

Executive Summary

Caregiving in the U.S.

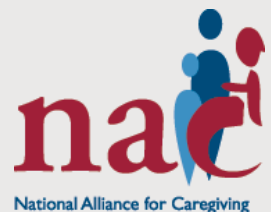


Conducted by



Real Possibilities

**Public Policy
Institute**



Acknowledgments

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

Many people played important roles throughout the research process, including:

Gail Gibson Hunt, National Alliance for Caregiving
Rick Greene, MSW, National Alliance for Caregiving
C. Grace Whiting, JD, National Alliance for Caregiving
Susan Reinhard, PhD, AARP Public Policy Institute
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
Nancy Vuckovic, PhD, Intel
Donna Wagner, PhD, New Mexico State University
Jennifer Wolff, PhD, Johns Hopkins University

This research was made possible through generous sponsorship from:

- AARP
- Archstone Foundation
- Eli Lilly
- Home Instead Senior Care
- MetLife Foundation
- Family Support Research and Training Center (FSRTC), University of Illinois-Chicago¹
- Pfizer
- UnitedHealthcare

The research was conducted for NAC and the AARP Public Policy Institute by Greenwald & Associates, with study direction by Lisa Weber-Raley and Erin Smith.

(c) 2015 NAC and AARP Public Policy Institute
Reprinting with permission

¹ With respect to funding received from FSRTC, this work was performed under a subcontract with the University of Illinois at Chicago and made possible by grant number H113B140046 from the U.S. Department of Education/NIDRR. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the U.S. Department of Education/NIDRR.

Table of Contents

I.	Introduction.....	4
II.	Overview of Methodology	6
III.	Key Findings	9
	Prevalence of Caregiving.....	9
	Basics of the Caregiving Situation	9
	Care Recipient Condition.....	12
	Caregiving Activities and Burden of Care	13
	Medical/Nursing Tasks	16
	Presence of Other Help	18
	Choice	19
	Stress and Strain of Caregiving	20
	Impact of Caregiving on Work	22
	Information Needs and Caregiving Support	24
	Long-Range Planning.....	27
IV.	Summary and Conclusions	29
V.	Respondent Profile.....	30

Table of Figures

Figure 1: Estimates of Individual Caregiving Prevalence by Age of Recipient	9
Figure 2: Spotlight on Caregivers Ages 75 or Older.....	10
Figure 3: Duration of Care for Recipient.....	11
Figure 4: Where Care Recipient Lives.....	11
Figure 5: Types of Care Recipient Conditions.....	12
Figure 6: Spotlight on Higher-Hour Caregivers	13
Figure 7: Help with Activities of Daily Living (ADLs).....	14
Figure 8: Difficulties with Activities of Daily Living	14
Figure 9: Help with Instrumental Activities of Daily Living (IADLs)	15
Figure 10: Help with Other Key Activities	16
Figure 11: Level of Care Index	16
Figure 12: Help with Medical/Nursing Tasks	17
Figure 13: Medical/Nursing Task Difficulty	17
Figure 14: Medical/Nursing Task Preparation	18
Figure 15: Presence of Other Unpaid Caregivers	18
Figure 16: Choice in Taking on Caregiver Role.....	19
Figure 17: Spotlight on Caregivers Having No Choice	19
Figure 18: Impact of Caregiving on Caregiver's Health	20
Figure 19: Emotional Stress of Caregiving	21
Figure 20: Financial Strain of Caregiving	21
Figure 21: Work Impacts Due to Caregiving.....	22
Figure 22: Selected Work Impacts by Hours Worked per Week	23
Figure 23: Hours Worked and Work Impacts by Self-Employment	23
Figure 24: Workplace Benefits by Hours Worked per Week	24
Figure 25: Need Gap in Conversations with Providers.....	25
Figure 26: Affordable Assistance in Care Recipient's Area	26
Figure 27: Helpfulness of Caregiving Support Policies	27
Figure 28: Expectations of Future Caregiving Roles	27
Figure 29: Demographic Summary by Hours Spent Caregiving per Week.....	30

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

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 summary highlights *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 them. 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).

In addition to this executive summary report, other publications resulting from this study are the following:

- A full report of findings, including appendices with the questionnaires and detailed methodology.
- Two companion reports (forthcoming), that separately explore the experiences of caregivers whose loved one is 1) age 18 to 49, and 2) age 50 or older.

II. Overview of Methodology

This report is based primarily on quantitative online interviews with 1,248 caregivers ages 18 and older who provide care to an adult. 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.

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*

³ These two screening questions, used to identify caregivers, are the same questions used in *Caregiving in the U.S. 2009*, with very minor edits to make them suitable for online self-administration without changing the meaning of the questions in any way.

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.

establishes a new baseline for examining changes to unpaid family caregiving in the future.

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 adults⁵ (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).

In addition to the 1,248 caregiver interviews in the base study, the study included an oversample of 209 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 (landline and 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 the 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.

All of the data gathered from the screener were used to estimate prevalence—the proportion of caregiving individuals and households in the United States. All fully screened respondents—regardless of caregiver status—were weighted by the

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.

individual's age, sex, and race/ethnicity to be representative of the United States as a whole.⁷

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.

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.

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.

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 questions with multiple response categories may sum 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.

⁷ For more details about the use of the screener to identify caregivers, estimation method for prevalence, or weighting, see appendix B, Detailed Methodology.

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.⁸ About 18.2% of the respondents surveyed reported being caregivers. The estimated prevalence of caring for an adult is 16.6%, or 39.8 million Americans.⁹ Approximately 34.2 million Americans have provided unpaid care to an adult age 50 or older in the prior 12 months.

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

	Prevalence	Number of Adults Ages 18+ in the U.S.	Estimated Number of Adult Caregivers in the U.S.
Overall	18.2%	239,340,657	43.5 million
Only child recipients	1.6%	239,340,657	3.7 million
Only adult recipients	13.9%	239,340,657	33.3 million
Both adult and child recipients	2.7%	239,340,657	6.5 million
Caregivers of recipients ages 50+	14.3%	239,340,657	34.2 million

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 old, 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 caregivers¹⁰ are almost four times as likely to be caring for a spouse/partner.

