nursing tasks without prior preparation.

Presence of Other Help

Only about half of caregivers say another unpaid caregiver helps their recipient (53%). Certain groups of caregivers are more likely to be the sole unpaid caregiver, including higher-hour caregivers (57% with no other unpaid help) and those caring for a spouse (78%).

Only 32 percent of caregivers report their loved one gets paid help from aides, housekeepers, or other people paid to help them. One in three caregivers have no help at all—paid or unpaid.

Choice

When asked if they had a choice in taking on the responsibility to provide care for their loved one, half of caregivers self-reported they had no choice in taking on their caregiving responsibilities.

In many ways, caregivers who feel they had no choice in taking on their role are different from those who feel they had a choice, often finding themselves facing complex care situations, and increased stress and strain. Policy makers and care providers may be unable to change a caregiver’s perception of choice in taking on his or her role, especially given that this perception is closely tied to the relationship between the caregiver and care recipient, as well as the presence of other unpaid family caregivers. However, providing supportive services to caregivers who feel this sense of “obligation” may help mitigate some of the negative impacts arising from the care situations in which these caregivers find themselves. Reflecting this, caregivers who feel they had no choice in taking on their role are more likely to state that each of six policy supports would be helpful.

Stress and Strain of Caregiving

Half of caregivers feel their health is *excellent* or *very good* (48%), while 17 percent say it is *fair* or *poor.* By comparison, 10 percent of the general adult population describe their health as *fair* or *poor.*[14] The longer a caregiver has been providing care, the more likely she or he is to report *fair* or *poor* health.

When asked about the impact that caregiving has had on their health, 22 percent of caregivers felt their health had gotten worse as a result of caregiving. Caregivers most vulnerable to negative health impacts include higher-hour caregivers (29% worse health), those caring for someone with a mental health issue (34%), co-resident caregivers (30%), those doing medical/nursing tasks (27%), and primary caregivers (25%).

One in five caregivers reports a high level of physical strain resulting from caregiving (19%), while two in five consider their caregiving situation to be emotionally stressful (38%). Experiencing physical strain (32%) and emotional stress (46%) is more common among higher-hour caregivers. Over half of those who feel they had no choice in taking on their caregiving role report high levels of emotional stress (53%).

Caring for a close relative, like a spouse or parent (45% and 44%, respectively), is more emotionally stressful for caregivers than caring for another relative (35%) or non-relative (18%). Chronic or long-term conditions among care recipients seem to be particularly likely to cause emotional stress for caregivers, as about one out of every two caregivers of someone with a mental health issue (53%), Alzheimer's or dementia (50%), or a long-term physical condition (45%) report feeling emotional stress.

About one in five caregivers reports experiencing financial strain (18%). Financial strain is more commonly reported by higher-hour caregivers.

As with emotional stress, financial strain is greater among co-resident caregivers, but only for higher-hour caregivers, who are twice as likely to report strain (31%) than co-resident lower-hour caregivers (15%) and non-co-resident caregivers (15%). Caregivers who live more than an hour away from their care recipient also report higher levels of financial strain (21%), perhaps because 41 percent of long-distance caregivers report the use of paid help. In addition, the longer a caregiver has been providing care, the more likely they are to feel the financial strain (22% high financial strain among those who provided care for a year or longer).

Impact of Caregiving on Work

Six in 10 caregivers report being employed at some point in the past year while caregiving. Among them, 56 percent worked full time, and on average, they worked 34.7 hours a week.

When it becomes difficult to balance caregiving with work, or if the demands of work come into conflict with one's caregiving responsibilities, some caregivers make changes to their work situation. Six in 10 caregivers report having to make a workplace

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[14] CDC/NCHS, National Health Interview Survey, January–June 2014, Family Core component.

accommodation as a result of caregiving, such as cutting back on their working hours, taking a leave of absence, receiving a warning about performance or attendance, or other such impacts. Higher-hour caregivers are more likely to report experiencing nearly all of these work impacts.

Caregivers working at least 30 hours a week are more likely to report having workday interruptions as a result of caregiving. Caregivers who are employed for fewer than 30 hours are more likely to report they cut back their work responsibilities.

One in six working caregivers is self-employed or owns their own business (17%). In comparison, 9.4 percent of U.S. workers are self-employed.[15] Self-employed caregivers report working fewer hours than those who work for an employer (not self-employed). In addition, self-employed caregivers are more likely to report scaling back their work or retiring early. This suggests that caregivers may be dropping out of the employee-employer relationships and opting into self-employment to better fit their caregiving situation because it offers greater flexibility. Alternatively, self-employed individuals may more often be "chosen" for or volunteer to provide care because of their ability to better control their own work.[16] Additional research on working caregivers and self-employment is needed to determine causality.

What are employers doing to support working caregivers? Among employed caregivers who are not self-employed, more than half report that their supervisor at work is aware of their caregiving responsibility (56%). Higher-hour caregivers who work for an employer are more likely to say their supervisor is aware of their role (76%). As a working caregiver's burden of care increases, so too does the chance that his or her work supervisor is aware of their caregiving role (77% high burden vs. 56% medium burden vs. 41% low burden).

Among employed caregivers who are not self-employed, half say their employer offers flexible work hours (53%) or paid sick days (52%).[17] Fewer working caregivers say their employers offer employee assistance programs (23%) or telecommuting (22%). Nearly all workplace benefits are more commonly reported by caregivers working full time.

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[15] Current Population Survey, Annual Social and Economic Supplement, 2012 data, presented in: Bureau of Labor Statistics. "Female Self-Employment in the United States: An Update to 2012." *Monthly Labor Review*. October 2014.

[16] Looking at the prevalence of caregiving by work status, those who report being self-employed at the time of the online interview are more likely to be caregivers (21.6% care for someone of any age) than those working for an employer as a paid employee at the time of survey (17.4%). For reference, the national estimate is 18.2 percent.

[17] Among the general U.S. population of private-sector workers, 62 percent report having at least 1 paid sick day, while 38 percent do not have any paid sick days. Access to paid sick days is related to hours worked, similar to results we find among caregivers. Farrell, J., & Venator, J. "Paid Sick Days: Paid Sick Days Work for U.S. Employees and Employers," Fact Sheet. Center for American Progress, August 16, 2012.

Information Needs and Caregiving Support

One third of caregivers (32%) say a health care provider, such as a doctor, nurse, or social worker, has asked about what was needed to care for their recipient. Half as many caregivers say a health care provider has asked what they need to take care of themselves (16%).

Caregivers in more complex care situations are more likely to report having these kinds of conversations, both about their needs for recipient care and needs for self-care, including: higher-hour caregivers (44% discussed recipient needs; 23% discussed self-needs), Alzheimer's caregivers (46% recipient needs; 25% self-needs), and those performing medical/nursing tasks (42% recipient needs; 21% self-care needs).

However, these conversations still are not occurring for a majority of caregivers, even among those groups likely to discuss these things with health care providers.

In fact, when we compare the percentage of caregivers who report having had these kinds of conversations with the percentage of caregivers who would find these conversations helpful—the need gap—we see the need is greater than what is being reported by caregivers. For conversations about recipient care, there is a 6 percent gap, while there is a 10 percent need gap for conversations about self-care. The need gap is significantly larger in terms of discussions about the caregiver's own needs than it is for discussions about recipient care.

Higher-hour caregivers have a greater unmet need for conversations with health care providers about their own self-care than they have an unmet need for conversations about recipient care. Higher-hour caregivers are vulnerable in that they have high levels of emotional stress, physical strain, and worsening health, and are therefore in need of some self-care support.

Indeed, more than 8 out of 10 caregivers (84%) state that they could use more information or help on caregiving topics. Caregivers most commonly want information about keeping their loved one safe at home (42%) and about managing their own stress (42%). Higher-hour caregivers are especially interested in managing stress (51%), managing their loved ones' challenging behaviors (18%), and dealing with incontinence or toileting problems (17%).

Despite caregivers' need for support, only one out of three caregivers has made modifications to their loved ones' home (34%), and fewer have requested financial assistance (28%), used transportation (23%), or respite services (15%) for their loved one. Higher-hour caregivers are more likely to report having used at least one of these services, as are those who have been caring for at least a year.

The inability to access affordable services may be an issue for caregivers, especially those in complex care situations. One in four caregivers says it is very difficult to get affordable services in their loved one's community that would help with their care (25%).

Difficulty accessing affordable services is more common among higher-hour caregivers and those in complex care situations, such as high burden caregivers (31% vs. 20% low burden), those performing medical/nursing tasks (29% vs. 19% not performing these), and those caring for someone with a long-term physical condition (29% vs. 20% without).

When gauging how helpful several policy proposals might be to their caregiving experience, nearly half of caregivers feel a policy to have their own name on the recipient's medical chart (49%) would be helpful. Roughly 4 in 10 feel it would be helpful to require hospitals to demonstrate medical/nursing tasks or inform them about major decisions.

Higher-hour caregivers are more likely to say respite services would be helpful. Respite services are especially appealing to higher-hour caregivers who live with their care recipient (44%).

Of three potential national policies or programs focused on providing financial support to caregivers, 3 in 10 caregivers felt that being paid for some of their care hours (30%) and an income tax credit to offset the cost of care (30%) would be most helpful. Higher-hour caregivers are more likely to prefer being paid for some of their caregiving hours, while lower-hour caregivers prefer the tax credit or a partially paid leave of absence from work. Lower-income caregivers are more interested in being paid to provide care, while higher-income caregivers show greater interest in a tax credit.

Long-Range Planning

Half of caregivers expect they will be a caregiver for an adult (either their current loved one or someone else) during the next 5 years.

Caregivers who feel they did not have a choice in their caregiving role are more likely to say their role will continue during the next 5 years (57% vs. 47% of those with a choice). This is notable, as those who feel they did not have a choice are especially likely to report negative impacts as a result of providing care and most likely will continue to experience these impacts well into the future.

One in five caregivers would like additional information about making end-of-life decisions (22%). Caregivers of someone age 65 or older (25%) are most likely to want this kind of information, as are those caring for someone with a long-term physical condition (27%).

Fewer than half of caregivers report their recipient has made plans for his or her future care (46%). High burden caregivers (38%) and those living with their loved one (40%) are especially likely to indicate a lack of plans.

Four in 10 caregivers have plans for their own future care. The older the caregiver and the higher his or her household income, the more likely he or she is to have made plans for their own care.

Demographics

Six in 10 caregivers are female, and caregivers' average age is 49.2. More than 60 percent are white, and nearly 20 percent are Hispanic. More than one-third (36%) have a high school education or less, higher than the number who have a college degree (34%). Caregivers who provide 21 or more hours of care a week are on average 4 years older than those who provide fewer hours.

Caregivers' median household income of $54,700 is comparable to the $53,046 for the United States overall.[18] Most caregivers are married or living with a partner, and 28 percent have a child or grandchild under the age of 18 living in their household. Six in 10 caregivers are employed. Higher-hour caregivers are less likely to be employed. Most caregivers live in an urban/suburban setting. One in 10 caregivers has served in the armed forces, and a similar proportion of their care recipients have. Nine percent self-identify as lesbian, gay, bisexual, and/or transgender (LGBT).[19]

IV. Detailed Findings

A. Prevalence of Caregiving

Of the 7,660 people who were screened in the online interview, the proportion of initial respondents who had served as unpaid caregivers was 18.2 percent.[20] Using a late 2014 estimate of 239,340,657 Americans ages 18 or older, the study estimates 43.5 million adults have been caregivers to an adult or child in the 12 months prior to the study.

Adding the estimated 13.9 percent caring for an adult only to the 2.7 percent caring for both a child and adult yields an estimated prevalence of caring for an adult of 16.6 percent.

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[18] U.S. Census Bureau, American Community Survey, 2013.

[19] Of all screened respondents in *Caregiving in the U.S. 2015*, 6.9 percent self-identify as LGBT. In addition, we find that caregiving for an adult is more common among those who identify as LGBT (20.4% vs. 16.5% not identifying as LGBT). Nationally, Gallup estimates 5.6 percent of Americans are LGBT. Gates, G.J. *LGBT Demographics: Comparisons among Population-Based Surveys*. The Williams Institute, October 2014.

[20] As with prior *Caregiving in the U.S.* studies, prevalence estimates are inclusive of anyone providing care to someone in the 12 months before the time they were surveyed, whether they were currently a caregiver at the time of survey, or had been a caregiver in the prior 12 months but no longer were.

Figure 1: Estimates of Individual Caregiving Prevalence by Age of Recipient

Type of Recipient	Prevalence	Estimated Number of Caregivers
Overall	18.2%	43.5 million
Only child recipients	1.6%	3.7 million
Only adult recipients	13.9%	33.3 million
Both adult and child recipients	2.7%	6.5 million

We are able to estimate there are 34.2 million adults in the United States who have been a caregiver to an adult age 50 or older in the prior 12 months (roughly 14.3% of all American adults are a caregiver to someone age 50 or older).

The prevalence of caregiving varies by racial/ethnic group. It is highest among Hispanics (21.0 percent), while whites report the lowest rates of caregiving.

Figure 2: Estimates of Individual Caregiving Prevalence by Race/Ethnicity

	Prevalence	Estimated Number of Caregivers
White (Non-Hispanic)	16.9%	26.5 million
African American	20.3%	5.6 million
Asian American	19.7%	2.7 million
Hispanic	21.0%	7.6 million

B. Basics of the Caregiving Situation

Current versus Past Care

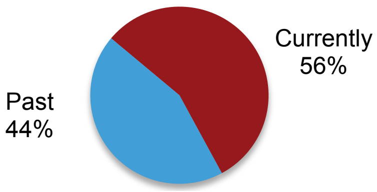
Almost 6 in 10 caregivers (56%) are currently caring for a loved one, while more than 4 in 10 (44%) provided care in the last 12 months but are no longer doing so.

Among higher-hour caregivers—that is those who provide 21 or more hours of care a week—most are currently providing care (55%), similar to lower-hour caregivers (56%).

Figure 3: Current versus Past Care

Q1. Are you currently providing unpaid help to an adult relative or friend, or was this something you did in the past 12 months and are no longer doing?

Base: Caregivers of Recipient Age 18+ (n=1,248)



% Currently

Hours Caregiving per Week

0-20 (n=826)	21+ (n=416)
56%	55%

Number of Care Recipients

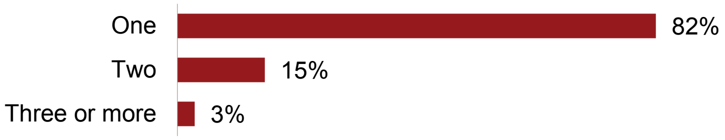
Eight in 10 caregivers care for just one adult (82%), 15 percent take care of two adults, and 3 percent care for three or more adults.

Among higher-hour caregivers, 84 percent care for just one adult, similar to lower-hour caregivers.

Figure 4: Number of Adult Care Recipients

Q2. How many adults are you currently caring for/did you care for in the past 12 months?

Base: Caregivers of Recipient Age 18+ (n=1,248)



Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
81%	84%
16	13
2	3

2015 Caregiver Subgroups

- The likelihood of caring for just one adult rises in relation to the age of the caregiver, with 79 percent of 18- to 49-year-old caregivers providing care to one adult, while 92 percent of caregivers ages 75-plus care for just one adult recipient.

While some caregivers do provide care for multiple adults, this research asks caregivers to focus on the main adult for whom they provide care. Results presented hereafter refer to the caregiving situation for that main adult recipient.

Care Recipient and Caregiver Gender

Three in five caregivers are female (60%) and two in five are male (40%). Two out of three care recipients are female (65%).

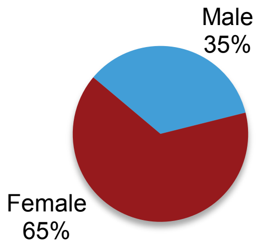
Higher-hour caregivers tend to be female (62%) caring for a female (64%), similar to lower-hour caregivers.

Figure 5: Gender of Care Recipient and Caregiver

Q9. And is/was the person you care/cared for …
Caregiver gender provided by panel or recorded by interviewer.

Base: Caregivers of Recipient Age 18+ (n=1,248)

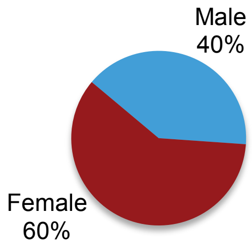
Care Recipient Gender



% Female Recipients

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
66%	64%

Caregiver Gender



% Female Caregivers

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
59%	62%

2015 Caregiver Subgroups

- The younger the care recipient, the more likely the recipient is to be male. Among 18- to 49-year-old recipients, 45 percent are male, shifting to just 33 percent among recipients ages 50 or older.
- When caregivers provide care to a parent, it is more often their mother (73% female), while those caring for a spouse are most often doing so for a male spouse (55%).[21]

Age of Care Recipient

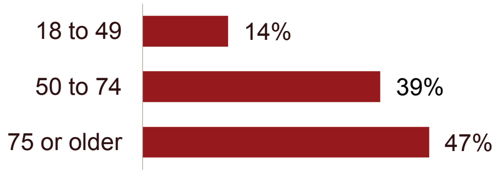
On average, the care recipient is 69.4 years old. Nearly half of caregivers care for someone age 75 years or older, and 39 percent care for someone age 50 to 74.

Higher-hour caregivers care for an adult 68.4 years old, on average, about on par with lower-hour caregivers' recipients (69.8 years old on average).

Figure 6: Age of Main Care Recipient

Q5. How old is that adult/was that adult at the time you provided care?

Base: Caregivers of Recipient Age 18+ (n=1,248)



Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
13%	16%
38	40
49	44

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[21] Spouse is inclusive of same-sex partnerships, same-sex marriages, or partner relationships regardless of sexual identification.

2015 Caregiver Subgroups

- Younger caregivers tend to provide care to younger recipients, while older caregivers care for older recipients.

Figure 7: Age of Main Care Recipient by Age of Caregiver

	Caregiver Age			
	18 to 49 (n=503) A	50 to 64 (n=472) B	65 to 74 (n=213) C	75 or older (n=269) D
Average Care Recipient Age	*63.5*	*73.9*^{A}	*77.0*^{AB}	*77.1*^{AB}
Recipient age 18–49	18% ^{BCD}	11%	8%	8%
Recipient age 50–74	52% ^{BCD}	25%	33% ^{BD}	19%
Recipient age 75+	29%	64% ^{A}	59% ^{A}	73% ^{ABC}

- Asian Americans care for the oldest recipients (72.8 years old, on average), followed by whites (71.1), African Americans (66.3), and Hispanics (65.3).

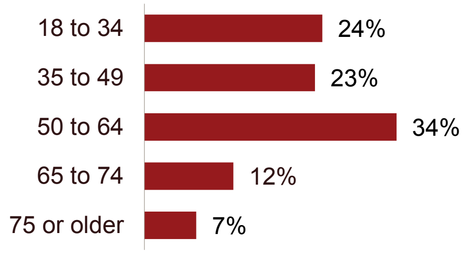
Age of Caregiver

On average, caregivers of adults are 49.2 years old. Nearly half are between the ages of 18 and 49 (48%). Higher-hour caregivers are older on average (51.8 years old), than those providing fewer hours of care (48.0).

