CONSENT CALENDAR

April 5, 2022

HOUSE OF REPRESENTATIVES

REPORT OF COMMITTEE

The Committee on Health, Human Services and Elderly Affairs to which was referred SB 414-FN-A,

AN ACT (New Title) relative to the definition of Alzheimer's disease and related disorders. Having considered the same, report the same with the recommendation that the bill OUGHT TO PASS.

Rep. Jerry Knirk

FOR THE COMMITTEE

Original: House Clerk
Cc: Committee Bill File

COMMITTEE REPORT

Committee:	**Health, Human Services and Elderly Affairs**
Bill Number:	**SB 414-FN-A**
Title:	**(New Title) relative to the definition of Alzheimer's disease and related disorders.**
Date:	**April 5, 2022**
Consent Calendar:	**CONSENT**
Recommendation:	**OUGHT TO PASS**

STATEMENT OF INTENT

This bill broadens the definition of Alzheimer’s Disease and Related Disorders (ADRD) in RSA 161-F:66 to include individuals who have not received a formal diagnosis but who have significant dementia symptoms which interfere with activities of daily living. Meeting this definition is necessary to be eligible for respite services under RSA 166-F:67. Family caregivers suffer greatly caring for their loved one(s) at home. The respite program is in place to support family caregivers, therefore supporting care in the less costly home setting rather than in institutions. Clinical diagnosis of Alzheimer’s or related dementias can be difficult and is often delayed due to stigma, patient and family denial, problems accessing the appropriate specialists, and cost barriers to obtaining care. This bill will improve our respite program by increasing eligibility.

Vote 21-0.

Rep. Jerry Knirk
FOR THE COMMITTEE

Original: House Clerk
Cc: Committee Bill File

CONSENT CALENDAR

Health, Human Services and Elderly Affairs
SB 414-FN-A, (New Title) relative to the definition of Alzheimer's disease and related disorders. **OUGHT TO PASS.**
Rep. Jerry Knirk for Health, Human Services and Elderly Affairs. This bill broadens the definition of Alzheimer's Disease and Related Disorders (ADRD) in RSA 161-F:66 to include individuals who have not received a formal diagnosis but who have significant dementia symptoms which interfere with activities of daily living. Meeting this definition is necessary to be eligible for respite services under RSA 166-F:67. Family caregivers suffer greatly caring for their loved one(s) at home. The respite program is in place to support family caregivers, therefore supporting care in the less costly home setting rather than in institutions. Clinical diagnosis of Alzheimer's or related dementias can be difficult and is often delayed due to stigma, patient and family denial, problems accessing the appropriate specialists, and cost barriers to obtaining care. This bill will improve our respite program by increasing eligibility. **Vote 21-0.**

Original: House Clerk
Cc: Committee Bill File

HOUSE COMMITTEE ON HEALTH, HUMAN SERVICES AND ELDERLY AFFAIRS

EXECUTIVE SESSION on Bill # SB414-FN-A

TITLE: AN ACT relative to the definition of Alzheimer's disease and related disorders.

DATE: **4/5/2022**

LOB ROOM: 205-7

MOTION:

OTP

Moved by Rep. Knirk Seconded by Rep. Pearson Vote: 21-0

CONSENT CALENDAR: __X___ YES _____ NO

Minority Report? ______ Yes ______ No If yes, author, Rep:______________ Motion __________

baf

Respectfully submitted: ____

Rep. Beth Folsom, Clerk

STATE OF NEW HAMPSHIRE
OFFICE OF THE HOUSE CLERK

9/28/2021 11:15:01 AM
Roll Call Committee Registers
Report

2022 SESSION

Health, Human Services and Elderly Affairs

Bill #: SB414-FN-A **Motion:** OTP **AM #:** **Exec Session Date:** 4/5/2022

Members	YxEAS	Nays	NV
Pearson, Mark A. Chairman	X		
Layon, Erica J. Vice Chairman	X		
McMahon, Charles E.	X		
Acton, Dennis F.	X		
Gay, Betty I.	X		
Cushman, Leah P.	X		
Folsom, Beth A. Clerk	X		
Kelsey, Niki	X		
King, Bill C.	X		
Kofalt, Jim	X		
DeLemus, Susan	X		
Weber, Lucy M.	X		
MacKay, James R.	X		
Snow, Kendall A.	X		
Knirk, Jerry L.	X		
Salloway, Jeffrey C.	X		
Cannon, Gerri D.	X		
Nutter-Upham, Frances E.	X		
Schapiro, Joe	X		
Woods, Gary L.	X		
Merchant, Gary	X		
TOTAL VOTE:	21	0	

HOUSE COMMITTEE ON HEALTH, HUMAN SERVICES AND ELDERLY AFFAIRS

PUBLIC HEARING on Bill # SB414

BILL TITLE: AN ACT relative to the definition of Alzheimer's disease and related disorders.

DATE: **4/5/2022**

ROOM: **LOB 205-7** **Time Public Hearing Called to Order: 11:37am**

Time Adjourned: 11:55am

<u>Committee Members</u>: **Reps. M. Pearson, Layon, Folsom, Acton, McMahon, Cushman, Kelsey, Gay, B. King, Kofalt, MacKay, DeLemus, Weber, Knirk, Nutter-Upham, Salloway, Snow, Cannon, Schapiro, Woods and Merchant,**

TESTIMONY

Rep. Knirk introduced the bill.

- The bill revises the definition of ADRD to include those who demonstrate symptoms of Alzheimer’s or other conditions of similar irreversible dementia. This broadens the spectrum to be eligible for respite services.
- Symptoms that would interfere with daily living make an individual eligible for respite services.

Mackenzie Nicholson, Alzheimers Association – Supports

- Caregivers have a difficult job, this would help them with a break before they get burned out. Some medical providers are resistant for one reason or another to make the official Alzheimer’s diagnosis. This just expands the definition so more families can qualify for a respite care grant.

Wendy Aultman, DHHS, Bureau Chief for Elderly and Adult Services - Supports

- Resources have been earmarked to go toward respite grants.
- DHHS works with families and may do a home visit to see if they qualify for respite care
- Doctors often refer patients to the program.
- ARPA funds are helping to cover costs
- Monitoring with proceed and if additional funds are needed they will go through the proper legislative budget process.

Respectfully submitted,

Rep. Beth Folsom, Clerk

SIGN UP SHEET

To Register Opinion If Not Speaking

Bill #: SB414

Date: 4/5/22

Committee: HHS & EA

**** Please Print All Information ****

Name	Address	Phone	Representing	Pro	Con
Heather Carroll			NH AHA	✓	
Susan Buxton	Office of LTC Ombudsman + NH Comm. Aging			✓	

House Remote Testify

Health, Human Services and Elderly Affairs Committee Testify List for Bill SB414 on 2022-04-05

Support: 13 Oppose: 1 Neutral: 0 Total to Testify: 0

Export to Excel

Name	City, State Email Address	Title	Representing	Position	Testifying	Non-Germane	Signed Up
Carson, Senator Sharon	SD 14, NH sharon.carson@leg.state.nh.us	An Elected Official	Myself	Support	No	No	3/29/2022 12:22 PM
Birdsell, Senator Regina	Hampstead, NH regina.birdsell@leg.state.nh.us	An Elected Official	Senate District 19	Support	No	No	3/29/2022 12:37 PM
Watters, Senator David	Dover, NH david.watters@leg.state.nh.us	An Elected Official	Myself	Support	No	No	3/30/2022 8:35 AM
Rosenwald, Cindy	Nashua, NH cindy.rosenwald@leg.state.nh.us	An Elected Official	SD 13	Support	No	No	4/1/2022 11:52 AM
French, Senator Harold	Canterbury, NH kathryn.cummings@leg.state.nh.us	An Elected Official	Senate District 7	Support	No	No	4/1/2022 1:39 PM
Soucy, Donna	Manchester, NH donna.soucy@leg.state.nh.us	An Elected Official	SD 18	Support	No	No	4/1/2022 4:15 PM
Lacroix, Marc	Concord, NH Malacroix@aol.com	A Member of the Public	Myself	Support	No	No	4/2/2022 2:50 PM
Donnelly, Ryan	Hudson, NH rdonnelly@gsil.org	A Member of the Public	Granite State Independent Living	Support	No	No	4/4/2022 2:26 PM
Hennessey, Erin	Senate District 1, NH peter.oneill@leg.state.nh.us	An Elected Official	Myself	Support	No	No	4/4/2022 4:21 PM
Hallock, Linda	Cornish, NH LINDASH@MAIL.COM	A Member of the Public	Myself	Oppose	No	No	4/4/2022 6:38 PM
Reagan, Senator John	Deerfield, NH kathryn.cummings@leg.state.nh.us	An Elected Official	Senate District 17	Support	No	No	4/5/2022 8:41 AM
Delaney, Jennifer	Concord, NH jddelaney@aarp.org	A Lobbyist	AARP New Hampshire	Support	No	No	4/5/2022 10:23 AM
Desrosiers, Roger	Concord, NH rdesros@comcast.net	A Member of the Public	Myself	Support	No	No	4/5/2022 10:32 AM

Fortier, Merry	Canterbury, NH mfortier28@gmail.com	A Member of the Public	Myself	Support	No	No	4/5/2022 10:50 AM

Archived: Friday, April 22, 2022 9:19:08 AM
From: Delaney, Jennifer
Sent: Tuesday, April 5, 2022 10:28:40 AM
To: ~House Health Human Services and Elderly Affairs
Subject: AARP NH Testimony in Support of SB414
Importance: Normal
Attachments:
AARPNHSB414Testimony4-4-22.pdf ;Caregiving in the U.S. 2020 - AARP Research Report.pdf ;

Dear Chairman Pearson and House Health, Human Services and Elderly Affairs Committee Members,

Please find attached herewith AARP NH Testimony in Support of Senate Bill 414 before the Committee on April 5, 2022, and a 2020 AARP Report on Caregiving in the U.S. for your reference.

Thank you for your consideration.

Sincerely,

Jennifer Delaney
Associate State Director for Advocacy and Outreach
AARP New Hampshire | 45 South Main Street, Suite 202 | Concord, NH 03301
O 603.230.4106 | C 603.937.4230
www.aarp.org/nh

AARP New Hampshire

45 South Main Street | Concord, NH 03301
1-866-542-8168 (toll free) | Fax:1-603-224-6211
aarp.org/nh | nh@aarp.org | twitter: @aarpnh
facebook.com/nh

April 5, 2022

Chairman Mark Pearson
Health, Human Services and Elderly Affairs Committee
New Hampshire House
Legislative Office Building, Room 205
Concord, New Hampshire 03301

RE: AARP New Hampshire Testimony in Support of SB 414

Dear Chairman Pearson and Committee Members:

Thank you for your support on the issues most important to residents 50+ in the Granite State. AARP NH urges favorable passage of Senate Bill No. 414 relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders (ADRD) and making an appropriation therefor.

177,000 caregivers across the Granite state provide on average 148 hours of care per year, with a value of $2.3 billion to the State. While Alzheimer's disease is the most common cause of dementia in older adults, other irreversible dementia related disorders interfere with daily living and require caregiving services. It is critical that all ADRD caregiver have access to respite care, and appropriations are made for this purpose. According to the AARP Public Policy Institute:

- More Americans (26%) are caring for someone with Alzheimer's disease or dementia up from 22% in 2015.
- More Americans (23%) say caregiving has made their own health worse up from 17% in 2015.
- Family caregiving spans across all generations, including Boomers, Gen-X, Gen-Z, Millennials, and Silent.
- 61% of family caregivers are also working.

Today, 42 million caregivers provide an invaluable resource in caring for friends and family at home — many on call 24 hours a day, seven days a week. Caring for a loved one with ADRD can be particularly taxing. This labor of love is worth more than $450 billion in unpaid care each year. And because of family caregivers' commitment, millions of older people are able to live at home rather than in costly institutions such as nursing homes. Respite care provides caregivers a temporary rest from caregiving, while the person living with ADRD continues to receive care in a safe environment.

AARP is fighting to make sure respite care programs are available in the community to all caregivers and strongly urges the Health, Human Services and Elderly Affairs Committee to favorably report out Senate Bill 414. Thank you.

Respectfully submitted,

	AARP New Hampshire		AARP New Hampshire
By:	*S.*	By:	*S.*
	Todd C. Fahey, J.D. State Director tfahey@aarp.org (603) 738-9260 (c) (603) 230-4109 (o)		Jennifer A. Delaney Associate State Director - Advocacy jddelaney@aarp.org (603) 937-4230(c) (603) 230-4106 (o)

https://www.aarp.org/content/dam/aarp/ppi/2019/11/family-caregivers-data-by-state.pdf

https://www.aarp.org/ppi/info-2020/caregiving-in-the-united-states.html

RESEARCH REPORT MAY 2020

2020 Report

Caregiving in the U.S.

Conducted by

AARP Family Caregiving™

National Alliance for Caregiving

Bottom left cover photo courtesy of Mediteraneo/stock.adobe.com.

Acknowledgments

The National Alliance for Caregiving (NAC) and AARP are proud to present *Caregiving in the U.S. 2020*. Many people played important roles throughout the research process, including:

C. Grace Whiting, JD, President and Chief Executive Officer, National Alliance for Caregiving

Patrice A. Heinz, Vice President, Strategy & Operations, National Alliance for Caregiving

Gabriela Prudencio, MBA, Hunt Research Director, National Alliance for Caregiving

Michael R. Wittke, BSW, MPA, Senior Director, Public Policy and Advocacy, National Alliance for Caregiving

Susan Reinhard, PhD, Senior Vice President and Director, AARP Public Policy Institute

Lynn Friss Feinberg, MSW, Senior Strategic Policy Advisor, AARP Public Policy Institute

Laura Skufca, MA, Senior Research Advisor, AARP

Robert Stephen, MBA, Vice President, Health & Caregiving, AARP Programs

Rita Choula, MA, Director, Caregiving Projects, AARP Public Policy Institute

ADVISORY PANEL

María P. Aranda, PhD, Associate Professor and Executive Director, USC Edward R. Roybal Institute on Aging, USC Suzanne Dworak-Peck School of Social Work

Joseph E. Gaugler, PhD, Robert L. Kane Endowed Chair in Long-Term Care and Aging and Professor, School of Public Health, University of Minnesota

Carol Levine, MA, Senior Fellow, United Hospital Fund, New York City (former Director of UHF Families and Health Care Project)

Feylyn Lewis, PhD, Research Fellow, University of Sussex

David Lindeman, PhD, Director Health, Center for Information Technology Research in the Interest of Society (CITRIS), UC Berkeley; Director, Center for Technology and Aging (CTA)

Nancy E. Lundebjerg, MPA, Chief Executive Officer, American Geriatrics Society

Steve Schwab, CEO, Elizabeth Dole Foundation (with special thanks to Laurel Rodewald)

Regina A. Shih, PhD, Senior Policy Researcher, RAND Corporation

The research was conducted by Greenwald & Associates with study direction by Lisa Weber-Raley, Senior Vice President, and project support from Karina Haggerty, Rashanda McLaurin, and Christina Baydaline. (www.greenwaldresearch.com)

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AARP
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EMD Serono Inc.
Home Instead Senior Care®
TechWerks
The Gordon and Betty Moore Foundation
The John A. Hartford Foundation
Transamerica Institute
UnitedHealthcare

Table of Contents

Figures

I. Introduction

This study presents a portrait of unpaid family caregivers[1] today. The National Alliance for Caregiving (NAC) and AARP are proud to present *Caregiving in the U.S. 2020*, based on data collected in 2019.

A national profile of family caregivers first emerged from the 1997 *Caregiving in the U.S.* study. Related studies were conducted in 2004, 2009, and 2015 by NAC in collaboration with AARP. This study builds on those prior efforts and replicates the new methodology implemented in 2015, allowing for examination of changes to caregiving since the last data collection effort in 2015.

The core areas 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
- Financial impact on caregivers
- Impacts on and supports provided to working caregivers
- Information needs and resources
- Technology and role of online supports

Because adult caregivers' circumstances can vary markedly depending on the age of their care recipient, NAC and AARP will be publishing two companion reports in the coming months that separately explore the experiences of caregivers whose recipient is (a) age 18 to 49, with trend comparisons to the 2015 study; and (b) age 50 or older, with trend comparisons to the 2015 study.

OVERVIEW OF METHODOLOGY

This report is based on nationally representative quantitative online surveys with 1,392 caregivers ages 18 and 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.*

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[1] Family caregivers are not exclusively related to the person they are providing care to; they include any adult who provides unpaid care or support to a family member or friend.

Additionally, 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[2]:

> *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.*

While caregivers of someone of any age were eligible to complete the full online survey, this report summarizes the findings for those caring for an adult only. Results from the screening question about caring for a child with special needs were included in the prevalence estimates only. A special report on family caregivers of children with special needs will be published in a forthcoming report. The questionnaire was designed to replicate many of the questions posed in the 1997, 2004, 2009, and 2015 NAC/AARP *Caregiving in the U.S.* studies, as well as to explore new areas. The full questionnaires, for both web and phone administration, are presented in appendix A to this report.

Caregiving in the U.S. 2020 utilized Ipsos' (formerly Gfk) national, probability-based, online KnowledgePanel® as was used in the 2015 wave. For more information about KnowledgePanel®, see appendix B to this report. Online surveys were conducted with a random sample of 1,320 caregivers. To supplement this random sample, 179 additional online surveys were conducted via targeted sampling of racial/ethnic groups, yielding the 1,499 base study, full online surveys with caregivers[3] (by race/ethnicity: 858 non-Hispanic White caregivers, 215 non-Hispanic African American caregivers, 222 Hispanic caregivers, 130 Asian American caregivers,[4] and 74 caregivers of another race/ethnicity). In addition to the 1,499 caregivers in the base study, the study included an oversample of 160 older caregivers ages 75 and older. Further, 80 Asian American caregivers were surveyed via telephone (73 landline and 7 cell phone) to bring the total Asian American subsample to 210 caregivers (197 caring for an adult and 13 caring for a child only).

Online respondents were given the option of conducting the survey in Spanish or English, and 31 percent of Hispanic respondents chose the Spanish version. The median length of the survey was 19.5 minutes online and 34.1 minutes via telephone. The surveys were conducted between May 29, 2019, and July 27, 2019.

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

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 2019 Current Population Survey, conducted by the U.S. Census Bureau.

The margin of error for the overall 2020 results is plus or minus approximately 2.5 percentage points at the 95 percent confidence level. This means that 95 times out of 100, a difference of greater than roughly 2.5 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. For a comparison of 2015 and 2020 results for caregivers of adults, see appendix C to this report.

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[2] These two questions used to identify caregivers are the same questions used in *Caregiving in the U.S. 2015*. These questions were also used in the 2009 study with minor wording edits made in 2015 to make them suitable for online self-administration.

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

[4] Asian American is defined to align with the U.S. Census and is inclusive of those of origin, background, or descent of areas of Southeast Asia, Indian subcontinent, and East Asia, as well as the Pacific Islands.

READING THIS REPORT

This report is based on a nationally representative quantitative online survey with 1,392 caregivers ages 18 and older who cared for an adult in the 12 months prior to the time of the survey. The sample sizes shown throughout represent the unweighted number of people who answered each question. All substantive results (means, medians, percentages) have been weighted and rounded.

To signal statistically significant differences between subgroup findings, the report uses an asterisk to highlight any numerical result that is significantly higher than the comparison group, at the 95 percent confidence level. When more than two groups are being compared in columns of a table, a superscript letter next to a numerical result indicates it is significantly higher (at the 95 percent confidence level) than the numerical result in the column designated by that letter.

In the graphics, significant increases or decreases are displayed as the percentage point change from 2015 to 2020 along with a graphic up or down arrow.

All substantive results (means, medians, percentages) 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.

II. Executive Summary

Family and friends comprise the most basic unit of any society. For individuals who take on the responsibility of caring for another person through sickness or disability, it can often be challenging to see beyond the individual experience. Yet in the aggregate, family caregivers—whether they be families of kin or families of choice—are woven into the fabric of America's health, social, economic, and long-term services and supports (LTSS) systems. As the country continues to age, the need to support caregivers as the cornerstone of society will only become more and more important.

Today, more than 1 in 5 Americans (21.3 percent) are caregivers, having provided care to an adult or child with special needs at some time in the past 12 months. This totals an estimated 53.0 million adults in the United States, up from the estimated 43.5 million caregivers in 2015.[5]

When looking at caregivers for adults only, the prevalence of caregiving has risen from 16.6 percent in 2015 to 19.2 percent in 2020—an increase of over 8 million adults providing care to a family member or friend age 18 or older, primarily driven by a significant increase in the prevalence of caring for a family member or friend who is age 50 or older. Figure 1 shows the prevalence rate, estimated number of caregivers in the United States, and change in the past five years.

Figure 1. Prevalence of Caregiving by Age of Care Recipient, 2020 Compared to 2015

	2020 Prevalence	Estimated Number of U.S. Adults Who Are Caregivers	2015 Prevalence	Estimated Number of U.S. Adults Who Are Caregivers
Overall	21.3%*	53.0 million	18.2%	43.5 million
Caregivers of recipients ages 0–17	5.7%*	14.1 million	4.3%	10.2 million
Caregivers of recipients ages 18+	19.2%*	47.9 million	16.6%	39.8 million
Caregivers of recipients ages 18–49	2.5%	6.1 million	2.3%	5.6 million
Caregivers of recipients ages 50+	16.8%*	41.8 million	14.3%	34.2 million

** Significantly higher than in 2015.*

Compared to 2015, a greater proportion of caregivers of adults are providing care to multiple people now, with 24 percent caring for two or more recipients (up from 18 percent in 2015). This finding, in combination with the increased prevalence of caregiving, suggests a nation of Americans who continue to step up to provide unpaid care to family, friends, and neighbors who might need assistance due to health or functional needs. This increase in prevalence may be due to any of the following:

- The increasingly aging baby boomer population requiring more care
- Limitations or workforce shortages in the health care or long-term services and supports (LTSS) formal care systems
- Increased efforts by states to facilitate home- and community-based services
- Increasing numbers of Americans who are self-identifying that their daily activities, in support of their family members and friends with health or functional limitations, *are* caregiving
- The confluence of all of these trends

---

[5] As with previous *Caregiving in the U.S.* studies, prevalence estimates include those who have provided care in the 12 months before the time they were surveyed, whether they were a caregiver at the time of survey or had been a caregiver in the prior 12 months but no longer were. With the margin of error, the estimated prevalence of being a caregiver for anyone in 2020 is 20.4 percent to 22.2 percent, which is outside the range estimated in 2015 of 17.3 percent to 19.1 percent.

The demographic characteristics of caregivers remain largely unchanged since 2015: caregiving remains an activity that occurs among all generations, racial/ethnic groups, income or educational levels, family types, gender identities, and sexual orientations. The shifts we do see in caregiver demographics reflect general changes in the demographic composition of the U.S. population over the past five years.

Six in 10 caregivers report being non-Hispanic White (61 percent), 17 percent are Hispanic or Latino, 14 percent non-Hispanic African American or Black, 5 percent Asian American and Pacific Islander, and 3 percent some other race/ethnicity, including multiracial. One in 10 is a student enrolled in college or other classes (11 percent), while 9 percent have served on active duty in the U.S. Armed Forces. Eight percent self-identify as lesbian, gay, bisexual, and/or transgender[6] (LGBTQ).

Most caregivers of adults care for a relative (89 percent), typically a parent or parent-in-law (50 percent), spouse or partner (12 percent), grandparent or grandparent-in-law (8 percent), or adult child (6 percent), though 10 percent provide care to a friend or neighbor. Many caregivers live together with their recipient (40 percent), a proportion that has grown since 2015 (34 percent). As in 2015, older caregivers tend to take care of similar-aged recipients, with 74 percent of caregivers ages 75 and older caring for a recipient age 75 or older, while younger caregivers tend to take care of someone older than themselves (81 percent of caregivers ages 18 to 49 care for someone age 50 or older).

Caregivers report that the adults who receive care (the "care recipient") have greater health and functional needs than was reported by caregivers in 2015. Compared to 2015, caregivers are more likely to report their adult care recipient needs care because of long-term physical conditions (63 percent, up from 59 percent in 2015), emotional or mental health issues (27 percent, up from 21 percent), and memory problems (32 percent, up from 26 percent), including Alzheimer's or dementia (26 percent, up from 22 percent in 2015). This increasing comorbidity[7] of conditions that require care, with caregivers reporting their recipient has 1.7 conditions categories on average (up from 1.5 in 2015), suggests that not only are more American adults taking on the role of unpaid caregiver, but they are doing so for adult recipients who may have increasingly complex medical or support needs.

The data suggest many caregivers may be taking on this role without adequate and affordable services and supports in place. Despite the increasing complexity of care recipients' conditions, fewer caregivers report their recipient had been hospitalized overnight (48 percent, down from 53 percent in 2015)[8] and just 3 in 10 report their recipient has any paid help (31 percent). The health care and LTSS systems in the United States can often be dispersed or fragmented, with many different settings to go to for care, services, or supports,[9] which can be frustrating, stressful, and costly.[10] Caregivers navigate this system—and face the choices in where to go for care and the implication it has for costs—along with their recipients. Our data suggest that this journey through the care system may not always be easy as, since 2015, more caregivers say it is difficult to coordinate their recipient's care across various providers (26 percent, up from 19 percent).[11] About one in 4 also report it is difficult to get affordable services in their recipient's area (27 percent).

---

[6] This includes anyone self-identifying as gay or lesbian, bisexual, or some other sexual orientation other than "straight, that is, not gay," as well as anyone self-identifying as transgender or some other transgender status other than "male" or "female."

[7] Comorbidity is when a person has more than one health issue or condition at the same time.

[8] Analysis of trends in hospital inpatient stays suggests this is occurring overall. See R. Sun, Z. Karaca, and H. S. Wong, "Trends in Hospital Inpatients Stays by Age and Payer, 2000–2015," HCUP Statistical Brief #235, Agency for Healthcare Research and Quality, Rockville, MD, January 2018, www.hcup-us.ahrq.gov/reports/statbriefs/sb235-Inpatient-Stays-Age-Payer-Trends.pdf.

[9] For a description of the health care system changes, see Mark Miller, "The Decade in Retirement: Wealthy Americans Moved Further Ahead," *New York Times*, December 14, 2019, https://www.nytimes.com/2019/12/14/business/retirement-social-security-recession.html.

[10] National Academies of Sciences, Engineering, and Medicine, *Families Caring for an Aging America* (Washington, DC: The National Academies Press, 2016).

[11] Among those who coordinate care, these percentages rise to 31 percent finding it difficult to coordinate care in 2020, up from 23 percent in 2015.

The support and complex care tasks the nation's caregivers provide are largely unchanged since 2015, with today's caregivers providing about 24 hours of care each week. As in 2015, nearly all of today's caregivers help with Instrumental Activities of Daily Living (IADLs; 99 percent), 6 in 10 help with Activities of Daily Living (ADLs; 60 percent), and nearly 6 in 10 help with medical/nursing tasks (58 percent). The Level of Care Index measuring the intensity of the caregiving situation is similar to 2015 (40 percent in a high-intensity care situation[12]).

The impact of disease or disability can ripple beyond the caregiver and recipient. Other members of the family or community, such as children in the home, may be called upon to carry out care tasks. About half of caregivers say there are others who provide unpaid help to their care recipient (53 percent). Among those who report the presence of other unpaid help, 14 percent say *at least* one of those unpaid caregivers is a child under age 18—so out of all caregivers of adults, 7 percent report the presence of a child caregiver. Beyond the estimated 48 million caregivers of adults in the United States, an additional 3.4 million child caregivers may be standing in their shadow.[13,14,15]


Photo credit: iStock.com/AlexRaths

While many caregivers feel their role has given them a sense of purpose or meaning (51 percent), these positive emotions often coexist with feelings of stress or strain. Caregivers report physical, emotional, and financial strain, with 2 in 10 reporting they feel alone (21 percent). When compared to 2015, fewer caregivers report their health status as excellent or very good (41 percent, down from 48 percent in 2015) and a greater proportion report being in fair or poor health (21 percent, up from 17 percent in 2015). One in 4 find it difficult to take care of their own health (23 percent) and a similar proportion report caregiving has made their own health worse (23 percent). This decline in caregiver self-reported health is concerning, as the stress associated with caregiving may exacerbate declines in health that occur with age. This means that supports for caregivers and their recipients will be even more critical if this trend in declining caregiver health continues to hold. From a policy perspective, the strain of disease or disability on a family unit can endanger larger system goals to improve health care and

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[12] The 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, 2009, and 2015 *Caregiving in the U.S.* studies, is replicated to convey the intensity or complexity of the caregiving situation. This index provides one way to articulate the impact of a disease or disability on the people who care for a patient during the caregiver journey. The index is based on the number of hours of care given as well as the number of ADLs and IADLs performed. High intensity is scoring a 4 or 5 on the 5-level index. The details of index construction are shown in appendix B.

[13] This may be an underestimate as the literature shows that adults are often hesitant to say that children are providing care. See C. Levine, "More Than 1 Million Young Caregivers Live in the United States, but Policies Supporting Them Are Still 'Emerging,'" *Health Affairs Blog*, August 7, 2017, https://www.healthaffairs.org/do/10.1377/hblog20170807.061390/full/.

[14] For comparison, 11.2 percent of caregivers of adults report living with their care recipient and there being children or grandchildren under the age of 18 also living in the same home at the time of care. This would project out 5.4 million child caregivers providing care to an adult, if at least one child in each of these households provided care.