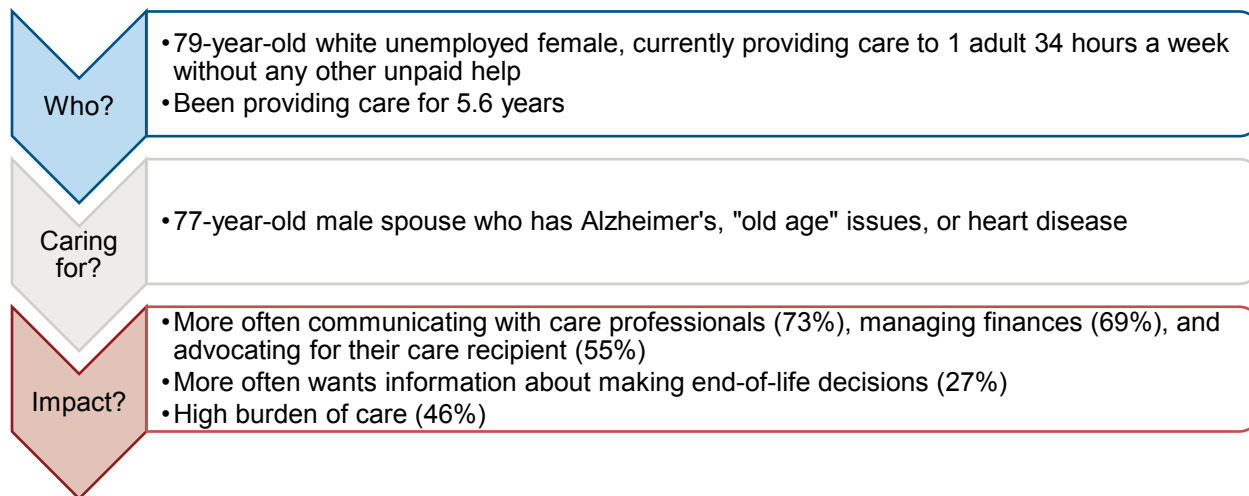
⁸ As with prior *Caregiving in the U.S.* studies, prevalence estimates are inclusive of those having provided care to someone in the 12 months before the time they were surveyed, whether they were currently a caregiver at the time of survey or had been a caregiver in the prior 12 months but no longer were.

⁹ Add the estimated 13.9% caring for an adult *only* plus the 2.7% caring for *both* a child and an adult to get the total prevalence estimate of caring for an adult.

¹⁰ 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.

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 2 shines a spotlight on these older caregivers by highlighting what is unique about them.¹¹

Figure 2: Spotlight on Caregivers Ages 75 or Older



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.

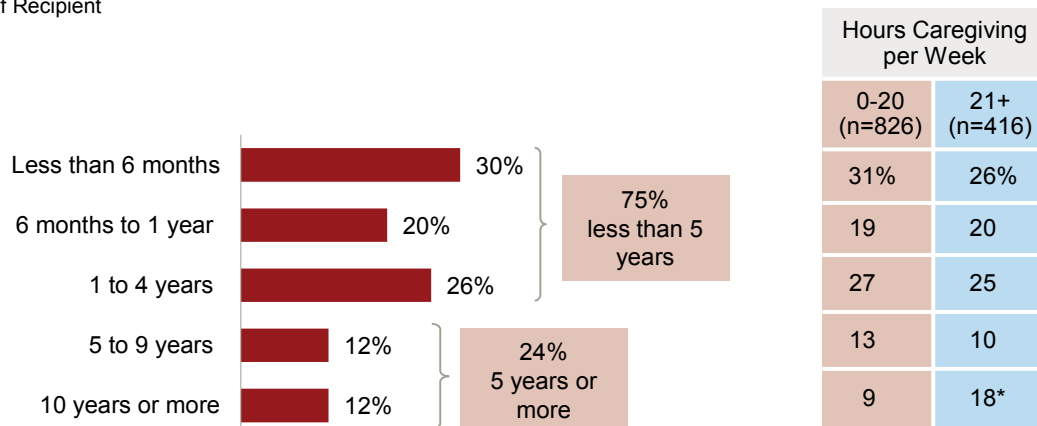
¹¹ Spotlights on caregivers provide a snapshot glance at significant findings that make this subgroup unique, relative to comparison groups—in this case, the comparison group is caregivers ages 18–74.

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.

Figure 3: 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)



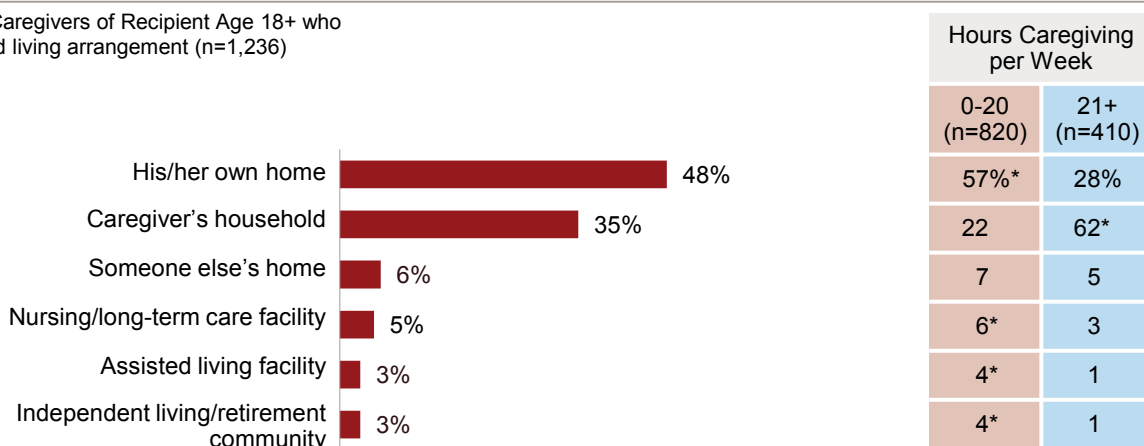
The typical care recipient is female (65%) and 69.4 years of age. Nearly half of caregivers provide care to someone 75 years old or older (47%).

Roughly half of care recipients live in their own home (48%). Higher-hour caregivers are more likely to live with their care recipient.