Figure 8: Age of Caregiver

Caregiver age provided by online panel.
SC2. [phone only] How old were you on your last birthday?

Base: Caregivers of Recipient Age 18+ (n=1,248)



Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
26%*	20%
24	22
33	35
11	13
6	11*

2015 Caregiver Subgroups

- Spousal caregivers are the oldest, at 62.3 years of age, on average.
- White caregivers are older than African American, Hispanic, and Asian American caregivers, on average.

Figure 9: Age of Caregiver by Caregiver Race/Ethnicity

	Caregiver Race/Ethnicity			
	White (n=698) A	African American (n=206) B	Hispanic (n=208) C	Asian American (n=201) D
Average Caregiver Age	*52.5* ^{BCD}	*44.2*	*42.7*	*46.6* ^{C}
Caregiver age 18–34	17%	34%^{A}	38%^{A}	30%^{A}
Caregiver age 35–49	21%	28%	29% ^{A}	25%
Caregiver age 50+	62% ^{BCD}	38%	34%	44% ^{C}

Spotlight: Nearly 1 in 10 caregivers is 75 years of age or older (7%). *Caregiving in the U.S. 2015* provides an in-depth glimpse into this older group of caregivers to see how they differ from younger caregivers. Figure 11 shines a spotlight on these older caregivers by highlighting what is unique about them.[22]

Figure 10: Spotlight on Caregivers Ages 75 or Older

Who?

- 79-year-old white unemployed female, currently providing care to one adult 34 hours a week without any other unpaid help
- Been providing care for 5.6 years

Caring for?

- 77-year-old male spouse who has Alzheimer's, "old age" issues, or heart disease

Impact?

- More often communicating with care professionals (73%), managing finances (69%), and advocating (55%)
- Wants information about making end-of-life decisions
- High burden of care (46%)

While the oldest caregivers in the study are not experiencing significantly more emotional stress or physical or financial strain than younger caregivers, they are more likely to be caregiving without other unpaid help. They are communicating with health care professionals and advocating for their recipient, making them an important part of the care team. They are less likely to be employed, more likely to be caring for their own spouse (and living with him or her), and more likely to be managing finances for their recipient. This means that, at a time of life when income may be fixed, they are performing the difficult task of managing household finances for both themselves and their spouse. Further research is needed to understand this

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[22] Spotlights on caregivers provide a snapshot glance at significant findings that make this subgroup unique relative to comparison groups—in this case, the comparison group is caregivers ages 18–74.

transition and some of the challenges these older caregivers are facing, relative to financial management and fixed income.

Care Recipient Relation to Caregiver

The vast majority of caregivers take care of a relative (85%), while just 15 percent care for a friend, neighbor, or other nonrelative. More care for a parent (42%) than any other relation (31 percent for their mother, 11 percent for father), with an additional 7 percent reporting they care for a parent-in-law.

Higher-hour caregivers are more likely to care for a relative (93%), specifically a spouse (24%), than lower-hour caregivers.

Figure 11: Care Recipient Relation to Caregiver by Hours of Care

Q7. Who are you caring/did you care for?

	Caregivers of Recipient Ages 18+ (n=1,248)	Hours of Care	
		0–20 (n=826) A	21 or more (n=416) B
Relative	85%	81%	93%[A]
Parent	42	42	43
Spouse or partner	12	7	24 [A]
Parent-in-law	7	8	5
Grandparent or grandparent-in-law	7	8 [B]	4
Adult child	5	5	6
Uncle or aunt	4	4	3
Sibling	3	3	3
Other relatives	3	3	3
Sibling-in-law	2	3	1
Grandchild	*	*	--
Nonrelative	15	19 [B]	7
Friend	10	13 [B]	4
Neighbor	3	3	2
Other nonrelative	2	3	2

2015 Caregiver Subgroups

- African American caregivers are more likely to care for a nonrelative (23% vs. 13% all other race/ethnic groups).
- Primary caregivers—those who provide all or the majority of the unpaid care for their recipient—are more likely to be caring for an immediate family member, such as a spouse or adult child (25%). Nonprimary caregivers are three times more likely to report providing care for extended family, such as a grandparent, parent-in-law, or aunt/uncle (28% vs. 11% for primary caregivers).

- As caregiver age rises, it is more likely they care for their spouse.

Figure 12: Care Recipient Relationship by Caregiver Age

	Caregiver Age			
	18–49 (n=503) A	50–64 (n=472) B	65–74 (n=213) C	75 or older (n=269) D
Spouse/partner	6%	9%	24%^{AB}	46%^{ABC}
Parent/parent-in-law	51 ^{CD}	61 ^{ACD}	34 ^{D}	8

Duration of Care for Recipient

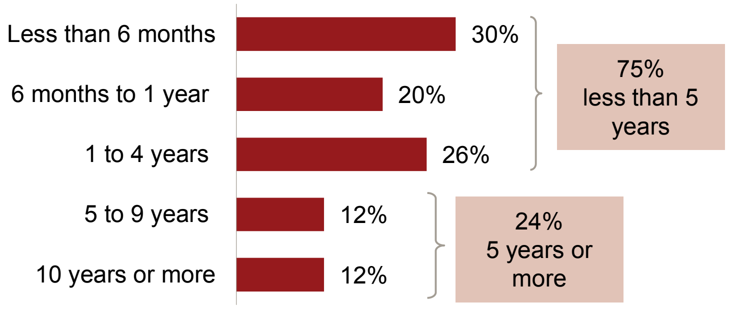
The average duration of caregiving is 4.0 years. About one-quarter have provided care for 1 to 4 years (26%), or 5 years or more (24%).

Higher-hour caregivers have been providing care to their recipient for 5.6 years on average, longer than the 3.2 years of care provided by lower-hour caregivers.

Figure 13: Duration of Care for Recipient

Q21. How long have you been providing/did you provide care to your [relation]?

Base: Caregivers of Recipient Age 18+ (n=1,248)



Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
31%	26%
19	20
27	25
13	10
9	18*

2015 Caregiver Subgroups

- Those who live with their care recipient—that is, co-resident caregivers—have been in their role longer (5.3 vs. 3.2 years for those who live separately).
- Primary caregivers have been in their role longer than nonprimary caregivers (4.6 years vs. 2.8 years, on average).
- High burden caregivers have provided care longer (4.8 years vs. 3.5 years for low burden and 3.2 years for medium burden caregivers).

Choice in Taking on Caregiver Role

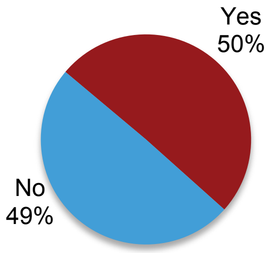
When asked if they had a choice in taking on the responsibility to provide care for their loved one, half of caregivers felt they had no choice in taking on this role (49%).

Higher-hour caregivers—those providing 21 hours of care or more each week—are more likely to feel they had no choice in taking on their caregiving role (59% vs. 45% of lower-hour caregivers).

Figure 14: Choice in Taking on Caregiver Role

Q39. Do you feel you had a choice in taking on this responsibility for caring for your [relation]?

Base: Caregivers of Recipient Age 18+ (n=1,248)



% No

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
45%	59%*

2015 Caregiver Subgroups

- The feeling of “obligation” or lack of choice is especially pronounced among those caregivers who live with their care recipient *and* who provide more than 20 hours of care weekly (64% reporting no choice).
- The feeling of choice seems to be a matter of *who* the recipient is, and whether anyone else is available to provide care. Caregivers caring for someone close to them, such as a spouse or parent, are more likely to report feeling they had no choice, regardless of whether or not others chipped in with unpaid help. However, caregivers caring for other relatives or nonrelatives are more likely to feel obligated when there are no other unpaid caregivers pitching in.

Figure 15: Choice of Providing Care by Care Recipient Relationship and Presence of Other Unpaid Help

	Spouse/ Partner		Parent		Other Relative		Nonrelative	
	Had help (n=35) A	No help (n=125) B	Had help (n=382) C	No help (n=229) D	Had help (n=153) E	No help (n=125) F	Had help (n=100) G	No help (n=90) H
Had no choice	58%^{EGH}	62%^{EGH}	57%^{EGH}	60%^{EGH}	34%^{G}	56%^{EGH}	13%	26%^{G}
Had a choice	42	38	43	40	64^{ABCDF}	43	87^{ABCDEFH}	74^{ABCDF}

Spotlight: In many ways, caregivers who feel they had no choice in taking on their role are different from those who feel they had a choice, often finding themselves facing complex care situations, and increased stress and strain.[23]

Figure 16: Spotlight on Having No Choice

Who?
- 50-year-old primary caregiver, currently providing care 28.3 hours a week
- Been providing care for 4.7 years
- Doing more: IADLs, medical/nursing tasks without training, and all three key activities (monitoring, communicating, advocating)

Caring for?
- A close relative (spouse or parent) who lives with the caregiver, who needs help with bathing/showering and incontinence
- Someone with a long-term physical condition, memory problem, emotional/mental health problem, or behavioral issues

Impact?
- Finds it difficult to do ADLs and medical/nursing tasks required
- Finds it difficult to coordinate care and find affordable services for recipient
- Experiences more emotional stress, and financial and physical strain
- Is more likely to be in poor or fair health and to say caregiving made their health worse

Policy makers and care providers may be unable to change a caregiver's perception of choice in taking on his or her role, especially given that this perception is closely tied to the relationship between the caregiver and care recipient, as well as the presence of other unpaid family caregivers. However, providing supportive services to caregivers who feel this sense of "obligation" may help mitigate some of the negative impacts arising from the complex care situations in which these caregivers find themselves. Reflecting this, caregivers who feel they had no choice in taking on their role are more likely to state that each of the six policy supports would be helpful (see section K: Information Needs and Caregiver Support for detailed results).

C. Care Recipient Living Situation

Care Recipient Living Alone

Three in 10 care recipients who are not in an assisted-living or skilled nursing facility live alone(31%). Higher-hour caregivers are less likely to report their loved one lives alone (16%), compared with lower-hour caregivers (37%).

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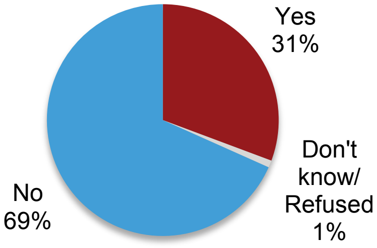
[23] Spotlights on caregivers provide a snapshot glance at significant findings that make this subgroup unique, relative to comparison groups—in this case, the comparison group is caregivers who felt they did have a choice in taking on care for their loved one.

Figure 17: Care Recipient Living Alone

Q14. Does/Did your [relation] live alone at the time you provided care?

Base: Caregivers of Recipient Age 18+ not in nursing home or assisted living (n=1,147)



% Yes

Hours Caregiving per Week	
0-20 (n=740)	21+ (n=401)
37%*	16%

2015 Caregiver Subgroups

- Older care recipients are more likely to live alone (37 percent of those ages 65 or older vs. 23 percent of those ages 50 to 64 vs. 14 percent of those ages 18 to 49).
- One in three white (33%) and African American (33%) caregivers say their care recipient lives alone, more than either Asian American (23%) or Hispanic (19%) caregivers.
- Those caring for a close relative are less likely to say he or she lives alone, while nonrelative care recipients most often live alone.

Figure 18: Living Alone by Care Recipient Relationship

	Spouse (n=158) A	Parent (n=552) B	Other Relative (n=258) C	Nonrelative (n=179) D
Percent living alone	1%	28%^{A}	36%^{A}	55%^{ABC}

Where Care Recipient Lives

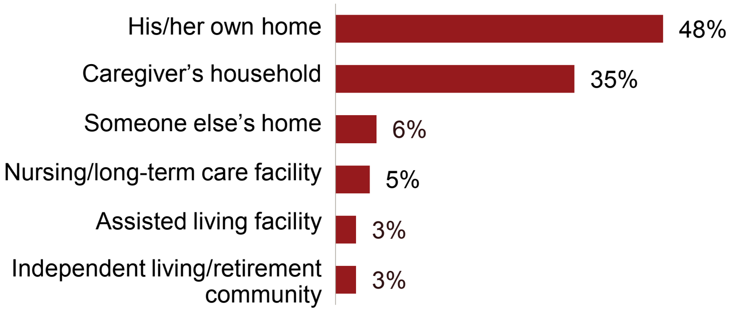
Half of caregivers report that their care recipient lives in the recipient's own home. More than one in three say their recipient lives in the caregiver's household (35%).

Higher-hour caregivers are predominately living with their care recipient (62%), while lower-hour caregivers are more likely to report their care recipient lives in his or her own home (57%), or in a facility or community with varying degrees of care support (14 percent in nursing or long-term care, assisted living, or independent living or retirement community).

Figure 19: Where Care Recipient Lives

Q13. Which of the following best describes where your [relation] lives/lived at the time you provided care?

Base: Caregivers of Recipient Age 18+ who reported living arrangement (n=1,236)



	Hours Caregiving per Week	
	0-20 (n=820)	21+ (n=410)
His/her own home	57%*	28%
Caregiver's household	22	62*
Someone else's home	7	5
Nursing/long-term care facility	6*	3
Assisted living facility	4*	1
Independent living/retirement community	4*	1

2015 Caregiver Subgroups

- Caregivers in more complex care situations are more likely to report co-residence with their recipient, including primary caregivers (47% vs. 12% of nonprimary caregivers), those who have provided care for 5 years or more (44% vs. 31% of those who cared less than a year), and those with a higher burden of care.

Figure 20: Where Care Recipient Lives by Burden of Care

	Low Burden (n=501) A	Medium Burden (n=216) B	High Burden (n=513) C
With Caregiver	19%	27%^{A}	54%^{AB}
In his/her own home	59 ^{C}	53 ^{C}	34
Community/care facility	14 ^{C}	13 ^{C}	6

- Other caregivers likely to report co-residence include the following:
    - Hispanic (43%) or Asian American (45%) caregivers (vs. 34% white and 28% African American)
    - Those with less than a college degree (38% vs. 28% with a bachelor's degree or greater)
- Recipients most often live in some sort of community or care facility when they have Alzheimer's or dementia (16% retirement community, assisted-living facility, or skilled nursing facility), or they are ages 65 or older (13%).

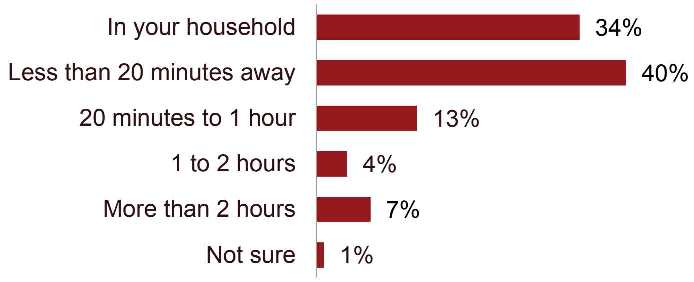
Caregiver Distance from Care Recipient

Most caregivers live within 20 minutes of their care recipient (75%). Higher-hour caregivers tend to live closer to their care recipient: more than 8 in 10 live within 20 minutes of their care recipient (84%), compared with just 7 in 10 lower-hour caregivers (70%).

Figure 21: Caregiver Distance from Care Recipient

Q11. Where does/did your [relation] live at the time you provided care?

Base: Caregivers of Recipient Age 18+ (n=1,248)



	Hours Caregiving per Week	
	0-20 (n=826)	21+ (n=416)
In your household	21%	62%*
Less than 20 minutes away	49*	23
20 minutes to 1 hour	17*	6
1 to 2 hours	4	3
More than 2 hours	8	5
Not sure	1	1

2015 Caregiver Subgroups

- Eight in 10 primary caregivers (81%) live within 20 minutes of their care recipient, compared with less than two-thirds (63%) of nonprimary caregivers.
- Similarly, as the burden of care rises, so does the proximity of the caregiver to the care recipient (81% of high burden live within 20 minutes vs. 71% medium burden and 71% low burden).
- As the caregiver's age increases, the distance between the caregiver and care recipient decreases. Among caregivers ages 75 or older, 84 percent live within 20 minutes of their care recipient (vs. 76 percent of caregivers ages 65–74, 72 percent ages 50–64, and 74 percent ages 18–49).

Frequency of Visits

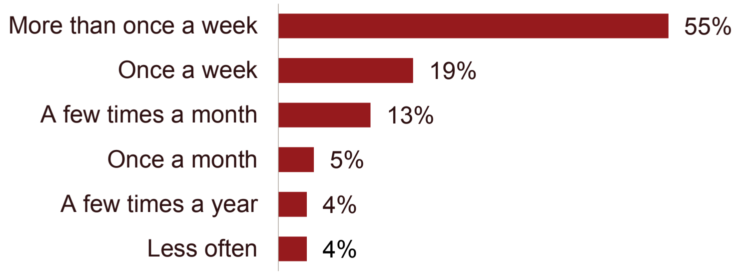
Of the caregivers who do not live with their care recipient, three-quarters say they visit their loved one at least once a week (74%), including more than half who say they visit multiple times a week (55%).

Among non-co-resident caregivers who perform 21 or more hours of care a week, more than 8 in 10 (83%) visit their care recipient once a week or more often. Less than three-fourths of lower-hour caregivers visit with the same frequency (72%).

Figure 22: Frequency of Visits

Q12. (If not in caregiver's household) On average, how often do/did you visit your [relation]?

Base: Caregivers of Recipient Age 18+ not living with recipient (n=808)



	Hours Caregiving per Week	
	0-20 (n=647)	21+ (n=157)
More than once a week	49%	78%*
Once a week	22*	5
A few times a month	15*	5
Once a month	6*	2
A few times a year	4	7
Less often	4	2

2015 Caregiver Subgroups

- Those with a higher care burden visit more often, perhaps out of necessity to provide higher levels of care and support for their higher-need care recipients. About 8 in ten high burden caregivers visit more than once a week (79%), compared to 58 percent of medium burden and 40 percent of low burden.
- Other groups among the most frequent visitors—that is, visiting at least once a week or more often—include those performing medical/nursing tasks (82%), those living within an hour of the recipient (82%), and primary caregivers (77%).

D. Care Recipient's Condition

Types of Care Recipient Conditions

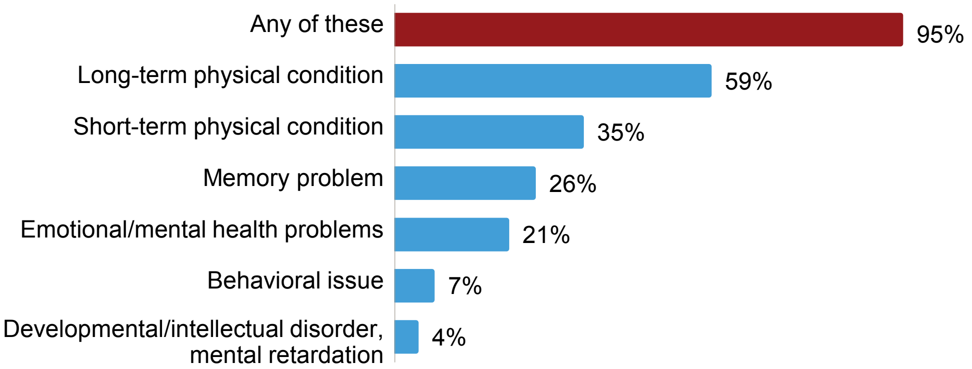
Six in 10 caregivers care for an adult with a long-term physical condition, while 35 percent say their loved one has a short-term physical condition. One in four indicates their loved one has a memory problem, and 21 percent say their care recipient has an emotional or mental health problem. Smaller proportions indicate their care recipient has behavioral issues (7%) or a developmental or intellectual disorder or mental retardation (4%). The small percentage of caregivers who do not report any of these six conditions are typically caring for a recipient whose main problem is "old age."