[15] Past estimates of the number of child caregivers in the United States placed the estimate at 1.3 million children. See G. Hunt, C. Levine, and L. Naiditch, "Young Caregivers in the U.S.: Report of Findings," National Alliance for Caregiving and United Hospital Fund, New York, NY, September 2005, https://www.caregiving.org/wp-content/uploads/2020/05/youngcaregivers.pdf.

reduce overall costs in an increasingly strained system. Caregivers who cannot care for themselves may become unavailable to care for others; likewise, caregivers have their own financial, health, and wellness needs, which begs the question, "Who will care for the caregivers?"

The shift in health care to community-based settings rather than traditional residential care settings[16] puts additional pressure on families to fill the gaps in LTSS. Caregivers increasingly provide and monitor complex care at home, navigating the care system, advocating for their care recipient, and paying for services to help the person with care needs.[17] While many caregivers rely on health care professionals (such as doctors, nurses, or social workers) as a source of information about providing care (55 percent), very few report having conversations with them about what they need to care for their recipient (29 percent) or to support their own well-being (13 percent).

The economic effects of family caregiving can result in financial strain with substantial financial consequences. One in 5 caregivers report high financial strain as a result of caregiving (18 percent). Four in 10 have experienced at least one financial impact as a result of their caregiving (45 percent). Most commonly, 3 in 10 have stopped saving (28 percent) and 1 in 4 have taken on more debt (23 percent), both of which could have longer-term repercussions on caregivers' financial security into the future, especially if the caregiving situation lasts a long time. Caregivers of adults find themselves providing care for 4.5 years, on average, and an increasing proportion have been providing care for 5 years or longer (29 percent, up from 24 percent in 2015).

In fact, caregivers' savings are eroding, with 22 percent who used up personal short-term savings and 12 percent who used up long-term savings (for things like retirement or education). Two in 10 have left bills unpaid or paid them late (19 percent), while another 15 percent borrowed money from family or friends. One in 10 have been unable to afford basic expenses like food (11 percent).

Six in 10 caregivers report working while caregiving (61 percent) and the majority have experienced at least one work-related impact (61 percent). As in 2015, most working caregivers report going in late, leaving early, or taking time off to accommodate care (53 percent). One in 10 working caregivers have had to give up work entirely or retire early (10 percent). When this happens, caregivers more often face financial impacts (2.9 on average) and are twice as likely to report high financial strain (35 percent). Employers appear to be taking note of the challenges facing caregivers in the workforce. Caregivers more often report having workplace benefits such as paid family leave (39 percent, up from 32 percent) and paid sick days (58 percent, up from 52 percent) than in 2015, likely an effect of a greater number of large employers and state and local governments taking action on paid leave. Despite this progress, most caregivers (61 percent) still report having no paid family leave at their workplace.

Caregivers of adults have information and training needs to support their daily life. Increasingly, caregivers are recognizing that some services and supports, like respite care, would be helpful to their own situation, though actual use of supports and services remains low. Just 14 percent report having used respite, though 38 percent feel it would be helpful (up from 33 percent in 2015). The most common information and support needs are related to keeping their care recipient safe at home (26 percent); managing their own (the caregiver's) stress (26 percent); and navigating forms, paperwork, and eligibility for services (25 percent). The majority of caregivers—about two in three for each—feel an income tax credit (68 percent) or program to pay caregivers to provide care (65 percent) would be helpful to defray the financial costs of care.

Some experts hope that technology might help support caregivers, but only about half of caregivers report using software or other technological tools to help them (53 percent), most commonly, tracking

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[16] J. E. Gaugler, "Innovations in Long-Term Care," in *Handbook of Aging and the Social Sciences*, edited by L. K. George and K. F. Ferraro (London, UK: Academic Press, 2016), 419–39.

[17] See S. C. Reinhard et al., *Home Alone Revisited: Family Caregivers Doing Complex Care* (Washington, DC: AARP Public Policy Institute, 2019); see also C. G. Whiting, N. Boice, and L. Weber-Raley, "Rare Disease Caregiving in America," National Alliance for Caregiving in partnership with Global Genes, Washington, DC, February 2018.

their care recipient's finances (35 percent). Despite how connected and smartphone-centric society is,[18] only 6 in 10 caregivers report going online to do something to help support care (60 percent). Caregivers most commonly go online to find more actual, hands-on help: searching for services, aides, facilities, or other help (32 percent). This may change in the future as millennial and generation X caregivers, who use these online tools more often, could drive continued advancement of and education about these online and technology support tools.

When it comes to looking forward, many caregivers are not preparing for their own or their care recipient's future needs. About half of caregivers expect to be caring for someone in the next five years (54 percent). However, making plans for future care, such as instructions for handling financial matters, health care decisions, or living arrangements, is still not the norm among caregivers: just 44 percent report their recipient has these plans in place and 45 percent of caregivers have their own future care plans in place.

Ultimately, caregivers are us, with one out of every five American adults providing care in a given year—from all walks of life and backgrounds. This research highlights the varied experiences and situations of caregivers in the United States and points to the impacts many caregivers face as a result of their stepping up to help family and friends. Unpaid caregiving is increasing in prevalence and the U.S. population continues to age and live longer with more complex and chronic conditions. Caregivers feel the push and pull of providing care on their time, their financial well-being, their health, their family, their work, and their own personal well-being. They may find themselves in need of information, resources, benefits, or programs—but these things are often difficult to find or access, or too expensive to afford. Unpaid caregivers are serving as a core piece of the health and LTSS systems, as well as the main source for long-term care for adults living at home and in the community.

Of key concern for policy makers and other stakeholders is whether this arrangement is sustainable with the care gap looming on the horizon, as more people need care and fewer potential family members are available to provide that everyday help.[19,20] Without greater explicit support for family caregivers in coordination among the public and private sectors and across multiple disciplines, overall care responsibilities will likely intensify and place greater pressures on individuals within families, especially as baby boomers move into old age. In addition, the caregivers *themselves* require support to ensure they do not suffer deteriorating health effects, financial insecurity, or a combination of these negative impacts. There is an opportunity for public health experts, policy makers, health and social providers, researchers, employers, financial institutions, and other stakeholders to work together to improve the health care and LTSS systems so they better address the needs of caregivers. Together, we can develop and enact solutions to support family caregivers and to improve their well-being and the well-being of those for whom they provide care.

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[18] The Pew Research Center "Mobile Fact Sheet" indicates that 81 percent of Americans own smartphones (see "Mobile Fact Sheet," Pew Research Center, June 12, 2019, https://www.pewresearch.org/internet/fact-sheet/mobile/).

[19] D. Redfoot, L. Feinberg, and A. Houser, "The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers," AARP Public Policy Institute, Washington, DC, 2013, https://www.aarp.org/home-family/caregiving/info-08-2013/the-aging-of-the-baby-boom-and-the-growing-care-gap-AARP-ppi-ltc.html.

[20] J. E. Gaugler and R. L. Kane, eds., *Family Caregiving in the New Normal* (San Diego, CA: Academic Press, 2015).

III. Detailed Findings

A. PREVALENCE OF CAREGIVING

Of the 7,309 people who were screened in the online survey, the proportion of initial respondents who had served as unpaid caregivers was 21.3 percent.[21] Using a 2019 estimate of 249,193,093 Americans ages 18 and older, the study estimates 53.0 million adults have been caregivers to an adult or child in the 12 months prior to the study. This means that today, more than 1 in 5 Americans are caregivers.

The estimated prevalence, as shown in Figure 2, of caring for an adult is 19.2 percent, or 47.9 million Americans, up from 16.6 percent in 2015.[22] The estimated prevalence of caring for a child with special needs under age 18 is 5.7 percent, or 14.1 million Americans, up from 4.3 percent in 2015.[23] Approximately 41.8 million Americans have provided unpaid care to an adult age 50 or older in the prior 12 months (16.8 percent), up from 2015 (14.3 percent).[24]

Figure 2. Estimates of Population Prevalence by Age of Recipient

Type of Recipient	Prevalence	Estimated Number of Caregivers
Overall	21.3%	53.0 million
Only child recipients	2.0%	5.1 million
Only adult recipients	15.6%	38.9 million
Both adult and child recipients	3.6%	9.0 million

The increase in prevalence of caregiving mirrors the face of caregivers: it is up among all racial/ethnic groups, educational levels, work statuses, genders, and nearly all generations,[25] mirroring results found in other studies of caregiving over time.[26] This increase in prevalence may be due to any of the following:

- The increasingly aging baby boomer population requiring more care
- Limitations or workforce shortages in the health care or LTSS formal care systems
- Increased efforts by states to facilitate home- and community-based services
- Increasing numbers of Americans who are self-identifying that their daily activities, in support of their family members and friends with health or functional limitations, *are* caregiving
- The confluence of all of these trends

To see detailed prevalence statistics by demographics and for more information about the prevalence increase, see appendix B to this report.

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[21] 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 a caregiver at the time of survey or had been a caregiver in the prior 12 months but no longer were.

[22] To calculate the prevalence of caring for an adult, add the estimated 15.6 percent caring for an adult only to the 3.6 percent caring for both a child and adult, which yields an estimated prevalence of caring for an adult of 19.2 percent. With the margin of error, the estimated prevalence of being a caregiver for an adult age 18 or older in 2020 is 18.3 percent to 20.1 percent, outside the 2015 estimated range of 15.7 percent to 17.5 percent.

[23] With the margin of error, the estimated prevalence of being a caregiver for a child in 2020 is 5.2 percent to 6.2 percent, outside the 2015 estimated range of 3.8 percent to 4.8 percent.

[24] With the margin of error, the estimated prevalence of caregiving for an adult age 50 or older in 2020 is 15.9 percent to 17.7 percent, outside the 2015 estimate of 13.7 percent to 14.9 percent.

[25] Prevalence of caregiving is increasing among generation Z, who are just aging into eligibility for this study. Millennials, generation X, and baby boomers also show increased prevalence of caregiving compared to 2015, while the silent and greatest generations are declining in their caregiving prevalence as they continue to age. See appendix B for detailed statistics.

[26] See J. L. Wolff et al., “Family Caregivers of Older Adults, 1999–2015: Trends in Characteristics, Circumstances, and Role-Related Appraisal,” *The Gerontologist* 58, no. 6 (2017): 1021–32.

B. BASICS OF THE CAREGIVING SITUATION

Who Are Caregivers?

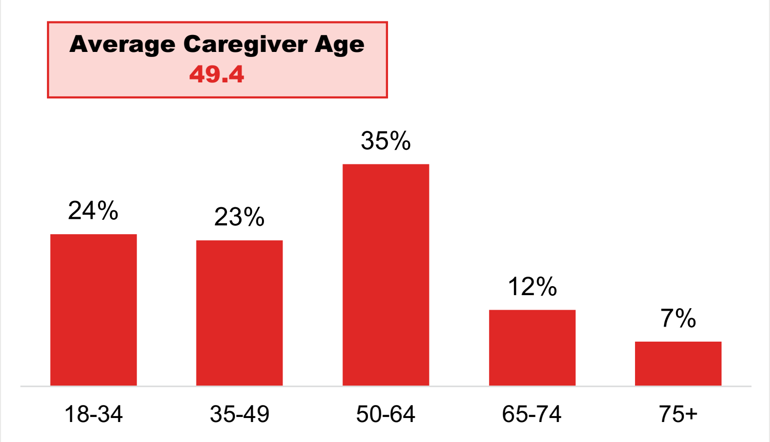
The demographic characteristics of caregivers remain largely unchanged since 2015: caregiving remains an activity that occurs among all generations, racial/ethnic groups, income or educational levels, family types, gender identities, and sexual orientations. The shifts we do see in caregiver demographics reflect general changes in the demographic composition of the U.S. population over the past five years.

Photo credit: VadimGuzhva/stock.adobe.com

Three in 5 caregivers are women (61 percent) and 2 in 5 are men (39 percent). Six in 10 caregivers report being non-Hispanic White (61 percent), 17 percent are Hispanic or Latino, 14 percent non-Hispanic African American or Black, 5 percent Asian American and Pacific Islander (hereafter, referred to as White, Hispanic, African American, and Asian American), and 3 percent some other race/ethnicity, including multiracial. For more detail on caregiver demographics, see this report section M: Respondent profile.

On average, caregivers of adults are 49.4 years old, with a median age of 51.0 years (see Figure 3).

Figure 3. Caregiver Age

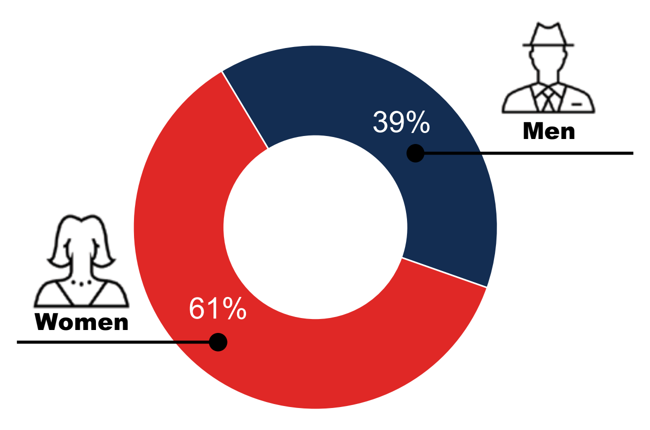


2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded; results may not add to 100 percent.

More than 4 in 10 are ages 18 to 49 (46 percent), while over half are ages 50 and older (54 percent, see Figure 3).

Figure 4. Caregiver Gender



2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

As generation Z ages into adulthood and generation X continues to age, as shown in Figure 5, they are increasingly part of the caregiving population in the United States.

Figure 5. Percentage of Caregivers of Adults Who Are in Each Generation, 2020 vs. 2015

	2020 (n = 1,392)	2015 (n = 1,248)
Generation Z (born 1997 or after)	6%*	–
Millennial (born 1981 to 1996)	23%	23%
Generation X (born 1965 to 1980)	29%*	25%
Baby Boomers (born 1946 to 1964)	34%	39%*
Silent/Greatest (born 1945 or prior)	7%	13%*

** Significantly higher than comparison year.*

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

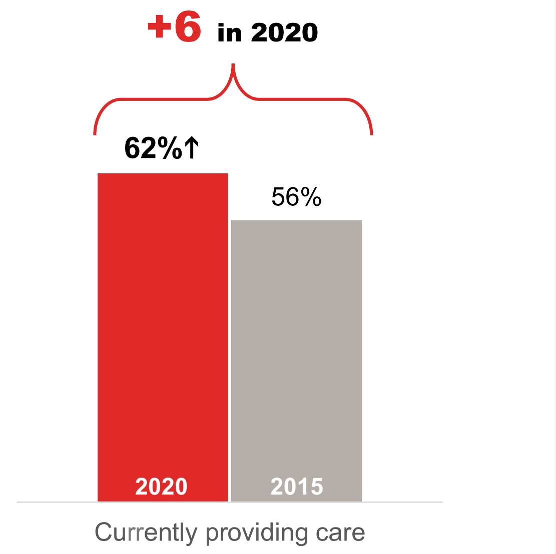
Subgroups: 2020

- Male caregivers are more often younger (42 percent among those 18 to 49) than those who are middle-aged (35 percent among those 50 to 64).
- Caregivers reflect the changing demographics of the United States as a whole: White caregivers are the oldest (51.7 years, on average), older than either African American (47.7 years, on average) or Hispanic (43.3 years, on average) caregivers.

Current Versus Past Care

Just over 6 in 10 caregivers of adults (62 percent, see Figure 6) are currently caring for a recipient, up significantly as compared to 2015 (56 percent), meaning 38 percent of caregivers have provided care in the past 12 months but are no longer doing so.

Figure 6. Current Versus Past Care



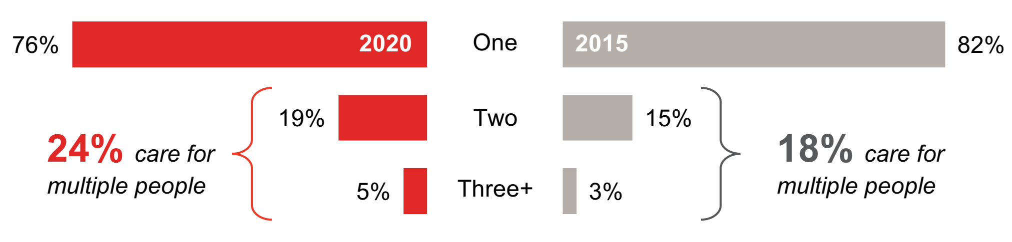
Q1. Are you currently providing unpaid help to that adult relative or friend, or was this something you did in the past 12 months and are no longer doing?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)
2015 Base: Caregivers of Recipient Age 18+ (n=1,248)

Number of Care Recipients

While most caregivers of adults care for one person (76 percent), 24 percent care for two or more adults, up significantly from 2015 (18 percent, see Figure 7). This finding, in combination with the increased prevalence of caregiving, suggests a nation of Americans who continue to step up to provide unpaid care to family, friends, and neighbors who might need assistance due to health or functional needs.

Figure 7. Number of Care Recipients



Q2. How many adults did you care for in the past 12 months?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)
2015 Base: Caregivers of Recipient Age 18+ (n=1,248)

Change Focus: 2020 vs. 2015

➔ The increase in caring for two or more adults is happening across all ages of caregivers, as shown in Figure 8:

Figure 8. Percentage Caring for Two or More Adults, by Caregiver Age

	2020	2015
18-49 (n = 552)	26%*	21%
50-64 (n = 546)	25%*	16%
65+ (n = 454)	20%*	11%

** Significantly higher than comparison year.*

Subgroups: 2020

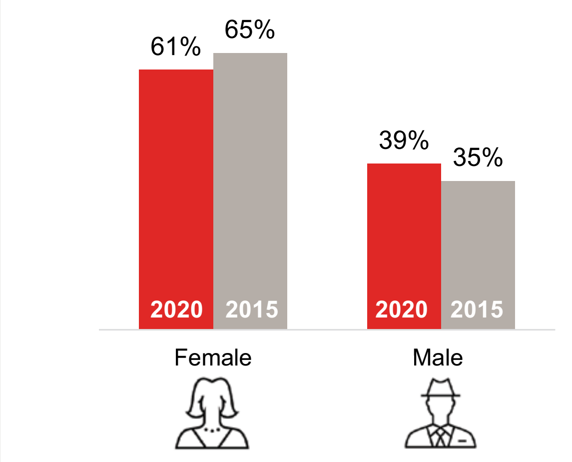
- Women are more often caring for two or more adults (27 percent vs. 20 percent for men caregivers).
- Those caring for a spouse/partner tend to be solely focused on their care: 91 percent care for a spouse/partner and no one else, while those caring for other adults (parents, other relatives, non-relatives) more often care for two or more people (26 percent).
- Caregivers who live in a rural area more often care for multiple people (34 percent vs. 23 percent of caregivers who live in a suburban or urban area).

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 Gender and Age

Two out of 3 care recipients are women (61 percent, see Figure 9) and about 4 in 10 are men (39 percent). A greater proportion of caregivers report caring for a man (39 percent) than in 2015 (35 percent).

Figure 9. Gender of Care Recipient



Q9. And is/was the person you care/cared for …

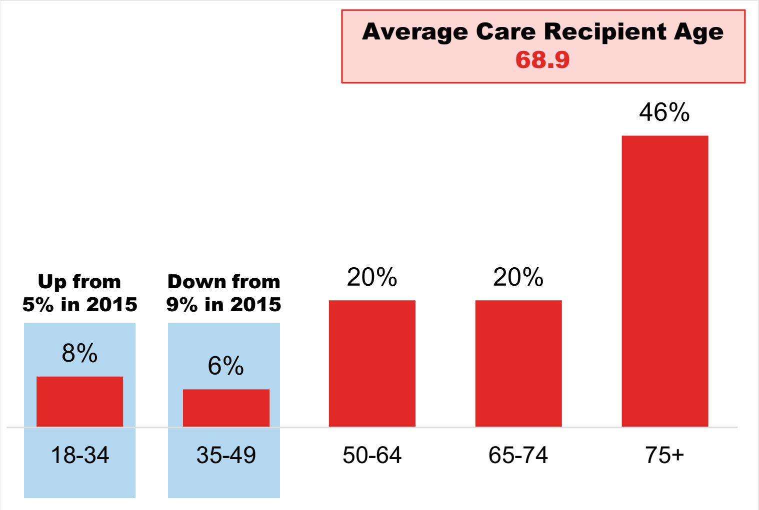
2020 Base: Caregivers of Recipient Age 18+ (n=1,392)
2015 Base: Caregivers of Recipient Age 18+ (n=1,248)

Change Focus: 2020 vs. 2015

- ➔ Caregivers who have been providing care for five years or longer more often report caring for a man (41 percent vs. 32 percent in 2015). Four out of 10 caregivers of a baby boomer are caring for a man (43 percent), an increase over 2015 (33 percent).

On average, the recipient is 68.9 years old, with a median age of 72.0 years old, as shown in Figure 10. About half of caregivers of adults are caring for someone age 75 or older (46 percent), with 40 percent caring for someone age 50 to 74. Significantly more caregivers report caring for an adult age 18 to 34 (8 percent compared to 5 percent in 2015).

Figure 10. Care Recipient Age



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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

The generational profile of care recipients continues to shift, with a greater proportion of recipients part of the younger generations (now generation Z and millennials) and a drop-off in the oldest generation (greatest, see Figure 11).

Figure 11. Care Recipient Generation

	2020 (n = 1,386)	2015 (n = 1,246)
Generation Z (born 1997 or after)	3%*	–
Millennial (born 1981 to 1996)	7%*	5%
Generation X (born 1965 to 1980)	9%	9%
Baby Boomers (born 1946 to 1964)	33%*	29%
Silent (born 1928 to 1945)	40%	42%
Greatest (born 1927 or prior)	8%	16%*

** Significantly higher than comparison year.*

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Relationship of Caregiver Age and Care Recipient Age

It is important to note that older caregivers tend to be taking care of someone similar in age to themselves, while younger caregivers provide care to someone older (Figure 12).

Figure 12. Age of Main Care Recipient by Age of Caregiver

	Caregiver Age			
	18–49 (n = 552) A	50–64 (n = 546) B	65–74 (n = 217) C	75+ (n = 237) D
Average Care Recipient Age	*62.6*	*73.6[A]*	*75.3[A]*	*77.7[AB]*
Recipient age 18–49	18%[BCD]	11%[D]	9%	6%
Recipient age 50–74	56%[BCD]	23%	38%[BD]	21%
Recipient age 75+	25%	65%[AC]	53%[A]	74%[ABC]

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

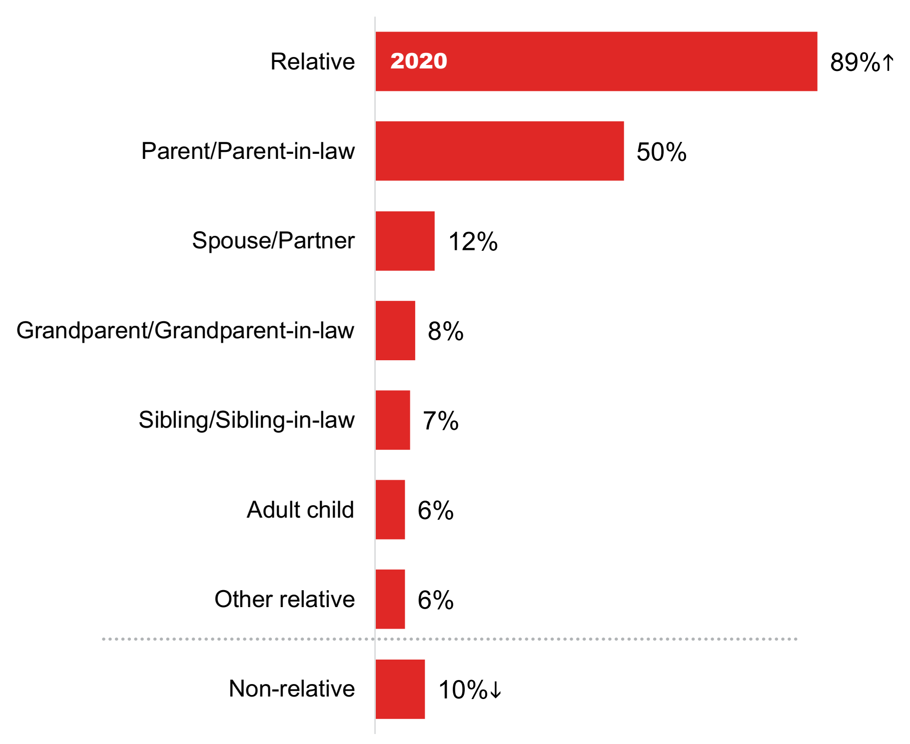
Subgroups: 2020

- The age of the care recipient varies by the caregivers' race/ethnicity, where White caregivers are caring for the oldest recipients (70.5 years, on average). This is older than either African American caregivers (caring for someone 64.9 years old, on average) or Hispanic caregivers (caring for someone 66.9 years old, on average). Asian American caregivers are caring for someone 69.1 years old, on average, older than African American caregivers' recipients.
- Those caring for a parent or parent-in-law are caring for someone older (76.1 years, on average), compared to those caring for a non-relative (69.3 years old), spouse or partner (61.5 years old), or some other relative (59.1 years old).
- Primary caregivers are caring for a younger recipient (67.2 years old, on average), compared to non-primary caregivers who are caring for someone age 72.1, on average.

Care Recipient Relation to Caregiver

Most caregivers take care of a relative (89 percent), while just 10 percent care for a friend, neighbor, or other non-relative. Significantly more caregivers report caring for a relative than in 2015 (85 percent). Most are caring for a parent (42 percent) or parent-in-law (8 percent), or for a spouse or partner (12 percent, see Figure 13).

Figure 13. Care Recipient Relation to Caregiver



Q7. Who are you caring/did you care for? Please select one relationship.

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Change Focus: 2020 vs. 2015

➔ The growth in caring for an adult relative is up markedly among African American caregivers (88 percent compared to 77 percent in 2015) and Hispanic caregivers (92 percent vs. 85 percent in 2015). The youngest caregivers are also more often caring for an adult relative (91 percent) than in 2015 (85 percent).

Photo credit: Africa Studio/stock.adobe.com

- Who is being cared for is driven greatly by the age of the caregiver, with older caregivers caring more for peers (spouse/partner, siblings, and non-relatives) while younger caregivers care more for an older generation (parents or grandparents), as is shown in Figure 14.

Figure 14. Care Recipient Relation to Caregiver by Caregiver Age

	Caregiver Age			
	18–49 (n = 552) **A**	**50–64** (n = 546) **B**	**65–74** (n = 217) **C**	**75+** (n = 237) **D**
Parent/Parent-in-law	52%^{CD}	59%^{ACD}	34%^{D}	8%
Grandparent/In-law	17%^{BCD}	1%^{CD}	–	–
Spouse/Partner	8%	11%	21%^{AB}	40%^{ABC}
Sibling/In-law	6%	5%	12%^{AB}	9%^{B}
Own child	3%	9%^{A}	10%^{A}	11%^{A}
Other relative	2%	1%	5%^{AB}	8%^{AB}
Non-relative	9%	9%	15%^{AB}	22%^{AB}

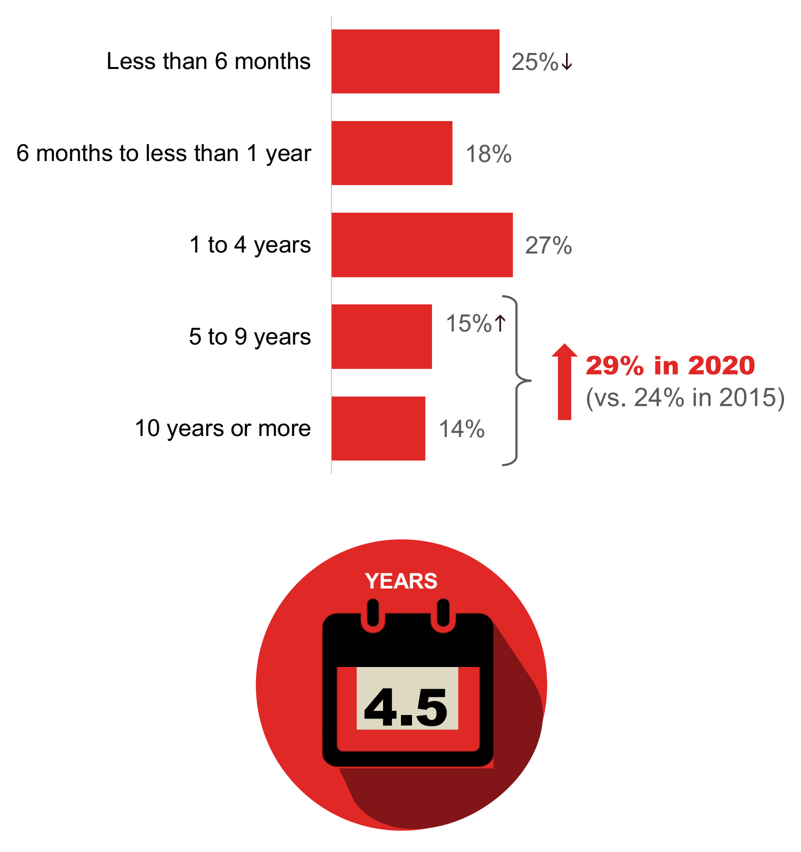
Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

- Additionally, men who provide care more often do so for a relative (92 percent) than women (88 percent).
- Asian American caregivers more often report caring for a parent (52 percent) than Whites (43 percent) and African Americans (33 percent).
- Long-term caregivers (those providing care for five years or longer) are more often caring for a relative (94 percent) than shorter duration caregivers (87 percent when caring for four years or less). Notably, long-term caregivers more often report caring for their own adult child (12 percent vs. 4 percent of shorter-term caregivers).
- Caregivers with lower household income (less than $50,000) more often report caring for a non-relative (14 percent) than caregivers with higher income (8 percent).