Figure 4: 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)

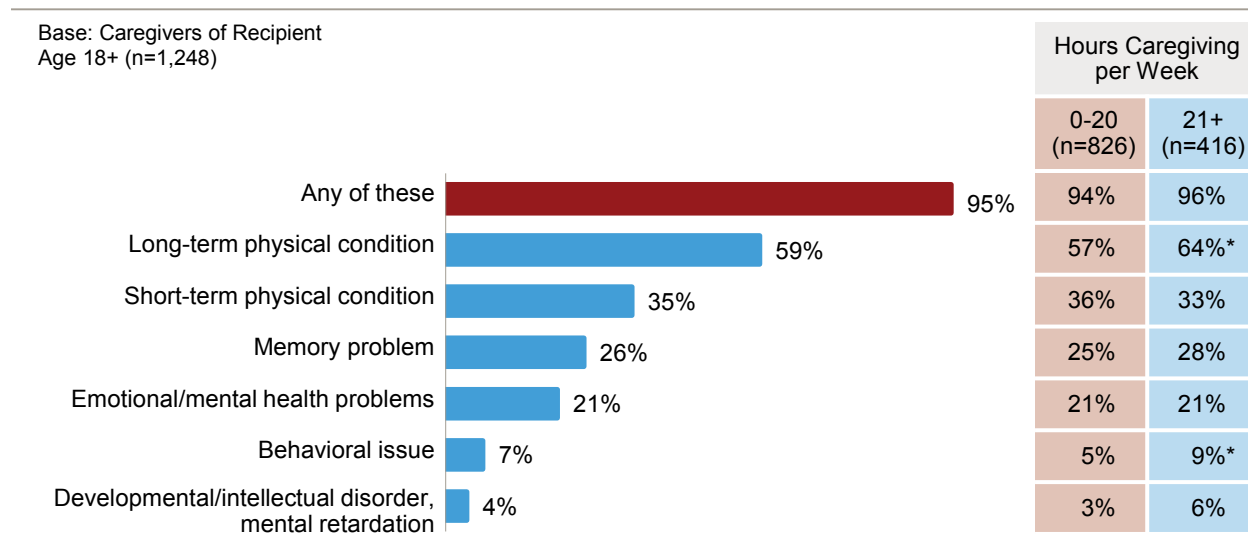


Care Recipient Condition

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%).¹²

Figure 5: Types of Care Recipient Conditions

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



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 percent of caregivers say their loved one does suffer from this type of condition.¹³

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

¹² Those who did not report the presence of any of the six selected conditions reported their loved one’s main condition was “old age.”

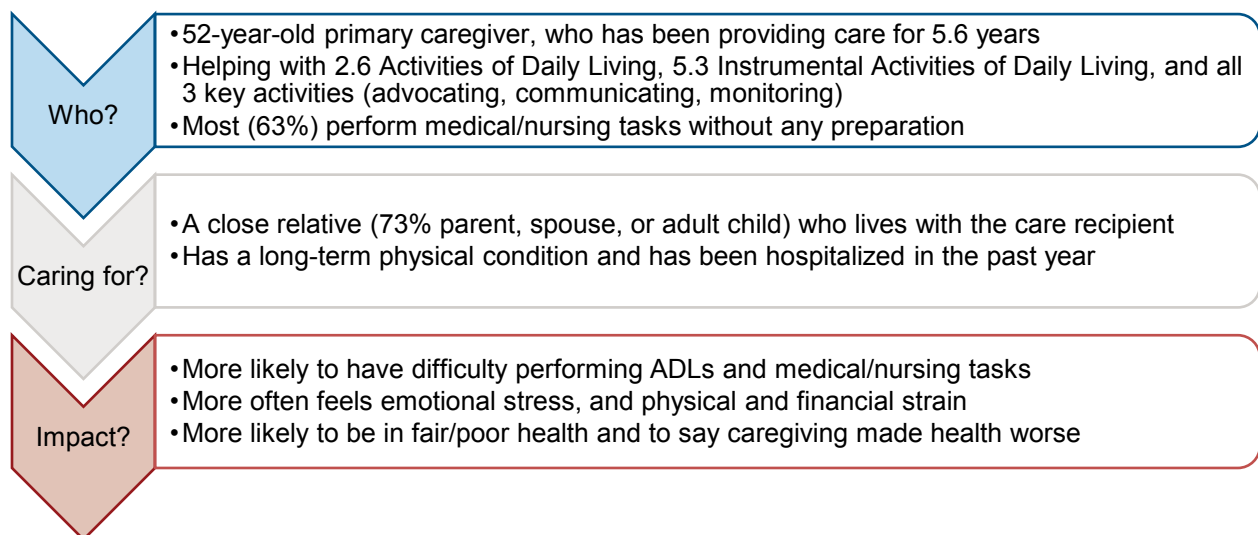
¹³ This includes anyone indicating the presence of Alzheimer’s disease, dementia, or other mental confusion either as the main condition or in a direct follow-up asking about the presence of these conditions.

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).

Spotlight: Higher-hour caregivers differ from lower-hour caregivers in some key ways, as shown in figure 6, which highlights what is unique about caregivers who provide 21 or more hours of care each week.¹⁴

Figure 6: Spotlight on Higher-Hour Caregivers

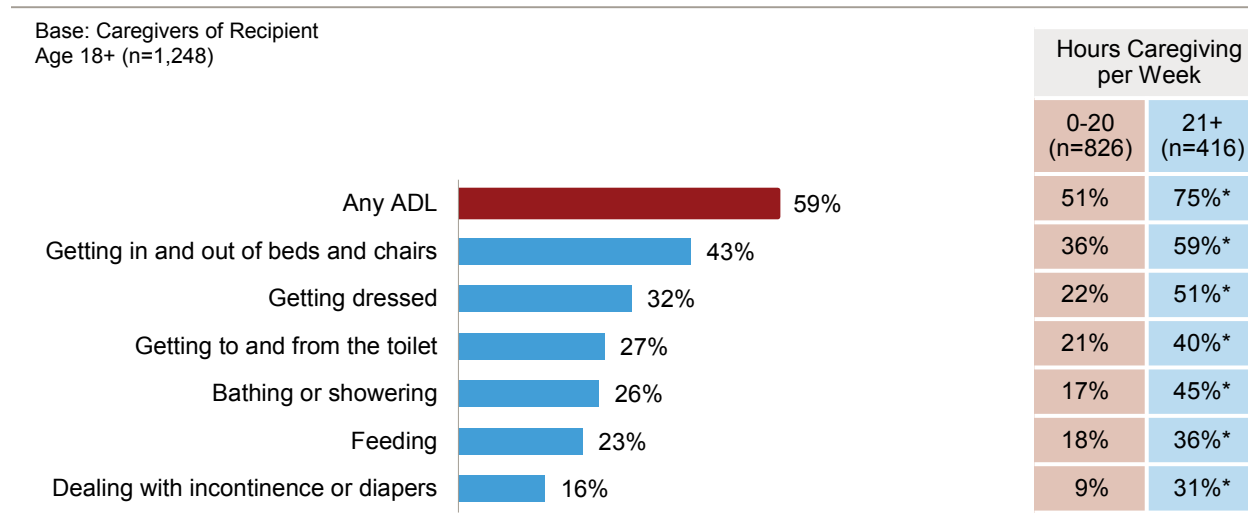


Higher-hour caregivers are a vulnerable population, more likely to experience emotional stress, physical and financial strain, and impacts on their health. They are performing a wide variety of care tasks for their loved one—everything from housework to advocating with health care professionals, to complex medical/nursing tasks. Their vulnerable position is echoed in their greater desire for conversations with care professionals about their needs for both their own self-care and in providing care to their loved one. They are more likely to want help or information about managing stress and their care recipient’s incontinence, and are more supportive of respite service policies.