Higher-hour caregivers are more likely than lower-hour caregivers to say their care recipient has a long-term physical condition or a behavioral issue.

Figure 23: Types of Care Recipient Conditions

Q17. Does/did your [relation] need care because of a...?

Base: Caregivers of Recipient Age 18+ (n=1,248)



	Hours Caregiving per Week	
	0-20 (n=826)	21+ (n=416)
Any of these	94%	96%
Long-term physical condition	57%	64%*
Short-term physical condition	36%	33%
Memory problem	25%	28%
Emotional/mental health problems	21%	21%
Behavioral issue	5%	9%*
Developmental/intellectual disorder, mental retardation	3%	6%

2015 Caregiver Subgroups

- High burden caregivers are more likely to report caring for someone with a long-term physical condition (63% vs. 53% low burden), memory problems (30% vs. 23% low burden), behavioral issues (8% vs. 5% low burden), or a developmental/intellectual disorder (5% vs. 3% low burden).
- Those who have been providing care for less than a year are among the most likely to report their loved one has a short-term physical condition (52%).
- The type of condition varies by the care recipient age, such that the oldest recipients are most likely to have a long-term physical condition or memory problem, while mental health or behavioral issues are most common among the youngest adult recipients.

Figure 24: Types of Care Recipient Conditions by Care Recipient Age

	Recipient Age 18 to 49 (n=159) A	Recipient Age 50 to 64 (n=234) B	Recipient Age 65 or older (n=853) C
Long-term physical condition	32%	$57\%^{A}$	$65\%^{AB}$
Short-term physical condition	$43\%^{C}$	38%	33%
Emotional or mental health problem	$36\%^{BC}$	$26\%^{C}$	17%
Behavioral issue	$17\%^{BC}$	3%	6%
Memory problems	11%	16%	$33\%^{AB}$
Developmental or intellectual disorder or mental retardation	$11\%^{C}$	$6\%^{C}$	2%

Care Recipient's Main Problem or Illness

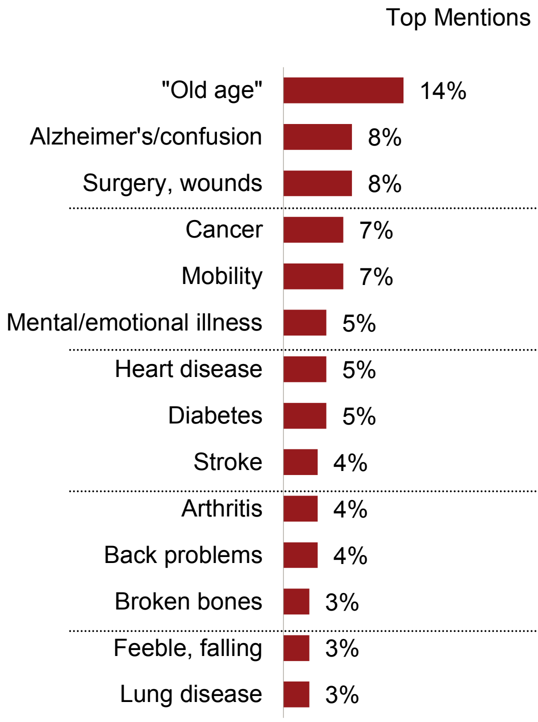
When caregivers are asked to identify their loved one's main problem or illness that causes them to need care, the three most common problems or illnesses cited by caregivers include: "old age" (14%), Alzheimer's or dementia (8%), or surgery/wounds (8%). Other illness or conditions for which the recipient needs care include cancer (7%), mobility (7%), mental/emotional illness (5%), heart disease (5%), and diabetes (5%). Note that these perceptions may not mirror independent health statistics.[24]

The most common problems mentioned by higher-hour caregivers are "old age" (10%), Alzheimer's (9%), surgery, wounds (9%), and cancer (9%). For lower-hour caregivers, the most common illnesses or problems are "old age" (15%), Alzheimer's (8%), surgery/wounds (8%), and mobility (8%).

Figure 25: Main Problem or Illness Identified by Caregiver

Q18. What is/was the main problem or illness your [relation] has/had for which he/she needs/needed your care?

Base: Caregivers of Recipient
Age 18+ (n=1,248)



	Hours Caregiving per Week	
	0-20 (n=826)	21+ (n=416)
"Old age"	15%*	10%
Alzheimer's/confusion	8	9
Surgery, wounds	8	9
Cancer	6	9
Mobility	8*	5
Mental/emotional illness	5	5
Heart disease	4	6
Diabetes	4	6
Stroke	4	4
Arthritis	5*	3
Back problems	5	3
Broken bones	3	3
Feeble, falling	4	3
Lung disease	3	2

---

[24] These are self-reports by caregivers about what they perceive their recipient's main problem to be for which he or she needs unpaid care.

- Caregivers who perform medical/nursing tasks are more likely to state they care for someone with cancer, diabetes, lung disease, or surgery/wounds, and less likely to say they care for someone with a mental illness or "old age."
- The main problem for which the recipient needs care varies greatly depending on the age of the recipient.

Figure 26: Selected Main Problem or Illness by Care Recipient Age

	Recipient Age 18 to 49 (n=159) A	Recipient Age 50 to 64 (n=234) B	Recipient Age 65 or older (n=853) C
Alzheimer's, dementia, forgetfulness	1%	2%	12%^{AB}
Arthritis	4	6	4
Back problems	5	8 ^{C}	3
Cancer	6	8	6
Diabetes	4	7	4
Heart disease	2	3	6 ^{AB}
Mental/emotional illness, depression	18 ^{BC}	10 ^{C}	1
Mobility	5	9	7
"Old age," frailty	—	3 ^{A}	20 ^{AB}
Stroke	2	3	5 ^{A}
Surgery, wounds	12	11	6

- Certain conditions are associated with a higher burden to the caregiver—cancer and surgery/wounds. Other conditions—including mental or emotional illness and "old age"—are more commonly associated with a low burden.

Figure 27: Main Problem or Illness by Burden Category

	Low Burden (n=504) A	Medium Burden (n=218) B	High Burden (n=428) C
Greater Prevalence in High Burden Situations			
Cancer	5%	4%	10%^{AB}
Surgery, wounds	5	11 ^{A}	9 ^{A}
Greater Prevalence in Low Burden Situations			
Mental/emotional illness, depression	8%^{BC}	3%	3%
"Old age," frailty	18 ^{C}	14	9

Presence of Alzheimer's or Other Mental Confusion

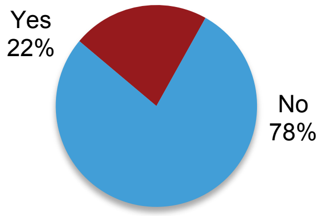
Although Alzheimer’s or dementia is cited by only 8 percent of caregivers as the main condition for which the care recipient needs help, a total of 22 percent of caregivers say their loved one does suffer from this type of condition.[25]

Higher-hour caregivers and lower-hour caregivers are just as likely to be caring for someone with Alzheimer’s or dementia.

Figure 28: Presence of Alzheimer's, Dementia, or Other Mental Confusion

Q18/Q20. Does/Did your [relation] suffer from Alzheimer’s or other mental confusion?

Base: Caregivers of Recipient Age 18+ (n=1,248)



% Yes

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
21%	23%

While most caregivers of those with Alzheimer’s or dementia say their recipient has memory problems (79%), nearly as many say he or she has a long-term physical condition (71%), and 41 percent say their loved one has emotional or mental health problems.

2015 Caregiver Subgroups

- As one would expect, the prevalence of Alzheimer’s or some other mental confusion is higher among caregivers of recipients ages 50 and older (24% vs. 9% recipients 18 to 49).[26]
- White and Asian American caregivers are more likely to report caring for someone with Alzheimer’s or dementia, but are also older, on average.

Figure 29: Presence of Alzheimer’s and Recipient Age by Caregiver Race/Ethnicity

	White (n=698) A	African American (n=206) B	Hispanic (n=208) C	Asian American (n=201) D
Alzheimer’s, Dementia, or Other Mental Confusion	24%^{C}	22%	17%	25%^{C}
Average age of recipient	71.1 ^{BC}	66.3	65.3	72.8 ^{BC}

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[25] This includes anyone indicating the presence of Alzheimer’s disease, dementia, or other mental confusion.

[26] Among the 9 percent of caregivers who report their younger adult recipients (18 to 49) have Alzheimer’s or other mental confusion, nearly all selected “other mental confusion” (8.4%), rather than the more formal “Alzheimer’s” (0.6%) wording on the interview.

Spotlight: Those who provide care to someone with Alzheimer's, dementia, or other mental confusion are often providing a wide variety of tasks for their care recipient, resulting in some difficulty with these tasks, emotional stress, and worsening health, as shown in figure 33.[27]

Figure 30: Spotlight on Caregivers of Someone with Alzheimer's, Dementia, or Other Mental Confusion

Who?

- 53-year-old who expects to continue his or her caregiving role over the next 5 years
- Helping with 2.2 ADLs, 4.6 IADLs, medical/nursing tasks, and more likely to help with 3 other key activities (monitoring, advocating, communicating)

Caring for?

- 77-year old relative who is more likely to be living in an assisted-living or skilled nursing facility

Impact?

- More likely to have difficulty with ADLs and medical/nursing tasks
- Half have high emotional stress
- More likely to say caring has adversely affected their own health

Caregivers of an adult with Alzheimer's, dementia, or other mental confusion are not only performing more ADLs, IADLs, medical/nursing tasks, and key activities, they are also more likely to report having difficulty performing ADLs and medical/nursing tasks. They are especially vulnerable to emotional stress and negative health impacts, and need outreach and support focused on their especially demanding situation.

Ease of Coordinating Care

One in four caregivers have at least some difficulty in coordinating care among their care recipient's providers (23%) and nearly half claim care coordination was only "*somewhat*" *easy*.

Among higher-hour caregivers, one in four found it difficult to coordinate care (26%), roughly the same as lower-hour caregivers (21%).

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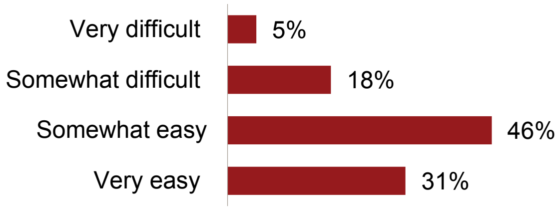
[27] Spotlights on caregivers provide a snapshot glance at significant findings that make this subgroup unique, relative to comparison groups—in this case, the comparison group is caregivers who reported their loved one had no Alzheimer's, dementia, or other mental confusion.

Figure 31: Ease of Coordinating Care

Q38. (If responsible for coordinating) Please think about all of the health care professionals or service providers who give/gave care or treatment to your [relation]. How easy or difficult is/was it for you to coordinate care between these providers?

Base: Caregivers involved in care coordination for Recipient Age 18+ (n=1,042)



	Hours Caregiving per Week	
	0-20 (n=662)	21+ (n=375)
Very difficult	5%	5%
Somewhat difficult	16	22
Somewhat easy	50*	40
Very easy	30	34

2015 Caregiver Subgroups

- Care coordination is more difficult when the caregiver is distant from his or her recipient. One in three caregivers who live an hour or more away from their recipient report difficulty with care coordination (34 percent vs. 23 percent of those living closer but not together, and 20 percent of co-resident caregivers). While nonprimary caregivers are more likely to find care coordination difficult (29% vs. 20% of primary caregivers), this is most likely due to the fact that nonprimary caregivers tend to live farther from their recipient than do primary caregivers.
- Care coordination is also more difficult when the recipient has multiple conditions requiring care. Few (9%) of those caring for someone with no reported conditions[28] have trouble coordinating care, but this figure climbs to 35 percent when the recipient has three or more conditions.

E. Caregiving Activities and Burden of Care

Hours of Care Provided

On average, caregivers spend 24.4 hours per week providing care.[29] About 1 in 4 provide care for 41 hours or more each week (23%) and 3 in 10 provide between 9 and 40 hours of care (31%).

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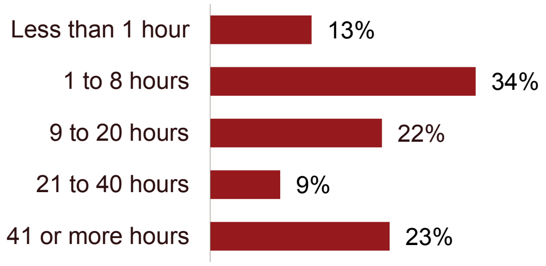
[28] Count of conditions is based on list of six condition categories: short-term physical condition, long-term physical condition, emotional/mental health issue, behavioral issue, developmental or intellectual delay, or memory problem. As noted earlier, typically when no conditions are selected, the recipient's main problem reported is "old age" or frailty.

[29] Any caregiver who typed in hours of care in excess of 98 hours per week is capped at this level, equivalent to 14 hours per day. Caregivers who selected constant care were capped at 77 hours per week, the mean hours of care derived from an imputation model predicting hours of care provided. For more details on the imputation model, see appendix B: Detailed Methodology.

Figure 32: Hours of Care Provided

Q25. Thinking now of all the kinds of help you provide/provided for your [relation], about how many hours do/did you spend in an average week helping him/her?

Base: Caregivers of Recipient Age 18+ (n=1,248)



	Hours Caregiving per Week	
	0-20 (n=826)	21+ (n=416)
Less than 1 hour	19%	--
1 to 8 hours	50	--
9 to 20 hours	32	--
21 to 40 hours	--	29%
41 or more hours	--	71

2015 Caregiver Subgroups

- Caregivers who provide the equivalent of a full-time job for caring each week, on average, include those caring for a spouse/partner (44.6 hours a week) and those living with their care recipient (40.5 hours a week).
- As caregiver age increases, so too does time spent caregiving. Caregivers ages 18 to 49 provide 21.7 hours of care weekly, on average, rising to 34.0 hours of care among caregivers ages 75 or older.
- Hispanic caregivers spend more time each week caring for a loved one than white caregivers (31.2 hours vs. 21.9 hours).
  - Roughly 3 in 10 Hispanics (32%) provide care at a full-time equivalency (41 hours or more each week), higher than either white (19%) or Asian American (21%) caregivers.

Help with Activities of Daily Living (ADLs)

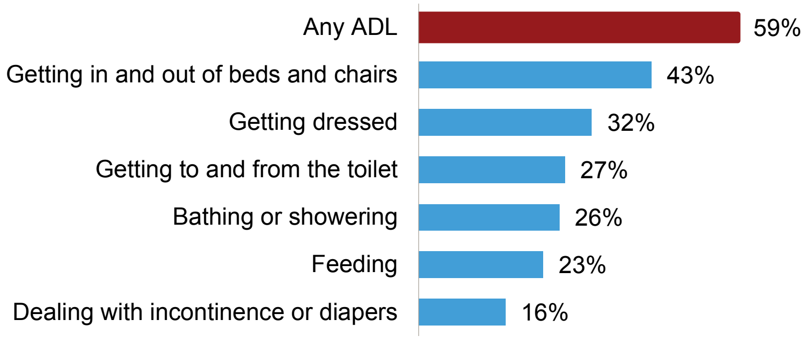
Six in 10 caregivers help their care recipient with at least one Activity of Daily Living. Most commonly, caregivers help their recipient get in and out of beds and chairs (43%). On average, caregivers help with 1.7 of the 6 ADLs.

Three-fourths of higher-hour caregivers are assisting with one ADL, more than those who provide less care (51%). On average, the higher-hour caregivers help with 2.6 ADLs, and are more likely to help with each of the 6 ADLs than lower-hour caregivers.

Figure 33: Help with Activities of Daily Living (ADLs)

Q22. Which of these do/did you help your [relation] with?

Base: Caregivers of Recipient Age 18+ (n=1,248)



	Hours Caregiving per Week	
	0-20 (n=826)	21+ (n=416)
Any ADL	51%	75%*
Getting in and out of beds and chairs	36%	59%*
Getting dressed	22%	51%*
Getting to and from the toilet	21%	40%*
Bathing or showering	17%	45%*
Feeding	18%	36%*
Dealing with incontinence or diapers	9%	31%*

2015 Caregiver Subgroups

- Seven in 10 of those caring for a spouse help with at least one ADL (71%), more than caregivers providing care to any other loved one (57%).
- Those who care for someone with a physical condition (short- or long-term) are more likely to help with an ADL (63%) than someone whose loved one does not have a physical issue (34%).
- Caregivers who help with medical/nursing tasks tend to aid their loved one with more ADLS (2.4 vs. 0.7 among caregivers not performing medical/nursing tasks).
- Caregivers of someone 50 or older are more often helping their loved one get in and out of beds and chairs (45% vs. 34% of caregivers of recipients ages 18–49), get to and from the toilet (28% vs. 20%), and with incontinence (18% vs. 9%).

Caregivers who perform a greater number of ADLs for their care recipient are more likely to say that caregiving has made their health worse. Just 16 percent of those who perform no ADLs say their health has gotten worse, compared to 20 percent of those performing 1 or 2 ADLs, 28 percent of those performing 3 to 5 ADLs, and 41 percent of those performing all 6 ADLs.

Difficulty with Activities of Daily Living (ADLs)

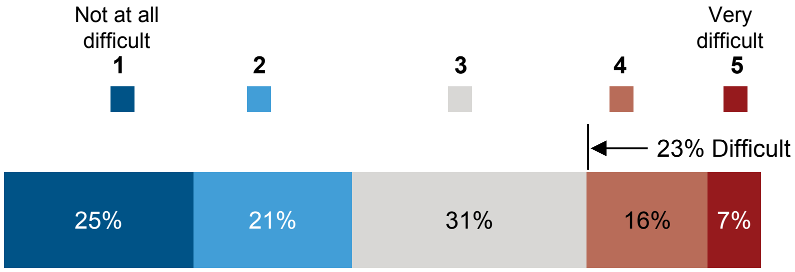
Among caregivers performing ADLs, one in four indicates it is difficult to assist their loved one with these tasks (23% rating 4 or 5 on a 5-point scale).

One in three higher-hour caregivers find it difficult to assist with ADLs, significantly more so than those caring for 20 hours or fewer each week (16%).

Figure 34: Difficulties with Activities of Daily Living

N1. (If doing ADLs) How difficult is/was it for you to help your [relation] with these/those kinds of tasks?