Duration of Care for Recipient

The average duration of caregiving is 4.5 years. Three out of 10 caregivers have provided care for 5 years or longer (29 percent), significantly more than in 2015 (24 percent, see Figure 15).

Figure 15. Duration of Care



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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Change Focus: 2020 vs. 2015

A greater proportion of caregivers is providing care for five years or longer, a change that is happening significantly among the following groups:

- ➔ Caregivers ages 50 to 64 (36 percent compared to 28 percent in 2015)
- ➔ Lower-hour caregivers (27 percent of those providing care for 20 hours or less each have been caregiving five years or longer, compared to 22 percent in 2015)
- ➔ Those caring for a recipient who has a long-term physical condition (37 percent vs. 31 percent in 2015)
- ➔ Generation X caregivers (33 percent vs. 21 percent in 2015)

Subgroups: 2020

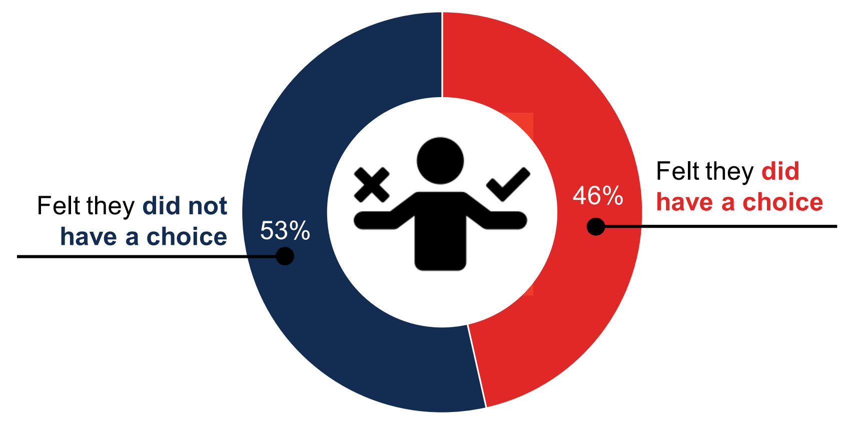
- Caregivers who are ages 50 to 64 have been caring for 5.6 years on average, longer than caregivers who are ages 18 to 49 (3.4 years on average) or ages 65 or older (4.5 years on average).
- However, when care recipients are younger (ages 18 to 49), care duration is longest at 7.9 years (on average, significantly longer than the 3.9 years of care provided when caring for someone age 50 or older).
- Those caring for some other relative (not a spouse or parent) have been caring for 6.1 years on average—longer than those caring for a parent/parent-in-law (4.0 years) or those caring for a non-relative (2.3 years on average).
- Primary caregivers have been providing care longer (4.8 years on average vs. 3.9 years for non-primary caregivers).
- Caregivers with household incomes of $50,000 or more have been providing care for 4.9 years on average, longer than those with lower household incomes (3.7 years).
- Generation X caregivers have been caring for 5.2 years on average, nearly 3 years longer than either millennial (2.9 years) or generation Z (2.4 years) caregivers.

Choice in Taking on Caregiver Role

Having a choice to take on care is an important aspect of caregiving, as found in *Caregiving in the U.S. 2015*, where those who reported having no choice were found to more often face complex care situations and increased stress and strain, results echoed again in this cycle's analysis.[27]

When asked if they had a choice in taking on the responsibility to provide care for their recipient, more than half of caregivers felt they had no choice in taking on this role (53 percent, see Figure 16).

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]?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

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[27] As shown throughout the report in subgroup analysis.

Change Focus: 2020 vs. 2015

While overall the feeling of choice has not changed since 2015, there are select subgroups of caregivers who more often feel they had no choice but to take on their caregiving role. Given the importance of choice perception to outcomes like stress and strain, these caregivers may be especially vulnerable:

- ➔ In 2020, all race/ethnicity groups report similar levels of feeling "choice," though Asian American caregivers more often report they had no choice in taking on their caregiving role (61 percent) than they reported in 2015 (46 percent).
- ➔ Women who provide care more often report having the lack of choice (55 percent compared to 50 percent in 2015).
- ➔ Generation X caregivers more often report they had no choice in taking on care (58 percent vs. 45 percent in 2015).
- ➔ Caregivers who do not live with their recipient more often report feeling they had no choice in providing care (51 percent compared to 43 percent in 2015).
- ➔ In addition, lower-hour caregivers also report an increase in feeling they had no choice in becoming a caregiver (52 percent of those who provide 20 or fewer hours of care weekly, compared to 45 percent in 2015). Similarly, non-primary caregivers more often feel they had no choice in taking on their role (46 percent vs. 40 percent in 2015).
- ➔ Caregivers of a recipient who lives in a rural area more often report having no choice in taking on care (51 percent) than they did in 2015 (43 percent).

Subgroups: 2020

- Those caring for a spouse/partner (66 percent) or for a parent or parent-in-law (61 percent) more often report having a lack of choice than do those caring for some other relative (45 percent) or a friend/neighbor (21 percent).
- Primary caregivers are more likely to feel they had no choice in taking on their role (57 percent vs. 46 percent of non-primary caregivers).
- As the length of time spent caregiving increases, so too does the feeling of having no choice: 63 percent of those who have been providing five or more years of care and 56 percent of those caring for one to four years report feeling no choice, compared to 45 percent when caring for less than a year.
- Higher-income caregivers more often report they had no choice in taking on their care role (57 percent of those with $50,000 or more in household income vs. 47 percent of those with less than $50,000).
- Near-full-time working caregivers (those working 30 hours or more a week) more often report feeling they had no choice (57 percent) compared to their unemployed (51 percent) or lesser-hour working (48 percent) peers.

C. CARE RECIPIENT LIVING SITUATION

Care Recipient Living Alone

One in four care recipients live alone (26 percent, see Figure 17) and among care recipients who are not in an assisted living or skilled nursing facility, 28 percent live alone.

Figure 17. Care Recipient Living Alone

Q14c. Does/Did your [relation] live alone at the time you provided care?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

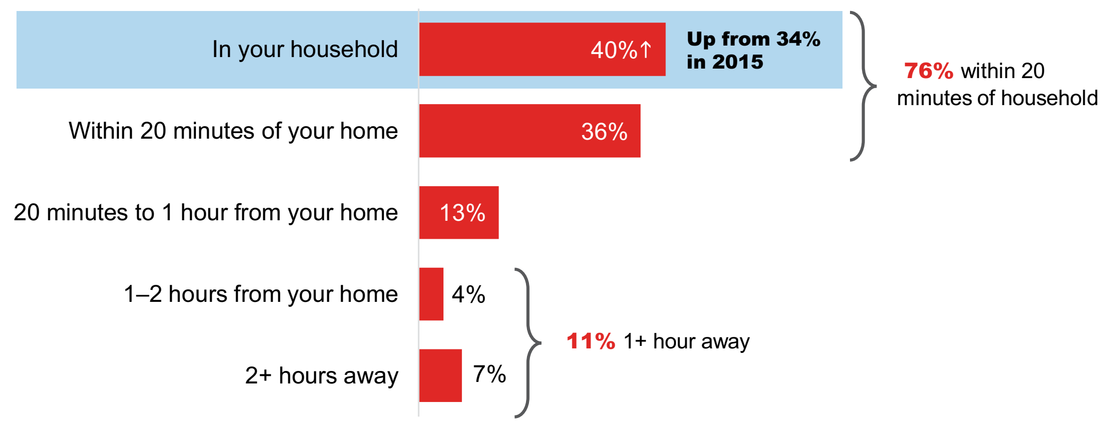
Subgroups: 2020

- Among those not living in a facility, the oldest recipients most often live alone: 37 percent of recipients ages 65 and older live alone, compared to 15 percent of those ages 50 to 64 and 8 percent of those ages 18 to 49.
- Those caring for non-relatives more often report that the friend or neighbor lives alone (45 percent) compared to those caring for a relative (27 percent, excluding spouse).

Caregiver Distance from Care Recipient

Most caregivers live within 20 minutes of their care recipient (76 percent, Figure 18).

Figure 18. Caregiver Distance from Care Recipient



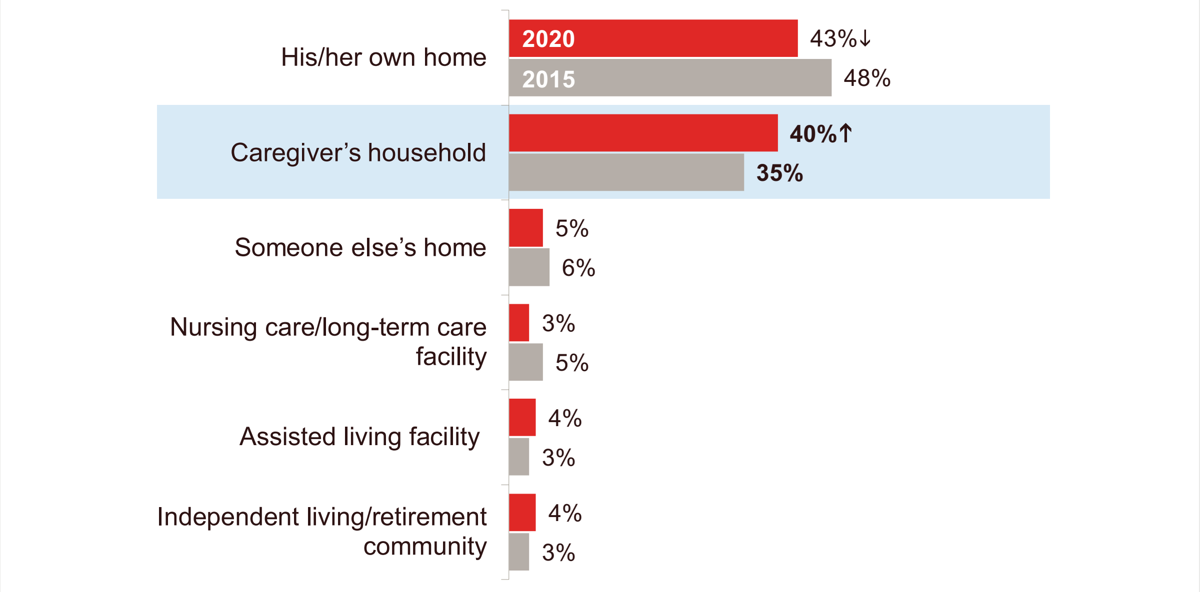
Q11. Where does/did your [relation] live at the time you provided care?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Where Care Recipient Lives

There has been a shift in residence over the past five years, where more caregivers report their recipient lives with them, the caregiver, instead of living in their (the recipient's) own home. About two out of five caregivers report their care recipient lives in the recipient's own home (43 percent, see Figure 19), significantly fewer than in 2015 (48 percent). Another 40 percent say their recipient lives in the caregiver's household, significantly more than in 2015 (35 percent).

Figure 19. Where Care Recipient Lives



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

2020 Base: Caregivers of Recipient Age 18+ Who Reported Living Arrangement (n=1,389)
2015 Base: Caregivers of Recipient Age 18+ Who Reported Living Arrangement (n=1,236)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Change Focus: 2020 vs. 2015

This shift in residence seems to be focused among several groups:

- ➔ African American caregivers more often report co-residing with their recipient (45 percent compared to 28 percent in 2015) and less often report their recipient lives in their own home (38 percent compared to 56 percent in 2015).
- ➔ Caregivers ages 18 to 49 report a similar pattern, more often living with their recipient (42 percent vs. 34 percent in 2015) and less often that their recipient lives in their own home (45 percent vs. 51 percent in 2015).
- ➔ Those caring for a relative (other than a parent/parent-in-law or spouse/partner) also report increased co-residence (36 percent vs. 26 percent in 2015) and less of the recipient living in their own home (43 percent vs. 54 percent in 2015).

Subgroups: 2020

- Caregivers who are Asian American (51 percent), Hispanic (48 percent), and African American (45 percent) are more likely than Whites (36 percent) to report their recipient lives in their home (the caregiver's home).

- Caregivers with lower household incomes more often report living in the same household as their care recipient (46 percent vs. 36 percent of those with $50,000 or more in annual household income). However, caregivers, regardless of income, more often report living with their recipient now than in 2015. Among those with less than $50,000 in household income, 46 percent live together (vs. 39 percent in 2015), while among higher-income caregivers, 36 percent live together (up from 31 percent in 2015).
- As might be expected, where the care recipient lives varies by the relationship of the caregiver and recipient, with spouses more often living together.

Figure 20. Where Care Recipient Lives by Relation to Caregiver

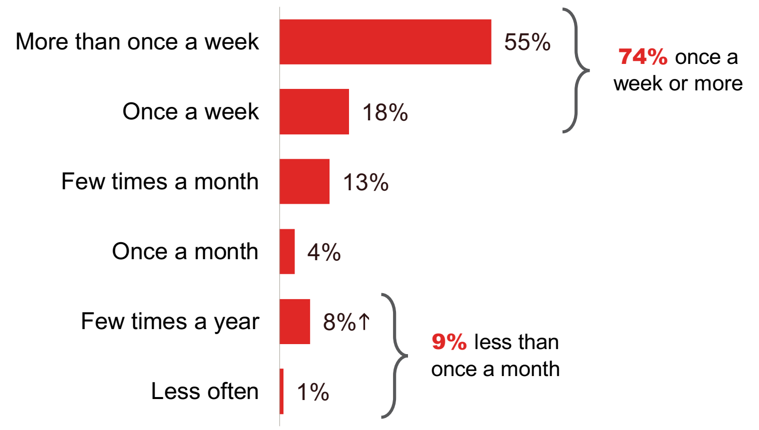
	Caregiver Is Caring for their…			
	Parent/ Parent-in-law (n = 703) A	Spouse/ Partner (n = 177) B	Other Relative (n = 355) C	Non-Relative (n = 149) D
Lives with caregiver	34%^{D}	90%^{ACD}	36%^{D}	17%
Lives in recipient's own home	47%^{B}	3%	43%^{B}	69%^{ABC}
Lives in someone else's home	4%	3%	9%^{AB}	6%
Independent living or retirement community	6%^{B}	–	4%^{B}	3%^{B}
Assisted living	5%^{BCD}	1%	2%	2%
Nursing care or long-term care facility	4%	3%	4%	2%

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

Frequency of Visits

Of the caregivers who do not live with their care recipient, three-quarters say they visit their recipient at least once a week (74 percent, see Figure 21), including more than half who say they visit multiple times a week (55 percent).

Figure 21. Frequency of Caregiver Visits



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

2020 Base: Caregivers of Recipient Age 18+ Not Living with Recipient (n=851)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Subgroups: 2020

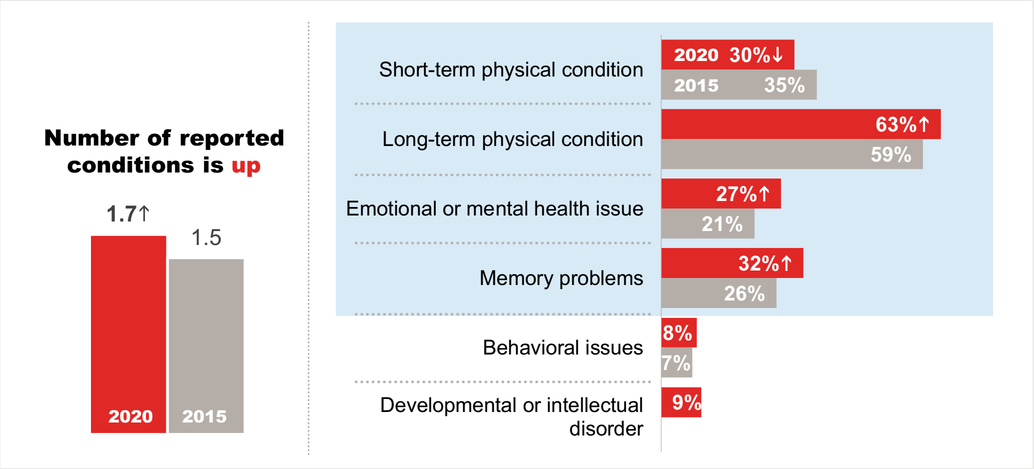
- Caregivers who live within an hour of their recipient more often report they see their recipient once a week or more (84 percent vs. 27 percent of those who live an hour or more away).
- Caregivers who are “doing more” visit more often, including:
  - — Primary caregivers: 79 percent visit more than once a week (vs. 67 percent of non-primary caregivers)
  - — Higher-hour caregivers: 73 percent visit more than once a week (vs. 51 percent of those providing 20 or fewer hours)
  - — Those in a high-intensity care situation[28]: 78 percent visit more than once a week (vs. 60 percent medium-intensity and 43 percent low-intensity caregivers)

D. CARE RECIPIENT’S CONDITION

Types of Care Recipient Conditions

Caregivers report their adult care recipients have greater health and functional needs than was reported by caregivers in 2015 (see Figure 22). Six in 10 caregivers care for an adult with a long-term physical condition (63 percent), significantly more commonly mentioned than in 2015 (59 percent). Another 30 percent say their recipient has a short-term physical condition, significantly less commonly mentioned than in 2015 (35 percent).

Figure 22. Types of Care Recipient Conditions



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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

2015 Base: Caregivers of Recipient Age 18+ (n=1,248)

Note: Respondents may select more than one response; results add to greater than 100 percent.

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[28] High-intensity care situation refers to caregivers who score a 4 or 5 on The Level of Care Index, first developed in the 1997 study *Family Caregiving in the U.S.* to provide one way to articulate the impact of a disease or disability on the people who care for a patient during the caregiver journey. The index is based on the number of hours of care given and the number of ADLs and IADLs performed. The details of index construction are shown in appendix B.

One in three indicates their recipient has a memory problem (32 percent), up significantly as compared to 2015 (26 percent). In addition, caregivers of adults more often mention their recipient having emotional or mental health issues (27 percent) than in 2015 (21 percent). Smaller proportions indicate the care recipient has behavioral issues (8 percent) or a developmental or intellectual issue (9 percent).

It is important to note that the type of condition varies by the care recipient's 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 more common among the youngest adult recipients, as shown in Figure 23.

Figure 23. Types of Care Recipient Conditions by Care Recipient Age

	Recipient Age 18–49 (n = 188) A	Recipient Age 50–64 (n = 256) B	Recipient Age 65+ (n = 944) C
Long-term physical condition	46%*	57%^{A}	69%^{AB}
Short-term physical condition	30%	40%^{AB}	26%
Emotional or mental health problem	41%^{C}	35%*^{C}	21%*
Behavioral issue	19%^{BC}	11%*^{C}	5%
Memory problems	13%	19%	39%*^{AB}
Developmental or intellectual disorder or delay	24%^{BC}	9%	5%

** Significantly higher than in 2015.*

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Respondents may select more than one response; results add to greater than 100 percent.

Subgroups: 2020

- The longer a caregiver has been providing care, the more likely they are to report their recipient is dealing with multiple conditions, while newer caregivers more often report their recipient's issue is a short-term physical one. However, longer-term caregivers are often older than newer caregivers, as are their care recipients (see Figure 24).
- Primary caregivers more often report behavioral issues (10 percent vs. 6 percent non-primary).

Figure 24. Types of Care Recipient Conditions by Caregiver Tenure

	Less Than 1 year (n = 574) A	1–4 years (n = 393) B	5+ years (n = 419) C
Average number of condition categories	1.5	1.7^{A}	1.9^{AB}
Long-term physical condition	43%	77%^{A}	79%^{A}
Short-term physical condition	48%^{BC}	19%^{C}	13%
Emotional or mental health problem	22%	28%^{A}	33%^{A}
Behavioral issue	6%	7%	13%^{AB}
Memory problems	23%	38%^{A}	38%^{A}
Developmental or intellectual disorder or delay	5%	5%	16%^{AB}
Presence of any Alzheimer's or dementia	18%	35%^{AC}	28%^{A}
Caregiver age (mean, in years)	46.8	50.7^{A}	51.8^{A}
Recipient age (mean, in years)	66.0	73.1^{AC}	69.2^{A}

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Respondents may select more than one response; results add to greater than 100 percent.

Change Focus: 2020 vs. 2015

Overall, comorbidity of conditions, as reported by caregivers, seems to be increasing. The changes since 2015 in specific condition categories that caregivers report include the following:

- *Long-term physical conditions* are more common in 2020 among the youngest recipients (46 percent vs. 32 percent in 2015).
- *Emotional or Mental health issues* are more often reported by those caring for someone age 50 or older (24 percent vs. 19 percent in 2015); by primary caregivers (28 percent vs. 21 percent in 2015); and by those also caring for someone with a long-term physical condition (28 percent vs. 21 percent in 2015).
- *Behavioral issues* are more often reported by caregivers of recipients ages 50 to 64 (11 percent vs. 3 percent in 2015).
- *Memory problems* are now more often mentioned by caregivers of those ages 65 and older (39 percent vs. 33 percent in 2015); by primary caregivers (32 percent vs. 25 percent in 2015); those caring for someone with a long-term physical condition (36 percent vs. 30 percent in 2015); and by caregivers who expect their role to continue five years into the future (36 percent vs. 30 percent in 2015).

Comorbidity of Conditions

A greater proportion of caregivers of adults reports their recipient is dealing with multiple condition categories, with 45 percent reporting two or more condition categories, compared to 37 percent in 2015. On average, caregivers report the presence of 1.7 condition categories, significantly higher than the 1.5 reported in 2015 (see data presented earlier, in Figure 22). This increasing comorbidity[29] of conditions that require care suggests that not only are more American adults taking on the role of unpaid caregiver, but they are doing so for adult recipients who may have increasingly complex medical or support needs.

Change Focus: 2020 vs. 2015

- This increase in caregiver-reported comorbidity of conditions is occurring among older recipients: 45 percent of those caring for someone age 50 or older report the presence of two or more conditions, up from 38 percent in 2015.
- Caregivers of a recipient who lives in a rural area report a sharp increase in comorbid conditions (51 percent reporting two or more categories of conditions vs. 38 percent in 2015), and while caregivers of recipients living in non-rural areas also report an increase in multiple conditions (43 percent vs. 37 percent in 2015), it is not as marked an increase as among caregivers of rural-dwelling recipients.
- Those who provide care to someone with a long-term physical condition more often report at least one other condition (57 percent), more than was reported in 2015 (49 percent).
- Caregivers who expect their role to continue into the future also more often report their recipient has two or more conditions (51 percent vs. 41 percent who do not expect to continue to provide care).

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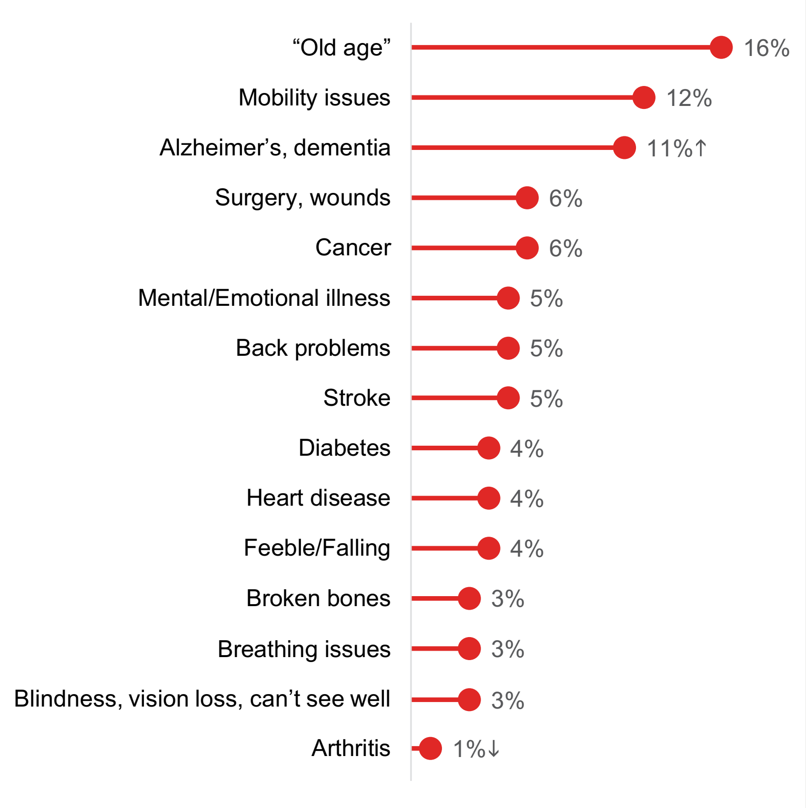
[29] Comorbidity is when a person has more than one health issue or condition at the same time.

Care Recipient's Main Problem or Illness

When caregivers are asked to identify the recipient's main problem or illness that causes them to need care, the three most common problems or illnesses cited by caregivers include "old age" (16 percent), mobility issues (12 percent), and Alzheimer's or dementia (11 percent, see Figure 25). Note that these perceptions may not mirror independent health statistics.[30]

Figure 25. Care Recipient's Main Problem or Illness



Q18. What is/was the main problem or illness your [relation] has/had, for which they need/needed your care?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Subgroups: 2020

- The main problem for which the caregiver's recipient needs care varies greatly depending on the recipient's age, as shown in Figure 26.

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[30] These are self-reports by caregivers about what they perceive their recipient's main problem to be for which they need unpaid care.

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

	Recipient Age 18–49 (n = 188) A	Recipient Age 50–64 (n = 256) B	Recipient Age 65+ (n = 944) C
Alzheimer's, dementia	2%	2%	15%^{*AB}
Back problems	8%^{C}	10%^{C}	3%
Cancer	6%	7%	6%
Developmental or intellectual disorder or disability	13%^{*BC}	1%	0%
Diabetes	2%	8%^{AC}	3%
Heart disease or attack	1%	4%^{A}	4%^{A}
Mental/Emotional illness	15%^{BC}	7%^{C}	2%
Mobility issues	7%	10%	13%^{A}
"Old age," frailty	–	4%^{A}	23%^{AB}
Stroke	1%	6%^{A}	5%^{A}
Substance abuse	5%^{C}	3%^{C}	0%
Surgery, wounds	4%	12%^{AC}	5%

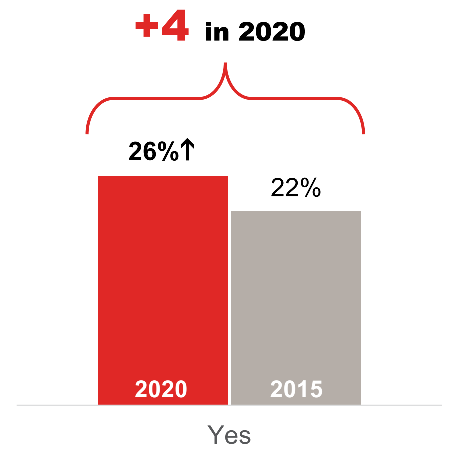
** Significantly higher than in 2015.*

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

Presence of Alzheimer's or Dementia

Although Alzheimer's or dementia is cited by only 11 percent of caregivers as the main condition for which the care recipient needs help, 26 percent of caregivers say their recipient does suffer from this type of condition, up significantly from 2015 (22 percent, see Figure 27).[31]

Figure 27. Presence of Alzheimer's or Dementia



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

2020 Base: Caregivers of Recipient Age 18+ (n=1,391)
2015 Base: Caregivers of Recipient Age 18+ (n=1,248)

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

Change Focus: 2020 vs. 2015

- ➔ Those caring for someone age 65 or older also more often report their recipient has Alzheimer's or dementia (32 percent vs. 27 percent of caregivers of someone age 65 or older in 2015).

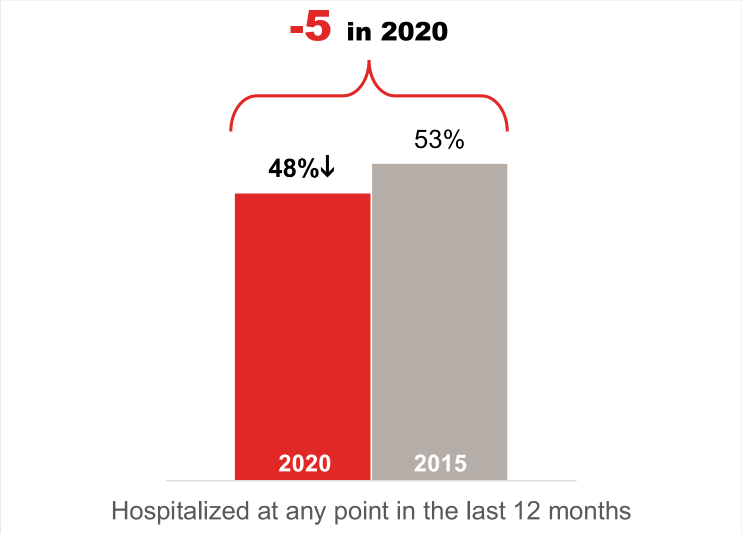
Subgroups: 2020

- One in three caregivers of someone age 65 or older reports the presence of Alzheimer's or dementia (32 percent vs. 12 percent when caring for someone under 65).

Frequency of Care Recipient Hospitalization

Despite the increasing comorbidity of conditions and increase in reported Alzheimer's or dementia, fewer caregivers of adults report their care recipient was hospitalized at least once over the past 12 months (48 percent, see Figure 28), down from 53 percent in 2015.