¹⁴ These profiles of 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 providing 0–20 hours of care weekly.

How do caregivers of adults spend their time? A majority of caregivers help their loved one with at least one personal care task, often referred to as Activities of Daily Living (ADLs; 59%), most commonly helping their care recipient get in and out of beds and chairs (43%). Higher-hour caregivers more often perform each ADL.

Figure 7: Help with Activities of Daily Living (ADLs)
 Q22. Which of these do/did you help your [relation] with?

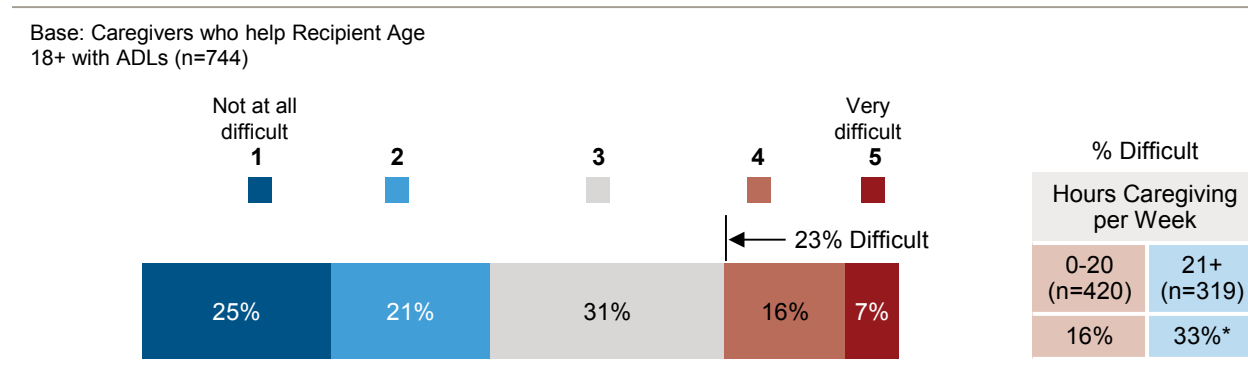


Among those performing ADLs, one in four find it difficult, with higher-hour caregivers more likely to report experiencing this difficulty. Half of caregivers providing assistance with all six ADLs find it difficult (48%).

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%).

Figure 8: Difficulties with Activities of Daily Living

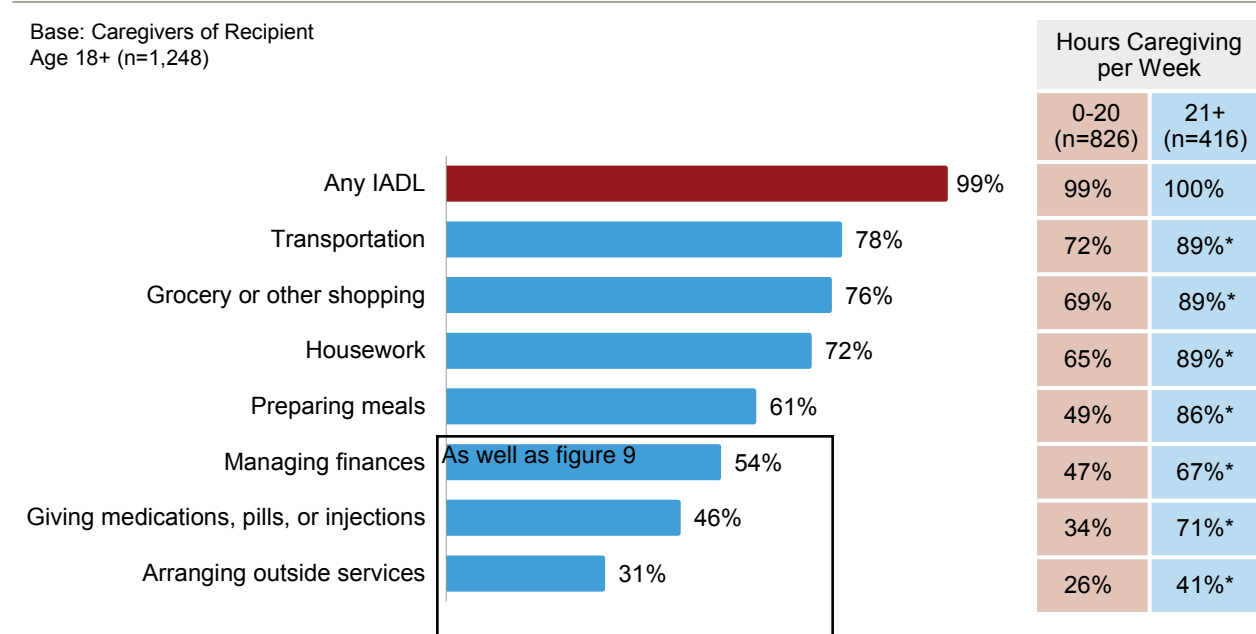
N1. (If doing ADLs) How difficult is/was it for you to help your [relation] with these/those kinds of tasks?



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.

Figure 9: Help with Instrumental Activities of Daily Living (IADLs)

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

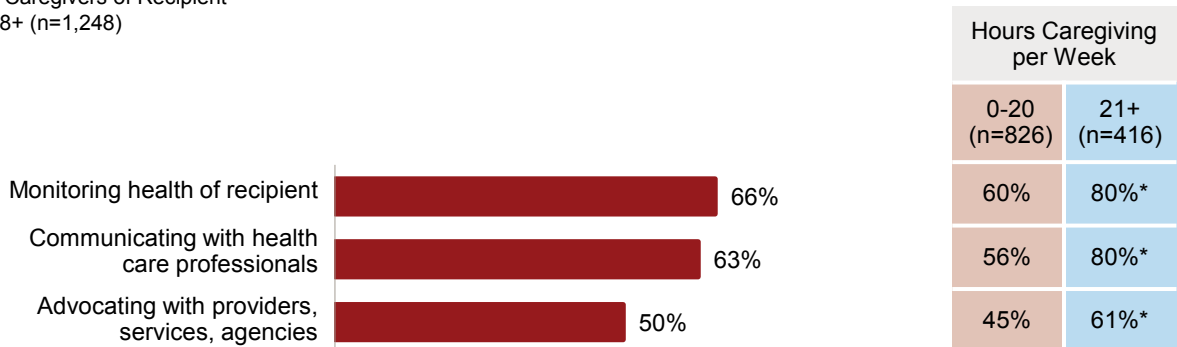


Caregivers' responsibilities often extend beyond the traditional ADLs and IADLs, to interacting with various providers, agencies, and professionals on their care recipient's behalf. Two out of three monitor their care recipients' condition to adjust care, 63 percent communicate with health care professionals, and half advocate for their care 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 caregiver's time.