Base: Caregivers who help Recipient Age 18+ with ADLs (n=744)



% Difficult

Hours Caregiving per Week	
0-20 (n=420)	21+ (n=319)
16%	33%*

Caregivers who provide more ADLs are more likely to report having difficulty doing them. Just 10 percent of those performing only one ADL have difficulty doing so, while half of those doing all six ADLs find it difficult (48%). The most difficult individual ADLs involve personal care activities, like dealing with incontinence or diapers (40% difficult), helping the recipient to and from the toilet (33%), and bathing/showering assistance (31%).

2015 Caregiver Subgroups

- Caregivers who are most likely to report a high difficulty in performing ADLs include those providing care to someone with Alzheimer's or dementia (32%), those who have provided care for 5 years or longer (32%), high burden caregivers (29%), and those caring for someone with a long-term physical condition (27%).

Help with Instrumental Activities of Daily Living (IADLs)

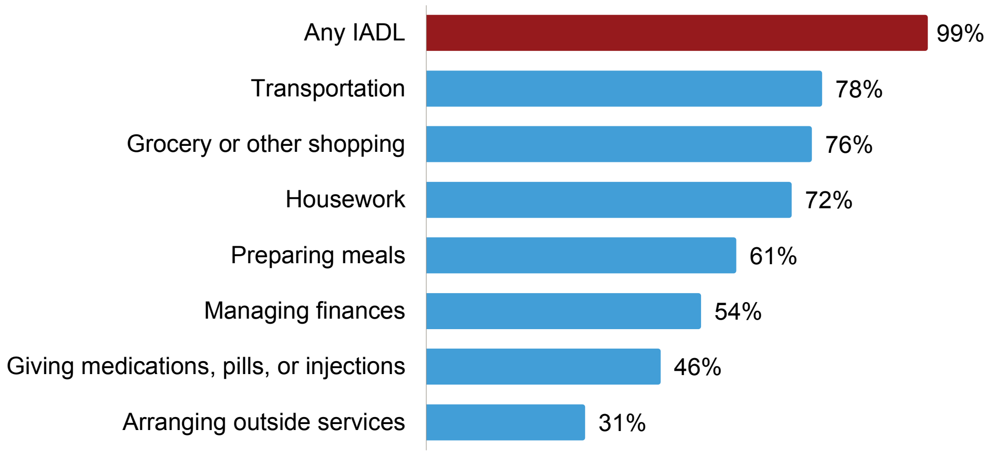
There is an established list of seven Instrumental Activities of Daily Living that pertain to adult caregiving. On average, caregivers help their loved one with 4.2 IADLs. Most commonly, caregivers are helping with transportation (78%), grocery or other shopping (76%), and housework (72%).

Higher-hour caregivers perform more IADLs (5.3 on average vs. 3.6 for lower-hour caregivers) and are more likely than their lower-hour counterparts to help with each of the seven IADLs.

Figure 35: Help with Instrumental Activities of Daily Living (IADLs)

Q23. Do/Did you provide help to your [relation] with...?

Base: Caregivers of Recipient Age 18+ (n=1,248)



	Hours Caregiving per Week	
	0-20 (n=826)	21+ (n=416)
Any IADL	99%	100%
Transportation	72%	89%*
Grocery or other shopping	69%	89%*
Housework	65%	89%*
Preparing meals	49%	86%*
Managing finances	47%	67%*
Giving medications, pills, or injections	34%	71%*
Arranging outside services	26%	41%*

2015 Caregiver Subgroups

- As with ADLs, similar groups of caregivers tend to help with more IADLs; usually those in more complex care situations, including co-resident caregivers (5.1 on average), those doing medical/nursing tasks (5.1 on average), and primary caregivers (4.5 on average).
- Nearly 9 in 10 Asian American caregivers provide transportation to their care recipient (85%), more than either white (78%) or African American caregivers (72%). Asian American caregivers (38%) are also more likely to arrange outside services than African American or Hispanic caregivers (28% and 28% respectively).
- Among the groups most likely to be managing finances are those caring for someone with Alzheimer's or other dementia (65%) or with an emotional or mental health condition (63%). These two groups are also more likely to arrange outside services (45% among caregivers of someone with Alzheimer's; 39% among caregivers of someone with a mental illness).

Help with Other Key Activities

Caregivers' responsibilities often extend beyond the traditional direct care ADLs and IADLs, to interacting with various providers, agencies, and professionals on their care recipient's behalf.[30]

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[30] These questions were asked of caregivers of children ages 0–17, first in the *Caregiving in the U.S. 2009* study. This represents the first time these questions were asked of caregivers of adults ages 18 and older.

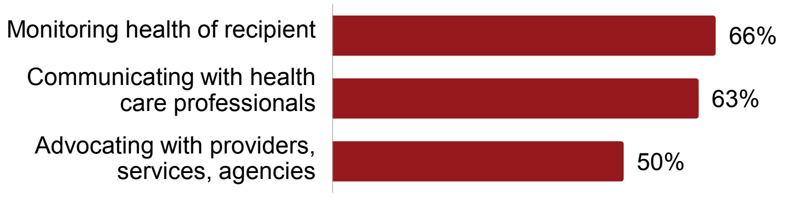
A majority monitor their care recipient's condition so they can adjust care accordingly (66%) and communicate with health care professionals about their recipient's care (63%). Half act as an advocate with care providers, community services, or government agencies.

Higher-hour caregivers are more likely to provide each of these key activities for their loved one, more so than caregivers providing fewer hours of care.

Figure 36: Help with Other Key Activities

Q23. And do/did you provide help to your [relation] by...?

Base: Caregivers of Recipient Age 18+ (n=1,248)



Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
60%	80%*
56%	80%*
45%	61%*

2015 Caregiver Subgroups

- As with ADLs and IADLs, caregivers in more complex caregiving situations are more likely to provide these key activities for their loved ones. Those caregivers include the following:
  - High burden caregivers (81% monitor the condition, 79% communicate, 61% advocate)
  - Those caring for someone with Alzheimer's or dementia (79% monitor, 79% communicate, 63% advocate)
  - Caregivers who perform medical/nursing tasks (79% monitor, 76% communicate, 59% advocate)
  - Co-resident caregivers (73% monitor, 71% communicate, 58% advocate)
- Asian American caregivers (76%) are more likely than white (64%), African American (56%), and Hispanic (64%) caregivers to communicate with health care professionals on behalf of their care recipient.
- Caregivers who are caring for a parent or spouse are more likely to perform these key activities than those caring for another relative or nonrelatives, while those caring for other relatives are, in turn, more likely to perform these activities than those caring for nonrelatives.

Figure 37: Help with Other Supportive Activities by Care Recipient Relationship

	Spouse/ Partner (n=160) A	Parent (n=614) B	Other Relative (n=282) C	Nonrelative (n=192) D
Monitoring health of recipient	73%^{CD}	74%^{CD}	61%^{D}	42%
Communicating with health care professionals	75%^{CD}	70%^{CD}	59%^{D}	39%
Advocating with providers, services, agencies	58%^{CD}	57%^{CD}	47%^{D}	26%

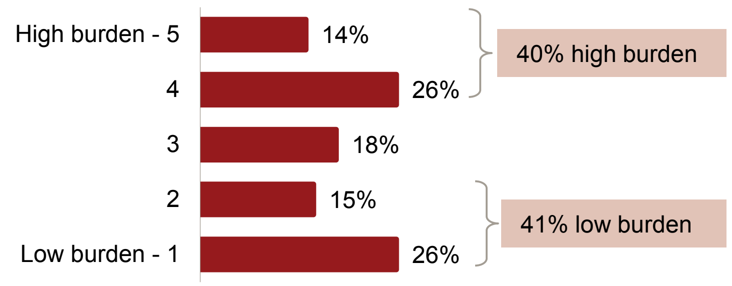
Burden of Care

A Level of Care Index, first developed in the 1997 study *Family Caregiving in the U.S.* (a predecessor to this research) and used in the 2004 and the 2009 *Caregiving in the U.S.* studies, is replicated in this study to convey in a simple measure the level of "burden" experienced by the caregiver. The index is based on the number of hours of care given, as well as the number of ADLs and IADLs performed. The details of the index's construction are shown in appendix B.

Four in 10 caregivers are in high burden situations (40%), 18 percent have a medium burden, and 41 percent have a low burden. More than nine in ten caregivers who provide 21 or more hours of care are in a high burden situation (92%), compared with just 16 percent of lower-hour caregivers.

Figure 38: Level of Care Index

Base: Caregivers of Recipient Age 18+ (n=1,248)



Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
--	45%*
16%	47*
23*	8
22*	--
39*	--

For each level of care, the average hours of care provided, ADLs performed, and IADLs performed are as follows:

Figure 39: Components of Level of Care by Burden Category

Level of Care	Low Burden (n=504)	Medium Burden (n=218)	High Burden (n=520)
Hours of care per week	4.9	9.6	51.6
Number of ADLs out of 6 total	0.2	2.1	3.0
Number of IADLs out of 7 total	3.2	4.1	5.2

2015 Caregiver Subgroups

- Three out of five co-resident caregivers have a high burden of care (62%), double that of caregivers who do not live with their recipient (28%).
- A high burden is also more commonly reported by the following subgroups of caregivers:
  - Those providing care to a spouse (72% vs. 39% of those caring for a parent, 34% another relative, and 27% non-relative)
  - Caregivers who assist with medical/nursing tasks (58% vs. 15% of those who do not perform these tasks)
  - Caregivers who were not employed while caregiving (48% vs. 34% of employed caregivers)

F. Medical/Nursing Tasks

Assistance with Medical/Nursing Tasks

Recent research revealed that, in addition to ADLs and IADLs, family caregivers are increasingly performing tasks that nurses typically perform.[31] Known now as “medical/nursing tasks,” these skilled activities include injections, tube feedings, catheter and colostomy care, and many other complex care responsibilities. About 6 in 10 caregivers assist with medical/nursing tasks (57%).

Higher-hour caregivers are more likely to provide medical/nursing tasks for their loved one (83% vs. 45% of lower-hour caregivers).

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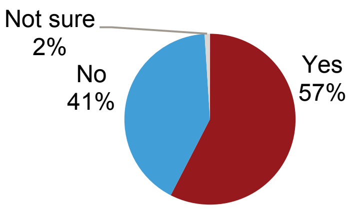
[31] Reinhard, S.C., Levine, C., & Samis, S. *Home Alone: Family Caregivers Providing Complex Chronic Care*. AARP Public Policy Institute & United Hospital Fund, 2012.

Figure 40: Help with Medical/Nursing Tasks

N3. Do/Did you help your [relation] with any medical/nursing tasks? This might include giving medicines like pills, eye drops, or injections; preparing food for special diets; tube feedings; or wound care. You could be monitoring things like blood pressure or blood sugar; helping with incontinence; or operating equipment like hospital beds, wheelchairs, oxygen tanks, nebulizers, or suctioning tubes.

Base: Caregivers of Recipient Age 18+ (n=1,248)



% Yes

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
45%	83%*

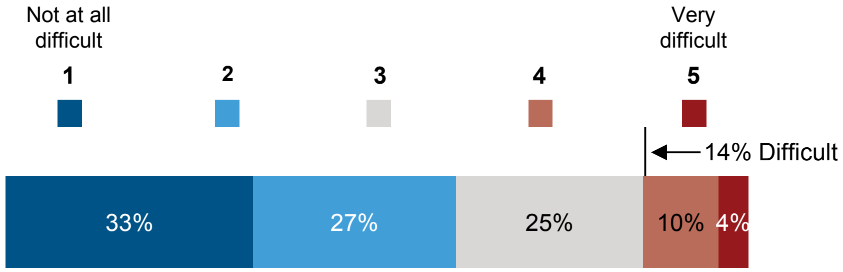
Difficulties with Medical/Nursing Tasks

Fourteen percent of those who do medical/nursing tasks find it difficult (rating 4 or 5 on a 5-point scale). Higher-hour caregivers are more likely to feel that performing medical/nursing tasks is difficult (20% vs. 9% of lower-hour caregivers).

Figure 41: Medical/Nursing Task Difficulty

N4. (If does medical/nursing tasks) How difficult is/was it for you to do the medical/nursing tasks that are/were required to help your [relation]?

Base: Caregivers who help Recipient Age 18+ with medical/nursing tasks (n=722)



% Difficult

Hours Caregiving per Week	
0-20 (n=369)	21+ (n=349)
9%	20%*

2015 Caregiver Subgroups

- One in five (22 percent) caregivers of someone with Alzheimer’s or dementia have difficulty with medical/nursing tasks, more so than those caring for someone without this disease or disorder (11 percent).
- Those who have been providing care for 5 years or longer are more likely to say medical/nursing tasks are difficult to provide(21% vs. 10% of those who have been caregiving for a year or less).
- High burden caregivers are most likely to say these tasks are difficult to provide(19% vs. 10% medium burden and 5% low burden).

Preparation for Medical/Nursing Tasks

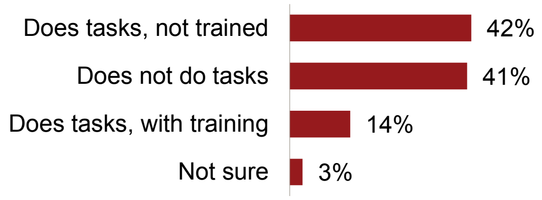
The intersection of feeling prepared to provide medical/nursing tasks with actually performing these tasks reveals some important gaps in caregiver preparation. Most commonly, caregivers are performing medical/nursing tasks without any preparation (42%). Just 14 percent of caregivers are providing medical/nursing tasks after some preparation or training. As noted above, 4 in 10 are not performing medical/nursing tasks (41%).

Over 6 in 10 higher-hour caregivers are performing medical/nursing tasks without any prior preparation (63% vs. 32% of lower-hour caregivers).

Figure 42: Medical/Nursing Task Preparation

N5. (If does medical/nursing tasks) Did anyone prepare you to do these tasks?
Analyzed in conjunction with N3

Base: Caregivers of Recipient
Age 18+ (n=1,248)



	Hours Caregiving per Week	
	0-20 (n=826)	21+ (n=416)
Does tasks, not trained	32%	63%*
Does not do tasks	53*	16
Does tasks, with training	12	19*
Not sure	3	2

2015 Caregiver Subgroups

Caregivers in the most complex care situations are the ones most likely to be performing medical/nursing tasks without any preparation.

- As burden of care increases, so too does the likelihood of providing medical/nursing tasks, and doing so without preparation.

Figure 43: Medical/Nursing Task Preparation by Burden of Care Index

	Low (n=504) A	Medium (n=218) B	High (n=520) C
Does tasks, prepared	7%	17%^{A}	20%^{A}
Does tasks, not prepared	23	43 ^{A}	62 ^{AB}
Does not do tasks	68 ^{BC}	37 ^{C}	15

- Half of caregivers of those with Alzheimer’s or dementia (51%), those who feel they had no choice in providing care (49%), and caregivers with a high school education or less (48%) are providing medical/nursing tasks without prior preparation.

Nearly three in five caregivers of a spouse are performing medical/nursing tasks without training, significantly more than any other relationship.

Figure 44: Medical/Nursing Task Preparation by Care Recipient Relationship

	Spouse (n=160) A	Parent (n=614) B	Other Relative (n=282) C	Nonrelative (n=192) D
Does tasks, prepared	19%	14%	13%	12%
Does tasks, not prepared	59 ^{BCD}	44 ^{D}	38	29
Does not do tasks	19	39 ^{A}	47 ^{A}	55 ^{AB}

Who Prepares Caregivers for Medical/Nursing Tasks?

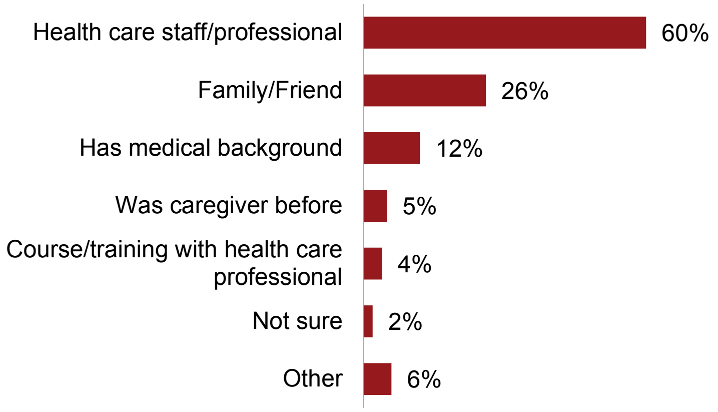
Of the limited proportion of caregivers who received training, most (60%) say they were taught by health care staff, while one in four learned from a family member or friend (26%).

Higher-hour caregivers are more likely to report getting training from health care staff (74% vs. 50% among lower-hour caregivers), while lower-hour caregivers are more likely to say a friend or family member prepared them to do the medical/nursing tasks (32% vs. 18% higher-hour).

Figure 45: Who Prepared Caregiver to Provide Medical/Nursing Tasks

N6. (If prepared to do medical/nursing tasks) Who prepared you to do the medical/nursing tasks needed to help your [relation]?

Base: Caregivers who were prepared to help Recipient Age 18+ with medical/nursing tasks (n=178)



	Hours Caregiving per Week	
	0-20 (n=94)	21+ (n=83)
Health care staff/professional	50%	74%*
Family/Friend	32%*	18%
Has medical background	12%	12%
Was caregiver before	3%	6%
Course/training with health care professional	5%	2%
Not sure	3%	1%
Other	8%	4%

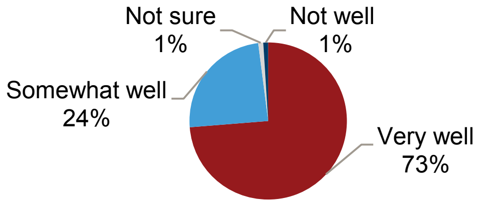
Evaluation of Medical/Nursing Training

Of the few caregivers who received some sort of preparation to perform medical/nursing tasks, three out of four feel they were prepared very well (73%). Caregivers' evaluation of their medical/nursing training does not vary by the number of hours they provide care.

Figure 46: Evaluation of Medical/Nursing Task Training

N7. (If prepared) How well do you feel that person prepared you to take on these medical/nursing tasks?

Base: Caregivers who were prepared to help Recipient Age 18+ with medical/nursing tasks (n=178)



% Very well

Hours Caregiving per Week	
0-20 (n=94)	21+ (n=83)
72%	76%

Medical/Nursing Task Training

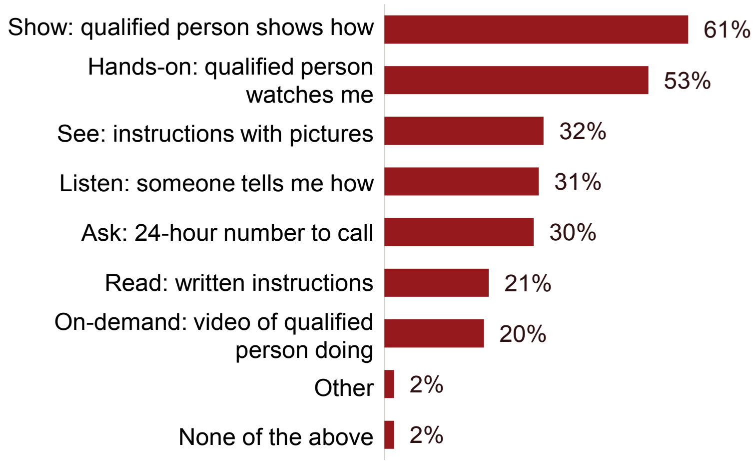
When all caregivers are asked how they would like to learn a medical/nursing task, the most popular method is having a qualified person *show* them how to do it (61%). About half would like *hands-on* training with a qualified person (53%). The fewest said they would want to *read* written instructions (21%) or watch an *on-demand* video (20%).