Figure 28. Frequency of Care Recipient Hospitalization



N9. In the last 12 months that you were caring for them, how many times was your [relation] hospitalized overnight?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)
2015 Base: Caregivers of Recipient Age 18+ (n=1,248)

Change Focus: 2020 vs. 2015

- ➔ Caregivers of recipients ages 65 and older less often report their recipient has been hospitalized at least once in the past year (49 percent, down from 56 percent in 2015), despite these same caregivers more often reporting their older care recipient is dealing with multiple conditions (more so than in 2015, see results on comorbidity above).
- ➔ Caregivers of recipients who have no physical condition (short- or long-term) report a sharp decline in hospitalization (18 percent hospitalized one or more times in past year vs. 33 percent in 2015).
- ➔ White (48 percent) and Asian American (43 percent) caregivers less often report their care recipient was hospitalized compared to 2015 (55 percent each).
- ➔ Hospitalization is down among new caregivers who have been providing care for less than a year (51 percent vs. 57 percent in 2015).

Subgroups: 2020

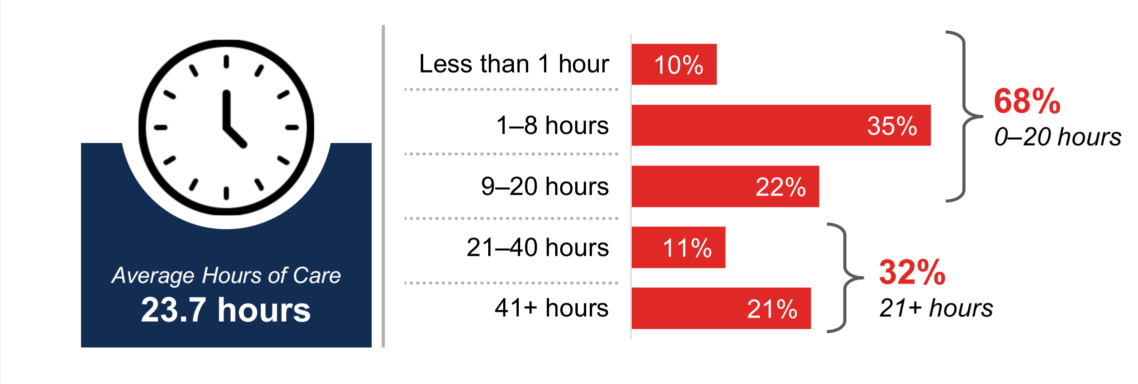
- Hospitalization is more common when the care recipient is age 50 or older (50 percent vs. 37 percent when recipient is 18 to 49).
- Caregivers in higher-intensity care situations more often report their recipient has been hospitalized (56 percent medium-to-high intensity vs. 38 percent low intensity). Similarly, those providing 21 or more hours of care each week more often report their recipient has been hospitalized (56 percent vs. 44 percent of those who provide care for 20 hours or less each week).

E. CAREGIVING ACTIVITIES AND LEVEL OF CARE

Hours of Care Provided

On average, caregivers spend 23.7 hours per week providing care (see Figure 29), with a median of 10 hours.[32] About one in three provides care for 21 hours or more each week (32 percent)[33] and 21 percent perform a full-time job of 41 or more hours of care each week.

Figure 29. 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 them?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Subgroups: 2020

- Caregivers whose recipient lives with them, in the caregiver's home, report providing care for 37.4 hours each week, more than those not living together (14.6 hours per week on average).
- Caregivers who have no other help (paid or unpaid) provide 27.4 hours of care weekly, more than those who share care (21.7). Similarly, primary caregivers provide more hours of care (26.7 vs. 18.3 hours among non-primary caregivers).

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[32] 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.

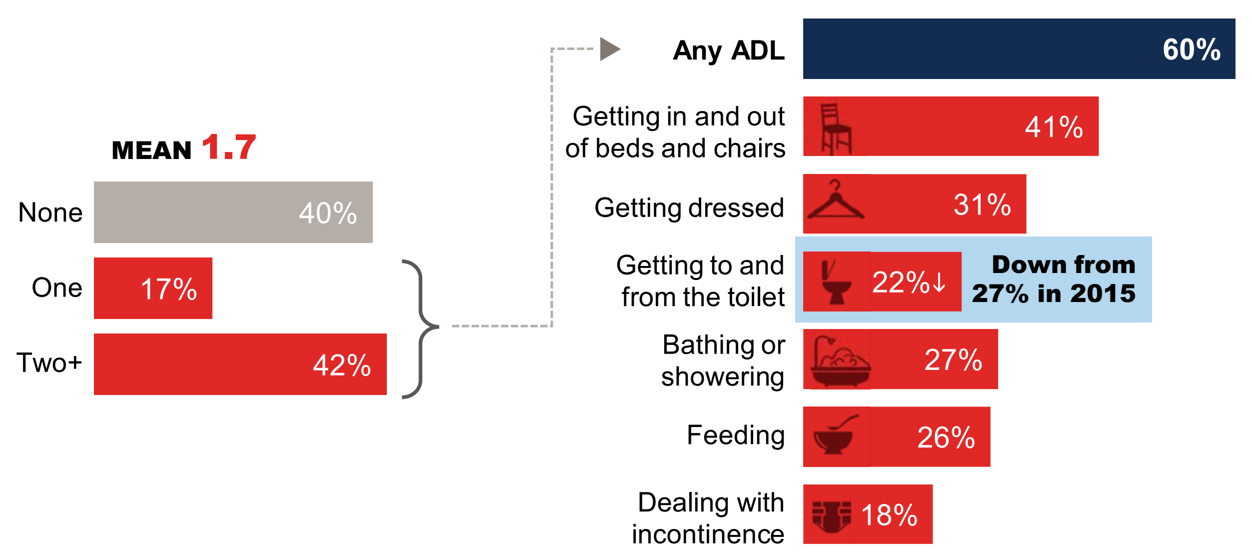
[33] Those providing 20 hours of care or less each week provide 7.1 hours of care on average, with 5.0 median hours of care. Those providing 21 or more hours of care each week provide 59.2 hours of care on average, with 77.0 median hours of care.

- African American caregivers report providing more hours of care each week (31.2 hours on average) than either White (21.2 hours) or Asian American (24.1) caregivers. Hispanic caregivers provide 26.0 hours of care weekly (significantly more than White caregivers).
- Those caregivers who feel they had no choice in taking on care report providing 25.8 hours of care weekly on average, more than those who feel they had a choice (21.4 hours).
- Caregivers who have been providing care for five years or longer provide 27.5 hours of care weekly, more than those who have been caring either for one to four years (20.9) or for less than one year (22.9).
- Caregivers whose recipient lives in a rural area provide 26.3 hours of care on average, each week, more than the 22.5 hours of care provided by caregivers of someone living in a suburban or urban setting.
    - — Caregivers of recipients living in both rural and non-rural settings have similar profiles of "other help," suggesting that this gap in hours of care is not due to lack of other help (paid or unpaid).
    - — However, caregivers of those living in a rural area report greater difficulty finding affordable services in their recipient's local area (32 percent vs. 25 percent of those caring for someone who lives in a suburban or urban area), suggesting that caregivers of someone in a rural setting may be filling in for needed services and supports.
- Unemployed caregivers provide 28.9 hours of care weekly, more than those who are employed (20.4).[34]

Help with Activities of Daily Living (ADLs)

Six in 10 caregivers help their care recipient with at least 1 Activity of Daily Living (ADL, see Figure 30). Most commonly, caregivers help their recipient get in and out of beds and chairs (41 percent). On average, caregivers help with 1.7 of the 6 ADLs.

Figure 30. Help with Activities of Daily Living (ADLs)



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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Respondents may select more than one response; results add to greater than 100 percent.

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[34] Lower-income and lower-education caregivers also provide greater hours of care weekly, but they also are less often employed and less often have help from others (paid or unpaid). This suggests that employment may limit caregivers' ability to provide the needed care hours, leading care to be stitched together across more caregivers (paid and unpaid), and/or that employment (and its corresponding higher income) allows caregivers to hire additional care support. Further research is needed.

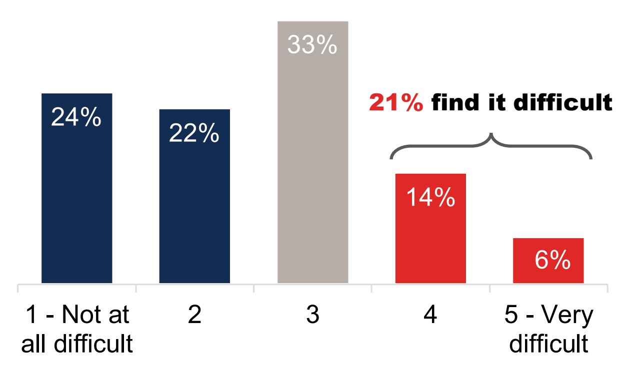
Subgroups: 2020

- Caregivers whose recipient lives with them in the caregiver's home perform at least one ADL for their recipient (68 percent vs. 54 percent of caregivers who do not co-reside with their recipient).
- Higher-hour caregivers (those providing 21 or more hours of care each week) are more often helping with ADLs (82 percent) than those helping for 20 hours or less weekly (49 percent).
- For the most part, performing ADLs is more common among caregivers of adults ages 50 and older (61 percent compared to 51 percent when caring for someone age 18 to 49).
- Caregivers who report that their recipient has memory problems are more often performing ADLs, with 69 percent performing at least 1 (vs. 56 percent when memory problems are absent). On average, caregivers of recipients with memory issues provide help with 2.2 ADLs, more than those caring for someone with a short-term physical condition (1.8) or emotional or mental health issue (1.8).
- Even though their care recipients tend to be younger, both Hispanic (71 percent) and African American (70 percent) caregivers more often help with at least one ADL than either White (55 percent) or Asian American (49 percent) caregivers.

Difficulty with Activities of Daily Living (ADLs)

Among caregivers performing ADLs, one in five indicates it is difficult to assist their recipient with these tasks (21 percent rating 4 or 5 on a 5-point scale, see Figure 31).

Figure 31. Difficulty of Helping with ADLs



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

2020 Base: Caregivers who help Recipient Age 18+ with ADLs (n=822)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Subgroups: 2020

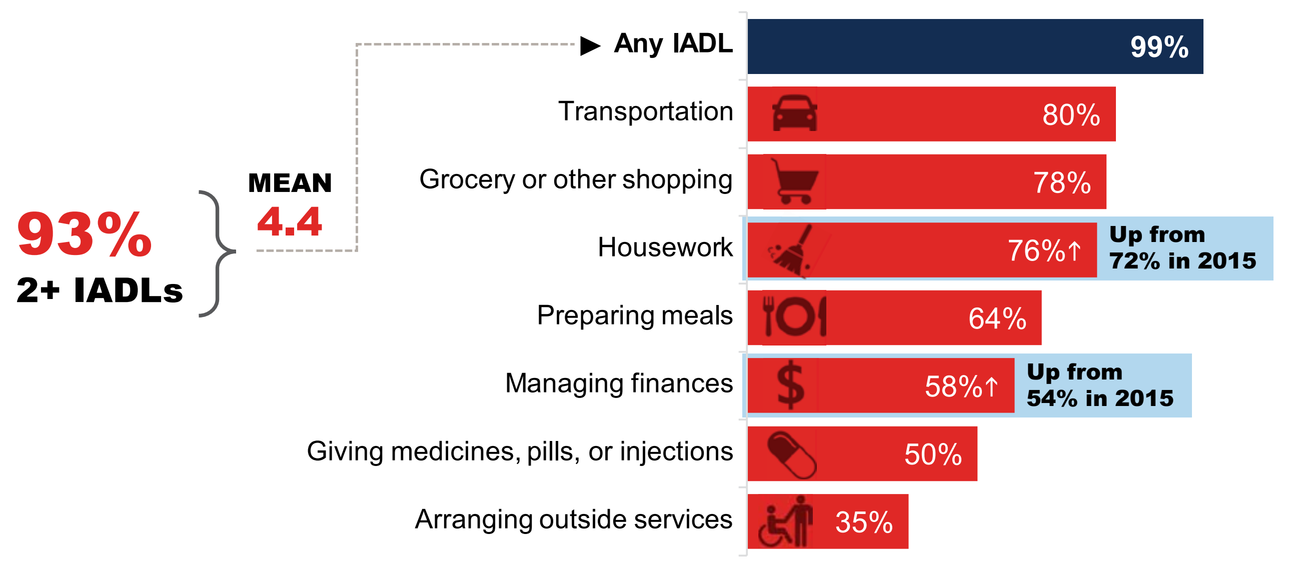
- Caregivers who feel they had no choice in taking on their caregiving role more often find performing ADLs difficult (26 percent), compared to 14 percent of those who had a choice.
- Higher-hour caregivers providing 21 or more hours of care weekly also more often find performing ADLs difficult (25 percent vs. 17 percent of those providing care 20 or fewer hours weekly).
- When a caregiver provides care to someone with a memory problem, not only are they more often performing ADLs but it is more difficult (28 percent vs. 16 percent of those caring for someone without memory problems).
- While caring for someone with emotional or mental health issues does not increase the chances of a caregiver performing ADLs, for those who do have to take on these personal care tasks it is especially difficult (30 percent vs. 17 percent of those caring for someone without emotional or mental health issues).

Help with Instrumental Activities of Daily Living (IADLs)

There is an established list of 7 Instrumental Activities of Daily Living (IADLs) that pertain to adult caregiving. On average, caregivers help their recipient with 4.4 IADLs (significantly more than in 2015 at 4.2, see Figure 32).

The performance of IADLs is fairly consistent with 2015 data, though a greater proportion of caregivers report helping with housework (76 percent) and managing their recipient's finances (58 percent).

Figure 32. Help with Instrumental Activities of Daily Living (IADLs)



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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Respondents may select more than one response; results add to greater than 100 percent.

Change Focus: 2020 vs. 2015

➔ Working caregivers perform more IADLs (4.4 on average) than in 2015 (4.1), with increases in housework (78 percent vs. 71 percent in 2015) and meal preparation (61 percent vs. 56 percent in 2015).

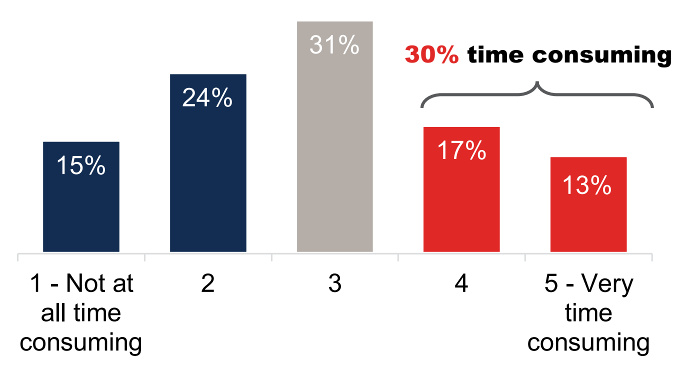
Subgroups: 2020

- Higher-hour caregivers (those providing 21 or more hours of care weekly) help with 5.6 IADLs on average, more than those providing 20 or fewer hours of care weekly (3.9 on average).
- Caregivers who live with their care recipient perform 5.1 IADLs on average, more than the 3.9 IADLs performed by those not living together.
  - Similarly, those caring for a spouse (who typically live together) perform 5.1 IADLs on average, more than the 4.4 performed by caregivers of other relatives and the 3.8 performed by those caring for a non-relative.
  - Primary caregivers perform 4.6 IADLs on average, more than non-primary caregivers (4.0).
- Those caring for someone with memory problems do 4.9 IADLs on average, more than those caring for someone with a long-term physical condition (4.6) or short-term physical condition (4.4). Caregivers of someone with an emotional or mental health issue perform 4.7 IADLs on average, more than those caring for someone with a short-term physical condition.
- Caregivers who report having had no choice in taking on care do 4.6 IADLs, more than those who feel they had a choice (4.1, on average).
- As years of care increase, so too do the number of IADLs performed. Those who have been providing care for less than a year perform 4.1 IADLs, which rises to 4.5 IADLs when caring for one to four years and 4.7 when caring for five years or longer.

Time Spent on Managing Recipient's Finances

Three in 10 caregivers of adults report that helping manage their recipient's finances is time consuming (30 percent rating 4 or 5 on a 5-point scale, see Figure 33).

Figure 33. Time Spent on Managing Recipient's Finances



M8. *(If helps with paperwork or finances)* How time consuming is/was it for you to help your [relation] with their finances, bills, or insurance claims?

2020 Base: Caregivers Who Help Manage Paperwork/Finances for Recipient Age 18+ (n=825)

Subgroups: 2020

- Caregivers who provide care for 21 or more hours a week often report that managing finances is highly time consuming (46 percent vs. 20 percent of those who manage finances but only provide 20 or fewer hours of care).
- One in three caregivers who had no choice in taking on care report that managing finances is time consuming (34 percent vs. 23 percent of those with a choice).

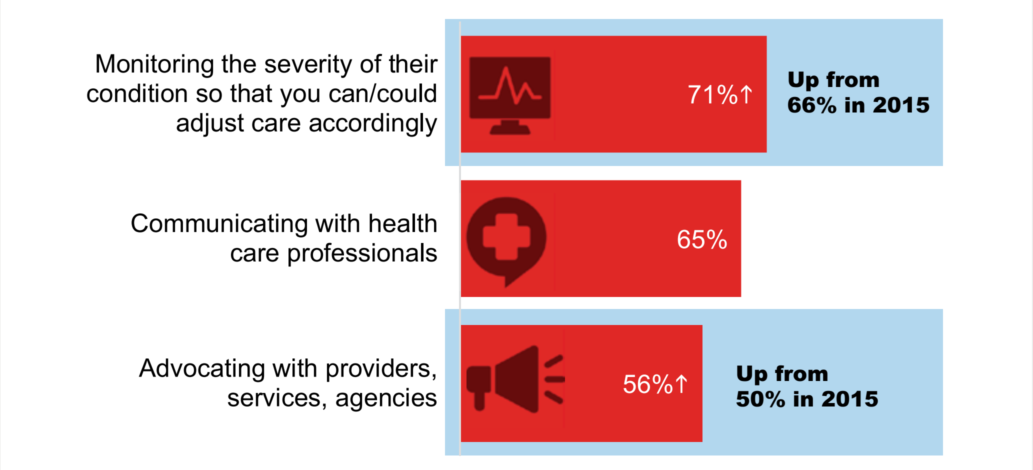
- Lower-income caregivers (35 percent vs. 28 percent of those with $50,000 or more in household income) and those with a high school education or less (37 percent vs. 25 percent of college-educated caregivers) are especially likely to find this task time consuming.
- Caregivers of someone with an emotional or mental health issue (42 percent vs. 24 percent without these issues) and those caring for someone with a memory problem (40 percent vs. 23 percent without) more often report finance management being time consuming.

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.

A majority monitor their care recipient's condition so they can adjust care accordingly (71 percent, see Figure 34), doing so more frequently than reported in 2015 (66 percent). Two out of three communicate with health care professionals about their recipient's care (65 percent). Over half (56 percent) act as an advocate with care providers, community services, or government agencies, taking on this responsibility more than in 2015 (50 percent).

Figure 34. Help with Other Key Activities



Q23_1. And do/did you provide help to your [relation] by...?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Respondents may select more than one response; results add to greater than 100 percent.

Change Focus: 2020 vs. 2015

- ➔ African American caregivers are more often doing each of these three support activities, as compared to 2015: monitoring recipient's condition (74 percent vs. 62 percent in 2015), communicating with care professionals (71 percent vs. 56 percent in 2015), and advocating (62 percent vs. 47 percent in 2015).
- ➔ Non-primary caregivers are increasingly advocating on behalf of their recipient (50 percent vs. 42 percent in 2015) and monitoring condition severity (67 percent vs. 60 percent in 2015).
- ➔ Caregivers of someone living in a rural area have more often taken on the role of advocate (60 percent vs. 42 percent in 2015) and are more frequently monitoring their recipient's condition to adjust care accordingly (70 percent vs. 63 percent in 2015).

- ➔ Advocating for the care recipient is increasingly more common now than in 2015 among several groups:
  - — Women caregivers (57 percent vs. 50 percent in 2015)
  - — Those caring for the youngest recipients (57 percent when caring for someone age 18 to 49 vs. 45 percent in 2015)
  - — Those caring for the oldest recipients (59 percent when caring for someone age 65 or older vs. 53 percent in 2015)
  - — Those with household incomes less than $50,000 (52 percent, up from 45 percent in 2015)

Subgroups: 2020

- Caregivers who report having had no choice in taking on their role more often report doing each of these three activities than those who had a choice: monitoring recipient's condition (76 percent vs. 64 percent with a choice), communicating with care professionals (72 percent vs. 57 percent with a choice), and advocating (64 percent vs. 46 percent with a choice).
- Those who provide 21 or more hours of care each week more often perform each of these three activities than caregivers in lower-intensity or lower-hour situations. For higher-hour caregivers, 70 percent advocate (vs. 49 percent lower-hour caregivers), 87 percent monitor (vs. 63 percent), and 82 percent communicate (vs. 57 percent).
- Similarly, primary caregivers more often perform each of these three tasks: advocating (59 percent vs. 50 percent non-primary), monitoring (73 percent vs. 67 percent), and communicating (69 percent vs. 58 percent).
- Those who have been providing care for one year or longer also more often take on these support tasks of advocating (64 percent vs. 46 percent of those caring for less than a year), monitoring (76 percent vs. 64 percent), and communicating (72 percent vs. 57 percent).
- Higher-income caregivers—those with $50,000 or more each year in household income—more often perform all three support activities of advocating (58 percent vs. 52 percent of those with less than $50,000 in household income), monitoring (73 percent vs. 67 percent), and communicating (68 percent vs. 61 percent).

Of note, performing these tasks, like advocating for the care recipient or communicating with care professionals, varies by the relationship the caregiver and care recipient have. When the caregiver is caring for a close family member (like a spouse/partner or parent), they more often do each of these three tasks than caregivers of more "distant" relatives. In turn, those caring for these more "distant" relatives (other relatives in Figure 35), more often do these three tasks than caregivers of non-relatives.

Figure 35. Help with Other Key Activities by Caregiver–Care Recipient Relationship

	Spouse/ Partner (n = 179) A	Parent/ Parent-In-Law (n = 703) B	Other Relative (n = 355) C	Non-Relative (n = 149) D
Communicating with health care professionals like doctors, nurses, or social workers about recipient's care	79%^{BCD}	67%^{D}	61%^{D}	48%
Monitoring the severity of their condition so that you can adjust care accordingly	78%^{CD}	73%^{D}	69%^{D}	54%*
Advocating for them with health care providers, community services, and government agencies	62%^{CD}	60%^{CD}	52%^{D}	40%*

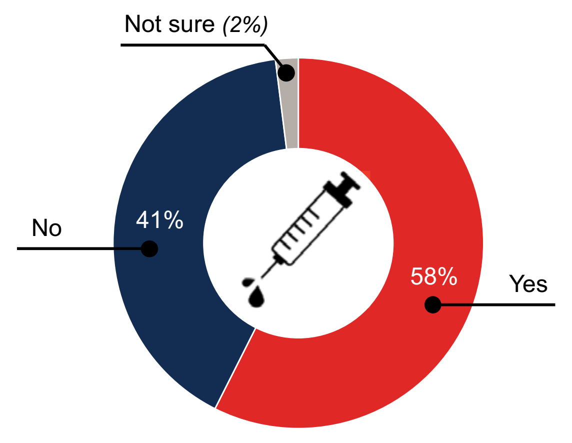
** Significantly higher than in 2015.*

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Respondents may select more than one response; results add to greater than 100 percent.

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.[35] 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 (58 percent, see Figure 36).

Figure 36. Assistance 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.

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

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[35] See Reinhard et al., *Home Alone Revisited*; S. C. Reinhard, C. Levine, and S. Samis, *Home Alone: Family Caregivers Providing Complex Chronic Care* (Washington, DC: AARP Public Policy Institute and United Hospital Fund, 2012).

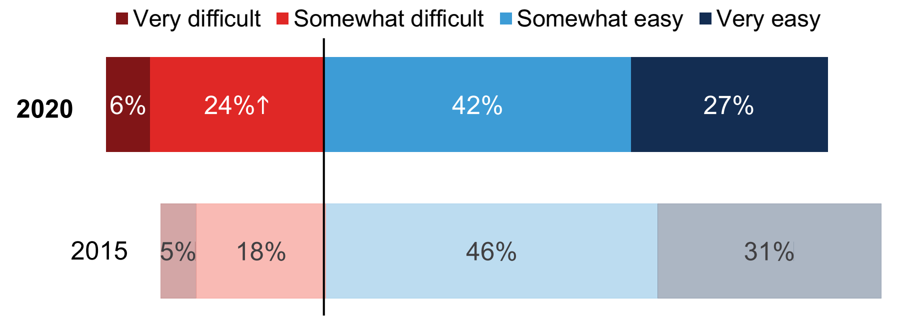
Subgroups: 2020

- African American and Hispanic caregivers (67 percent each) more often help with medical/nursing tasks than do White caregivers (52 percent).
- Caregivers who feel they had no choice in taking on care more often help with medical/nursing tasks (61 percent) than those who had a choice (54 percent).
- Those caring for a spouse/partner more often help with medical/nursing tasks (72 percent) than all other caregivers (56 percent). Similarly, caregivers who live with their recipient more often help with medical/nursing tasks (70 percent) than those who do not live together (49 percent).
- The more hours of care a caregiver provides, the more often they help with medical/nursing tasks: 84 percent of caregivers who provide 21 or more hours of care weekly are helping with medical/nursing tasks (compared to 45 percent of those providing 20 or fewer hours of care). A similar pattern also emerges for the level of care index, where caregivers in higher-intensity situations more often do medical/nursing tasks.
- Caregivers of recipients who live in a rural area more often report helping with medical/nursing tasks (62 percent vs. 56 percent of those caring for someone living in a non-rural area).

Ease of Coordinating Care

The challenges individuals face in navigating the health care and LTSS systems are often amplified for their caregivers, who are acting on their behalf.[36] Among those who coordinate care, a greater proportion of caregivers report having at least some difficulty in coordinating care among their care recipient's providers (31 percent vs. 23 percent in 2015, shown in Figure 37).

Figure 37. 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 those providers?

2020 Base: Caregivers Involved in Care Coordination for Recipient Age 18+ (n=1,200)

2015 Base: Caregivers Involved in Care Coordination for Recipient Age 18+ (n=1,042)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

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[36] National Academies of Sciences, Engineering, and Medicine, *Families Caring for an Aging America*.

Change Focus: 2020 vs. 2015

This increased difficulty in coordinating care seems to be fairly universal for caregivers in 2020. This significant increase in coordination difficulty is happening across all age groups under 75, gender, and income groups of caregivers; caregivers who felt they had a choice and those who feel they did not; both working and unemployed caregivers; caregivers providing any number of hours of care; and irrespective of where the recipient lives (rural vs. not).

- ➔ Caregivers with at least some college education show a marked increase in difficulty of care coordination (34 percent vs. 23 percent in 2015).
- ➔ Those caring for the oldest recipients ages 65 and older more often report having difficulty with care coordination (30 percent) than they did in 2015 (22 percent).
- ➔ Primary caregivers report more difficulty with care coordination (28 percent vs. 20 percent in 2015).
- ➔ Long-term caregivers who have been providing care for one year or longer more often report issues with care coordination (32 percent vs. 21 percent in 2015).

Subgroups: 2020

- Caregivers of those who have emotional or mental health issues report the most difficulty with care coordination (45 percent vs. 25 percent of those caring for a recipient without emotional or mental health issues). Those caring for someone with memory problems (37 percent) are also especially likely to find care coordination difficult (compared to 27 percent of those caring for someone without memory problems).
- Higher-hour caregivers more often report having difficulty (38 percent of those who provide 21 or more hours of care a week vs. 27 percent of those providing 20 hours or less), as do high-intensity caregivers (37 percent vs. 25 percent low- to mid-intensity caregivers).
- Those caregivers who feel they had no choice in taking on care also more often find care coordination difficult (37 percent vs. 23 percent who had a choice).

Level of Care Index

The 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, 2009, and 2015 *Caregiving in the U.S.* studies,[37] is replicated in this study to convey in a simple measure of the intensity or complexity of the caregiving situation. 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 index construction are shown in appendix B.

Four in 10 caregivers are in high-intensity situations (40 percent), 16 percent experience a medium intensity, and 43 percent have a low intensity (see Figure 38).

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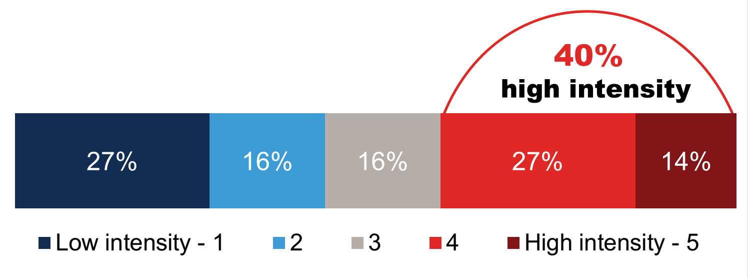
[37] In each of the prior waves, this index was referred to as the Burden of Care Index, with each level of the index referred to as high, moderate or medium, and low “burden.” For the 2020 cycle, we have adjusted the name to be Level of Care Index, with each level of the index referred to with the word “intensity” rather than “burden,” as this index is one way to measure the intensity or complexity of the caregiving situation.

Figure 38. Level of Care Index



2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

For each intensity level of care, Figure 39 shows the components of the index.

Figure 39. Components of Level of Care Index by Intensity Category

	Low Intensity (n = 595)	Medium Intensity (n = 231)	High Intensity (n = 559)
Hours of care per week	5.4	9.7	48.9
Number of ADLs out of six total	0.2	2.2	3.0
Number of IADLs out of seven total	3.5*	4.3	5.5*

** Significantly higher than in 2015.*

Change Focus: 2020 vs. 2015

➔ The youngest caregivers—those ages 18 to 49—more often are in a higher-intensity care situation (43 percent) than they were in 2015 (36 percent). This may be because a greater proportion of these caregivers are caring for a relative (91 percent vs. 85 percent in 2015), live together with their recipient (42 percent vs. 34 percent in 2015), care for a recipient with Alzheimer's or dementia (23 percent vs. 16 percent in 2015), and/or their recipient has more comorbid conditions (47 percent reporting two or more condition categories vs. 37 percent in 2015).