Figure 10: Help with Other Key Activities
 Q23. And do/did you provide help to your [relation] by...?

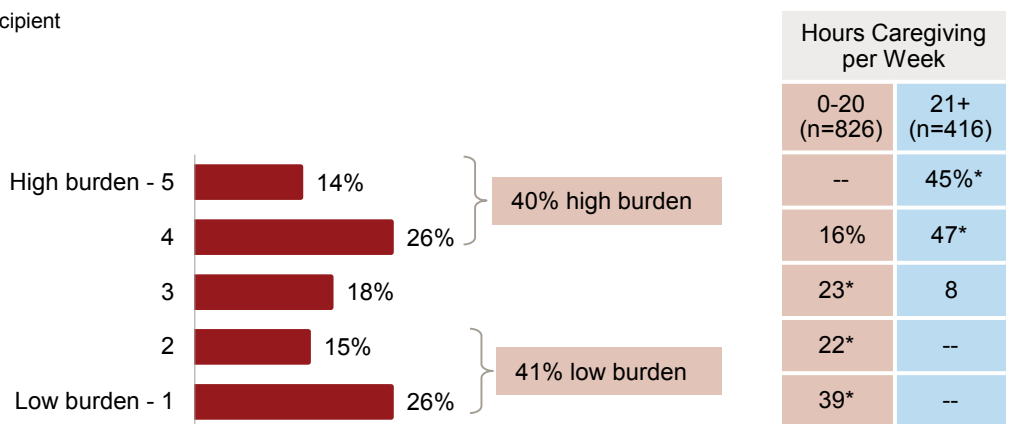
Base: Caregivers of Recipient
 Age 18+ (n=1,248)



The Level of Care, or burden, Index, first created in the 1997 study, is replicated. This index combines caregivers’ reports of their hours of care provided, ADLs, and IADLs.¹⁵ This index reveals 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.

Figure 11: Level of Care Index

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



Medical/Nursing Tasks

Recent research revealed that, in addition to ADLs and IADLs, family caregivers are increasingly performing tasks that nurses typically perform.¹⁶ Known now as “medical/nursing tasks,” these skilled activities include injections, tube feedings,

¹⁵ 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.

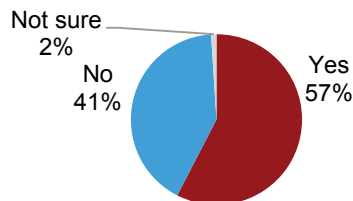
¹⁶ Reinhard, S.C., Levine, C., & Samis, S. *Home Alone: Family Caregivers Providing Complex Chronic Care*. AARP Public Policy Institute & United Hospital Fund, 2012.

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.

Figure 12: 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%*

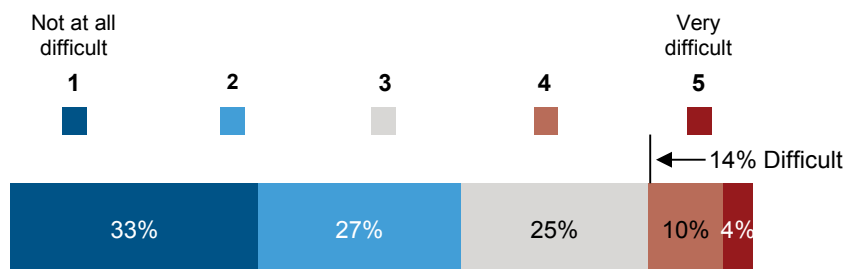
Fourteen percent of those caregivers who assist with medical/nursing tasks find it difficult.

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%).

Figure 13: 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%*

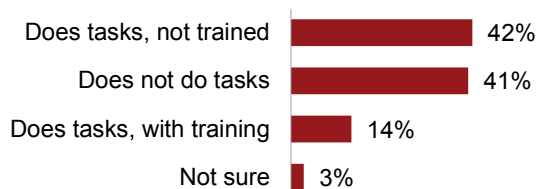
The intersection of feeling prepared to do medical/nursing tasks with actually doing these tasks reveals some important gaps in caregiver preparation. Most commonly, caregivers are doing medical/nursing tasks *without any* preparation (42%). Just 14 percent of caregivers who assist with medical/nursing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

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

Figure 14: 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)
32%	63%*
53*	16
12	19*
3	2

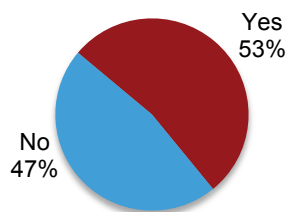
Presence of Other Help

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 percent with no other unpaid help) and those caring for a spouse (78%).

Figure 15: 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%

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.

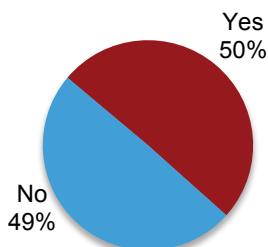
Choice

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.

Figure 16: Choice in Taking on Caregiver Role

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

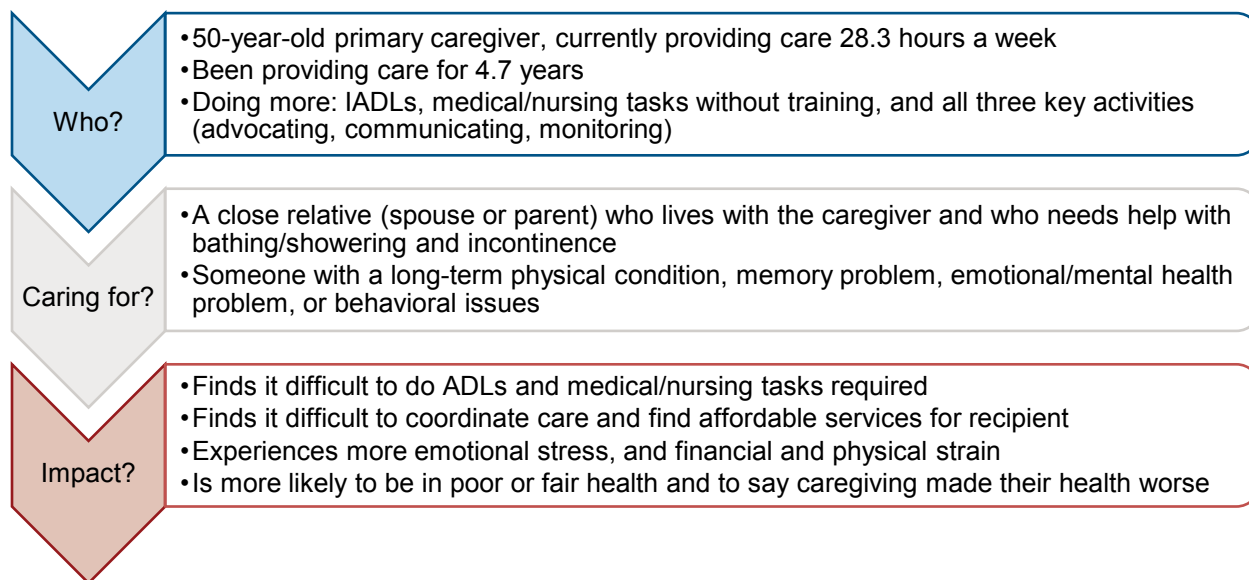
Base: Caregivers of Recipient Age 18+ (n=1,248)