Generally, higher-hour and lower-hour caregivers have similar learning profiles. Higher-hour caregivers are more likely to want to learn through instructions with pictures (*see*), to have someone tell them how to do the task (*listen*), or to watch an *on-demand* video.

Figure 47: Learning Preference for Medical/Nursing Tasks

N8. If you had to learn how to do a medical/nursing task, how would you prefer to learn?

Base: Caregivers of Recipient Age 18+ (n=1,248)



	Hours Caregiving per Week	
	0-20 (n=826)	21+ (n=416)
Show: qualified person shows how	61%	61%
Hands-on: qualified person watches me	54%	51%
See: instructions with pictures	30%	38%*
Listen: someone tells me how	28%	36%*
Ask: 24-hour number to call	29%	32%
Read: written instructions	20%	23%
On-demand: video of qualified person doing	19%	24%*
Other	2%	1%
None of the above	2%	2%

2015 Caregiver Subgroups

- Female caregivers are more likely to say they would like to learn medical/nursing tasks by having it *shown* to them (64% vs. 58% of males) or using a *hands-on* technique (55% vs. 49%).
- Caregivers ages 75 or older are more interested in *listen*ing to someone explain how to do the task (39% vs. 27% of caregivers ages 18 to 49 years) or *ask*ing on the phone (37% vs. 28%).
- Higher-income caregivers are more likely to want a qualified person to demonstrate the medical/nursing task (65% vs. 58% of those who earn less than $50,000).
- Those providing care to someone with Alzheimer's or dementia are more likely to prefer a *hands-on* approach to learning how to perform medical/nursing tasks (59% vs. 51% caring for someone without dementia).
- Caregivers who might be learning medical/nursing tasks for the first time—that is, caregivers who are not already providing medical/nursing tasks for their loved one—are more likely to want a qualified person to *show* them how to do it (65% vs. 59% of those already providing medical/nursing tasks).

G. Care Recipient Hospitalization

Frequency of Care Recipient Hospitalization

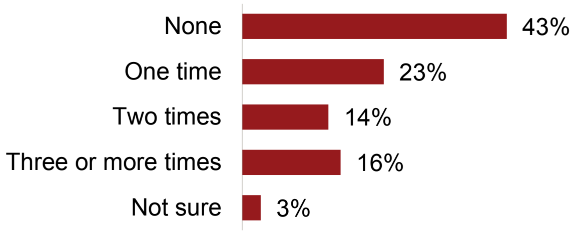
Over half (53%) of caregivers indicate their care recipient has been hospitalized in the past year. Sixteen percent say their loved one has been hospitalized three times or more.

Higher-hour caregivers are more likely to report that their loved one was hospitalized three or more times in the past year (22% vs. 13% of lower-hour caregivers).

Figure 48: Hospitalizations in the Past Year

N9. In the last 12 months, how many times was your [relation] hospitalized overnight?

Base: Caregivers of Recipient Age 18+ (n=1,248)



	Hours Caregiving per Week	
	0-20 (n=826)	21+ (n=416)
None	45%	40%
One time	24	22
Two times	14	15
Three or more times	13	22*
Not sure	4*	1

2015 Caregiver Subgroups

- Those performing medical/nursing tasks are among the most likely to say their loved one was hospitalized in the past year (61%).
- New caregivers—that is, those having been caring for less than a year—are more likely to report their care recipient was hospitalized in the past year (57% vs. 44% of those who have been providing care 5 or more years), perhaps because the hospitalization event resulted in the need for caregiving.
- Caregivers of someone with a physical condition (short- or long-term) are more likely to report their care recipient was hospitalized (57% vs. 33% of those caring for someone without a physical condition).
- High or medium burden caregivers (62% and 58%, respectively) are more likely to report their loved one being hospitalized than low burden caregivers (43%).

Included in Health Care Discussions at the Hospital

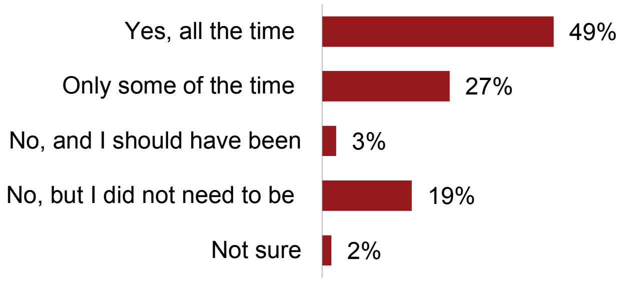
Among caregivers whose recipient has been hospitalized in the past year, more than a quarter say they were included in discussions about their loved one’s care only some of the time. About half say they were included all the time.

Higher-hour caregivers are more likely to say they were included in care discussions all the time (59% vs. 44% of lower-hour caregivers). However, lower-hour caregivers were also more likely to feel they did not need to be included in these discussions (23% vs. 11% higher-hour).

Figure 49: Care Discussion Inclusion

N10. (If care recipient was in hospital) When your [relation] was in the hospital, were you included by health care workers, like nurses, doctors, or social workers, in discussions about your [relation’s] care?

Base: Caregivers of Recipient Age 18+ who was hospitalized in past year (n=676)



	Hours Caregiving per Week	
	0-20 (n=424)	21+ (n=248)
Yes, all the time	44%	59%*
Only some of the time	27	26
No, and I should have been	3	3
No, but I did not need to be	23*	11
Not sure	2	1

2015 Caregiver Subgroups

- Primary caregivers are more likely to say they were included all the time(53% vs. 43% of nonprimary caregivers), while nonprimary caregivers are more likely to say they did not need to be included (26% vs. 15% primary caregivers).

Medical/Nursing Task Preparation for Hospitalized Care Recipients

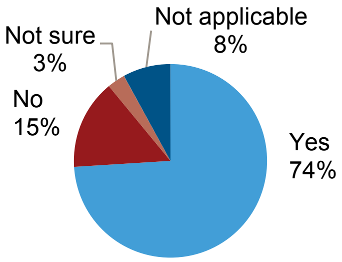
Fifteen percent of caregivers performing medical/nursing tasks for a recipient who was hospitalized say no one gave them instructions about these tasks before their loved one was discharged.

Among this group, higher-hour caregivers are more likely to report they did receive medical/nursing task instructions (85% vs. 63% of lower-hour caregivers).

Figure 50: Hospital Instructions to Caregiver

N11. (If care recipient was in hospital and needed medical/nursing tasks) Before your [relation] left the hospital or was discharged, did you receive clear instructions about any medical/nursing tasks you would need to perform for your [relation]?

Base: Caregivers doing medical/nursing tasks for Recipient Age 18+ who was hospitalized in past year (n=443)



% No

Hours Caregiving per Week	
0-20 (n=224)	21+ (n=217)
19%*	10%

2015 Caregiver Subgroups

- Those more likely to say they did *not* receive training include caregivers of adults ages 18 to 49 (29% vs. 13% caring for someone older), those caring for someone with a mental health condition (23% vs. 12% of those caring for someone without a mental health condition), and male caregivers (20% vs. 11% female).

H. Presence of Other Help

Presence of Other Unpaid Caregivers

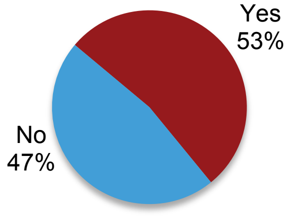
About half of all caregivers report that someone else has also provided unpaid care to their care recipient over the past year.

Higher-hour caregivers have less additional unpaid help (43%) than caregivers who provide care for 20 hours or fewer each week (58%).

Figure 51: Presence of Other Unpaid Caregivers

Q28. Has anyone else provided unpaid help to your [relation] during the last 12 months?

Base: Caregivers of Recipient Age 18+ (n=1,248)



% Yes

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
58%*	43%

2015 Caregiver Subgroups

- Certain groups of caregivers are more likely be the sole unpaid caregiver. This includes the following:
    - Those caring for a spouse (78% with no other unpaid help),
    - Co-resident caregivers (66% with no help),
    - Those caring for recipients ages 18 to 49 (60%),
    - High burden caregivers (53%), and
    - Caregivers with household incomes of $50,000 or less (53%).
- Alzheimer’s or dementia caregivers are more likely to have other unpaid help (61% vs. 51% of those caring for someone without these issues).

Primary Caregiver Status

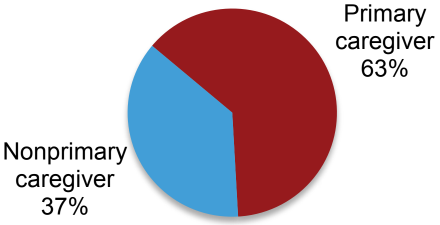
Over six in 10 caregivers perceive themselves to be the primary unpaid caregiver, meaning either that they are sole caregivers (47%) or that there are other unpaid caregivers, but they themselves provide the majority of unpaid care (16%). The 37 percent who are non-primary caregivers includes 12 percent who share caregiving equally with someone else and 25 percent who say another caregiver provides most of the unpaid care.

Three out of four higher-hour caregivers are their recipient’s primary caregiver, more so than lower-hour caregivers (56%).

Figure 52: Primary Caregiver Status

Q28. Has anyone else provided unpaid help to your [relation] during the last 12 months?
Q29. Who would you consider to be the person who provides/provided most of the unpaid care for your [relation]?

Base: Caregivers of Recipient Age 18+ (n=1,248)



% Primary

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
56%	77%*

On average, primary caregivers are caring for someone younger (67.5 years old, on average) and they have been providing care for almost 2 years longer (4.6 years duration of care vs. 2.8 years for nonprimary). Most feel they had no choice in taking on their responsibility to provide care (55%). Nearly half co-reside with their recipient (47%), they provide 4.5 IADLs on average, and they are more likely to be helping with medical/nursing tasks and each of the three key activities (monitoring, communicating, advocating), leading to 28.5 hours of care provided a week, more than nonprimary caregivers (17.7 hours weekly).

Primary caregivers are more likely to be in a high burden care situation (45% vs 31% nonprimary). They are less likely to report having paid help (29% vs. 37% nonprimary) and less likely to work while providing care (58% vs. 64% nonprimary). One in four primary caregivers says caregiving has made their health worse. They are less educated and have lower household incomes than nonprimary caregivers.

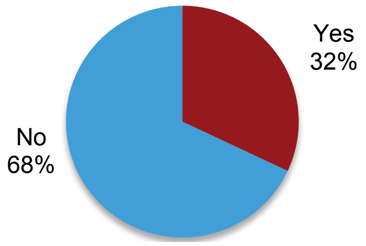
Use of Paid Services

Among caregivers whose recipient was not in a nursing home, one in three reports their loved one received paid help from aides, housekeepers, or others in the past year (32%). The use of paid services is comparable across higher- and lower-hour caregivers.

Figure 53: Use of Paid Services

Q30. During the last 12 months, did your [relation] receive paid help from any aides, housekeepers, or other people who were paid to help him/her?

Base: Caregivers of Recipient Age 18+ not in nursing home or assisted living (n=1,147)



% Yes

Hours Caregiving per Week	
0-20 (n=740)	21+ (n=401)
30%	34%

- Use of paid help is more common among caregivers who are less present, either physically or in their role as primary caregiver.
  - Caregivers not living with their recipient are more likely to report use of paid services (36% vs. 25% co-resident caregivers). However, among co-resident caregivers, higher-hour caregivers are twice as likely to have utilized paid services (32%) than lower-hour caregivers (15%).
  - Nonprimary caregivers are more likely to say their loved one receives paid help (37% vs. 29% of primary).
- Use of paid services is related to the care recipient's illness or condition, and therefore, his or her presumed need for help with daily living. Caregivers that are among the most likely to report the presence of paid help include the following:
  - Those caring for someone with Alzheimer's or dementia (45%),
  - Those caring for someone with a long-term physical condition (38%),
  - Caregivers of recipients ages 65 or older (38%).
- Lower income caregivers are among the least likely to report that their loved one receives paid help (27% of those with less than $30,000 in household income).

I. Strain and Stress of Caregiving

Caregiver Health

Half of caregivers (48%) consider their health to be *excellent* or *very good*, 35 percent evaluate their health as *good,* and 17 percent say it is *fair* or *poor*.[32] By comparison, 10 percent of the general adult population describes their health as *fair* or *poor*.[33]

Higher-hour caregivers are more likely to say their health is *fair* or *poor* (22% vs. 14% of those providing 0 to 20 hours of care), and less likely to describe their health as *excellent* or *very good* (40% vs. 52% of lower-hour caregivers).

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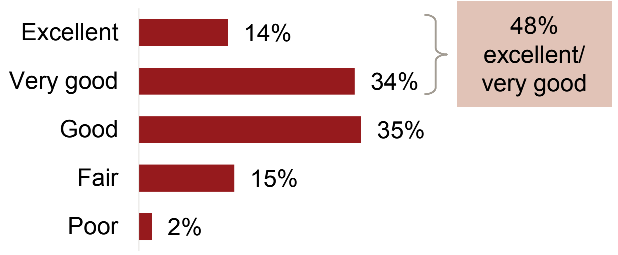
[32] Idler, E.L., & Benyamini, Y. "Self-Rated Health and Mortality: A Review of Twenty-Seven Community Studies." *Journal of Health and Social Behavior* Vol 38:1.

[33] CDC/NCHS, National Health Interview Survey, January–June 2014, Family Core component.

Figure 54: Caregiver Health

D1. How would you describe your own health?/When you were last caregiving, was your health…?

Base: Caregivers of Recipient Age 18+ (n=1,248)



% Excellent/ very good	
Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
52%*	40%

2015 Caregiver Subgroups

- The toll on the caregiver’s health appears to increase over time. Of those providing care for 5 years or more, 20% report their health is *fair* or *poor*, compared with 14% of those who have been giving care for less than a year. Similarly, as burden rises, so too does the percentage of caregivers in *fair* or *poor* health (21% high burden vs. 13% low burden).
- The caregiver's health is strongly correlated to his or her household income. Of caregivers with less than $30,000 in household income, 30 percent report *fair* or *poor* health, and this percentage declines sharply to 7 percent of caregivers with household incomes of $100,000 or more. There is a similar pattern with caregiver education levels.
- Other groups apt to say their health is *fair* or *poor* include those caring for a spouse (27% vs. 15% all other relationships) or for someone who has a mental health condition (25% vs. 14% without this condition), or those who perform medical/nursing tasks (20% vs. 12% not doing this).
- Younger caregivers—that is, those 18 to 49 years old—report better health than caregivers 65 and older.

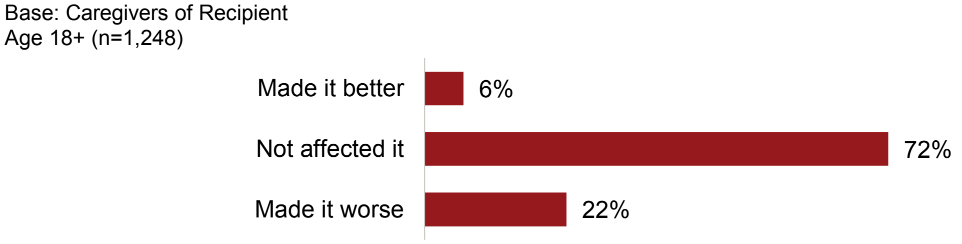
Caregiver Health Changes

While 7 out of 10 caregivers feel that providing care has not affected their own health (72%), 2 out of 10 feel caregiving has made their health worse.

Higher-hour caregivers are more likely to feel caregiving has had a negative impact on their health (29% vs. 18% of lower-hour caregivers).

Figure 55: Impact of Caregiving on Caregiver's Health

D2. How would you say taking care of your [relation] has affected your health?



% Made it Worse

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
18%	29%*

2015 Caregiver Subgroups

- Those caring for a close relative, such as a spouse or parent, are at a much greater risk of declining health as a result of caregiving.

Figure 56: Impact on Caregiver Health by Care Recipient Relationship

	Spouse (n=160) A	Parent (n=614) B	Other Relative (n=282) C	Nonrelative (n=192) D
Made it worse	37%^{BCD}	25%^{CD}	17%^{D}	5%
Not affected it	60	70 ^{A}	75 ^{A}	84 ^{ABC}
Made it better	4	4	7	11 ^{AB}

- As with health status, caregivers in more complex care situations are more likely to report their health has suffered as a result of providing care. These caregivers include those caring for someone with a mental or emotional health issue (34%), co-resident caregivers (30%), those providing medical/nursing tasks (27%), and primary caregivers (25%).
- White and Asian American (26% and 24%, respectively) caregivers say caregiving has negatively affected their health, significantly more than either African Americans (14%) or Hispanics (15%).
- Married women (27%) more often say that providing care has been detrimental to their own health than do unmarried women (16%) or men (20% any marital status).

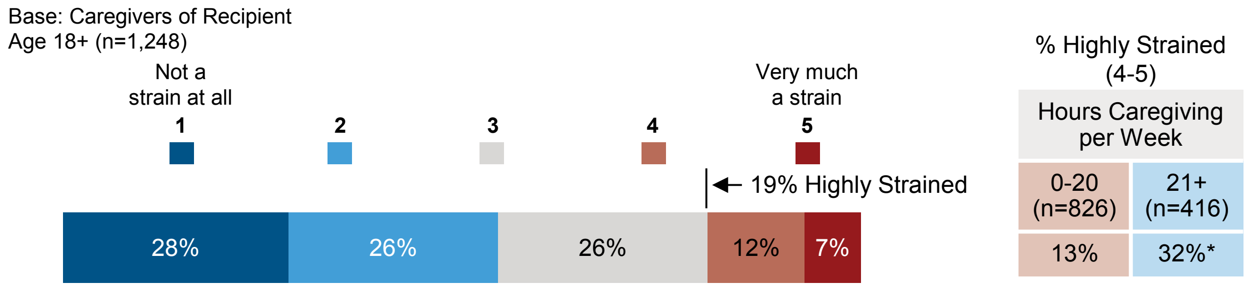
Physical Strain of Caregiving

One in five caregivers report a high level of physical strain as a result of their caregiving duties (19% rating a 4 or 5 on a 5-point scale). One in four experience a moderate strain (26% rating a 3), while about half feel little physical strain (54% rating 1 or 2).

One in three higher-hour caregivers experience a high level of physical strain, more than double that of lower-hour caregivers (13%).

Figure 57: Physical Strain of Caregiving

Q35. How much of a physical strain would you say that caring for your [relation] is/was for you?