Subgroups: 2020

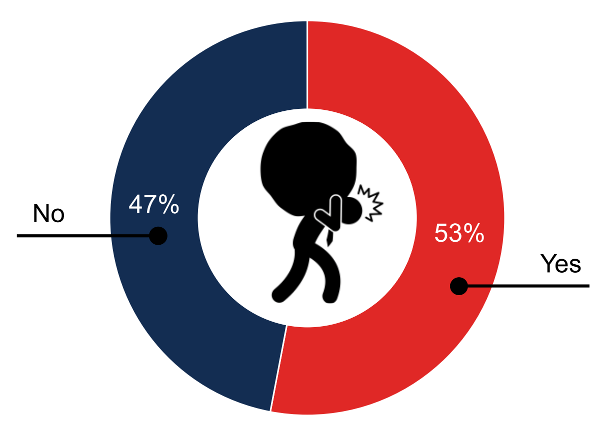
- African American (54 percent) and Hispanic caregivers (49 percent) more often are in high-intensity care situations than either White (35 percent) or Asian American (32 percent) caregivers.
- Those caring for a spouse/partner are most often in the high-intensity category (59 percent), more so than those caring for a parent/parent-in-law (35 percent), other relative (44 percent), or non-relative (31 percent). Likewise, caregivers who live with their recipient more often are in a high-intensity care situation (61 percent vs. 27 percent not living together).
- Primary caregivers more often are in a high-intensity care situation (44 percent) than non-primary caregivers (33 percent).
- Those who have been providing care for five years or longer more often are in high-intensity care situations (47 percent vs. 38 percent of those who have been providing care for less time).
- Lower-income caregivers more often are in high-intensity situations (46 percent vs. 37 percent of those with $50,000 or more in household income), as are caregivers with less than a college degree (43 percent vs. 35 percent of those with a bachelor's degree or higher).

F. PRESENCE OF OTHER HELP

Presence of Other Unpaid Caregivers

About half of all caregivers report that someone else also provided unpaid care to their care recipient over the past year (53 percent, see Figure 40).

Figure 40. Presence of Other Unpaid Caregivers



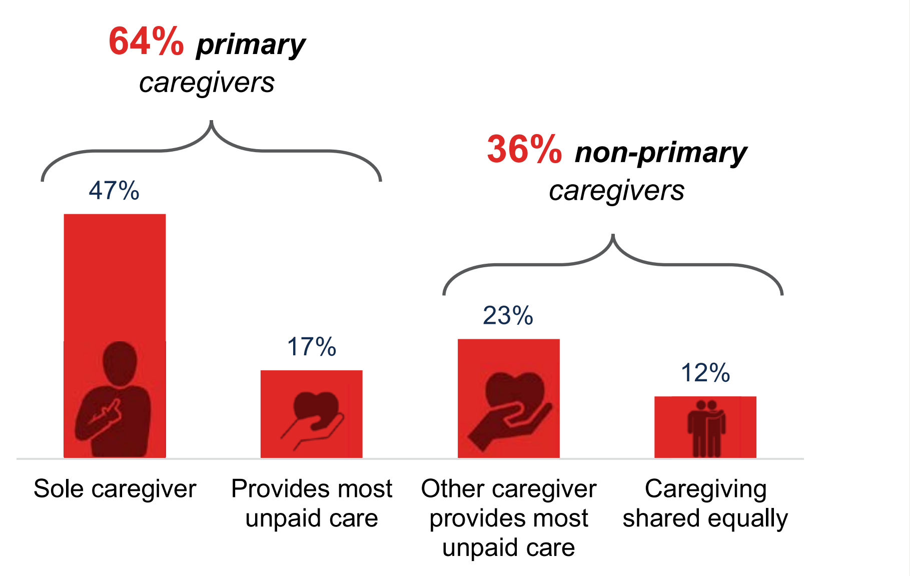
Q28. Has anyone else provided unpaid help to your [relation] during the last 12 months?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Primary Caregiver Status

Over 6 in 10 caregivers perceive themselves to be the primary unpaid caregiver, meaning either they are sole caregivers (47 percent, see Figure 41) or there are other unpaid caregivers but they themselves provide the majority of unpaid care (17 percent). The 36 percent who are non-primary caregivers includes 12 percent who share caregiving equally with someone else and 23 percent who say another caregiver provides most of the unpaid care.

Figure 41. 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]?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Change Focus: 2020 vs. 2015

➔ Caregivers of recipients who live in a rural area are more often the primary caregiver (67 percent) than they were in 2015 (57 percent).

Subgroups: 2020

- African American caregivers (55 percent) more often are the sole unpaid caregiver for their recipient, more so than White (44 percent) or Asian American (43 percent) caregivers.[38]
- Women caregivers are more often the primary caregiver (67 percent vs. 59 percent of men caregivers).
- LGBTQ caregivers are more likely to report being the primary caregiver (78 percent vs. 63 percent of caregivers not identifying in this way).
- Those caring for someone age 18 to 49 are more often the primary caregiver (73 percent vs. 63 percent of those caring for someone older). Moreover, they are more often the *sole* caregiver for the adult age 18 to 49 (59 percent vs. 45 percent of those caring for someone older).
- Those who report having no choice in providing care more often are the primary caregiver (69 percent vs. 59 percent with choice), with 50 percent reporting they are the sole caregiver.
- Caregivers of a spouse/partner are predominately the sole caregiver (80 percent), more than those caring for a parent/parent-in-law (44 percent), other relative (40 percent), or non-relative

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[38] Fifty-two percent of Hispanic caregivers report being the sole unpaid caregiver, not significantly different from any other racial/ethnic group listed.

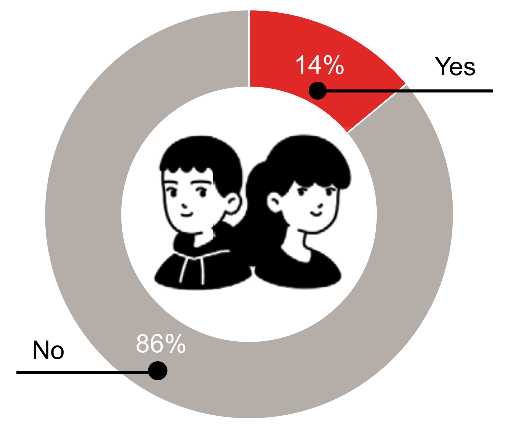
(45 percent). Similarly, caregivers who live with their care recipient often are the sole caregiver (61 percent vs. 38 percent of those who do not co-reside).

- Among caregivers who provide 21 or more hours of care each week, 53 percent report being the sole caregiver, more than the 44 percent of caregivers who provide 20 or fewer hours of care weekly. High-intensity caregivers more often are the primary caregiver (71 percent vs. 60 percent of those in low- to mid-intensity situations).
- Caregivers who do not work (67 percent) or who work fewer than 30 hours a week (69 percent) more often are the primary caregiver than those who work 30 hours or more (60 percent).
- Perhaps related to working, caregivers with lower household incomes more often report being the primary caregiver for their recipient (70 percent), compared to those with $50,000 or more in household income (61 percent).

Caregivers Who Are Children

The other members of the family or community who may be called upon to carry out care tasks includes children. Among those who report having unpaid help, 14 percent say at least one of these unpaid caregivers is a child under age 18 (see Figure 42). Therefore, in total, 7 percent of caregivers of adults report a child helps provide care to the recipient. Based on a population of 47.9 million caregivers of adults, this estimates at least 3.4 million children under age 18 in the United States are providing care to an adult recipient.[39]

Figure 42. Caregivers who are Children



Q29Z. *(If has other unpaid help)* Of all the people who help provide/helped provide care to your [relation], are/were any of them children under the age of 18? They might help or assist/have helped or assisted you with the care you provide/provided. The child(ren) may also help/have helped with things like bringing items to or from your [relation], doing chores or other housework, running errands, or just generally helping watch over your [relation].

2020 Base: Caregivers With Other Unpaid Help for Recipient Age 18+ (n=738)

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[39] For comparison, 11.2 percent of caregivers of adults report living with their care recipient, with children or grandchildren under the age of 18 also living in the same home at the time of care. This would project out 5.4 million child caregivers providing care to an adult, if at least one child in each of these households provided care.

Subgroups: 2020

- Younger caregivers more often report at least one child helping to provide care, though they also more often have at least one child living in their home, as is shown in Figure 43.
- When the caregiver lives in the same home as the care recipient, children more often provide care (19 percent vs. 11 percent of those not co-residing).
- Children helping to provide care is more common among non-White caregivers, with about one in five reporting their presence: 21 percent Hispanic, 20 percent African American, and 17 percent Asian American compared to 9 percent White.
- Caregivers in high-intensity care situations more often report children helping to provide care (17 percent) than those in a low-intensity setting (10 percent).

Figure 43. Children Providing Care, Children in Household, and Co-Residence with Recipient by Caregiver Generation

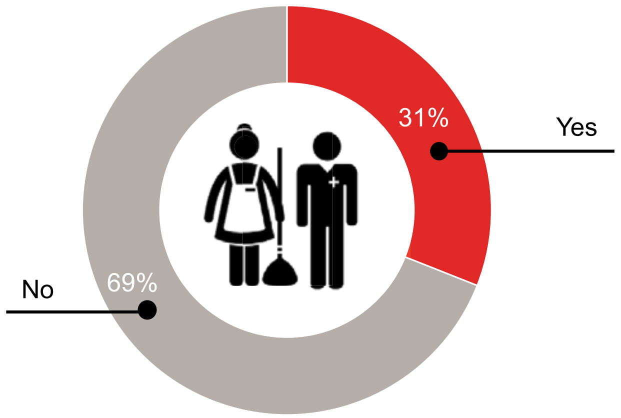
	Generation Z (n = 34) A	Millennial (n = 283) B	Generation X (n = 392) C	Baby Boomer (n = 594) D	Silent (n = 89) E
At least one child caregiver	16%^{DE}	9%^{DE}	9%^{DE}	4%	2%
At least one child lives with the caregiver	36%^{DE}	44%^{DE}	47%^{DE}	10%	8%
Care recipient lives in caregiver's home	44%	41%	39%	36%	55%^{BCD}

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

Use of Paid Help

Despite the increasing complexity or comorbidity of conditions that adult care recipients are dealing with, the majority of caregivers have no paid help in caring for their recipient (69 percent, Figure 44). Among caregivers whose recipient was not in a nursing home or assisted living facility, just 3 in 10 report their recipient received paid help from aides, housekeepers, or others in the past year (31 percent).

Figure 44. Use of Paid Help



Q30. (If recipient not in nursing home or assisted living) During the last 12 months, did your [relation] receive paid help from any aides, housekeepers, or other people who were paid to help them?

2020 Base: Caregivers of Recipient Age 18+ Not in Nursing Home or Assisted Living (n=1,285)

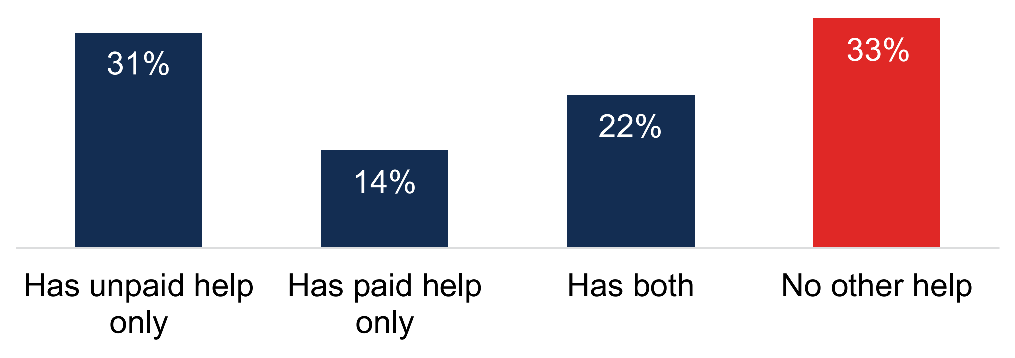
Subgroups: 2020

- Women caregivers more often report the use of paid help (34 percent vs. 26 percent of men caregivers).
- Use of paid services is most common among caregivers of those ages 65 and older (38 percent vs. 16 percent of those caring for someone ages 18 to 64).
- Caregivers who do not live with their care recipient more often report the presence of paid help (36 percent vs. 23 percent who live together).
- Those in a high- to medium-intensity care situation more often report the use of paid help (36 percent vs. 24 percent of low-intensity caregivers).
- Caregivers with higher household incomes more often report their recipient has paid help (33 percent of those with $50,000 or more vs. 27 percent of those with less than $50,000 in household income).

Combination of Paid or Unpaid Help

One in three caregivers of adults is providing care completely alone, with no help from anyone else (paid or unpaid, 33 percent as shown in Figure 45). Another 22 percent is at the other end of the help spectrum—reporting the presence of both paid and unpaid help. One in three have other unpaid caregivers helping out but no paid help (31 percent), while 14 percent report having paid help but report that they themselves are the only unpaid caregiver.

Figure 45. Combination of Paid or Unpaid Help



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

Q30. (If recipient not in nursing home or assisted living) During the last 12 months, did your [relation] receive paid help from any aides, housekeepers, or other people who were paid to help them?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Caregivers who "do it alone" without any other help (paid or unpaid) report providing more hours of care weekly and are more often living together, as shown in Figure 46.

Figure 46. Caregiving Situation by Presence of Paid and Unpaid Help

	Has Both Paid and Unpaid Help (n = 318) A	Has Unpaid Help but No Paid (n = 417) B	Has Paid Help but No Unpaid (n = 195) C	Has No Other Help (n = 457) D
Hours of care provided weekly by caregiver (average)	22.5	20.8	22.3	27.4^{ABC}
Number of ADLs performed by caregiver (average)	2.3^{BD}	1.3	2.0^{BD}	1.4
Number of IADLs performed by caregiver (average)	4.4	4.2	4.8^{ABD}	4.4
Years of care (average)	4.1	4.0	5.1	4.9
Number of condition categories care is provided for (average)	1.8^{BD}	1.6	2.0^{BD}	1.5
High-intensity care situation (percent)	42%^{B}	35%	43%	43%^{B}
Recipient lives with caregiver (percent)	22%	35%^{A}	32%^{A}	59%^{ABC}
Caregivers' median household income	*$80,000*	*$67,500*	*$80,000*	*$55,000*

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

Subgroups: 2020

- The older the recipient, the more often they have help from both paid and unpaid sources (27 percent when care recipient is age 65 or older vs. 11 percent for younger recipients ages 18 to 64).
- White (24 percent) and Asian American (23 percent) caregivers more often report the presence of both paid and unpaid help than do Hispanic caregivers (14 percent), which may be because their care recipients are often older.[40]
- Half of caregivers who live with their recipient report having no help at all (paid or unpaid), significantly more than caregivers who do not co-reside with their recipient (23 percent).
- Similarly, those caring for a spouse/partner (who almost always live together) are often providing care totally alone (66 percent without paid or unpaid help), while the majority of those caring for someone else have at least one other source of help (71 percent paid or unpaid).

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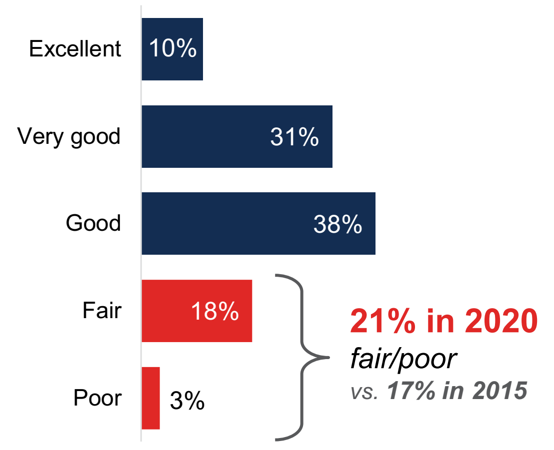
[40] Twenty percent of African American caregivers report the presence of both paid and unpaid caregivers, not significantly different than any other racial/ethnic group reported above.

G. WELL-BEING OF CAREGIVERS

Caregiver Health

Caregiver self-rated health seems to have declined during the past five years; alarmingly, the stress associated with caregiving may exacerbate declines in health that occur with age. Four in 10 caregivers (41 percent, see Figure 47) consider their health to be *excellent* or *very good*, down significantly from 2015 (48 percent), while 1 in 5 say it say it is *fair* or *poor* (21 percent), up significantly from 2015 (17 percent)[41] and comparable to other research.[42]

Figure 47. Caregiver Self-Rated Health



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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

By comparison, using the same self-rated health measure, the general U.S. population has not seen a comparable decline over the past five years, as shown in Figure 48.[43] Supports for caregivers and their recipients will be even more critical if this trend in declining caregiver health continues to hold.

Figure 48. Self-Rated Health Status of Caregivers Compared to General U.S. Adult Population

	2020 Caregivers (n = 1,392)	National estimate 2018**	2015 Caregivers (n = 1,248)	National estimate 2014***
Excellent/Very good	41%*	62%	48%	62%
Good	38%	26%	35%	26%
Fair/Poor	21%*	12%	17%	12%

** Significantly different than 2015 (higher or lower)*

*** See note 42.*

**** CDC/NCHS,* Summary Health Statistics: National Health Interview Survey, 2014.

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[41] Self-rated health is typically asked on this 5-point scale. See E. L. Idler and Y. Benyamini, "Self-Rated Health and Mortality: A Review of Twenty-Seven Community Studies," *Journal of Health and Social Behavior* 38, no. 1.

[42] Researchers found that 20 percent of informal, unpaid caregivers self-reported fair or poor health. See V. J. Edwards et al., "Characteristics and Health Status of Informal Unpaid Caregivers—44 States, District of Columbia, and Puerto Rico, 2015–2017," *MMWR Morbidity and Mortality Weekly Report* 69 (2020):183–88. doi:http://dx.doi.org/10.15585/mmwr.mm6907a2.

[43] CDC/NCHS, *Summary Health Statistics: National Health Interview Survey*, 2018, https://ftp.cdc.gov/pub/Health_Statistics/NCHS/NHIS/SHS/2018_SHS_Table_A-11.pdf.

Change Focus: 2020 vs. 2015

The drop-off in caregiver self-rated health since 2015 is happening across most subgroups of caregivers. Caregivers report significantly worse health across all hours of care and ages of recipients; among both low- and high-income caregivers; among all marital statuses; and among both those who had a choice and those who had no choice in providing care.

The following groups of caregivers stand out as having significant declines in self-rated health, while their peers have not.

- ➔ The youngest caregivers—those ages 18 to 49—are less likely to say they are in excellent or very good health (40 percent in 2020 vs. 52 percent in 2015) and are more likely to report having fair or poor health (21 percent in 2020 vs. 15 percent in 2015). The decline seems to be concentrated among millennials, who say they are in worse health now than they were in 2015 (40 percent rating excellent or very good in 2020 vs. 56 percent in 2015, and 22 percent rating their health as fair or poor in 2020 vs. 14 percent in 2015). Other research suggests that generally, as a whole, millennials are experiencing health declines at earlier ages than generations before them,[44] so perhaps millennial caregiver health declines are reflective of overall population health declines among their generation. Further research is needed.

Alarmingly, caregivers in the more “demanding” or “intense” care situations have had the greatest slides in self-rated health in the past five years:

- ➔ Fewer than 4 in 10 caregivers who have *no other help at all* (either paid or unpaid) report having excellent or very good health (36 percent), down from 50 percent in 2015.
- ➔ The highest-intensity care situations are experiencing health declines: 35 percent report being in excellent or very good health (down from 42 percent in 2015) while 27 percent report being in fair or poor health (up from 21 percent in 2015).
- ➔ Caregivers who live with their care recipient are experiencing health declines (35 percent in excellent or very good health, down from 45 percent in 2015), while those who do not live together are down in health status only slightly.
- ➔ Primary caregivers’ health is also declining, with just 39 percent reporting excellent or very good health compared to 49 percent in 2015.

Other groups showing significant declines in self-rated health include the following:

- ➔ Hispanic caregivers (35 percent rate their own health as excellent or very good vs. 51 percent in 2015)
- ➔ Asian American caregivers (41 percent vs. 60 percent in 2015)
- ➔ Women caregivers (40 percent, down from 48 percent in 2015)
- ➔ Working caregivers generally (46 percent vs. 53 percent in 2015), and “full-time” working caregivers specifically (47 percent of those working 30 hours or more vs. 54 percent in 2015)
- ➔ Caregivers with a high school diploma or less education (31 percent vs. 43 percent in 2015)
- ➔ Caregivers who do not live in a rural area (42 percent vs. 50 percent in 2015)
- ➔ Those caring for a spouse/partner (32 percent excellent or very good vs. 45 percent in 2015) and caring for a relative other than a parent (40 percent vs. 53 percent in 2015)

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[44] BlueCross BlueShield Health of America, *The Economic Consequences of Millennial Health*, November 6, 2019, https://www.bcbs.com/sites/default/files/file-attachments/health-of-america-report/HOA-Moodys-Millennial-10-30.pdf.

Subgroups: 2020

- Groups that rate themselves in better health include the following:
  - — White caregivers (45 percent rate their own health as excellent or very good), compared to African American (34 percent) or Hispanic (35 percent) caregivers
  - — Caregivers who feel they had a choice in taking on their role (45 percent rating excellent or very good vs. 38 percent had no choice)
  - — Higher-income caregivers (47 percent in excellent or very good health vs. 31 percent of those with less than $50,000 in household income)
  - — More educated caregivers (51 percent of those with a college degree or higher vs. 41 percent of those with some college vs. 31 percent of those with a high school diploma or less)

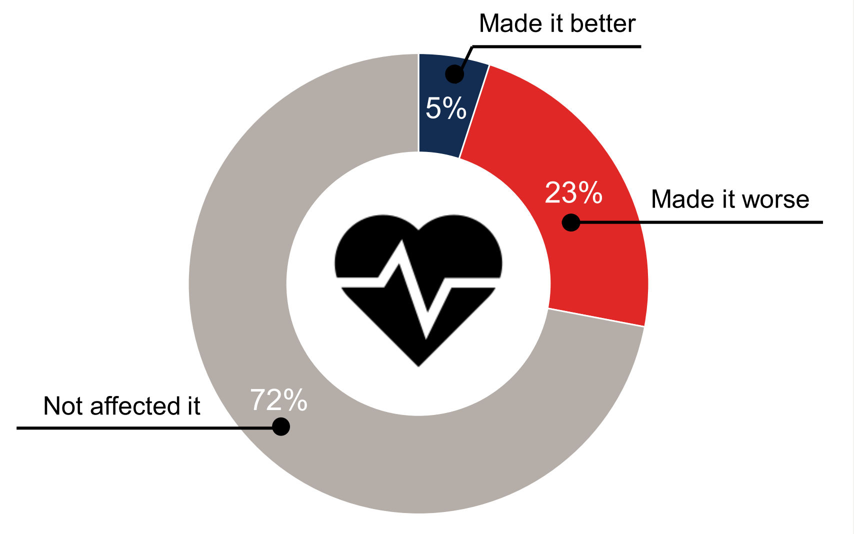
At the other end of the health spectrum, caregivers who more often self-rate as being in fair or poor health include:

- — Those who feel alone (30 percent vs. 16 percent of those who do not feel alone)
- — Caregivers who live with their care recipient (27 percent vs. 16 percent of those not living together)
- — Those in high-intensity caregiving situations (27 percent vs. 16 percent in medium- to low-intensity situations)
- — Primary caregivers (23 percent vs. 16 percent non-primary)

Caregiver Health Changes

While 7 out of 10 caregivers feel that providing care has not affected their own health (72 percent), nearly 1 out of 4 feel caregiving has made their health worse (23 percent, see Figure 49).

Figure 49. Caregiver Health Changes



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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Subgroups: 2020

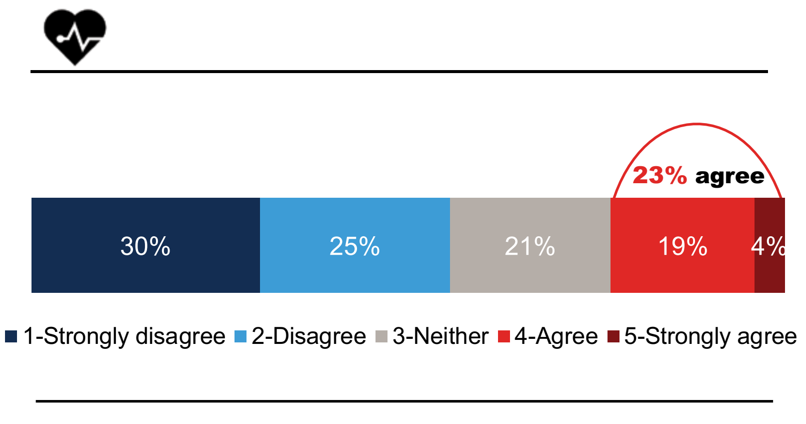
- Half of those who feel alone feel that caregiving has made their health worse (50 percent), compared to just 13 percent of those who do not feel alone.

- Caregivers who report lesser or lower health status are the same caregivers reporting that their role has made their health worse, including:
  - — Those in high-intensity caregiving situations (32 percent say it has made their health worse vs. 16 percent in medium- to low-intensity situations)
  - — High-hour caregivers (33 percent when providing 21 or more hours of care weekly vs. 18 percent of lower-hour caregivers)
  - — Caregivers who live with their care recipient (29 percent vs. 18 percent not living together)
  - — Those who feel they had no choice in taking on their role (32 percent vs. 12 percent had a choice)
  - — Primary caregivers (25 percent vs. 18 percent non-primary)
- White (24 percent) and Asian American (27 percent) caregivers more often report that caregiving has made their health worse, as compared to Hispanic caregivers (17 percent); and while Asian American caregivers are older than Hispanic caregivers, caregiver age has no effect on the health impact of caregiving.
- One out of three caregivers of a spouse/partner report caregiving has made their health worse (33 percent), compared to 21 percent of those caring for all others.
- As the length of caregiving rises, so too does the reported impact on caregiver health, for the worse: 27 percent of those who have provided care for a year or longer report caregiving making their health worse vs. just 17 percent of those who have cared for less than a year.

Difficulty Caring for Own Health

Nearly one in four caregivers say it is difficult to take care of their own health (23 percent), while 55 percent disagree (see Figure 50).

Figure 50. Difficulty Caring for Own Health



M5b. How much do you agree or disagree with each statement below about being a caregiver for your [relation]? "I find/found it difficult to take care of my own health."

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Nearly across the board, caregivers who say caregiving has made it difficult to take care of their own health report a higher-intensity or demanding care situation: they perform more hours of care weekly, perform more ADLs and IADLs, more often live with their recipient, and report their recipient has multiple condition categories (as shown in Figure 51). They more often say they are in worse health and more often report feeling physical strain, emotional stress, and loneliness.

Figure 51. Caregiver Well-Being by Difficulty Taking Care of Health

	Difficulty to Take Care of Own Health		
	Not Difficult (n = 768) A	Neither (n = 300) B	Difficult (n = 317) C
Care Situation			
High intensity	32%	45%^{A}	57%^{AB}
Average hours of care weekly	19.2	25.8^{A}	32.9^{AB}
ADLs (average)	1.4	1.7^{A}	2.1^{AB}
IADLs (average)	4.1	4.5^{A}	5.1^{AB}
Average condition categories recipient has	1.5	1.7^{A}	2.1^{AB}
Recipient lives with caregiver	35%	45%^{A}	47%^{A}
Self-Rated Health Status			
Excellent/Very good	55%^{BC}	30%^{C}	20%
Fair/Poor	10%	25%^{A}	42%^{AB}
Made health worse	8%	19%^{A}	60%^{AB}
Stress and Strain			
Feels alone	8%	21%^{A}	55%^{AB}
High physical strain	8%	19%^{A}	38%^{AB}
High emotional stress	22%	40%^{A}	70%^{AB}
High financial strain	10%	23%^{A}	36%^{AB}
Had no choice in taking on care	44%	57%^{A}	72%^{AB}
Basics			
Age of caregiver (average)	49.9	48.6	48.4
Age of care recipient (average)	70.5^{BC}	67.7	66.2

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

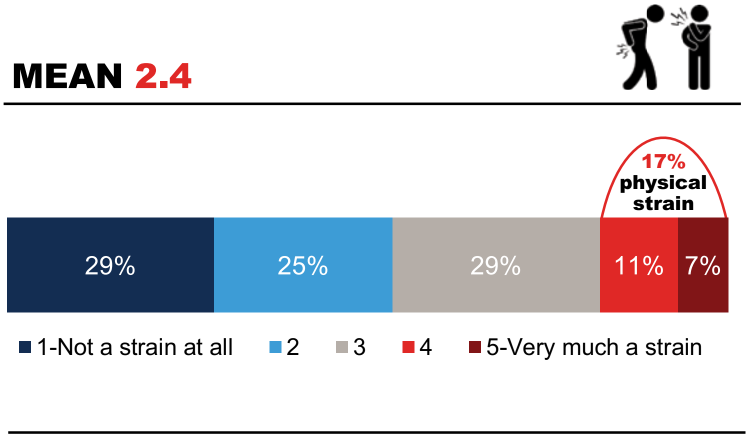
Subgroups: 2020

- Caregivers ages 18 to 64 more often agree that caregiving has made it difficult to take care of their own health (24 percent vs. 18 percent of those ages 65 and older).
- As with the other health subgroups seen above, caregivers who are likely to report having difficulty taking care of their own health include:
  - — Those who had no choice in taking on care (31 percent vs. 14 percent with choice)
  - — Those caring for a spouse/partner (31 percent vs. 22 percent others)
  - — Those who live with their care recipient (27 percent vs. 20 percent not co-residing)
  - — Those who have been providing care for a year or longer (27 percent vs. 17 percent less than a year)
  - — Those in high-intensity care situations (32 percent vs. 16 percent medium- to low-intensity situations)
  - — Primary caregivers (26 percent vs. 17 percent non-primary)

Physical Strain of Caregiving

Nearly one in five caregivers report high physical strain as a result of their caregiving duties (17 percent rating a 4 or 5 on a 5-point scale, see Figure 52). On average, caregivers of adults report a physical strain of 2.4 (out of 5).