% No	
Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
45%	59%*

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.¹⁷

Figure 17: Spotlight on Caregivers Having No Choice



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

¹⁷ These profiles of 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 feel they *did* have a choice in taking on their caregiving role.

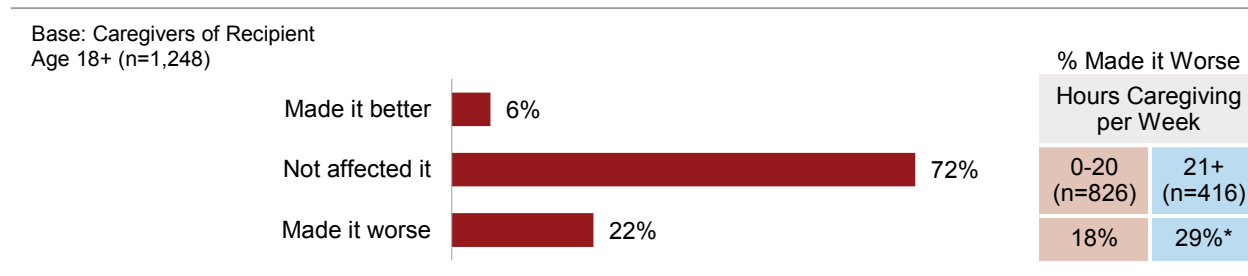
tied to the relationship between the caregiver and care recipient, as well as the presence of other unpaid family caregivers. However, providing supportive services to caregivers who feel this sense of “obligation” may help mitigate some of the negative impacts arising from the complex care situations 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 (presented later) 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 describes their health as *fair* or *poor*.¹⁸ 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 feel their health has gotten worse as a result of caregiving.

Figure 18: Impact of Caregiving on Caregiver's Health
 D2. How would you say taking care of your [relation] has affected your health?



Caregivers in more complex, demanding care situations—including those caring for someone with a mental health issue (34% worse health), coresident caregivers (30%), higher-hour caregivers (29%), those doing medical/nursing tasks (27%), and primary caregivers (25%)—are more likely to report worsening health.

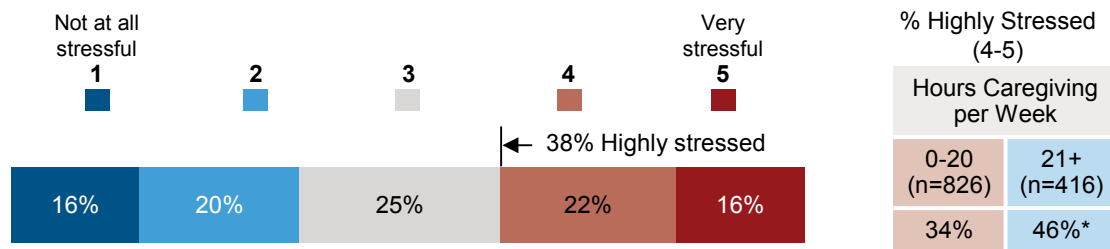
One in five caregivers reports a high level of physical strain resulting from caregiving (19%), while two in five consider their caregiving situation to be emotionally stressful (38%).

¹⁸ CDC/NCHS, National Health Interview Survey, January–June 2014, Family Core component.

Figure 19: Emotional Stress of Caregiving

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

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



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%).

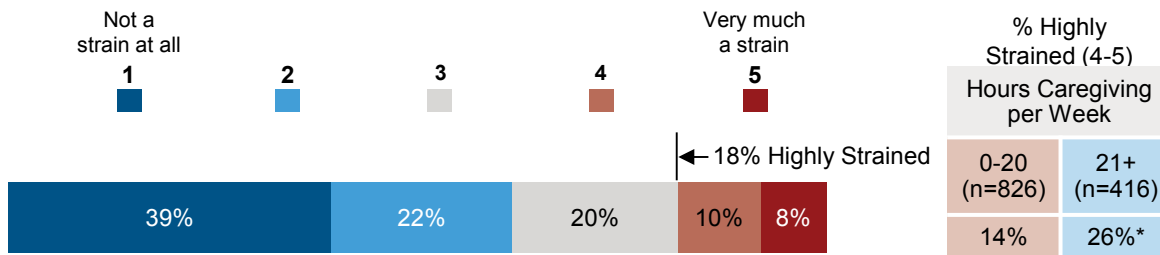
Caring for a close relative, like a spouse or parent (45% and 44%, respectively), is more emotionally stressful for caregivers than caring for another relative (35%) or non-relative (18%). Chronic or long-term conditions among care recipients seem to be particularly likely to cause emotional stress for 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%) reports feeling emotional stress.

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

Figure 20: Financial Strain of Caregiving

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

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



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 4 out of 10 long-distance caregivers report the

use of paid help (41%). In addition, the longer a caregiver has been caring, the more likely he or she is to feel financial strain (22% among those who provided care for a year or longer).