2015 Caregiver Subgroups

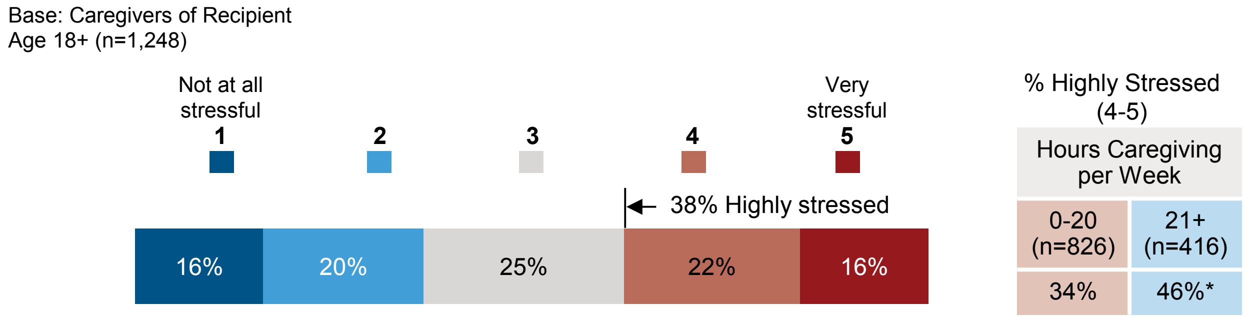
- Subgroups who are more likely to report a high degree of physical strain (4 or 5 on a 5-point scale) include the following:
  - High burden caregivers (31% vs. 16% medium and 9% low burden)
  - Alzheimer's or dementia caregivers (28% vs. 17%)
  - Co-resident caregivers (25% vs. 17% of those who live separately)
  - Those providing care for a year or longer (23% vs. 16% less than a year)
  - Those caring for someone with a long-term physical condition (23% vs. 13% caring for someone with only a short-term physical condition)
  - Older caregivers (23% age 65+, compared with 17% those 18–49)

Emotional Stress of Caregiving

Four in 10 caregivers consider their caregiving situation to be highly stressful (38% rating stress 4 or 5 on a 5-point scale). An additional 25 percent report moderate stress (rating of 3), while 36 percent indicate little to no stress (rating of 1 or 2). Nearly half of higher-hour caregivers find their role emotionally stressful (46% rating 4 or 5), more so than lower-hour caregivers (34%).

Figure 58: Emotional Stress of Caregiving

Q36. How emotionally stressful would you say that caring for your [relation] is/was for you?



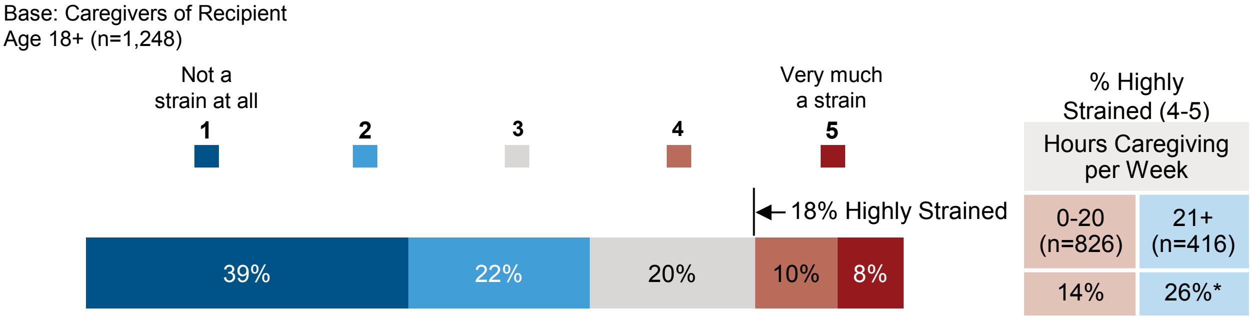
- Caring for a close relative, like a spouse (45%) or parent (44%), is more emotionally stressful for caregivers than caring for another relative (35%) or nonrelative (18%).
- Co-residence can create emotional stress, but only among higher-hour caregivers (52%), who report experiencing stress more often than co-resident lower-hour caregivers (35%) or non-co-resident caregivers (34%).
- The proportion of caregivers reporting high emotional stress (rating 4 or 5) rises in relation to the following:
    - Burden of care (46% high vs. 36% medium and 30% low)
    - Care duration (45% of those caring for a year or more vs. 31% of those caring for less than a year)
    - Perceived lack of choice in taking on their caregiving role (53% vs. 24% of those who feel they had a choice)
    - Performing medical/nursing tasks (44% vs. 30% not)
- Chronic or long-term conditions among care recipients seem to be particularly likely to cause emotional stress for caregivers. About half of those caring for someone with a mental health issue (53%), Alzheimer's or dementia (50%), or a long-term physical condition (45%) report feeling emotional stress.
- White caregivers (42%) are more likely than African Americans (31%), Hispanics (32%), or Asian Americans (34%) to report emotional stress.

Financial Strain from Caregiving

About one in five caregivers report experiencing financial strain as a result of providing care (18% rating 4 or 5 on a 5-point scale). One in five report moderate financial strain. Higher-hour caregivers are more likely to indicate they experience financial strain than lower-hour caregivers (26% vs. 14%).

Figure 59: Financial Strain of Caregiving

Q37. How much of a financial strain would you say that caring for your [relation] is/was for you?



- As with emotional stress, co-residence seems to create financial strain most often for higher-hour caregivers, who are twice as likely to report strain (31%) than co-resident lower-hour caregivers and non-co-resident caregivers (15% each).
    - Caregivers who live more than an hour away from their care recipient also report higher levels of financial strain (21% rating 4 or 5) than those who live closer (13% who live within an hour of their care recipient but not in the same household), perhaps because 41 percent of long-distance caregivers report the use of paid help.
- The longer a caregiver has been caring, the more likely they are to feel financial strain. One in five caregivers who have provided care for at least a year feels financial strain(22%), compared with just 14 percent of shorter-term caregivers.
- Groups more likely to feel financial strain also include high burden caregivers (25% vs. 13% low and medium burden caregivers), caregivers of someone with a mental health condition (25% vs. 16% without), and primary caregivers (21% vs. 13% nonprimary caregivers).

J. Impact of Caregiving on Work

Concurrence of Employment and Caregiving

Sixty percent of caregivers were employed at some point in the past year while also caregiving.

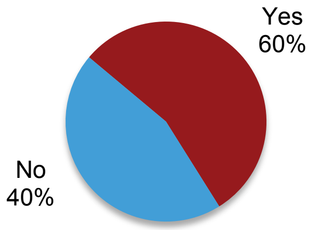
Higher-hour caregivers are less likely to indicate they were employed while caregiving in the past year (48% vs. 66% of lower-hour caregivers).

Figure 60: Concurrence of Employment and Caregiving

Q32A. Are/Were you currently employed?

Q33. Were you employed at any time in the last year while you were also helping your [relation]?

Base: Caregivers of Recipient Age 18+ (n=1,248)



% Yes

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
66%*	48%

- The rate of employment is quite different for caregivers who are 65 years of age or older—only 21 percent have been employed while caregiving in the past year, compared with 68 percent of younger caregivers.
- Employment while caregiving is more prevalent among the following subgroups of caregivers:
    - Low and medium burden caregivers (68% and 61%, respectively, compared with only 51 percent of high burden caregivers)
    - Nonprimary caregivers (64% vs. 58% primary caregivers)
    - Males (66% vs. 55% of female caregivers)
    - Caregivers with children (67% vs. 57% without children)
    - Those who attended at least some college (66% vs. 49% of high school graduates or less)
- Hispanic and Asian American caregivers (68% and 67%, respectively) are more likely to have worked while caregiving in the past year compared with white (56%) and African American caregivers (60%).

Current Employment Status of Caregiver

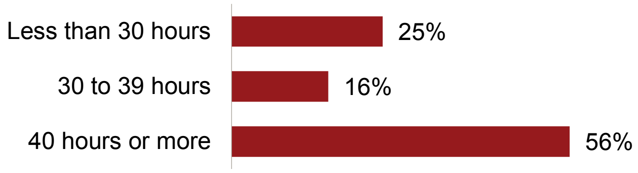
Over half of employed[34] caregivers work full time (56%) and another 16 percent work between 30 and 39 hours. One in four work fewer than 30 hours a week. On average, employed caregivers work 34.7 hours a week.

Higher-hour caregivers who are employed work 33.5 hours on average, comparable to caregivers who provide fewer hours of care weekly (35.2 hours).

Figure 61: Number of Hours Worked per Week by Caregiver

N13. About how many hours a week, on average, do/did you work?

Base: Working Caregivers of Recipient Age 18+ (n=746)



	Hours Caregiving per Week	
	0-20 (n=540)	21+ (n=203)
Less than 30 hours	24%	27%
30 to 39 hours	15	17
40 hours or more	58	51

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[34] Employed caregivers refers to caregivers who were both working and providing care at the same time in the past 12 months.

- Not surprisingly, the pattern of employment is quite different for caregivers who are 65 years of age or older—79 percent do not work, and of those who do work, only 33 percent work full time.[35] Younger caregivers are more likely to work full time(57% of those age 18 to 49 and 60% of those age 50 to 64).
- Other subgroup differences are similar to those found in the previous analysis of the concurrence of employment and caregiving. Also of note:
    - White and Asian American caregivers are more likely to work full time. (59% and 61%, respectively, compared to 52% of African Americans and 48% of Hispanics)
    - Married male caregivers work 39.2 hours a week on average, more than unmarried male (34.3) or female (32.5 any marital status) caregivers.

Self-Employed Caregivers

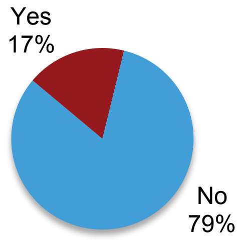
One in six caregivers is self-employed or own their own business while also providing care (17%). In comparison, 9.4 percent of U.S. workers are self-employed.[36]

Similar proportions of higher-hour and lower-hour caregivers are self-employed.

Figure 62: Caregiver Self-Employed/Own Their Own Business

N13B. Are/Were you currently self-employed or do/did you own your own business?

Base: Working Caregivers of Recipient Age 18+ (n=746)



% Yes

Hours Caregiving per Week	
0-20 (n=540)	21+ (n=203)
17%	19%

Self-employed caregivers report working fewer hours than those who work for an employer (not self-employed). In addition, self-employed caregivers are more likely to report scaling back their work or retiring early. This suggests that caregivers may be dropping out of the employee-employer relationships and opting into self-employment to

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[35] Projecting to all caregivers ages 65 and older, this means that just 7 percent are working full time, 14 percent work part time, and 79 percent do not work. In 2010, the U.S. Census reported that 16.1 percent of those 65 and older were employed. Of those 65 and older who were employed, 44.3 percent were full time, meaning 7 percent of those ages 65 and older are employed full time nationally. Kromer, B., & Howard, D. "Labor Force Participation and Work Status of People 65 Years and Older," American Community Survey Briefs. January 2013.

[36] Current Population Survey, Annual Social and Economic Supplement, 2012 data, presented in: Bureau of Labor Statistics. "Female Self-Employment in the United States: An Update to 2012." *Monthly Labor Review*. October 2014.

better fit their caregiving situation because it offers greater flexibility. Alternatively, self-employed individuals may more often be “chosen” for or volunteer to provide care because of their ability to better control their own work.[37] Additional research on working caregivers and self-employment is needed to determine causality.

Figure 63: Hours Worked and Work Impacts by Self-Employment

	Self-Employed (n=136) A	Works for Employer (n=585) B
Mean Hours Worked	29.1	36.0^{A}
Work Impacts:		
Reduce work hours or take less-demanding job	26%^{B}	11%
Choose early retirement	10%^{B}	3%
Give up working entirely	9%	5%

Supervisor Knowledge of Caregiver’s Role

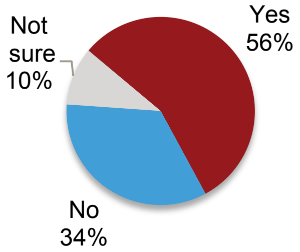
Among employed caregivers who are not self-employed, over half report that their supervisor at work is aware of their caregiving responsibility (56%).

Higher-hour caregivers who work for an employer (76%) are more likely than lower-hour caregivers (49%) to say their supervisor is aware of their role.

Figure 64: Supervisor’s Knowledge of Caregiving

N14. Does/Did your supervisor know that you are/were caring for your [relation]?

Base: Working and not self-employed Caregivers of Recipient Age 18+ (n=587)



% Yes

Hours Caregiving per Week	
0-20 (n=430)	21+ (n=155)
49%	76%*

2015 Caregiver Subgroups

- As a working caregiver’s burden of care increases, so too does the chance that his or her work supervisor is aware of his or her caregiving role (77 percent high burden vs. 56 percent medium burden vs. 41 percent low burden).

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[37] Looking at the prevalence of caregiving by work status, those who report being self-employed at the time of the online interview are more likely (21.6% care for someone of any age) to be caregivers than those working for an employer as a paid employee at the time of survey (17.4%). For reference, the national estimate is 18.2 percent.

- Again, working caregivers whose recipient has complex care needs are especially likely to say their supervisor is aware of their caregiving responsibilities, including those caring for someone with Alzheimer's or dementia (71%), those performing medical/nursing tasks (67%), and co-resident caregivers (65%).
- If a working caregiver is providing care for a close relative, such as a spouse (73%) or parent (61%), it becomes increasingly common for the caregiver's supervisor to be aware of their care role.

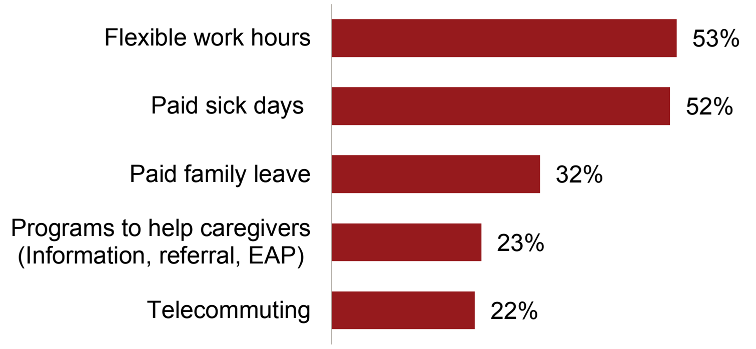
Workplace Benefits for Caregivers

Among working caregivers, half say their employer offers flexible work hours (53%) or paid sick days (52%).[38] Nearly a third say their employer offers paid family leave (32%), but less than a quarter offer employee assistance programs (23%) or telecommuting (22%).[39] Higher- and lower-hour working caregivers report similar workplace benefits.

Figure 65: Workplace Benefits for Caregivers

N16. For employees in your position, which of the following does/did your employer offer?

Base: Working and not self-employed Caregivers of Recipient Age 18+ (n=587)



	Hours Caregiving per Week	
	0-20 (n=430)	21+ (n=155)
Flexible work hours	52%	55%
Paid sick days	52%	51%
Paid family leave	30%	36%
Programs to help caregivers (Information, referral, EAP)	26%	20%
Telecommuting	24%	17%

2015 Caregiver Subgroups

- Nearly all workplace benefits, with the exception of flexible work hours, are more commonly reported by caregivers working full time.

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[38] Among the general U.S. population of private-sector workers, 62 percent report having at least 1 paid sick day, while 38 percent do not have any paid sick days. Access to paid sick days is related to hours worked, similar to results we find among caregivers. Farrell, J., & Venator, J. "Paid Sick Days: Paid Sick Days Work for U.S. Employees and Employers," Fact Sheet. Center for American Progress, August 16, 2012.

[39] These numbers may be higher than actual occurrence because prior research has shown that 40 percent of employees do not fully understand their benefits package. Society for Human Resource Management (SHRM). "40% Don't Understand Their Benefit Options; Web-Based Tools Can Help." SHRM Online, December 2011.

- While college-educated and higher-income caregivers are more likely to say their employer offers benefits, these groups are also more likely than less-educated and lower-income caregivers to be working full time.

Figure 66: Workplace Benefits by Hours Worked per Week

	Hours Worked per Week *Among those not self-employed*		
	Less than 30 (n=134) A	30 to 39 (n=78) B	40 or More (n=375) C
Flexible work hours	57%	54%	51%
Paid sick days	21%	46%^{A}	64%^{AB}
Telecommuting or working from home	19%	15%	25%^{B}
Programs to help caregivers (information, referral, EAP)	13%	15%	29%^{AB}
Paid family leave	11%	34%^{A}	38%^{A}

Work Impacts as a Result of Caregiving

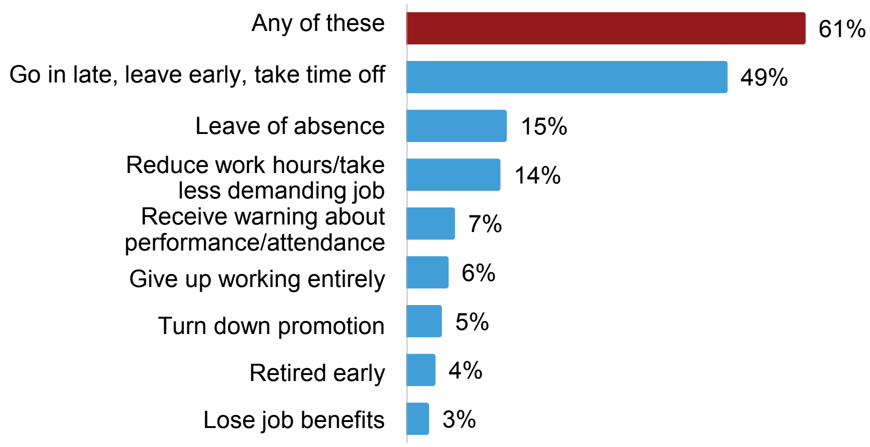
When it becomes difficult to balance caregiving with work, or if the demands of work come into conflict with one's caregiving responsibilities, sometimes caregivers choose to make changes to their work situation.

Six in 10 caregivers report having experienced at least one impact or change to their employment situation as a result of caregiving, such as cutting back on their working hours, taking a leave of absence, receiving a warning about performance or attendance, or other such impacts. Higher-hour caregivers are more likely to report any of the 8 work impacts (69% vs. 58% of lower-hour caregivers).

Figure 67: Work Impacts Due to Caregiving

Q34. As a result of caregiving, did you ever experience any of these things at work?

Base: Working Caregivers of Recipient Age 18+ (n=724)



	Hours Caregiving per Week	
	0-20 (n=527)	21+ (n=194)
Any of these	58%	69%*
Go in late, leave early, take time off	47%	53%
Leave of absence	12%	23%*
Reduce work hours/take less demanding job	10%	25%*
Receive warning about performance/attendance	5%	11%*
Give up working entirely	4%	12%*
Turn down promotion	3%	11%*
Retired early	3%	8%*
Lose job benefits	2%	5%

2015 Caregiver Subgroups

- Indeed, working caregivers in complex care situations are more likely to report work impacts, again suggesting that caregivers have to modify employment to fulfill their caregiving responsibilities.
    - Co-resident higher-hour caregivers are more likely than lower-hour caregivers (regardless of co-residence) to report that they cut back their hours (27% vs. 10%), took a leave of absence (26% vs. 12%), turned down a promotion (13% vs. 3%), gave up work entirely (13% vs 4%), or retired early (10% vs. 3%).
    - High burden caregivers are among the most likely to report having experienced any work impacts as a result of caregiving (73% vs. 65% moderate burden and 50% low burden). They are more likely to report they experienced 7 of the 8 work impacts (exception is being warned about performance or attendance).
    - Primary caregivers are also more likely to report impacts on their work (66% vs. 53% of non-primary caregivers), as are those who feel they had no choice in taking on their caregiving role (71% vs. 51% with a choice).
    - Caregivers who perform medical/nursing tasks are more likely to have experienced 6 out of 8 work impacts (70% report experiencing at least one vs. 51% of those not doing medical/nursing tasks).
- Those working at least 30 hours a week are more likely to report having workday interruptions as a result of caregiving. Caregivers who worked fewer hours while

caregiving are more likely to report they cut back their work responsibilities, again suggesting that caregivers modify their work to fit their caregiving situation, rather than modifying their caregiving to fit employment.