Figure 52. Physical Strain of Caregiving



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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

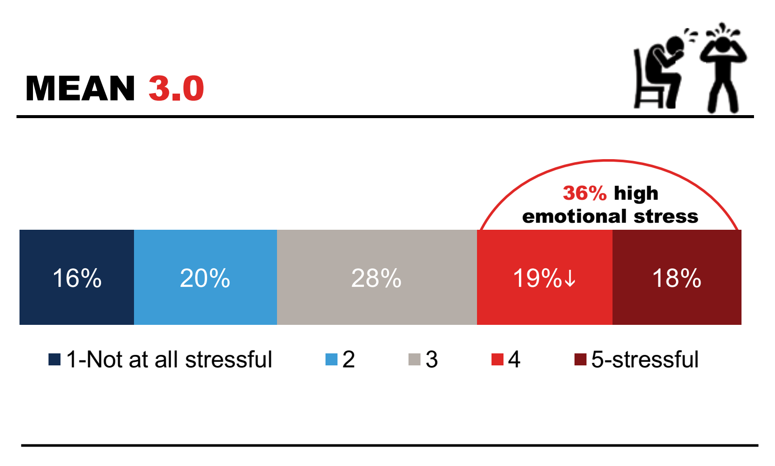
Subgroups: 2020

- Caregivers who say they had no choice in taking on their care role more often report high physical strain (21 percent vs. 13 percent with choice).
- Those in high-intensity caregiving situations more often report high physical strain (29 percent), more than those in medium-intensity situations (14 percent), who in turn more often report physical strain than those in low-intensity care situations (7 percent).
- Similarly, those who provide 21 or more hours of care weekly report higher physical strain (30 percent) than those providing fewer hours of care (11 percent).
- Caregivers who report feeling alone also report high physical strain (37 percent vs. 11 percent of those who don't feel alone).

Emotional Stress of Caregiving

Nearly 4 in 10 caregivers consider their caregiving situation to be highly stressful (36 percent rating stress 4 or 5 on a 5-point scale, shown in Figure 53), while an additional 28 percent report moderate emotional stress. On average, caregivers of adults report emotional stress of 3.0 (out of 5).

Figure 53. Emotional Stress of Caregiving



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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

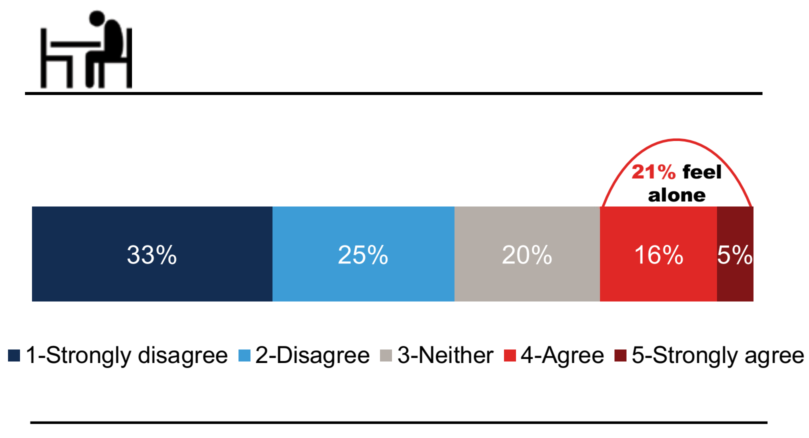
Subgroups: 2020

- When caregivers feel alone, 72 percent report feeling high emotional stress, compared to just 24 percent of those who do *not* feel alone.
- Nearly half of caregivers who had no choice in providing care feel a high amount of emotional stress (48 percent vs. 23 percent who had a choice).
- Asian American caregivers more often report feeling high levels of emotional stress (44 percent), more so than either African American (29 percent) or Hispanic (32 percent) caregivers.
- Women who provide care are also more stressed (39 percent vs. 33 percent of men who are caregivers).
- Caregivers ages 18 to 64 also report higher emotional stress (38 percent) than older caregivers (30 percent).
- Those who have been providing care for one year or longer more often report high emotional stress (42 percent vs. 28 percent of those who have provided care for less time).
- Those caring for a relative more often feel high emotional stress (38 percent) than do those caring for a non-relative (23 percent).
- As with the health impacts and physical strain, those in care situations that are more intensive or involved feel higher emotional stress:
  - — Those living together with their recipient (40 percent high stress vs. 34 percent among those not co-residing)
  - — Those in high-intensity care situations (49 percent vs. 37 percent medium and 24 percent low)
  - — Those who provide 21 or more hours of care weekly (49 percent vs. 30 percent who provide 20 or fewer hours of care)

Feeling Alone

One out of five caregivers of adults feels alone (21 percent strongly agree or agree with the statement “I feel alone,” see Figure 54), while 58 percent disagree. Feelings of loneliness are associated with fairly strong feelings of stress and strain as well as decreased health for caregivers[45].

Figure 54. Feeling Alone



M5c. How much do you agree or disagree with each statement below about being a caregiver for your [relation]? “I feel/felt alone”

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don’t know/refused responses are not shown; results may not add to 100 percent.

Subgroups: 2020

- Despite living with another adult, caregivers who co-reside with their care recipient more often report feeling lonely (29 percent) than do caregivers who do not live with their recipient (16 percent). Similarly, those caring for a spouse/partner (29 percent) more often feel alone than those caring for someone else (20 percent).
- Caregivers who use social media more often report feeling alone, suggesting that in-person social interaction outside of the caregiver–care recipient relationship may be important to prevent social isolation.[46] This holds for caregivers who have used social media as a source for help or information about caregiving (30 percent feel alone vs. 19 percent of those who have not used social media as an information source) as well as for caregivers who have connected with other caregivers using online or social media support groups (34 percent feel alone vs. 22 percent of those who have not done this kind of thing online).
- Those in high-intensity care situations more often feel alone (29 percent vs. 16 percent medium- to low-intensity situations), as do those providing 21 or more hours of care (30 percent vs. 17 percent caring for 20 or fewer hours weekly).
- Caregivers who feel they had no choice in taking on care are more likely to feel alone (29 percent vs. 12 percent who had no choice).
- Primary caregivers are more likely to report feeling alone (27 percent vs. 11 percent of non-primary).

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[45] As shown throughout the report in subgroup analysis.

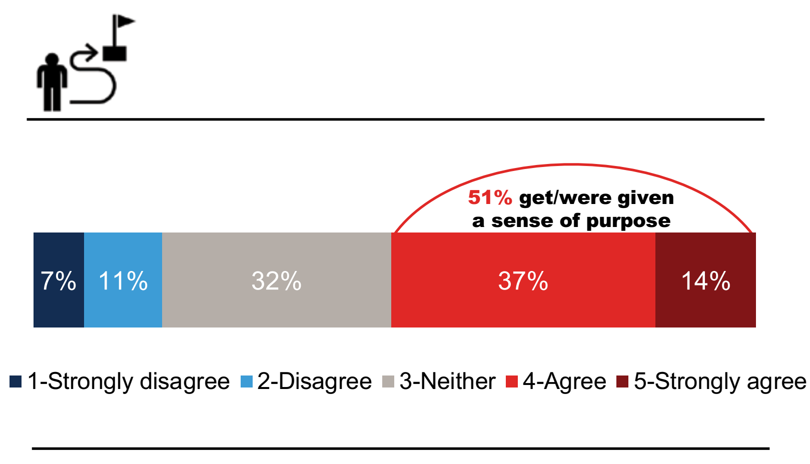
[46] This is echoed in other research; see G. O. Anderson and C. Thayer, “Loneliness and Social Connections: A National Survey of Adults 45 and Older,” AARP, Washington, DC, September 2018, https://www.aarp.org/research/topics/life/info-2018/loneliness-social-connections.html?CMP=RDRCT-PRI-HOMFAM-073118.

- As the years of providing care increase, so too does the feeling of being alone, with 14 percent of those caring for less than a year, 22 percent of those caring for one to four years, and 32 percent of those caring for five or more years feeling alone.
- Unmarried caregivers more often feel alone (25 percent vs. 19 percent of those who are married or with a partner), as do LGBTQ caregivers (33 percent vs. 20 percent of non-LGBTQ).

Sense of Purpose

For caregivers, positive emotions often coexist with feelings of isolation, stress, or strain. Half of caregivers feel their role as a caregiver gives them a sense of purpose or meaning in life (51 percent, see Figure 55).

Figure 55. Sense of Purpose



M5a. How much do you agree or disagree with each statement below about being a caregiver for your [relation]? “My role as a caregiver gives/gave me a sense of purpose or meaning in my life”

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don’t know/refused responses are not shown; results may not add to 100 percent.

Subgroups: 2020

- Hispanic (61 percent) and African American (59 percent) caregivers more often report that caregiving provides them with a sense of purpose, more than either White (46 percent) or Asian American (48 percent) caregivers. Despite performing more hours of care and care tasks, resulting in higher-intensity care situations, Hispanic and African American caregivers are not as emotionally stressed as their White and Asian American counterparts—perhaps suggesting that this sense of purpose or the cultural expectation to care for one’s family or community helps to buffer some of the emotional stress of caregiving. Further research is needed.

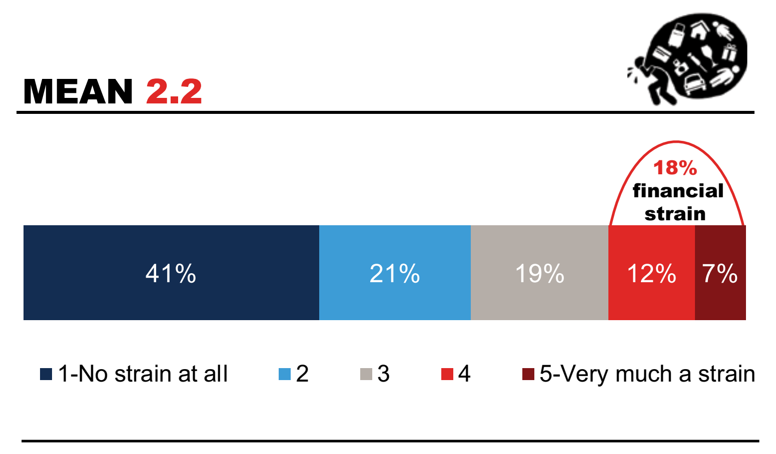
- Caregivers who say they had a choice in taking on their role more often feel a sense of purpose as a result of providing care (59 percent vs. 43 percent of those who had no choice).
- Those caring for more distant relations—non-relatives (60 percent) or relatives other than a parent or spouse (57 percent)—more often feel a sense of purpose or meaning from caregiving, as opposed to those caring for a parent (47 percent) or spouse (46 percent).
- In spite of, or perhaps because of, the demands of caregiving, those in higher-intensity (56 percent of those in high-to-medium intensity vs. 44 percent in low intensity) or higher-hour (57 percent caring for 21+ hours per week vs. 48 percent caring for fewer hours) care situations more often feel this sense of purpose.
- Primary caregivers more often feel this sense of purpose or meaning (53 percent vs. 46 percent of non-primary caregivers).

H. THE FINANCIAL SITUATION OF CAREGIVERS

Financial Strain

The economic effects of family caregiving can result in financial strain with substantial short-term and long-term financial consequences. About one in five caregivers report experiencing high financial strain as a result of providing care (18 percent rating 4 or 5 on a 5-point scale, see Figure 56). On average, caregivers of adults report a financial strain of 2.2 (out of 5).

Figure 56. Financial Strain of Caregiving



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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Change Focus: 2020 vs. 2015

Nearly across the board, most caregivers of adults are experiencing comparable levels of financial strain as were experienced by caregivers of adults in 2015.

- ➔ However, caregivers of adults ages 18 to 49 report greater financial strain (34 percent vs. 22 percent in 2015). Further research is needed to understand the financial burden of caring for a younger adult, though we do know that caregivers of younger adults more often experience financial impacts, like reducing savings, taking on more debt, or having trouble with expenses (see below).

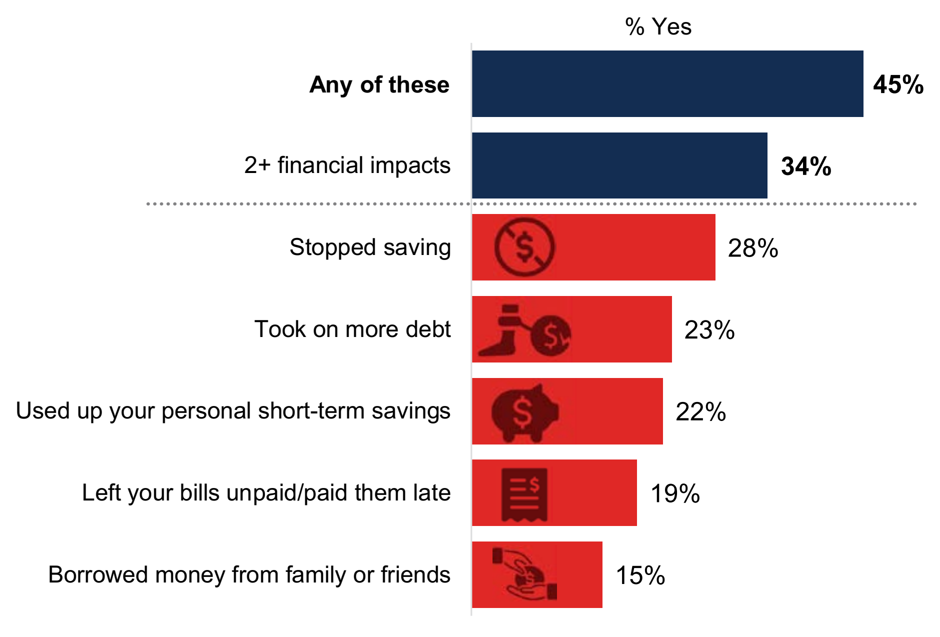
Subgroups: 2020

- The youngest caregivers—those ages 18 to 49—report the highest financial strain (22 percent rating 4 or 5 vs. 15 percent of caregivers ages 50 and older).
- LGBTQ caregivers more often report high financial strain (27 percent vs. 18 percent of those not identifying as such), though they are younger than non-LGBTQ caregivers by about 8 years (mean age 42.4 years old compared to 50.0 years for caregivers not identifying as lesbian, gay, bisexual, and/or transgender).
- Caregivers of a spouse/partner (26 percent) or other relative (22 percent) each report higher financial strain than those caring for a parent/parent-in-law or non-relative (15 percent).
- Similarly, those who live with their care recipient more often report financial strain (25 percent vs. 14 percent of those not living together), as do primary caregivers (21 percent vs. 13 percent of non-primary caregivers).
- Caregivers in high-intensity care situations report high financial strain (29 percent) more so than those in medium- to low-intensity situations (11 percent). Likewise, those who provide 21 or more hours of care weekly more often report high financial strain (31 percent vs. 13 percent of those who provide care 20 hours or less).
- Caregivers who have less than a college degree more often report financial strain (21 percent vs. 14 percent of those with a bachelor's degree or higher).

Financial Impacts

About half of caregivers have experienced at least one financial impact as a result of caregiving (45 percent), with 34 percent who have experienced two or more financial impacts (see Figure 57 showing top financial impacts).

Figure 57. Top Financial Impacts as a Result of Caregiving



M6. As a result of providing care to your [relation], have you ever experienced any of these financial things?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Respondents may select more than one response; results add to greater than 100 percent.

In terms of *savings*, 28 percent have stopped saving, 22 percent have used up their personal short-term savings, and 12 percent have used long-term savings (like retirement or education accounts) to pay for other things. With regard to *debt*, nearly one in four has taken on more (23 percent), while 15 percent have borrowed money from friends or family. Very few report they have missed or were late paying student loans (5 percent), while 3 percent have filed for bankruptcy (medical or personal).

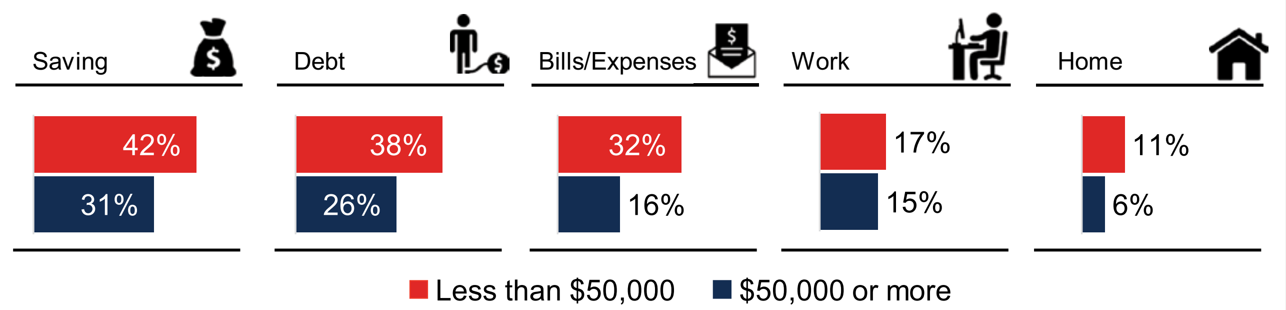
In terms of *bills and living expenses*, 1 in 5 has left bills unpaid or paid them late (19 percent), while 1 in 10 has been unable to afford basic expenses like food (11 percent). Fewer have had *home* impacts: 7 percent had to move to a less expensive home, apartment, or other living arrangement, while 2 percent report being evicted or having their home foreclosed.

Finally, some caregivers attempt to bridge the financial gap by finding more money through paid *work*. One in 10 had to start working, work more, or find a second job due to caregiving financial impacts (11 percent), while 9 percent put off when they planned to retire or decided to never retire.

Subgroups: 2020

- When caregivers have a household income under $50,000, they more often report having experienced financial impacts as a result of caregiving (2.2 on average vs. 1.4 among those with $50,000 or more in household income, see Figure 58).

Figure 58. Financial Impacts as a Result of Caregiving by Caregiver's Household Income



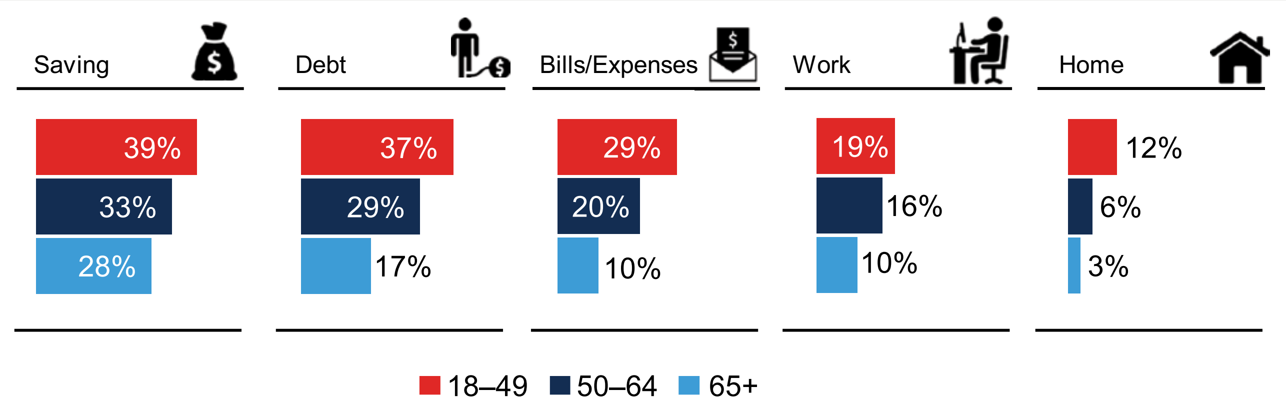
Experience change in at least one impact related to …

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Age has a buffering effect on experiencing financial impacts, for both caregiver age and the age of the care recipient, though caregivers who themselves are younger and caregivers who care for a younger recipient have lower household incomes.

- Financial impacts tend to be greater among younger caregivers. Caregivers ages 18 to 49 report 2.1 financial impacts, on average, more than those ages 50 to 64 (1.5), who in turn report more impacts than caregivers ages 65 and older (1.0). As shown in Figure 59, 1 out of three caregivers ages 50 to 64 who are approaching their retirement years are dipping into savings at a period when they should be saving for retirement, which could jeopardize their long-term financial security.

Figure 59. Financial Impacts as a Result of Caregiving by Caregiver Age



Experience change in at least one impact related to …

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

- Caregivers who provide care to an adult age 18 to 49 report high financial impacts (2.8, on average)—more than those caring for someone age 50 to 64 (2.1), who experience more impacts than caregivers of the oldest adults (1.3 impacts when caring for someone age 65+, see Figure 60).

Figure 60. Financial Impacts by Age of Care Recipient

	18-49 (n = 188) A	50-64 (n = 256) B	65+ (n = 944) C
Financial impacts experienced (mean)	2.8^{BC}	2.1^{C}	1.3
Experienced change in at least one impact related to …			
Debt	50%^{BC}	38%^{C}	23%
Saving	49%^{C}	44%^{C}	29%
Bills or expenses	34%^{C}	29%^{C}	17%
Work	26%^{C}	19%^{C}	13%
Home	10%	12%^{C}	6%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Respondents may select more than one response; results add to greater than 100 percent.

- African American caregivers report 2.4 financial impacts as a result of providing care, more than either Asian American (1.5) or White (1.4) caregivers, while Hispanic caregivers (2.0) have more impacts than Whites, as shown in Figure 61. Of note, these racial/ethnic disparities in financial impacts emerge when caregivers have household incomes of $50,000 or more, while caregivers with household incomes under $50,000 show comparable financial impacts, irrespective of their racial/ethnic background.

Figure 61. Mean Financial Impacts by Race/Ethnicity of Caregiver and Caregiver Household Income

	Non-Hispanic White (n = 801) A	Asian (n = 197) B	African American (n = 199) C	Hispanic (n = 205) D
Total	1.4	1.5	2.4^{AB}	2.0^{A}
By caregiver household income				
Less than $50,000	2.1	1.9	2.4	1.9
$50,000 or more	1.1	1.1	2.3^{AB}	2.0^{AB}

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

Other groups showing greater financial impacts include the following:

- Caregivers who report living with their care recipient experience more financial impacts (2.4) than those not co-residing (1.2, on average).[47] Co-residing caregivers more often experience each of the five categories of financial impacts than do those who do not live with their recipient.
- Higher-hour caregivers experience 2.5 financial impacts on average, more than lower-hour caregivers (1.3).[48]
- Similarly, caregivers in high-intensity care situations also report elevated financial impacts as a result of providing care (2.5 vs. 1.3 medium intensity and 1.1 low intensity).[49]
- Those caring for a spouse/partner experience 2.4 financial impacts, more than those caring for a non-relative (1.3), parent/parent-in-law (1.5), or some other relative (1.8). Nearly half of spousal caregivers report an impact in saving behavior (49 percent), while 39 percent report debt impacts.
- Caregivers who feel alone report 3.0 financial impacts on average, significantly more than the 1.2 reported by caregivers who do not feel alone.

Caregivers who report higher financial strain report more financial impacts—4.1, on average—which allows us to paint a picture of financial strain, as shown in Figure 62. High financial strain is being unable to save money (62 percent), taking on more debt (56 percent), and using up one's short-term savings (55 percent). About half the time it means leaving bills unpaid or paying them late (46 percent), while about a third of financially strained caregivers find themselves borrowing from friends and family (34 percent), having issues paying for basic expenses like food (31 percent), or drying up long-term savings to pay for other things (30 percent).

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[47] While co-residing caregivers more often report a household income of less than $50,000 (42 percent vs. 32 percent of those not living together), co-residing caregivers report a greater number of financial impacts than those not living together, across both low and high household income levels.

[48] While higher-hour caregivers more often report household incomes of less than $50,000 (43 percent vs. 32 percent of those providing 20 or fewer hours of care weekly), higher-hour caregivers report more financial impacts regardless of household income.

[49] High-intensity caregivers more often report lower household incomes (41 percent with less than $50,000 vs. 32 percent among those in a lower-intensity care situation).

Figure 62. Financial Impacts by Caregiver-Perceived Financial Strain

Financial Impact	High Financial Strain (n = 255) A	Moderate Financial Strain (n = 260) B	Low Financial Strain (n = 871) C
Financial impacts (average)	**4.1^{BC}**	**2.2^{C}**	**0.8**
Experienced change in at least one impact related to …			
Saving	73%^{BC}	48%^{C}	19%
Stopped saving	62%^{BC}	42%^{C}	15%
Used up personal short-term savings	55%^{BC}	29%^{C}	11%
Used up long-term savings, like retirement or education, to pay for other things	30%^{BC}	16%^{C}	5%
Debt	67%^{BC}	41%^{C}	16%
Took on more debt	56%^{BC}	33%^{C}	10%
Borrowed money from family or friends	34%^{BC}	18%^{C}	8%
Missed or was late paying student loan	11%^{C}	9%^{C}	2%
Filed for bankruptcy	8%^{C}	5%^{C}	1%
Bills or Expenses	52%^{BC}	25%^{C}	12%
Left bills unpaid or paid late	46%^{BC}	23%^{C}	9%
Was unable to afford basic expenses like food	31%^{BC}	10%^{C}	6%
Work	40%^{BC}	22%^{C}	7%
Had to start working, work more, or find a second job	28%^{BC}	14%^{C}	5%
Put off retirement or decided to never retire	24%^{BC}	12%^{C}	4%
Home	20%^{BC}	10%^{C}	4%
Moved to a less-expensive home, apartment, or other living arrangement	17%^{BC}	8%^{C}	4%
Was evicted or had home foreclosed	6%^{BC}	3%	1%

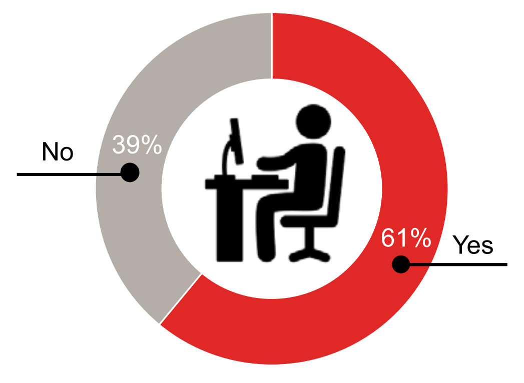
Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Respondents may select more than one response; results add to greater than 100 percent.

I. IMPACT OF CAREGIVING ON WORK

Working while Caring

Sixty-one percent of caregivers were employed at some point in the past year while also caregiving, as shown in Figure 63.

Figure 63. Working while Caregiving



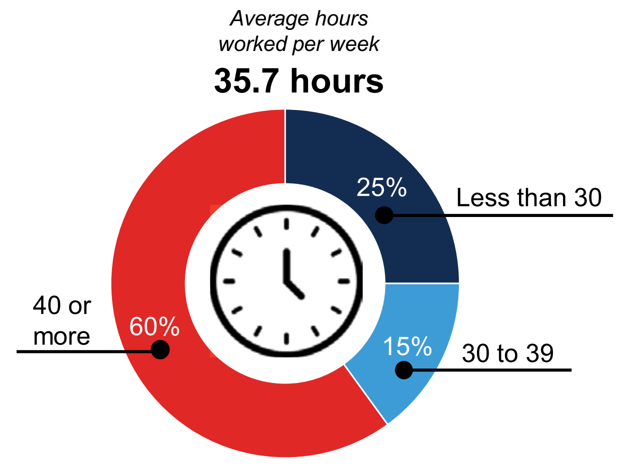
Q32A. Are/Were you currently employed?

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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Six in 10 employed[50] caregivers work full time (60 percent) and another 15 percent work between 30 and 39 hours. One in 4 work fewer than 30 hours a week. On average, employed caregivers work 35.7 hours a week (see Figure 64).

Figure 64. Hours Worked Among Employed Caregivers



N13. About how many hours a week, on average, do you work? / When you were last working and helping your [relation], about how many hours a week, on average, did you work?

2020 Base: Working Caregivers of Recipient Age 18+ (n=837)

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

Subgroups: 2020

- Men are more often employed while caregiving (67 percent vs. 58 percent women) and, on average, they work more hours per week (38.7) than do women caregivers who are employed (33.5).
- Younger caregivers more often work while providing care and work more hours weekly, on average: 72 percent of caregivers ages 18 to 49 work (36.1 hours weekly) and 67 percent of those ages 50 to 64 work (37.0 hours weekly), compared to just 24 percent of those ages 65 and older who work, reporting 26.4 hours of work weekly.
- Caregivers who have some college education or higher more often report working while providing care (65 percent) than those with a high school diploma or less (54 percent).
- Caregivers who live together with their care recipient *less* often report working (54 percent vs. 67 percent of those not co-residing).
- Those in high-intensity care situations also are *less likely* to work (56 percent) than those in medium- to low-care situations (65 percent). Similarly, higher-hour caregivers *less often* report working (54 percent) than those providing under 20 hours weekly (65 percent).[51]
- Those caring for a parent/parent-in-law more often report working (69 percent) than those caring for someone else (54 percent), perhaps helping to explain some of the lesser financial impacts caregivers of parents experience relative to caregivers of spouses, especially, as shown in Figure 65.