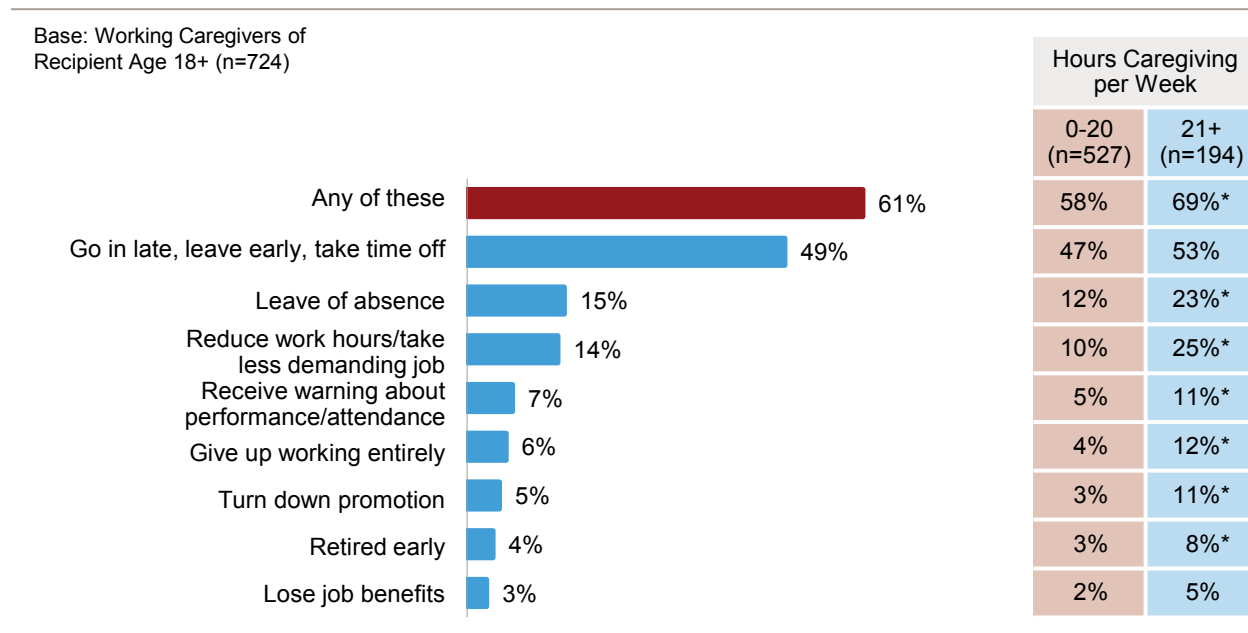
Impact of Caregiving on Work

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 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.

Figure 21: Work Impacts Due to Caregiving

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



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.

Figure 22: Selected Work Impacts by Hours Worked per Week

	Hours Worked per Week		
	Fewer 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%

One in six working caregivers is self-employed or owns his or her own business (17%). In comparison, 9.4 percent of U.S. workers are self-employed.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 better fit their caregiving situation because self-employment 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.²⁰

Figure 23: Hours Worked and Work Impacts by Self-Employment

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

¹⁹ 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.

²⁰ 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%.

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 state their supervisor is aware of their role (76%). As a working caregiver’s burden of care increases, so too does the chance that their 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%). 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.

Figure 24: Workplace Benefits by Hours Worked per Week

	Hours Worked per Week <i>among Those Not Self-Employed</i>		
	Fewer 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	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}

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-

²¹ Among the general U.S. population of private-sector workers, 62% report having at least 1 paid sick day, while 38% 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.

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.

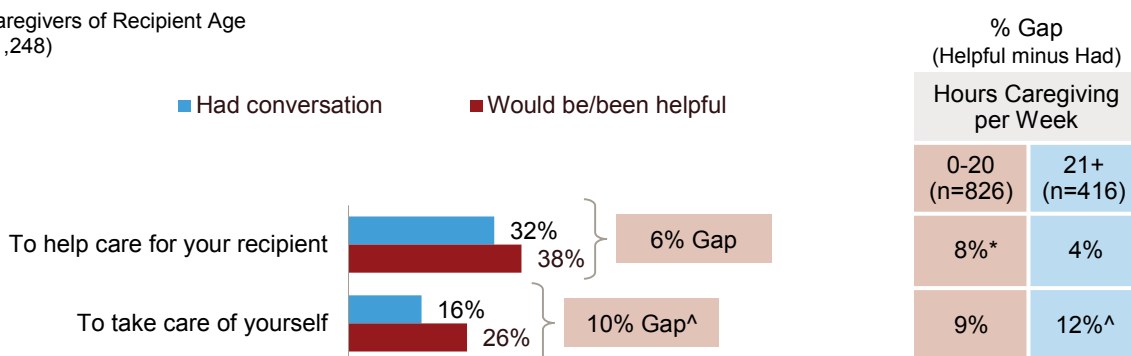
In fact, when we compare the percentage of caregivers who report having had these kinds of conversations with the percentage of caregivers who would find these conversations helpful—the need gap—we see the need is greater than what is being reported by caregivers. For conversations about recipient care, 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.

Figure 25: Need Gap in Conversations with Providers

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



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

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 one's 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.

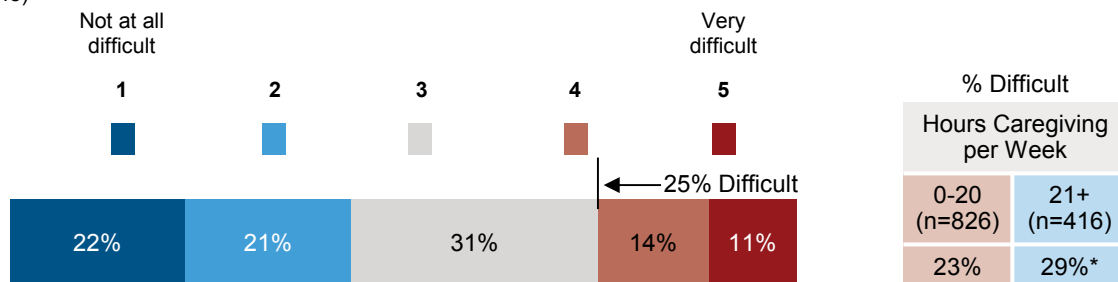
The inability to access affordable services may be an issue for caregivers, especially those in complex care situations. One in four caregivers says it is very difficult to get affordable services in their loved one's community that would help with their care (25%).

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).

Figure 26: 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?