Figure 68: Selected Work Impacts by Hours Worked per Week

	Hours Worked per Week		
	Less than 30 (n=185) A	30 to 39 (n=116) B	40 or More (n=423) C
Go in late, leave early, take time off during workday	36%	$49\%^{A}$	$54\%^{A}$
Reduce work hours or take less-demanding job	$23\%^{C}$	$22\%^{C}$	8%
Give up working entirely	$12\%^{BC}$	5%	4%
Retire early	$9\%^{C}$	6%	2%

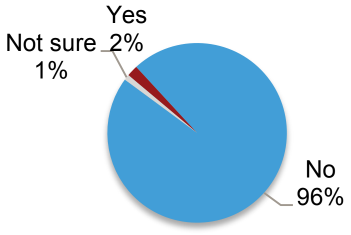
So why do working caregivers leave their job? Working caregivers who left their position (retired early or quit working entirely) most commonly do so to have more time to care for their loved one (39%) or because their work did not allow flexible hours (34%). Higher-hour caregivers are more likely to attribute their job loss to the inability to afford paid help for their loved one (29% vs. 7% of lower-hour caregivers).

Very few caregivers report they have ever been fired from any job as a result of being a caregiver (2%). Higher-hour caregivers are more likely to say they have been fired from a position due to their caregiver duties (4%) than lower-hour caregivers (2%).

Figure 69: Caregiving as a Reason for Being Terminated

N17. Have you ever been fired from any job as a result of being a caregiver for your [relation] or any other loved one?

Base: Caregivers of Recipient Age 18+ (n=1,248)



% Yes

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
2%	4%*

K. Information Needs and Caregiver Support

Caregiver Training and Information Needs

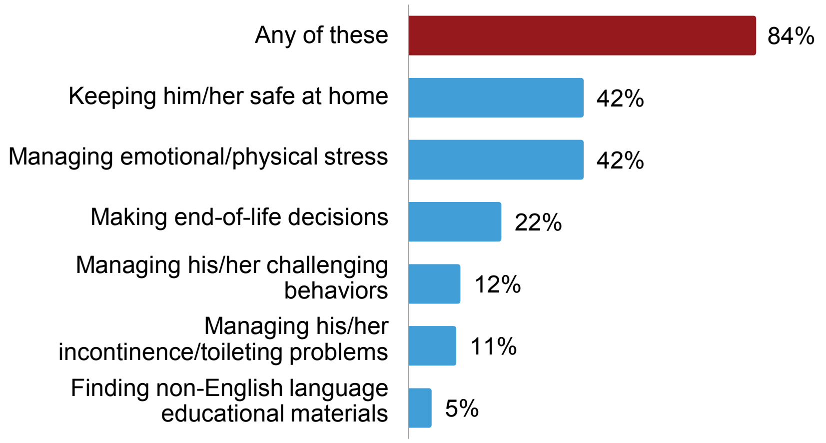
More than 8 out of 10 (84%) caregivers state that they could use more information on or help with caregiving topics. Caregivers most commonly want information about keeping their loved one safe at home (42%) and about managing their own stress (42%), and 22 percent want help about making end-of-life decisions.

Higher-hour caregivers are more likely (87 percent vs. 82 percent of lower-hour caregivers) to want information overall. Those higher-hour caregivers are especially interested in managing stress (51%), managing their loved one's challenging behaviors (18%), and dealing with incontinence (17%).

Figure 70: Caregiving Information Needs

Q48. Which of the following topics do you feel you need/needed more help or information?

Base: Caregivers of Recipient Age 18+ (n=1,248)



	Hours Caregiving per Week	
	0-20 (n=826)	21+ (n=416)
Any of these	82%	87%*
Keeping him/her safe at home	41%	43%
Managing emotional/physical stress	38%	51%*
Making end-of-life decisions	22%	23%
Managing his/her challenging behaviors	9%	18%*
Managing his/her incontinence/toileting problems	8%	17%*
Finding non-English language educational materials	4%	6%

2015 Caregiver Subgroups

- Caregivers of those ages 65 or older are more likely to be interested in *keeping their loved one safe at home* (45% vs. 36% caring for someone age 18–64).
- As noted earlier, those performing medical/nursing tasks report higher levels of physical strain and emotional stress, and are more likely to help their loved one with getting to and from the toilet and with incontinence. Therefore, it follows that caregivers who perform medical/nursing tasks are more likely to want information on managing emotional or physical stress (48%), making end-of-life decisions (25%), managing their recipient's challenging behaviors (17%), and dealing with incontinence (15%).

- Those caregivers who report high levels of emotional stress are the same caregivers likely to want more information about *managing stress*, including co-resident caregivers (54%), those caring for someone with a mental health issue (53%), those who feel they had no choice in taking on their role (52%), high burden caregivers (51%), those caring for someone with Alzheimer's or dementia (50%), and primary caregivers (46%).
- Caregivers who are more likely to want to learn more about *making end-of-life decisions* are older (27% of those ages 75-plus vs. 20% of those ages 50–74 and 20% of those ages 18–49), caring for someone with a long-term physical condition (27% vs. 16% with only a short-term physical condition), and caring for someone age 65 or older (25% vs. 17% caring for someone 18–64).
- *Managing challenging behaviors* is more likely to be an informational need for those caring for someone with Alzheimer's or dementia (30%), or with a mental health issue (24%).
- Wanting more help or information about *incontinence* is more common among those caring for someone with Alzheimer's or dementia (21% vs. 8%).
- Hispanic (22%) and Asian American (19%) caregivers are more likely to want non-*English language materials* (vs. 1% each whites and African Americans).
    - The youngest caregivers (ages 18 to 49) are more likely to want non-English materials (6% vs. 3% of caregivers age 50+), echoing the demographic shifts that make them more diverse than older caregivers.

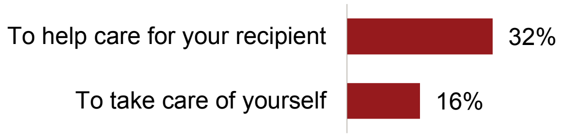
Conversations with Health Care Providers

A third of caregivers (32%) say a health care provider, such as a doctor, nurse, or social worker, has asked about what was needed to care for their recipient. Half as many say a health care provider has asked what they need to care for themselves. Higher-hour caregivers are more likely to say a health care provider has asked what is needed for their loved one's care (44% vs. 26% of lower-hour caregivers), as well as what they themselves needed (23% vs. 13% of lower-hour caregivers).

Figure 71: Conversations with Health Care Providers

Q45. In your experience as a caregiver, have you ever had: a doctor, nurse, or social worker ask you what you need/needed…

Base: Caregivers of Recipient Age 18+ (n=1,248)



	Hours Caregiving per Week	
	0-20 (n=826)	21+ (n=416)
To help care for your recipient	26%	44%*
To take care of yourself	13%	23%*

2015 Caregiver Subgroups

- Caregivers in more complex care situations are more likely to report having both of these kinds of conversations—about their needs for recipient care and needs for self-care. This includes:
    - Alzheimer's caregivers (46% had recipient care conversations; 25% discussed self-care)
    - Those performing medical/nursing tasks (42% discussed recipient care; 21% self-care)
    - High and medium burden caregivers (41% discussed recipient care; 21% self-care)
    - Caregivers of recipients with long-term physical condition (37% discussed recipient care; 18% self-care)
    - Co-resident caregivers (36% discussed recipient care; 20% self-care)

However, these conversations still are not occurring for a majority of caregivers, even among those groups likely to discuss these things with health care providers.

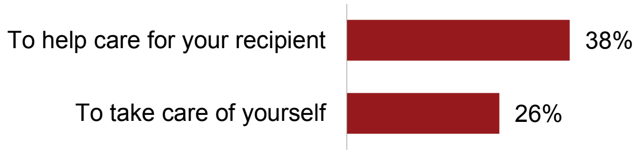
When indicating if these kinds of conversations would be helpful, nearly 4 in 10 say they would like to be asked about their needs for recipient care (38%) and 1 in 4 show interest in conversations about self-care.

Higher-hour caregivers are more likely to say that they would like health care providers to have conversations with them about what they need to take care of both their recipient and themselves.

Figure 72: Helpfulness of Conversations with Providers

N20. Which of the following do you think would be/have been helpful to you: require a doctor, nurse, or social worker to ask you about what you need/needed…

Base: Caregivers of Recipient Age 18+ (n=1,248)



	Hours Caregiving per Week	
	0-20 (n=826)	21+ (n=416)
To help care for your recipient	34%	48%*
To take care of yourself	22%	35%*

2015 Caregiver Subgroups

- Caregivers who are more likely to see the value in these discussions with health care providers, both about recipient care and self-care, tend to be caregivers in more complex care situations, who also report higher levels of emotional stress and physical strain. These caregivers include the following:

  - High burden caregivers (48% would find conversations about recipient care needs helpful; 36% would find self-care conversations helpful)
  - Caregivers of someone with Alzheimer's or dementia (47% recipient care conversations helpful; 34% self-care conversations helpful)
  - Those performing medical/nursing tasks (45% recipient care conversations helpful; 32% self-care conversations helpful)
  - Co-resident caregivers (44% recipient care conversations helpful; 33% self care conversations helpful)
  - Those who had no choice in their caregiving role (42% recipient care conversations helpful; 32% self-care conversations helpful)
- African American and Asian American caregivers are especially likely to feel these conversations would be helpful.

Figure 73: Helpfulness of Conversations with Providers by Caregiver Race/Ethnicity

	Caregiver Race/Ethnicity			
Require a doctor, nurse, or social worker ask you about what you need to…	White (n=698) A	African American (n=206) B	Hispanic (n=208) C	Asian American (n=201) D
Help care for your recipient	37%	$48\%^{AC}$	36%	$56\%^{AC}$
Take care of yourself	22%	$36\%^{A}$	$30\%^{A}$	$44\%^{AC}$

Need Gap in Conversations

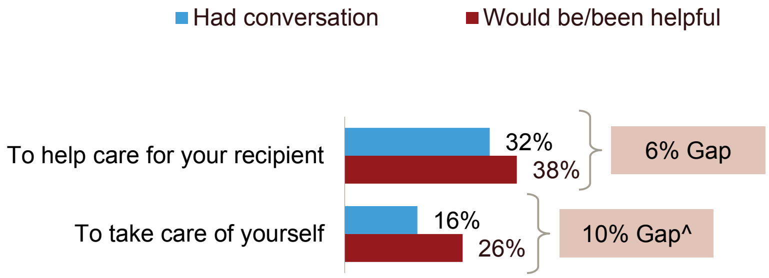
Comparing the number of caregivers who report having had these conversations with those who think they would be helpful reveals a need gap in both conversations about recipient care (6% gap) and self-care (10% gap). The need gap is greater in terms of discussions about the caregiver's own needs for self-care than it is for discussions about recipient care.

Higher-hour caregivers have a greater need for conversations with health care providers about their own self-care than about recipient care. Lower-hour caregivers have a greater need gap for recipient care conversations than higher-hour caregivers, suggesting that these conversations about support for recipient care are not occurring as often among lower-hour caregivers.

Figure 74: Need Gap in Conversations with Providers

Combined analysis of Q45 and N20

Base: Caregivers of Recipient Age 18+ (n=1,248)



% Gap (Helpful minus Had)

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
8%*	4%
9%	12%^

^ Gap is significantly higher for self-care conversations than for recipient care conversations

Use of Caregiver Support Services

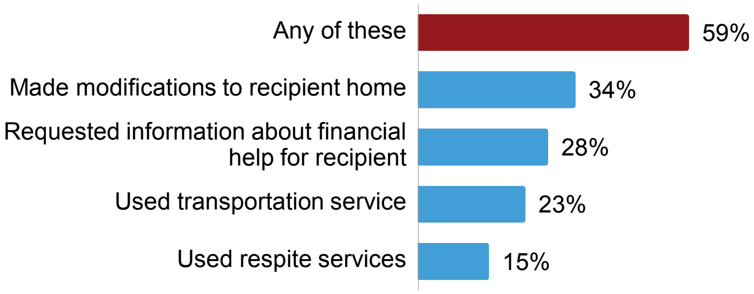
Three out of five caregivers have received or experienced at least one supportive service (59%). Most common is having modifications made to their loved ones' home (34%), followed by requesting financial assistance (28%) for their loved one. Fewer have used transportation or respite services.

Higher-hour caregivers are more likely to report having used at least one of these things.

Figure 75: Use of Services

Q45. In your experience as a caregiver, have you ever…?

Base: Caregivers of Recipient Age 18+ (n=1,248)



Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
55%	66%*
30%	42%*
27%	31%
23%	24%
13%	20%*

- The likelihood of using these supports or services goes up markedly (for all but respite) once caregivers have been providing care for a year or longer.

Figure 76: Use of Services by Duration of Care

	Less than a Year (n=596) A	1 Year or Longer (n=649) B
Had modifications made to recipient's home	26%	42%^{A}
Requested information about financial help	20%	35%^{A}
Used transportation service	19%	27%^{A}
Used respite services	14%	16%

- Caregivers of a close relative, like a parent or spouse are more likely to report having made home modifications (40%), more so than those caring for other relatives (30%) or non-relatives (15%).
- Those providing care to someone with a mental or emotional health issue are among the most likely (40 percent vs. 25 percent without such issues) to have requested information about financial help for their loved one. Other groups more likely to have requested financial help include those who feel they did not have a choice in providing care (34% vs. 22% with choice), those caring for a parent (32%), and primary caregivers (31% vs. 23% non-primary). Each of these groups is also more likely to report high levels of financial strain.
- Caregivers who do not live with their loved one are more likely to report the use of transportation services (26% vs. 19% co-resident). African American caregivers are also more likely to report use of these services (34% vs. 22% all other racial/ethnic groups).
- The use of respite services is more common among Asian American, Hispanic (22% each), and African American (20%) caregivers than it is among white caregivers (12%).

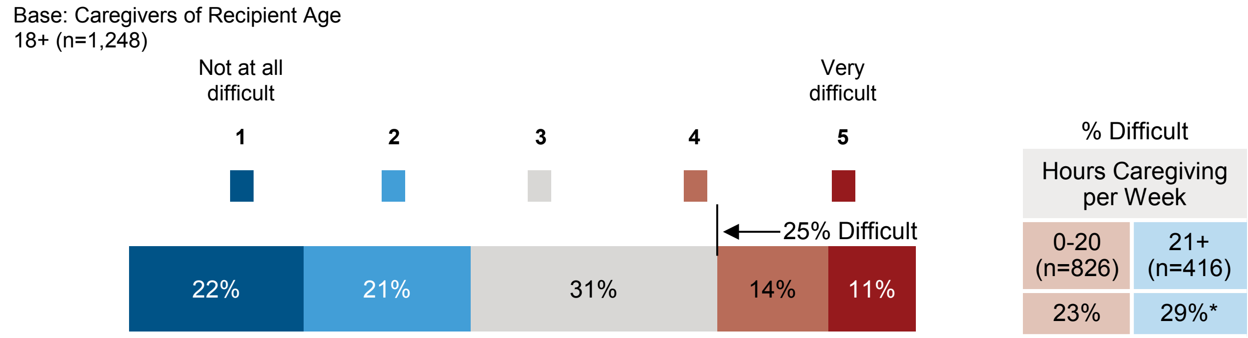
Affordability of Services

One in four (25%) caregivers say it is very difficult to get affordable services in their loved one's community that would help with their care.

Higher-hour caregivers are more likely to say finding affordable services is difficult (29% vs. 23% of lower-hour caregivers).

Figure 77: Affordable Assistance in Care Recipient’s Area

N19. How difficult is/was it to get affordable services in your [relation’s] local area or community that could help/would have helped you care for your [relation], like delivered meals, transportation, or in-home health services?



2015 Caregiver Subgroups

- Caregivers in more complex care situations often have more difficulty finding affordable support services. This includes high burden caregivers (31% vs. 20% low burden), those performing medical/nursing tasks (29% vs. 19% not performing these), and those caring for someone with a long-term physical condition (29% vs. 20% without).

Policy Proposals for Caregiver Support

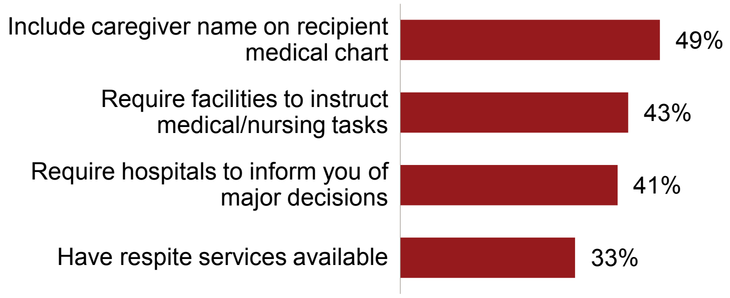
When gauging how helpful several policy proposals might have been to their caregiving experience, nearly half (49%) of caregivers feel a policy to have their own name on the recipient’s medical chart would be helpful. Roughly 4 in 10 feel it would be helpful to require hospitals to demonstrate medical/nursing tasks or inform them about major decisions.

Higher-hour caregivers are more likely to say respite services would be helpful. Respite services are especially appealing to higher-hour caregivers who live with their care recipient (44%).

Figure 78: Helpfulness of Caregiving Support Policies

N20. Various organizations are thinking about ways to help caregivers like you. Which of the following do you think would be/have been helpful to you?

Base: Caregivers of Recipient Age 18+ (n=1,248)



	Hours Caregiving per Week	
	0-20 (n=826)	21+ (n=416)
Include caregiver name on recipient medical chart	48%	52%
Require facilities to instruct medical/nursing tasks	42%	46%
Require hospitals to inform you of major decisions	41%	42%
Have respite services available	30%	41%*

2015 Caregiver Subgroups

- As caregiver age, education, income, and care recipient age rises, so too does the perceived helpfulness of the three facility/hospital related policies (include caregiver name on recipient medical chart, instruction of medical/nursing tasks, and inform caregiver of major decisions about recipient care).
- Those who feel they did not have a choice in taking on their caregiver role, those doing medical/nursing tasks, and those caring for someone with a long-term physical condition are each more likely than their respective comparison groups to find helpfulness in all four proposed policies, revealing that those most vulnerable caregivers are open to policy-enacted support.
- As time spent caregiving rises, so too does the perceived helpfulness of having the caregiver's name on their loved one's medical chart (41% helpful among those caring less than a year vs. 52% caring 1–4 years vs. 60% caring 5 years or longer).
- The idea of "getting a break" by having respite services available is especially appealing to high and medium burden caregivers (42% and 36%, respectively, vs. 24% low burden), co-resident caregivers (39% vs. 31% non-co-resident), those caring for someone with Alzheimer's or dementia (46% vs. 30% without), and those caring for someone with a mental health issue (39% vs. 32% without).