Figure 65. Work, Financial Impacts, and Age by Relationship of Caregiver and Recipient

	Parent/ Parent-in-Law (n = 703) A	Spouse/ Partner (n = 179) B	Other Relative (n = 355) C	Non-Relative (n = 149) D
Employed (percent)	$69\%^{BCD}$	51%	$57\%^{D}$	46%
Hours worked, weekly (average)	36.9^{C}	35.7	33.3	35.3
High financial strain (percent rating 4 or 5 on 5-point scale)	15%	$26\%^{AD}$	$22\%^{A}$	15%
Number of financial impacts (average)	1.5	2.4^{ACD}	1.8	1.3
Age of caregiver (average)	47.8	58.7^{ACD}	46.6	53.3^{AC}
Age of care recipient (average)	76.1^{BCD}	61.5	59.1	69.3^{BC}
Hours of care provided, weekly (average)	20.8^{D}	36.0^{ACD}	27.3^{AD}	13.2

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

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[51] The relationship of employment and hours of care provided is complex; we can say only that these two things are related but we cannot be certain of causality. There is some evidence that the recipient's need for more care results in the caregiver reducing work hours or stopping work (see next sections about work impacts among those caregivers who did work while providing care), but it may also be that caregivers who work less or do not work are more often the ones to step in and provide care due to their relative availability.

Photo credit: Prostock-studio/stock.adobe.com

Type of Employment

Over half of employed caregivers are paid hourly (54 percent), while 39 percent report being salaried. In comparison, 58 percent of U.S. workers are paid hourly.[52] Fifteen percent of caregivers are self-employed or own their own business. In comparison, 10 percent of U.S. workers are self-employed.[53]

Subgroups: 2020

- White, African American, and Hispanic caregivers are each more often working at a position that is paid hourly (55 percent), while Asian American caregivers more often report having a salaried job (55 percent).
- Men who provide care more often are salaried (45 percent vs. 34 percent women caregivers), while women caregivers more often work hourly (58 percent vs. 49 percent men caregivers).
- The youngest caregivers—those ages 18 to 49—more often work hourly (60 percent vs. 48 percent of those ages 50 to 64), while those ages 50 to 64 more often are salaried (43 percent vs. 36 percent of those ages 18 to 49). This may explain why younger caregivers experience more financial strain and financial impacts as a result of caregiving—each hour they spend caring is one less hour they can work for income—and hourly worker caregivers more often report lower incomes, fewer workplace benefits, and work fewer hours than salaried caregivers.
- Long-distance caregivers—those living one hour or more away from their recipient—more often report having a salaried position (51 percent) than those who live with or closer to their recipient (36 percent).
- Perhaps not surprising, caregivers who work fewer than 30 hours a week more often are paid hourly (67 percent vs. 50 percent of those who work more), while those who work 30 or more hours a week more often are salaried (46 percent vs. 18 percent of those who work fewer hours).

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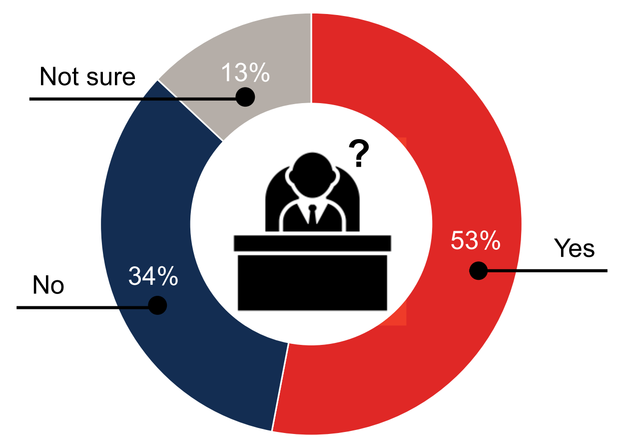
[52] Bureau of Labor Statistics, *Highlights of Women's Earnings in 2018*, Report 1083, November 2019, https://www.bls.gov/opub/reports/womens-earnings/2018/pdf/home.pdf.

[53] Current Population Survey, 2014 data, as analyzed and presented in: Pew Research Center, "10 Facts about American Workers," News in the Numbers Report, Pew Research Center, Washington, DC, August 29, 2019, https://www.pewresearch.org/fact-tank/2019/08/29/facts-about-american-workers/.

Supervisor Knowledge of Caregiver's Role

Among employed caregivers who are not self-employed, about half report that their supervisor at work is aware of their caregiving responsibility (53 percent, see Figure 66).

Figure 66. Supervisor Knowledge of Caregiver's Role



N14. Does your supervisor know that you are caring for your [relation]? / At that time, did your supervisor know that you were caring for your [relation]?

2020 Base: Working and Not Self-Employed Caregivers of Recipient Age 18+ (n=707)

Subgroups: 2020

- Caregivers ages 50 and older who work more often report their supervisor is aware of their caregiving role (62 percent) than younger caregivers (47 percent).

It seems that the caregiving situation is what drives the need to share or alert the supervisor, as employed caregivers in more intensive care situations more often report their supervisor is aware of their caregiving role:

- Caregivers in a high-intensity (67 percent) or medium-intensity (64 percent) care situation more often report their supervisor is aware of their role than those in a low-intensity situation (38 percent). Similarly, higher-hour caregivers more often report their supervisor is aware of their role (69 percent) than lower-hour caregivers (47 percent).
- Those who feel they had no choice to take on caregiving more often report their supervisor at work is aware of their role (57 percent vs. 48 percent of those with choice).[54]
- Those caring for a spouse (69 percent) are more likely to report their supervisor is aware than all other relationship types, while those caring for a parent/parent-in-law (53 percent) or other relative (55 percent) more often report their supervisor knows about their role than those caring for a non-relative (28 percent).
- Caregivers of someone with a long-term physical condition more often report their supervisor is aware of their caregiving role outside work (58 percent vs. 48 percent of those caring for someone with an emotional or mental health issue).

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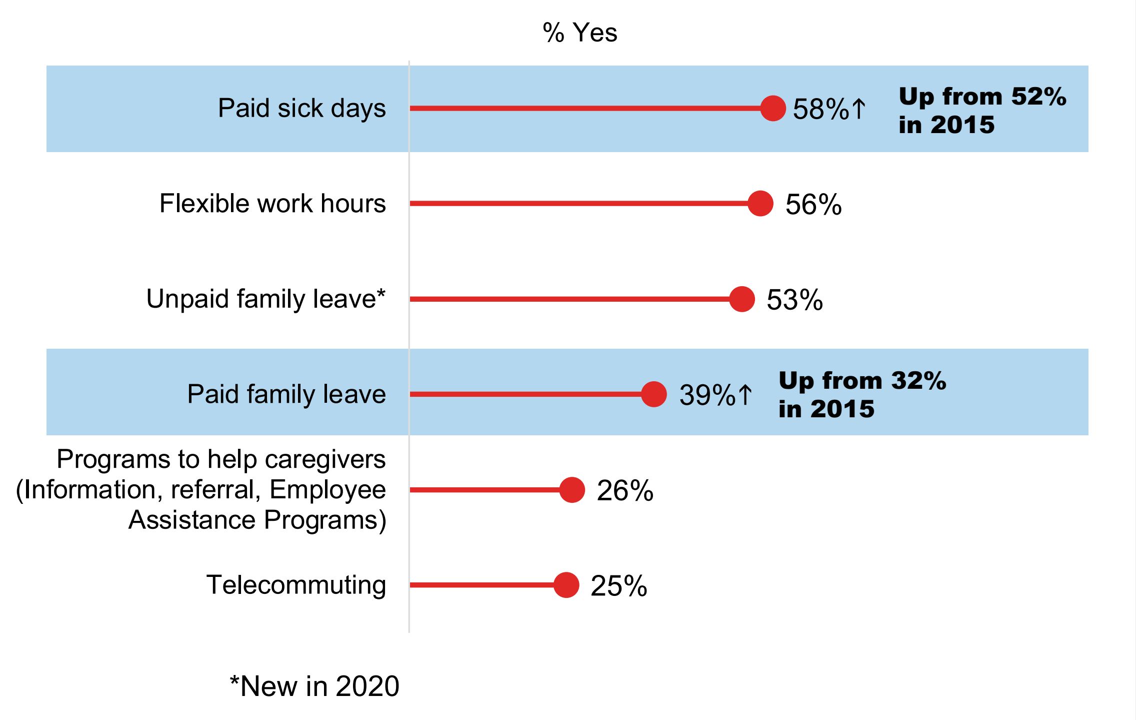
[54] Those who had no choice in taking on care are more often salaried in their position, but there are no differences in supervisor awareness by pay type, suggesting that this awareness is more about the caregiving situation than the work arrangement.

Workplace Benefits for Caregivers

Among working caregivers, over half say their employer offers paid sick days[55] (58 percent, up from 52 percent in 2015), while 56 percent report having flexible work hours (see Figure 67). About half report having unpaid family leave (53 percent). Nearly 4 in 10 say their employer offers paid family leave (39 percent, up from 32 percent in 2015),[56] but only a quarter say their employer offers employee assistance programs (26 percent) or telecommuting (25 percent).

Figure 67. Workplace Benefits for Caregivers



*New in 2020

N16. For employees at your work in a similar role or job as yours, which of the following does your employer offer? / At the time when you were last working and providing care for your [relation], for employees at your work in a similar role or job as yours, which of the following did your employer offer?

2020 Base: Working and Not Self-Employed Caregivers of Recipient Age 18+ (n=707)

Note: Respondents may select more than one response; results add to greater than 100 percent.

In recent years, some workplace supports for employed family caregivers have received increased attention from the public and private sectors, and a number of states and municipalities have moved forward to enact paid family leave programs and paid sick days benefits to cover employees caring for ill family members. Eight states and the District of Columbia have or will soon have paid family leave programs, and more employers (especially large employers) are offering paid family leave programs.[57]

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[55] Among the general U.S. population of workers, 76 percent have paid sick leave. Bureau of Labor Statistics, "Employee Benefits in the United States–March 2019," news release, September 19, 2019, https://www.bls.gov/news.release/pdf/ebs2.pdf.

[56] Nationally, 16 percent of private industry workers and 25 percent of state and local government workers had access to paid family leave, and 88 percent of private industry workers and 94 percent of state and local government workers had access to unpaid family leave. See Bureau of Labor Statistics, U.S. Department of Labor, "Access to Paid and Unpaid Family Leave in 2018," *The Economics Daily*, accessed January 29, 2020, https://www.bls.gov/opub/ted/2019/access-to-paid-and-unpaid-family-leave-in-2018.htm.

[57] See L. F. Feinberg, *Breaking New Ground: Supporting Employed Family Caregivers with Workplace Leave Policies* (Washington, DC: AARP Public Policy Institute, 2018). See also S. Reinhard et al., *Valuing the Invaluable: 2019 Update, Charting a Path Forward* (Washington, DC: AARP Public Policy Institute, 2019).

The lack of support in the workplace has a real effect on retention and turnover—when caregivers have particular benefits at work, they are less likely to stop working altogether. Just 6 percent of caregivers with paid sick days and 6 percent of those with unpaid family leave stop working entirely (vs. 11 percent who stop working among caregivers who do not have each benefit).

Change Focus: 2020 vs. 2015

The increase in paid leave time (either sick days or family leave) seems to be occurring among select groups.

- ➔ Whites report more paid family leave than they did in 2015 (35 percent vs. 28 percent), while African Americans more often say they have paid sick days (70 percent vs. 53 percent in 2015).
- ➔ Women caregivers more often report having paid family leave (40 percent vs. 29 percent in 2015).
- ➔ Those ages 50 to 64 have more paid family leave (44 percent vs. 30 percent in 2015).

Subgroups: 2020

- Nearly all workplace benefits are more commonly reported by caregivers working 30 hours or more each week.[58] In addition, these benefits are more common among salaried caregivers (see Figure 68 for comparison of both work hours and pay structure). 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 and to be salaried.

Figure 68. Workplace Benefits by Hours Worked Per Week

	Hours Worked Per Week *Among Those Not Self-Employed*		Payment Structure	
	Less Than 30 (n = 156) A	30 or More (n = 549) B	Salaried (n = 314) C	Hourly (n = 378) D
Flexible work hours	67%^{B}	53%	59%	55%
Paid sick days	28%	67%^{A}	81%^{D}	43%
Telecommuting or working from home	22%	26%	40%^{D}	13%
Programs to help caregivers (information, referral, EAP)	17%	29%^{A}	37%^{D}	19%
Paid family leave	19%	46%^{*A}	51%^{D}	31%
Unpaid family leave	37%	58%^{A}	64%^{D}	47%

** Significantly higher than 2015*

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Respondents may select more than one response; results add to greater than 100 percent.

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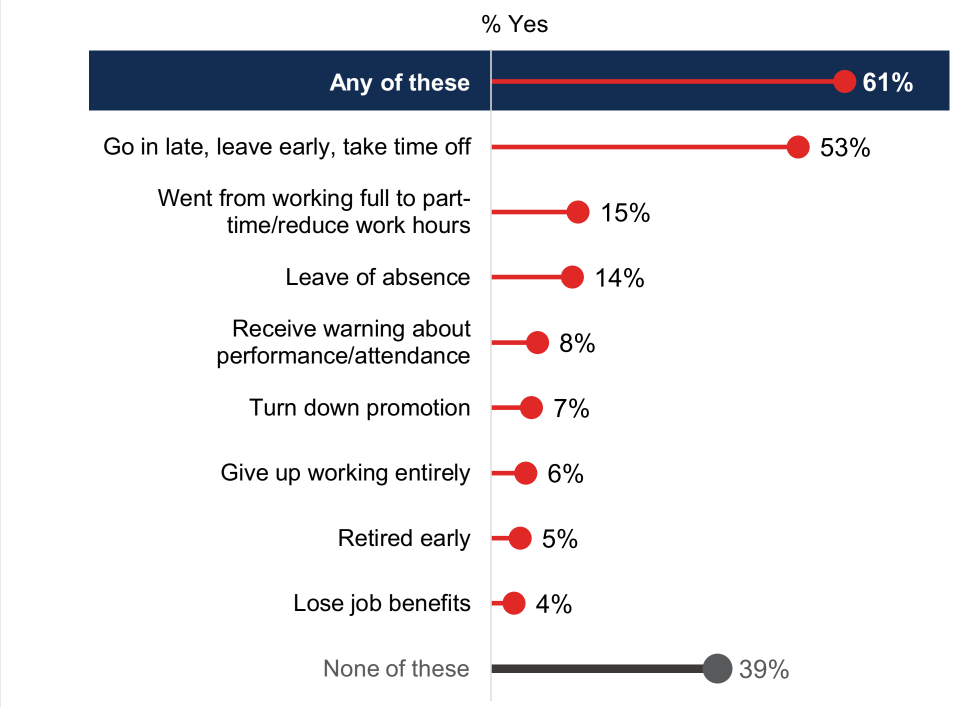
[58] After the passage of the Affordable Care Act in 2010 and implementation in 2014, the threshold for eligibility of health benefits became 30 hours a week (or more), so that threshold cut is used here.

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 or are forced to make changes to their work situation.

Six in 10 caregivers report having experienced at least 1 impact or change to their employment situation as a result of caregiving (61 percent), with about half having to go in late, leave early, or take time off to provide care (53 percent). Other impacts include cutting back on their working hours (15 percent), taking a leave of absence (14 percent), or receiving a warning about performance or attendance (8 percent, see Figure 69). On average, caregivers report having experienced 1.1 work impacts.

Figure 69. Work Impacts as a Result of Caregiving



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

2020 Base: All Working Caregivers of Recipient Age 18+ (n=837)

Note: Respondents may select more than one response; results add to greater than 100 percent.

Subgroups: 2020

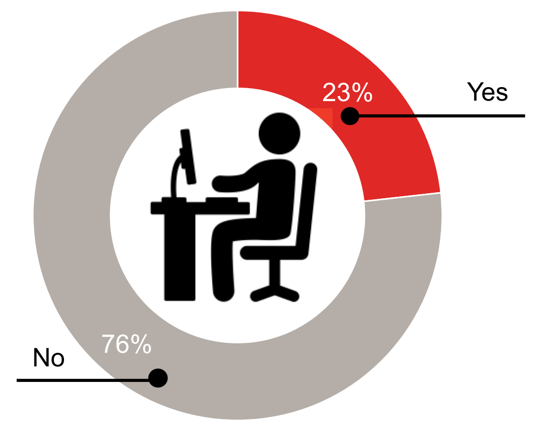
- Caregivers in high-intensity care situations more often report having each of these 8 work impacts than do caregivers in medium- to low-intensity care situations. On average, high-intensity caregivers report having 1.6 work impacts (vs. 1.0 medium and 0.8 low-intensity care situation). Three out of four high-intensity caregivers report at least 1 work impact (73 percent) and 40 percent report 2 or more.
- Similarly, higher-hour caregivers more often report experiencing 7 out of 8 work impacts than caregivers providing 20 or fewer hours of care weekly. On average, they report 1.6 work impacts (vs. 0.9 among lower-hour caregivers). Just over 4 in 10 report having 2 or more work impacts (44 percent vs. 19 percent of lower-hour caregivers).

- Primary caregivers also are more likely to report having any work impacts (65 percent vs. 54 percent of non-primary).
- Those caring for a parent/parent-in-law (56 percent) or spouse/partner (65 percent) are more likely to go in late or leave early than those caring for some other relative (46 percent) or a non-relative (40 percent).
- Those working at least 30 hours a week are more likely to report having workday interruptions (58 percent going in late, leaving early, or taking time off during the workday compared to 39 percent of those working fewer than 30 hours a week). However, lower-hour workers (those working fewer than 30 hours a week) are more likely to report cutting back their work hours (24 percent went from full- to part-time work or otherwise cut back their hours compared to 12 percent of those working 30 hours or more). This suggests caregivers modify their work to fit their caregiving situation, rather than modifying their caregiving to fit employment.

Reasons for Leaving Work

Among caregivers who have not worked while providing care in the past 12 months, 23 percent worked at some point while providing care to their recipient (see Figure 70).[59]

Figure 70. Employment in Past while Caregiving



M2. At <u>any time</u> while you have been providing/provided care to your [relation], have you worked or had a job?

2020 Base: Caregivers Not Employed in the Past While Caregiving for Recipient Age 18+ (n=555)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

So why do working caregivers leave their job? Working caregivers who left their position, either sometime in the past year or ever while also caregiving, most commonly did so to have more time to care for their recipient (49 percent), while 15 percent say their job didn't allow flexible work hours.

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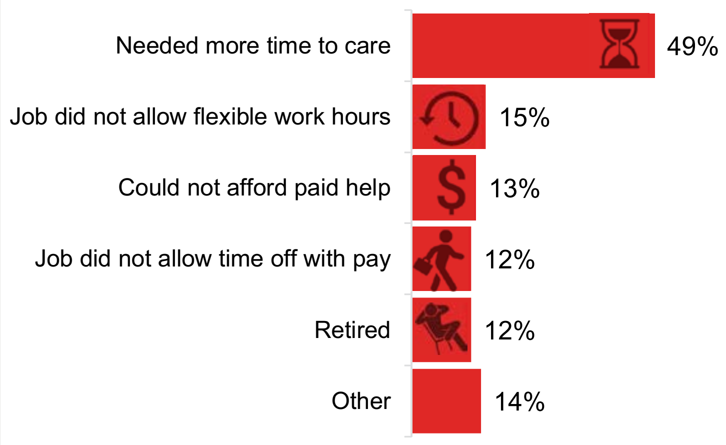
[59] This past working while providing care is more common among caregivers under age 65 (26 percent) than it is among caregivers already at retirement age or older (15 percent of those age 65+).

Fewer say they could not afford paid help (13 percent), they retired (12 percent), or their job did not allow time off with pay (12 percent, see Figure 71).[60]

Figure 71. Reasons Caregivers Stopped Working



N15. *(If took leave of absence, gave up work, or retired early)* Why did you leave your job, take a leave of absence, or otherwise decide to not work while also providing care?

2020 Base: Caregivers Who Took a Leave of Absence, Gave Up Work, Retired Early, or Used to Work More While Providing Care (n=276)

Note: Respondents may select more than one response; results add to greater than 100 percent.

Discrimination

Few caregivers of adults report feeling that their responsibilities as a caregiver led to them being penalized or discriminated against at work (7 percent).[61]

Subgroups: 2020

- Caregivers ages 18 to 49 more often report feeling discriminated against at work due to caregiving (9 percent vs. 6 percent for ages 50 to 64 and 1 percent for ages 65 and older).
- One in 10 higher-hour caregivers report feeling discriminated against at work (10 percent), more than lower-hour caregivers (5 percent). Similarly, those in high- to medium-intensity care situations more often report feeling discriminated against (9 percent vs. 3 percent low intensity).
- LGBTQ caregivers more often report feeling discriminated against at work due to caregiving (17 percent vs. 6 percent of caregivers not self-identifying this way).
- Caregivers who are caring for someone with an emotional or mental health issue more often feel they (the caregiver) have been discriminated against at work (12 percent vs. 5 percent not caring for someone with emotional or mental health issues); similarly, those caring for someone with memory problems also report higher feelings of discrimination (11 percent vs. 5 percent not).

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[60] While a similar question about reasons for stopping work was asked in *Caregiving in the U.S. 2015*, the question was asked as a free response with no answers provided to respondents on the screen. In 2020, we leveraged learnings from the 2015 study to offer respondents some answers in a check-all-that-apply format with an additional free response option. Due to this shift in question structure, data should not be compared or trended.

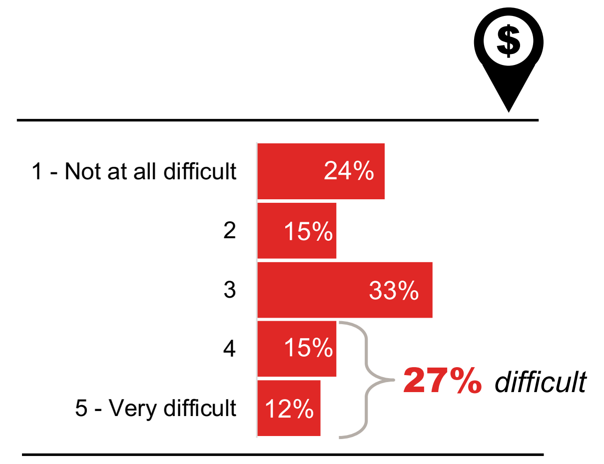
[61] As of 2016, at least 15 localities or states (including the District of Columbia) have laws to protect workers from employment discrimination; see http://www.longtermscorecard.org/publications/fs-protecting-family-caregivers-from-employment-discrimination.

J. SERVICES, SUPPORT, AND INFORMATION

Affordability of Services

One in four caregivers say it is very difficult to get affordable services in their recipient's community, like delivered meals, transportation, or in-home health services, that would help with their care (27 percent rating a 4 or 5 on a 5-point scale, see Figure 72), while another 33 percent feel it is moderately difficult.

Figure 72. Affordability of Services in 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?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Change Focus: 2020 vs. 2015

Several select groups of caregivers report it is more difficult to obtain affordable services for their recipient than in 2015, including:

- ➔ Higher-hour caregivers (37 percent of those providing 21 or more hours of care vs. 29 percent in 2015)
- ➔ Women caregivers (29 percent vs. 23 percent in 2015)

Subgroups: 2020

- Caregivers caring for someone in a rural setting more often report difficulty in finding affordable services in their recipient's local area, like meal delivery, transportation, or in-home health services (32 percent vs. 25 percent of those caring for someone in an urban or suburban setting).
- The youngest caregivers—those ages 18 to 49—report having the most difficulty in finding affordable services (31 percent vs. 22 percent of caregivers ages 50 and older).[62]
- Caregivers who co-reside with their recipient more often report difficulty in getting affordable services (31 percent vs. 24 percent of those not living together).

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[62] While younger caregivers tend to care for relatively younger recipients, there is no difference in difficulty finding affordable services by care recipient age, suggesting that younger caregivers may be less aware of services like delivered meals, transportation, or in-home health services.

- Those in the highest-intensity care situations more often report difficulty finding affordable services (36 percent), compared to those in medium- to low-intensity situations (20 percent). Similarly, higher-hour caregivers also report more difficulty (37 percent of those who provide 21 or more hours of care weekly vs. 22 percent of those caring for 20 hours or less).
- Caregivers of someone with an emotional or mental health issue report high difficulty finding affordable services (37 percent) more often than those caring for someone without such issues (23 percent), as do caregivers of someone with memory problems (36 percent vs. 23 percent not) and long-term physical conditions (31 percent vs. 20 percent not).

Financial Help for Recipient

Just one in four have requested information about how to get financial help for their recipient (25 percent, see Figure 73).

Figure 73. Financial Help for Recipient

1 in 4 caregivers have requested information about how to get financial help for their care recipient

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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Change Focus: 2020 vs. 2015

For the most part, caregivers are as likely to request information about how to get financial help for their recipient as they were in 2015. However, several groups show changes in requesting this information.

➔ Those caring for a parent/parent-in-law are *less* often requesting this information (24 percent vs. 32 percent in 2015).

➔ Lower-hour caregivers are also *less* often requesting information about this kind of help (22 percent of those who provide 20 or fewer hours of care weekly vs. 27 percent in 2015).

Subgroups: 2020

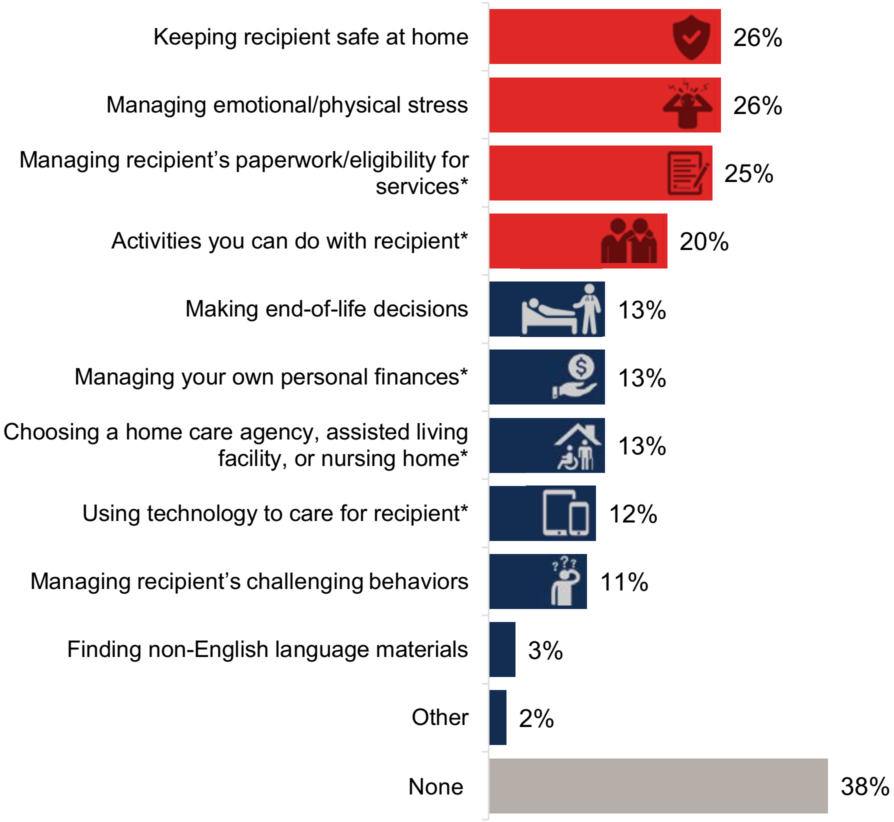
- Four out of 10 caregivers of younger adults ages 18 to 49 have requested information about how to get financial help for their recipient (40 percent), more than caregivers of older adults (23 percent of those caring for someone age 50 or older).
- Caregivers who feel they had no choice in taking on care more often report they requested this information to financially help their recipient (29 percent vs. 20 percent with a choice).
- Caregivers who live close to their recipient—either with the recipient (27 percent) or within an hour of the recipient (26 percent)—more often report requesting information about financial help than those who live farther away (16 percent).
- Those in high-intensity care situations more often have requested this information (31 percent) than caregivers in medium- to low-intensity situations (21 percent). Similarly, higher-hour caregivers more often request financial help information (32 percent vs. 22 percent of caregivers providing 20 or fewer hours of care).
- Those who have been caring for their recipient for a year or longer more often have requested this information (31 percent vs. 17 percent of those caring for under a year).

Caregiver Training and Information Needs

Many caregivers could use more information on or help with caregiving topics, with 62 percent needing help with at least one topic (see Figure 74).[63] Caregivers most commonly want information about keeping their recipient safe at home and about managing their own stress (26 percent each), while one in four want help figuring out forms, paperwork, and eligibility for service (25 percent).

About one in eight need help with critical care decisions for their recipient, such as making end-of-life decisions or choosing home care, assisted living, or a nursing home (13 percent each). Some caregivers also want help for things like managing their own finances (13 percent), using technology for care support (12 percent), and managing challenging behaviors of their recipient (11 percent). Few want non-English-language materials (3 percent).

Figure 74. Caregiver Training and Information Needs



*New in 2020

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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Respondents may select more than one response; results add to greater than 100 percent.

Subgroups: 2020

- Across the board, caregivers in higher-intensity care situations more often need help or information with each of the 10 caregiving topics.

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[63] Data from 2020 are not comparable to the same information needs question asked in 2015, as the 2020 list of needs expanded to 10 total items, while 2015 asked about 6 total items, with only 5 items overlapping.