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

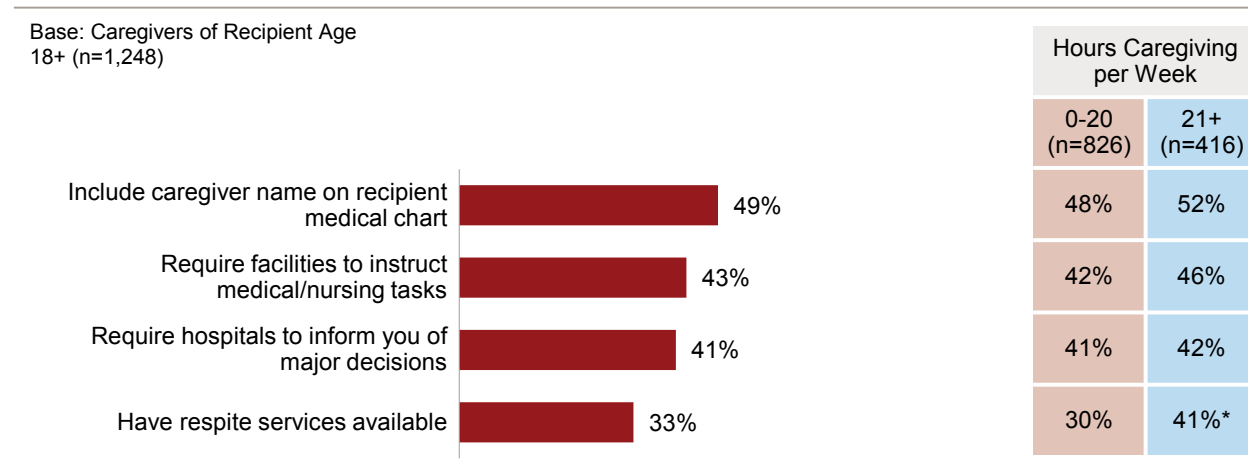


When gauging how helpful several policy proposals might be to their caregiving experience, nearly half of caregivers feel a policy to have their own name on the recipient's medical chart (49%) would be helpful. Roughly 4 in 10 feel it would be helpful to require hospitals to demonstrate medical/nursing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

Figure 27: 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?



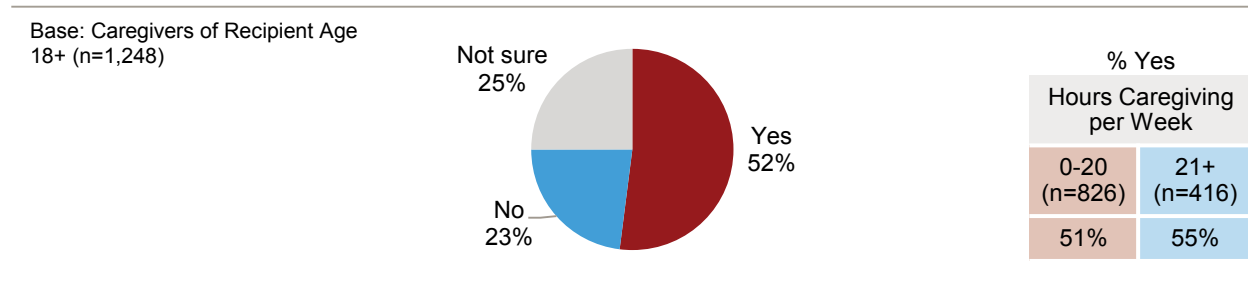
Of three potential national policies or programs focused on providing financial support to caregivers, 3 in 10 caregivers felt that being paid for some of their care hours (30%) and an income tax credit to offset the cost of care (30%) would be most helpful. Higher-hour caregivers are more likely to 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. A similar proportion of higher- and lower-hour caregivers expect to continue their caregiving role in the near future.

Figure 28: 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?



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 end-of-life 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.

IV. Summary and Conclusions

Unpaid family caregiving is an activity that knows no bounds—it cuts across all ages, genders, race/ethnicities, and relationship types. Caregiving experiences can be relatively easy to manage; they can also be challenging and stressful. *Caregiving in the U.S. 2015* draws special attention to those vulnerable groups, like the higher-hour caregivers, who face complex care situations with ever-present demands, resulting in higher emotional stress, financial strain, and declining health for the caregiver.

Caregivers are often performing tasks beyond the traditional Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). They frequently help with more advanced care, such as medical/nursing tasks, that health care professionals might typically perform. Caregivers are acting as advocates and communicators on behalf of their loved ones. They want to have conversations with health care providers about their care recipient's needs. Caregivers also want to discuss their own care needs with health care professionals, and many anticipate continuing to be a caregiver for an adult over the next 5 years. There is a lack of planning for future care among care recipients. Caregivers are working while providing care, resulting in impacts on their work, with some being forced to opt out of the workforce altogether.

Our population is rapidly aging, while the number of available family caregivers in younger generations is diminishing. The nearly 40 million Americans who provide unpaid care to an adult are an extension of, and partner with, our formal health care and long-term services and supports (LTSS) systems. It is essential to support these caregivers by doing the following:

- 1) Identify and help caregivers who are most at risk for deteriorating health, financial security, and quality of life.
- 2) Identify and advocate for programs that could make a real difference in caregivers' well-being and in their ability to continue providing care, including helping them balance paid employment and unpaid care.
- 3) Give caregivers resources to cope with the sometimes unexpected and sudden entry into providing care.
- 4) Extend training to caregivers who perform ADLs, medical/nursing tasks, and other activities, including communicating and interacting with the formal care system.
- 5) Encourage families to proactively plan for and discuss aging and health/disability, including plans for future care and scenarios where the current unpaid caregiver may no longer be able to provide care.

V. 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 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.

Figure 29: 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
<i>Mean age</i>	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

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

Caregivers' median household income of \$54,700 is comparable to the \$53,046 for the United States overall.²² 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.

Demographic Summary by Hours Spent Caregiving per Week (continued)

	Total (n=1,248)	0–20 (n=826) A	21+ (n=416) B
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
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
<i>Median household income</i>	<i>\$54,700</i>	<i>\$59,700</i>	<i>\$45,700</i>
Children/Grandchildren in Caregiver's Household			
Yes	28%	30% ^B	24%
No	70	69	74 ^A

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

²² U.S. Census Bureau, American Community Survey, 2013.

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).²³

Demographic Summary by Hours Spent Caregiving per Week (continued)

	Total (n=1,248)	0–20 (n=826) A	21+ (n=416) B
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% ^B	48%
Not employed	40	34	52 ^A
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.

²³ 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.

About AARP

AARP is a nonprofit, nonpartisan organization, with a membership of nearly 38 million, that helps people turn their goals and dreams into real possibilities, strengthens communities and fights for the issues that matter most to families such as healthcare, employment and income security, retirement planning, affordable utilities and protection from financial abuse. We advocate for individuals in the marketplace by selecting products and services of high quality and value to carry the AARP name as well as help our members obtain discounts on a wide range of products, travel, and services. A trusted source for lifestyle tips, news and educational information, AARP produces AARP The Magazine, the world's largest circulation magazine; AARP Bulletin; www.aarp.org; AARP TV & Radio; AARP Books; and AARP en Español, a Spanish-language website addressing the interests and needs of Hispanics. AARP does not endorse candidates for public office or make contributions to political campaigns or candidates. The AARP Foundation is an affiliated charity that provides security, protection, and empowerment to older persons in need with support from thousands of volunteers, donors, and sponsors. AARP has staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. Learn more at www.aarp.org.

This report was made possible with generous sponsorship from