Of three national policies or programs presented to caregivers as potential ways to help them, equal proportions felt that being paid for some of their care hours (30%) and an income tax credit (30%) would be most helpful.[40]

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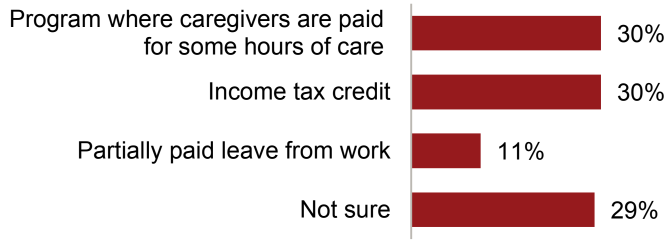
[40] Caregivers were asked to pick the one financial policy they find/would have found most helpful, unlike the caregiver support policies where caregivers were able to indicate helpfulness of multiple policies.

Higher-hour caregivers are more likely to prefer some reimbursement for the hours of care they provide, while lower-hour caregivers are more likely to prefer the tax credit or a partially paid leave of absence from work.

Figure 79: Most Preferred Financial Support Policy

Q47. Which one would you find/ have found most helpful?

Base: Caregivers of Recipient Age 18+ (n=1,248)



Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
26%	41%*
32*	26
13*	8
30	25

2015 Caregiver Subgroups

- Lower-income caregivers are more interested in being paid to provide care, while higher-income caregivers show greater interest in a tax credit.[41]

Figure 80: Most Preferred Financial Support Policy by Caregiver Household Income

	Less than $30,000 (n=352) A	$30,000 to $49,999 (n=226) B	$50,000 to $99,999 (n=387) C	$100,000 or More (n=283) D
Income tax credit	18%	28%^{A}	34%^{A}	39%^{AB}
Paid for some hours of care provided	43%^{BCD}	32%^{D}	27%^{D}	18%
Partially paid leave of absence from work	12%	10%	10%	13%

- Caregivers who are not working prefer to be paid for the hours of care they provide (37% vs. 26% employed), while those working prefer the tax credit (36% vs. 21% not working), or the leave of absence (14% vs. 8% not working).
- The idea of being paid for at least some hours of care is more popular among co-resident higher-hour caregivers (43% vs. 29% co-resident lower-hour and 25% non-co-resident lower-hours caregivers). However, co-resident higher-hour caregivers are among the most likely to not work.

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[41] While there are some differences in financial policy preference by race/ethnicity and caregiver age, these are due to income differentials in these key demographic groups.

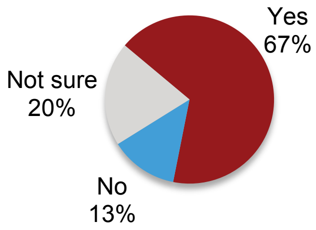
Caregivers generally show support for an additional policy proposal of banning workplace discrimination against workers with caregiving responsibilities, with two out of three in support of this proposal.

Higher-hour and lower-hour caregivers show similar levels of support for a ban on workplace discrimination against caregivers.

Figure 81: Workplace Caregiving Discrimination Ban

N18. Would you support banning workplace discrimination against workers who have caregiving responsibilities?

Base: Caregivers of Recipient Age 18+ (n=1,248)



% Yes

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
66%	70%

L. Long-Range Planning

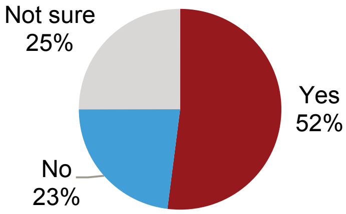
Expectations of Future Caregiving Role

Half of caregivers expect they will be a caregiver for some adult (either their current loved one or someone else) during the next 5 years. A similar proportion of higher- and lower-hour caregivers expect to continue their caregiving role in the near future.

Figure 82: Expectations of Future Caregiving Roles

N12. Do you expect to have some responsibility for the care of your [relation] or another adult family member or friend in the next 5 years?

Base: Caregivers of Recipient Age 18+ (n=1,248)



% Yes

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
51%	55%

2015 Caregiver Subgroups

- Those who feel they did not have a choice in their caregiving role feel their role will continue during the next 5 years (57% vs. 47% of those with a choice). This is notable, as those who feel they did not have a choice are especially likely to report negative impacts as a result of providing care and most likely will continue to experience these impacts well into the future.

- Asian American caregivers are more likely to believe their caregiving role will continue during the next 5 years (66% vs. 52% all other racial/ethnic groups).
- Of note, those caring for someone with Alzheimer's or dementia are more likely to expect their caregiving role to continue over the next 5 years (61% vs. 49% of those caring for someone without this condition).
- Those caring for a relative, particularly a spouse (55%) or parent (62%), are especially likely to believe their caregiving role will continue in the next 5 years, more so than those caring for another relative (42%) or a nonrelative (32%).
- The expectation for continued caregiving also rises with caregiver age (57% of those ages 50 or older vs. 46% ages 18–49), education (59% of college educated vs. 47% of those with a high school diploma or less), and income (57% of those with household income of $50,000 or more vs. 46% with lower income).
- Perhaps because they have the knowledge of knowing how long caregiving can last, those who have provided care for longer also expect to continue their role well into the future.

Figure 83: Expectation of Future Caregiving by Caregiver Tenure

	Less than a Year (n=596) A	1–4 Years (n=333) B	5 or More Years (n=316) C
Expects to be caregiver	38%	59%^{A}	73%^{AB}

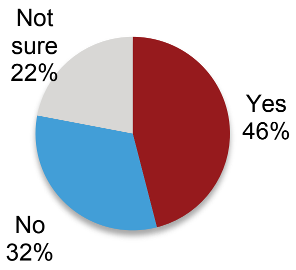
Long-Range Planning

Less than half of caregivers report that their care recipient has/had plans in place for future care. One in 3 report there are no such plans in place, while 2 in 10 are not sure. Similar proportions of higher-hour and lower-hour caregivers report that their loved one has or had future plans in place.

Figure 84: Recipient's Plans for the Future

N21. Does/did your [relation] have plans in place for his/her future care, such as instructions for handling financial matters, health care decisions, or living arrangements?

Base: Caregivers of Recipient Age 18+ (n=1,248)



% Yes

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
47%	43%

- Alarmingly, the most vulnerable caregivers—those dealing with complex care situations—are more likely to indicate their loved one has no plans in place for future care, including co-resident caregivers (40% vs. 28% non-co-resident), high burden caregivers (38% vs. 27% medium burden and 29% low burden), and those who feel they had no choice in taking on care (39% vs. 26% had a choice).
- Those caring for a spouse are especially likely to indicate a lack of planning, mostly due to their own surety about the lack of plans, while those caring for a nonrelative are most often unsure about their loved one's plans.

Figure 85: Care Recipient's Future Care Planning by Care Recipient Relationship

	Spouse (n=160) A	Parent (n=614) B	Other Relative (n=282) C	Nonrelative (n=192) D
Has made plans for future care	46%	51%^{CD}	39%	41%
Has no plans for future care	42 ^{BD}	32 ^{D}	37 ^{D}	18
Unsure if recipient has made plans	11	18 ^{A}	24 ^{A}	40 ^{ABC}

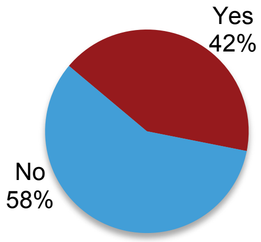
- Some caregivers are more likely to report their loved one has made future care plans, including the following:
    - Caregivers of those with Alzheimer's or dementia (56% vs. 43% of those without)
    - Those caring for older adults (50% ages 50 or older vs. 23% of those caring for someone 18–49)
    - College-educated caregivers (51% vs. 41% of high school graduates or less)
    - Higher income (50% with household income of $50,000 or more vs. 41% of lower-income caregivers).

About 4 in 10caregivers indicate they have plans in place for their own future care (42%). A similar proportion of higher-hour and lower-hour caregivers have plans in place for their own future care.

Figure 86: Caregiver's Plans for the Future

N22. Do you have your <u>own</u> plans for your own future care, such as handling financial matters, health care decisions, or living arrangements?

Base: Caregivers of Recipient Age 18+ (n=1,248)



% Yes

Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
41%	44%

2015 Caregiver Subgroups

- Married male caregivers are more likely to have future care plans (52% vs. 41% of female caregivers and 32% of unmarried male caregivers).
- As might be expected, older caregivers are more likely to have plans in place. Just 34 percent of caregivers ages 18 to 49 have future care plans, compared to 78 percent of caregivers ages 75 or older.
- As income rises, so too does future planning (36% earning less than $50,000 vs. 45% earning $50,000 to $99,999 vs. 51% earning $100,000 or more).

M. Respondent Profile

Six in 10 caregivers are female, and caregivers' average age is 49.2. More than 60 percent are white, and nearly 20 percent are Hispanic. More than a third (36%) have less than a high school education, higher than the number who have a college degree (35%).

Figure 87: Demographic Summary—All Caregivers and by Race/Ethnicity

	Total (n=1,248)	White (n=698) A	African American (n=206) B	Hispanic (n=208) C	Asian American (n=201) D
Caregiver Gender					
Male	40%	38%	41%	44%	45%
Female	60	62	59	56	55
Age of Caregiver					
18 to 34	24%	17%	34%^{A}	38%^{A}	30%^{A}
35 to 49	23	21	28	29^{A}	25
50 to 64	34	39^{BCD}	25	23	30
65 to 74	12	14^{BC}	7	8	12
75 or older	7	9^{CD}	6^{CD}	2	2
Mean age	*49.2*	*52.5*^{BCD}	*44.2*	*42.7*	*46.6*^{C}
Race/Ethnicity of Caregiver					
White	62%	100%	—%	—%	—%
African American	13	—	100	—	—
Hispanic	17	—	—	100	—
Asian American	6	—	—	—	100
Other	2	—	—	—	—
Caregiver Education					
Less than high school	8%	5%^{D}	6%^{D}	24%^{ABD}	1%
High school graduate	28	30^{D}	27^{D}	32^{D}	6
Some college	22	22^{D}	30^{ACD}	18^{D}	8
Technical school	8	8^{D}	8	7	4
College graduate	20	20^{C}	14	13	46^{ABC}
Graduate school	15	15^{C}	15^{C}	6	35^{ABC}
Caregiver Marital Status					
Married	57%	63%^{BCD}	33%	51%^{B}	50%^{B}
Living with a partner	8	6	9	11	8
Widowed	5	7^{D}	4	4	2
Separated	1	1	3	2	1
Divorced	8	8	9	7	8
Single, never married	19	14	38^{ACD}	25^{A}	24^{A}

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

About half of caregivers have at least $50,000 in household income and 6 in 10 are employed. Most live in an urban/suburban setting and 28 percent have minors living in their household. One in 10 have served in the armed forces, and a similar proportion of their care recipients also have.

Demographic Summary—All Caregivers and by Race/Ethnicity *(continued)*

	Total (n=1,248)	White (n=698) A	African American (n=206) B	Hispanic (n=208) C	Asian American (n=201) D
Caregiver Household Income					
Less than $50,000 (net)	47%	42%^{D}	62%^{AD}	61%^{AD}	30%
Less than $15,000	12	8	19^{AD}	23^{AD}	6
$15,000 to $29,999	16	15	24^{AD}	19^{D}	11
$30,000 to $49,999	18	19	19	20	14
$50,000 or more (net)	53	58^{BC}	38	39	68^{ABC}
$50,000 to $74,999	17	17	14	17	19
$75,000 to $99,999	13	15^{C}	10	9	15
$100,000 or more	23	26^{BC}	14	13	31^{BC}
Median household income	*$54,700*	*$62,200*	*$37,700*	*$38,600*	*$74,700*
Children/Grandchildren in Caregiver's Household					
Yes	28%	24%	34%^{A}	38%^{A}	34%^{A}
No	70	75^{BCD}	64	61	64
Care Recipient Living Location					
Urban/suburban	71%	70%^{D}	72%^{D}	72%^{D}	60%
Rural	28	30^{D}	26^{D}	27^{D}	12
Caregiver Living Location					
Urban/suburban	84%	80%	88%^{A}	94%^{A}	89%^{A}
Rural	16	20^{BCD}	12	6	10
Caregiver Employment Status					
Employed in past year while caregiving	60%	56%	60%	68%^{A}	67%^{A}
Not employed	40	44^{CD}	40	32	33
Caregiver Service in Armed Forces					
Served on active duty	10%	11%^{C}	12%^{C}	5%	8%
Did not ever serve	89	88	86	94^{AB}	90
Care Recipient Service in Armed Forces					
Served on active duty	14%	18%^{BCD}	8%	5%	6%
Did not ever serve	85	81	90^{A}	92^{A}	92^{A}
Caregiver LGBT status					(n=95)
Yes	9%	7%	11%^{D}	15%^{AD}	3%
No	91	93^{C}	89	85	97^{BC}

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

The profile of respondents, broken down by the age of the care recipient, is as follows.

Figure 88: Demographic Summary by Care Recipient Age

	Total (n=1,248)	Caregivers of Younger Adults 18 to 49 (n=159) A	Caregivers of Older Adults 50+ (n=1,087) B
Caregiver Gender			
Male	40%	39%	40%
Female	60	61	60
Age of Caregiver			
18 to 34	24%	40% ^{B}	21%
35 to 49	23	22	24
50 to 64	34	26	35 ^{A}
65 to 74	12	7	12 ^{A}
75 or older	7	5	8
Mean age	*49.2*	*42.8*	*50.3* ^{A}
Race/Ethnicity of Caregiver			
White	62%	59%	62%
African American	13	12	13
Hispanic	17	22	16
Asian American	6	3	7 ^{A}
Other	2	4	2
Caregiver Education			
Less than high school	8%	13% ^{B}	7%
High school graduate	28	29	28
Some college	22	25	21
Technical school	8	8	7
College graduate	20	16	20
Graduate school	15	8	16 ^{A}
Caregiver Marital Status			
Married	57%	57%	57%
Living with a partner	8	13 ^{B}	7
Widowed	5	6	5
Separated	1	1	2
Divorced	8	5	8
Single, never married	19	17	20

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

Caregivers' median household income of $55,000 is comparable to the $53,046 for the United States overall.[42]

Demographic Summary by Care Recipient Age *(continued)*

	Total (n=1,248)	Caregivers of Younger Adults 18 to 49 (n=159) A	Caregivers of Older Adults 50+ (n=1,087) B
Caregiver Household Income			
Less than $50,000 (net)	47%	47%	46%
Less than $15,000	12	13	12
$15,000 to $29,999	16	18	16
$30,000 to $49,999	18	16	19
$50,000 or more (net)	53	53	54
$50,000 to $74,999	17	16	18
$75,000 to $99,999	13	15	13
$100,000 or more	23	21	23
Median household income	*$54,700*	*$53,900*	*$55,000*
Children/Grandchildren in Caregiver's Household			
Yes	28%	33%	28%
No	70	67	71
Care Recipient Living Location			
Urban/suburban	71%	71%	71%
Rural	28	28	28
Caregiver Living Location			
Urban/suburban	84%	81%	85%
Rural	16	19	15
Caregiver Employment Status			
Employed in past year while caregiving	60%	65%	59%
Not employed	40	35	41
Caregiver Service in Armed Forces			
Served on active duty	10%	14%	10%
Did not ever serve	89	85	89
Care Recipient Service in Armed Forces			
Served on active duty	14%	3%	15%^{A}
Did not ever serve	85	94^{B}	83
Caregiver LGBT status			
Yes	9%	8%	9%
No	91	92	91

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

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[42] U.S. Census Bureau, American Community Survey, 2013.

Caregivers who provide 21 or more hours of care a week are on average 4 years older than those who provide fewer hours.

Figure 89: Demographic Summary by Hours Spent Caregiving per Week

	Total (n=1,248)	0–20 (n=826) A	21+ (n=416) B
Caregiver Gender			
Male	40%	41%	38%
Female	60	59	62
Age of Caregiver			
18 to 34	24%	26%^{B}	20%
35 to 49	23	24	22
50 to 64	34	33	35
65 to 74	12	11	13
75 or older	7	6	11^{A}
Mean age	*49.2*	*48.0*	*51.8*^{A}
Race/Ethnicity of Caregiver			
White	62%	65%^{A}	54%
African American	13	12	16
Hispanic	17	15	21^{A}
Asian American	6	6	6
Other	2	2	3
Caregiver Education			
Less than high school	8%	7%	10%
High school graduate	28	26	33^{A}
Some college	22	21	23
Technical school	8	8	7
College graduate	20	23^{B}	14
Graduate school	15	15	13
Caregiver Marital Status			
Married	57%	58%	53%
Living with a partner	8	8	8
Widowed	5	5	5
Separated	1	2	1
Divorced	8	7	9
Single, never married	19	18	21

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

Nine percent self-identify as LGBT.[43]

Demographic Summary by Hours Spent Caregiving per Week *(continued)*

	Total (n=1,248)	0-20 (n=826) A	21+ (n=416) B
Caregiver Household Income			
Less than $50,000 (net)	47%	43%	54%^{A}
Less than $15,000	12	10	16^{A}
$15,000 to $29,999	16	15	19
$30,000 to $49,999	18	18	19
$50,000 or more (net)	53	57^{B}	46
$50,000 to $74,999	17	17	18
$75,000 to $99,999	13	14	11
$100,000 or more	23	25^{B}	17
Median household income	*$54,700*	*$59,700*	*$45,700*
Children/Grandchildren in Caregiver's Household			
Yes	28%	30%^{B}	24%
No	70	69	74^{A}
Care Recipient Living Location			
Urban/suburban	71%	70%	74%
Rural	28	29	25
Caregiver Living Location			
Urban/suburban	84%	84%	86%
Rural	16	16	14
Caregiver Employment Status			
Employed in past year while caregiving	60%	66%^{A}	48%
Not employed	40	34	52^{B}
Caregiver Service in Armed Forces			
Served on active duty	10%	9%	13%
Did not ever serve	89	89	87
Care Recipient Service in Armed Forces			
Served on active duty	14%	13%	16%
Did not ever serve	85	85	83
Caregiver LGBT status			
Yes	9%	9%	9%
No	91	91	91

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

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[43] Of all screened respondents in *Caregiving in the U.S. 2015*, 6.9 percent self-identify as LGBT. In addition, we find that caregiving for an adult is more common among those who identify as LGBT (20.4% vs. 16.5% not identifying as LGBT). Nationally, Gallup estimates 5.6 percent of Americans are LGBT. Gates, G.J. *LGBT Demographics: Comparisons among Population-Based Surveys*. The Williams Institute, October 2014.

About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance supports a network of 80+ state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations. Learn more at www.caregiving.org.

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