- Caregivers who report feeling alone want help with 8 of the 10 topics more often than those who do not feel alone.[64]
- Caregivers who feel they had no choice in taking on their role more often report needing help with 6 of these 10 topics, as compared to those who feel they had a choice.[65]

Otherwise, caregiver needs depend on the situation of the caregiver and care recipient, emphasizing the diversity of caregiving experiences and the importance of connecting caregivers to the right resources at the right time. Some examples of this include stress management, figuring out forms and eligibility, and end-of-life decision making.

- Caregivers who would like help or information about *managing stress* are generally those who report higher levels of emotional stress, including:
  - Caregivers of a spouse/partner (35 percent vs. 25 percent all others)
  - Those who live with their recipient (34 percent vs. 20 percent not co-residing)
  - Higher-hour caregivers (34 percent vs. 22 percent when providing 20 or fewer hours of care weekly)
  - Primary caregivers (29 percent vs. 19 percent non-primary)
  - Those who report feeling alone (55 percent vs. 15 percent not feeling alone)
  - Those caring for someone with an emotional or mental health issue (41 percent vs. 20 percent not)
  - Those caring for someone with a memory problem (32 percent vs. 23 percent not)
  - LGBTQ caregivers (36 percent vs. 25 percent not identifying as such)
  - Those who report having moderate-to-high financial strain as a result of caregiving (39 percent vs. 18 percent low-strain caregivers)
- Caregivers who want help or information about *figuring out forms or eligibility* include:
  - Younger caregivers ages 18 to 64 (27 percent vs. 19 percent ages 65 and older)
  - Those caring for someone with an emotional or mental health issue (35 percent vs. 21 percent not)
  - Those caring for someone with a memory problem (31 percent vs. 22 percent not)
  - Caregivers with some college education or higher (28 percent vs. 21 percent high school or less)
  - Caregivers who feel higher financial strain (41 percent high, 32 percent moderate, and 19 percent low)
  - Those who feel care is likely to continue into the next five years (29 percent vs. 21 percent no or not sure)
  - Caregivers who report feeling alone (35 percent vs. 21 percent not)
- Caregivers who want help or information about *end-of-life decision making* include:
  - Higher-hour caregivers (17 percent vs. 11 percent of those providing 20 or fewer hours of care weekly)
  - Those caring for someone with memory problems (18 percent vs. 11 percent not)
  - Those caring for someone with a long-term physical condition (16 percent vs. 7 percent not)
  - Those caring for a baby boomer or silent generation recipient (14 percent vs. 5 percent generation X recipient)

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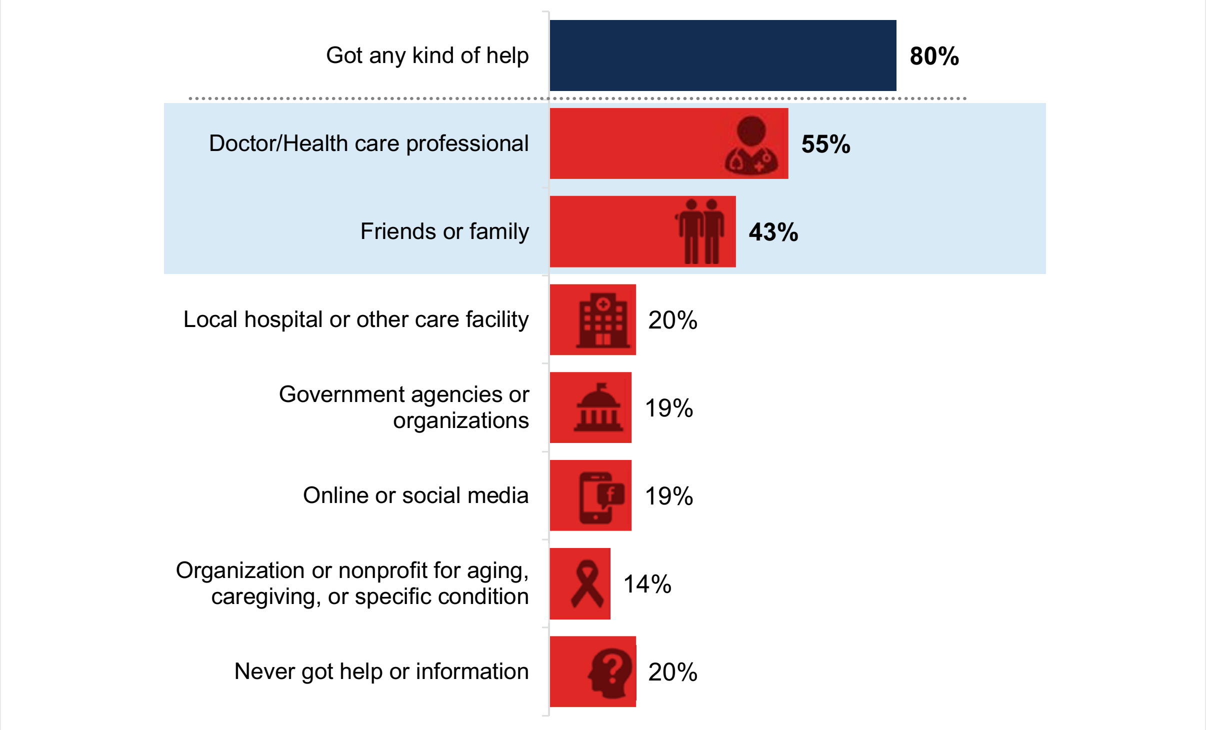
64 The two exceptions are choosing a home care agency, assisted living facility, or nursing home; and finding non-English-language materials.

65 The four exceptions are finding activities to do with recipient, using technology to care for recipient, making end-of-life decisions, and helping with managing their own (the caregiver's) finances.

Sources of Help or Information

Most caregivers report having at least one source of help or information about providing care (80 percent), though 20 percent have never gotten any help or information. Most commonly, caregivers rely on health care professionals (55 percent, see Figure 75) followed by family and friends (43 percent). About one in five rely on their local hospital or care facility (20 percent), government agencies or organizations (19 percent), or online or social media (19 percent). Fourteen percent rely on an organization or nonprofit for aging, caregiving, or a specific condition.

Figure 75. Sources of Help or Information used by Caregivers



M1. Where do/did you go for help or information about caring for your [relation]? Please select all that apply.

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Respondents may select more than one response; results add to greater than 100 percent.

Subgroups: 2020

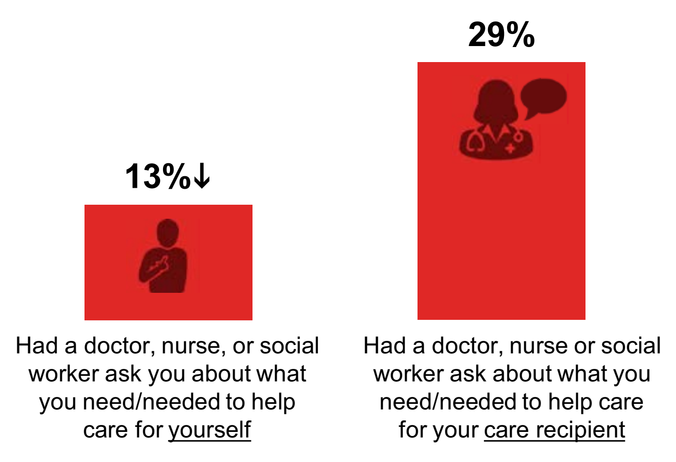
- Several groups report using more sources for help or information, perhaps because their caregiving situation or experience requires it, as these same groups are among those experiencing the most stress and strain:
    - Those who have no choice in providing care (1.9 sources on average vs. 1.5 for those with a choice)
    - Caregivers in a high-intensity (1.9 on average) or medium-intensity (1.8) care situation (vs. 1.5 among those in low-intensity situations)
    - Higher-hour caregivers (2.0 vs. 1.6 for those providing 20 or fewer hours of care)
- Caregivers in moderate-to-high financial strain report 2.0 sources of help or information, more than those who report low financial strain (1.6).
- Those who feel alone report 2.0 sources, more than those who do not feel alone (1.6).

- The longer caregivers have been providing care, the more sources they report relying on: when providing care for a year or longer, they report having 1.9 sources (vs. 1.5 less than a year). This continues for caregivers who expect to continue caring (1.9 sources for those who expect to care five years into the future vs. 1.5 for those who do not).
- Hispanic caregivers most often report having *no* source for help or information (26 percent), more than either African American (17 percent) or Asian American (12 percent) caregivers.
- Caregivers who are the sole care provider, providing care without help from either paid or unpaid helpers, more often report having *no* sources of help or information (29 percent vs. 15 percent of others who have help).
- Women caregivers report a greater reliance on friends and family (47 percent vs. 38 percent of men caregivers), as do caregivers who do not live with their care recipient (47 percent vs. 37 percent of those who co-reside).
- Caregivers ages 50 and older rely more on doctors or health care professionals (61 percent vs. 47 percent of those ages 18 to 49), while the youngest caregivers use online/social media sources more (23 percent vs. 15 percent of those ages 50 and older).
- Those caring for a relative more often use a doctor or health professional as a source (57 percent) than do non-relatives (37 percent).
- Caregivers who have higher levels of education report more sources for caregiving help (2.0 among those with a college degree or higher vs. 1.7 among those with some college vs. 1.4 among those with a high school diploma or less).

Conversations with Health Care Providers

Fewer than 3 in 10 say a health care provider, such as a doctor, nurse, or social worker, has asked about what was needed to care for their recipient (29 percent, see Figure 76). Just 13 percent say a health care provider has asked what they need to care for themselves, down significantly from 16 percent in 2015.

Figure 76. Conversations with Health Care Providers



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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Change Focus: 2020 vs. 2015

Several groups are particularly less likely to report having these care conversations, despite caregivers, overall, reporting higher difficulty navigating the care system in 2020.

- ➔ Those who live with their care recipient are less often having conversations about both their recipient's care needs (30 percent compared to 37 percent in 2015) and their own needs (15 percent vs. 20 percent in 2015).
- ➔ Caregivers who feel they had no choice in taking on care are also less likely to report having these conversations both about recipient (29 percent vs. 36 percent in 2015) and self (13 percent vs. 18 percent in 2015).
- ➔ Those caring for a parent/parent-in-law are also less likely to report both recipient (30 percent vs. 36 percent in 2015) and self (12 percent vs. 17 percent in 2015) care conversations.
- ➔ Long-term caregivers—those who have been providing care for five years or longer—are less likely to have had these care conversations than in 2015, both about their recipient (32 percent vs. 40 percent in 2015) and about themselves (15 percent vs. 22 percent in 2015).
- ➔ Those who expect to continue providing care in the future also less often report having these conversations about their recipient's needs (30 percent vs. 36 percent in 2015) and their own needs (13 percent vs. 17 percent in 2015).
- ➔ LGBTQ caregivers less often report having these conversations about recipient needs (31 percent vs. 50 percent in 2015) and about self-care (13 percent vs. 26 percent in 2015).
- ➔ Finally, several groups of caregivers report significant declines in having conversations with care providers about their own needs:
    - — Primary caregivers (15 percent vs. 19 percent in 2015)
    - — Lower-income caregivers (13 percent of those with less than $50,000 in household income vs. 19 percent in 2015)
    - — Caregivers with a high school diploma or less (13 percent vs. 20 percent in 2015)
    - — Rural caregivers (10 percent vs. 20 percent in 2015)

Subgroups: 2020

- Caregivers of a relative (30 percent) more often report being asked about what is needed to care for their recipient than those caring for a non-relative (15 percent), perhaps because caregivers are more likely to accompany their recipient to the doctor when the recipient is a relative (as suggested by the result in communicating with health care professionals on their behalf), or perhaps because caregivers of non-relatives are less likely to have permission from the care recipient to discuss their care. Further research is needed to understand the dynamics of caregiver, care recipient, and provider conversations.
    - — Those caring for a spouse/partner are more likely to report having conversations about their own self-care (19 percent vs. 13 percent all others).
- As care situation intensity increases, so too does the likelihood that caregivers have had conversations with health care professionals about needs, as shown in Figure 77. However, a majority still report *not having* these conversations.

Figure 77. Discussions with Care Professionals by Level of Care Index (Intensity) and Hours of Care

Had Conversations About …	Level of Care Index			Hours of Care Weekly	
	Low Intensity (n = 595) A	Medium Intensity (n = 231) B	High Intensity (n = 559) C	0–20 (n = 939) D	21+ (n = 446) E
What is needed to care for recipient	18%	28%^{A}	39%^{AB}	24%	38%^{D}
Self-care needs	8%	10%	21%^{AB}	10%	20%^{D}

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

Desired Conversations with Health Care Providers

The majority of caregivers of adults are *not* having these conversations about their needs, though many would like to have these conversations. When indicating if these kinds of conversations would be helpful, nearly one in three (30 percent) say they would like to be asked about their needs to help care for their recipient and about one in five (22 percent) show interest in conversations about self-care.[66]

Subgroups: 2020

Several groups of caregivers would find it helpful to require care providers to have conversations about care needs, both for the recipient and for themselves, the caregiver. This includes:

- Those caring for someone age 50 to 64—37 percent want conversations about recipient needs (vs. 23 percent of those caring for someone age 18 to 49 and 30 percent of those caring for someone age 65 or older) and 29 percent want conversations about self-care (vs. 20 percent when recipient is age 18 to 49 and 21 percent age 65 or older).
- Caregivers who work 30 hours or more a week—34 percent want conversations about recipient needs (vs. 27 percent of those who do not work or work less) and 25 percent want self-care conversations (vs. 19 percent of caregivers who do not work or work less).
- Caregivers who feel they had no choice in taking on care—34 percent want conversations about their recipient's care needs (vs. 27 percent with a choice), while 25 percent want self-care conversations (vs. 20 percent had a choice).
- Those in higher-intensity care situations also more often would like to have these kinds of conversations required. Thirty-four percent of those in moderate- to high-intensity care situations would like conversations about recipient needs (vs. 27 percent low intensity) while 28 percent of those in high-intensity situations would like self-care conversations (vs. 17 percent low intensity).

Several groups of caregivers are more interested in conversations about self-care needs, including:

- Those who feel alone (34 percent vs. 19 percent not)
- African American caregivers (32 percent vs. 22 percent White and 16 percent Hispanic)

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[66] Data were not trended to 2015 as the structure of the question asked changed (from helpfulness of six policy options in 2015 to helpfulness of just three policy options in 2020), so results are not comparable.

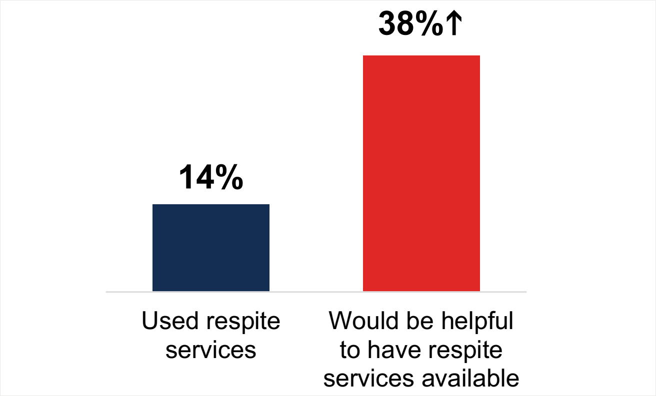
- Those who live with their care recipient (26 percent vs. 20 percent not co-residing),
- LGBTQ caregivers (34 percent vs. 21 percent not)
- Those caring for someone with memory problems (30 percent vs. 19 percent not)
- Those caring for someone with mental or emotional health issues (29 percent vs. 20 percent not)
- Younger generation caregivers (32 percent generation Z, 30 percent millennial, 23 percent generation X, 17 percent baby boomer, and 14 percent silent)

Finally, Asian American caregivers more often want conversations about their recipient's needs (46 percent) than all others (30 percent), while those caring for a parent or parent-in-law are also especially interested in discussing their recipient's care needs (36 percent vs. 25 percent all other relationships).

Respite Services

Nearly 4 in 10 caregivers feel having respite services available would be helpful (38 percent, see Figure 78).[67] However, only 14 percent of caregivers report having used respite services, where someone provided care to the recipient to give the caregiver a break. This relatively low respite use is comparable to other studies.[68]

Figure 78. Respite Services



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

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?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Subgroups: 2020

- Higher-hour caregivers (42 percent vs. 35 percent of lower-hour caregivers) and those in a high-intensity care situation (46 percent vs. 32 percent of caregivers in a medium- to low-intensity care situation) are each especially likely to see the helpfulness of respite. These same groups are also more likely to have used respite, with 19 percent of higher-hour caregivers and 21 percent of high-intensity caregivers having done so.
- Those caring for someone with a memory problem are more likely to say respite would be helpful (46 percent vs. 34 percent not) and to have used respite (22 percent vs. 11 percent not).

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[67] Data were not trended to 2015 as the structure of the question asked changed (from helpfulness of six policy options in 2015 to helpfulness of just three policy options in 2020), so results are not comparable.

[68] See Wolff et al., "Family Caregivers." In this study, use of respite care by family caregivers of older adults (age 65+) was found to be 15.7 percent in 2015.

- Those caring for someone with an emotional or mental health issue more often say respite would be helpful (46 percent vs. 35 percent not) and also say they used respite services (21 percent vs. 13 percent not).
- Similarly, caregivers of those with a long-term physical condition more often say respite would be helpful (43 percent vs. 28 percent not) and say they have used respite (16 percent vs. 10 percent not).
- Caregivers who say their recipient has paid help more often report the use of respite (26 percent vs. 8 percent of those without paid help), perhaps because this paid help was a respite service or because having paid help more easily allowed the caregiver to take a break from care demands.
- Finally, several groups are especially likely to feel respite services would be helpful to their care situation:
  - Caregivers ages 18 to 64 (39 percent vs. 31 percent among those ages 65 and older)
  - Caregivers who feel they had no choice in taking on care (43 percent vs. 31 percent with a choice)
  - Those who have been providing care for five years or longer (44 percent vs. 32 percent less than a year)
  - Those who expect to be providing care in the future (42 percent vs. 32 percent of those who do not expect to or are unsure)
  - Caregivers who feel alone (47 percent vs. 35 percent not)
  - Working caregivers (39 percent vs. 35 percent not)
  - Those with higher incomes (40 percent vs. 33 percent of those with less than $50,000 in household income)
  - Caregivers with at least some college education (41 percent vs. 29 percent with high school diploma or less)

Use of Caregiver Support Services

About two in five caregivers report they have had to make modifications to the home where their recipient lives in order to more easily provide care (37 percent, see Figure 79). One in four have used transportation services for their care recipient (25 percent).

Figure 79. Use of Caregiver Support Services

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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Subgroups: 2020

Several groups of caregivers more often report having done both of these support activities, including those in a high- or medium-intensity care situation, higher-hour caregivers, those who have been caring longer, caregivers of a recipient with memory problems, those caring for someone with a long-term physical condition, and those who report their recipient has paid help.

Some caregivers are likely to report having made home modifications, including:

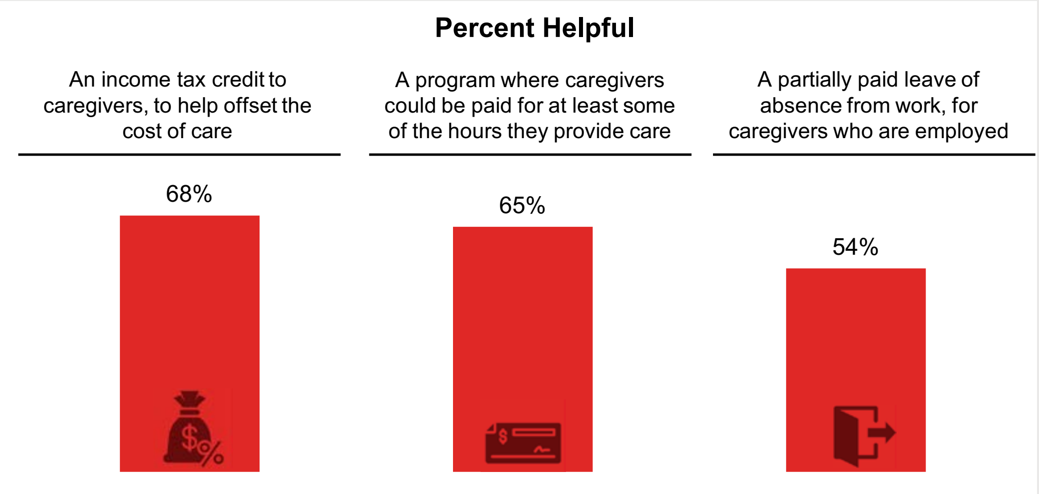
- Caregivers of the oldest recipients, ages 65 and older (42 percent vs. 27 percent of those caring for someone age 18 to 64)
- Those who expect to continue caring into the future (41 percent vs. 32 percent of those who do not or are not sure)
- Higher-income caregivers (41 percent of those with $50,000 or more in household income vs. 29 percent of those with less)
- Those who are married or have a partner (40 percent vs. 32 percent not)

Unmarried caregivers more often report using transportation services (29 percent vs. 22 percent married/partner).

Policy Proposals for Caregiver Support

Of three national policies or programs presented to caregivers as potential ways to help them, two out of three caregivers would find an income tax credit helpful (68 percent, shown in Figure 80), while a similar percentage would find a program to pay caregivers for some hours of their care helpful (65 percent). More than half feel a partially paid leave of absence from work would be helpful (54 percent); though this number rises to 62 percent among caregivers who work 30 hours or more each week.

Figure 80. Policy Proposals for Caregiver Support



M9. Below are some ways that people are proposing to help caregivers financially. How helpful would you find/have found each?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Subgroups: 2020

- Women caregivers are more likely than men caregivers to find each of the three policies helpful (70 percent income tax credit vs. 63 percent men; 69 percent paid for some care vs. 58 percent men; and 58 percent leave vs. 47 percent men).
- Caregivers in high-intensity care situations more often say being paid for some hours of care provided (76 percent) or taking a partially paid leave of absence (61 percent) would be helpful, compared to those in medium- to low-intensity situations (57 percent paid for care and 49 percent leave of absence).

- Those reporting moderate-to-high levels of financial strain also view each of these three financial support policies as helpful (75 percent tax credit, 74 percent paid for care, and 60 percent leave), more so than those reporting low financial strain (64 percent, 59 percent, and 50 percent, respectively).
- Several groups more often find the income tax credit helpful, including those who have been caring for five years or longer (73 percent vs. 65 percent for less than five years), those who expect to continue caring into the future (73 percent vs. 62 percent of those who do not expect to or are unsure), and caregivers with $50,000 or more in household income (70 percent vs. 63 percent with lower incomes).

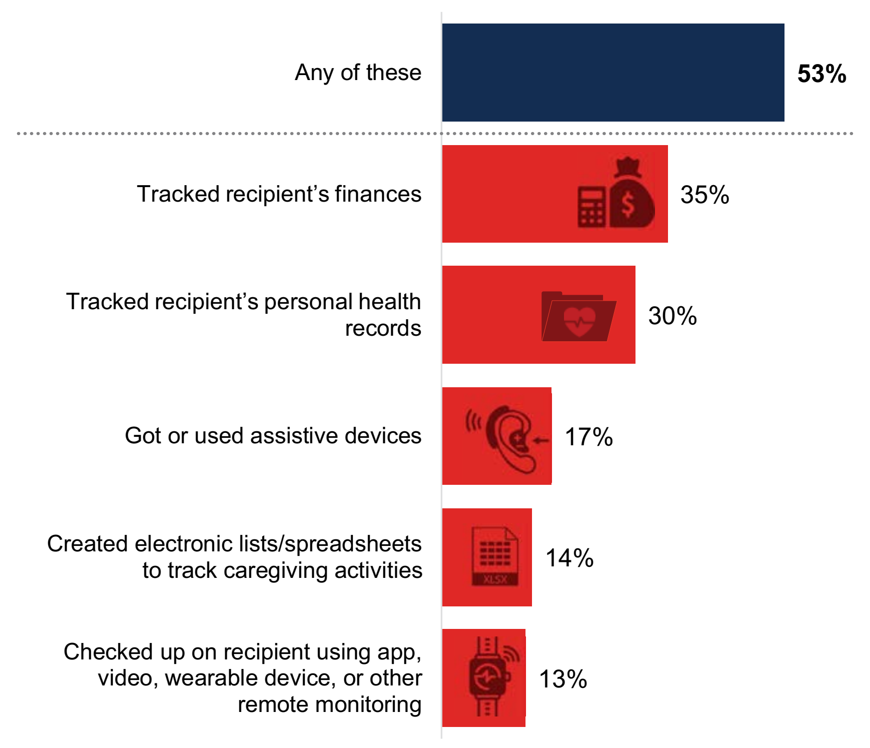
K. TECHNOLOGY

Many experts feel that technology might help support caregivers, but use of technology and online solutions is limited.

Software and Monitoring Solutions

Half of caregivers have used at least one technology or software to help with caregiving (53 percent, see Figure 81). Most commonly, 1 in 3 caregivers have used technology or software to track their recipient's finances (35 percent). Three in 10 have tracked their recipient's personal health records with technology or software. Fewer have used assistive devices for their recipient (17 percent) or have used apps, video, wearables, or other remote monitoring to check up on their recipient (13 percent). Fourteen percent have created electronic lists to track activities related to providing care.

Figure 81. Software and Monitoring Solutions



M11. In your experience as a caregiver for your [relation], have you ever done the following things using technology or software?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Respondents may select more than one response; results add to greater than 100 percent.

Subgroups: 2020

Some groups of caregivers are especially likely to report use of each of the five technology or software tools to aid caregiving, including:

- Higher-hour caregivers—those providing 21 or more hours of care weekly
- Caregivers who report feeling alone
- Those who expect to provide care into the future
- Those reporting high financial strain
- Higher-income caregivers—that is, those with $50,000 or more in household income
- Caregivers with a college degree or higher
- Those caring for someone with a memory problem
- Caregivers whose recipient has an emotional or mental health issue

Use of specific types of technology or software is higher among select groups, depending on the technology or software.

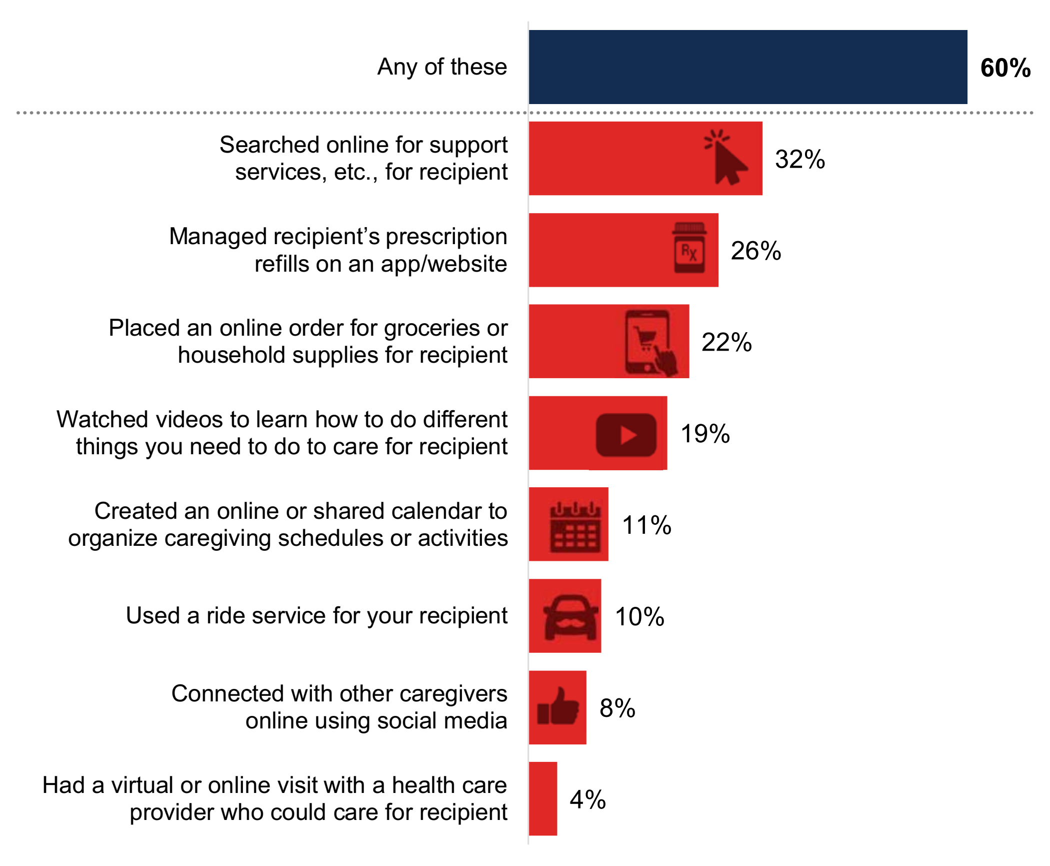
- *Tracking recipient finances* is more common among:
  - — Caregivers who feel they had no choice (41 percent vs. 29 percent who had a choice)
  - — Older caregivers—those ages 50 and older (39 percent vs. 31 percent of caregivers ages 18 to 49)
  - — More tenured caregivers (49 percent when caring for five years or longer vs. 37 percent caring for one to four years vs. 24 percent caring for less than a year)
  - — Primary caregivers (39 percent vs. 28 percent not)
  - — Those caring for a recipient who lives in an urban or suburban setting (38 percent vs. 30 percent rural-dwelling recipients)
  - — Caregivers of someone with a long-term physical condition (38 percent vs. 32 percent not)
- *Tracking recipient health records* is more common among:
  - — Caregivers who feel they had no choice (34 percent vs. 26 percent had a choice)
  - — Those caring for a spouse/partner (42 percent vs. other relatives 30 percent and non-relatives 16 percent)
  - — Caregivers who have been caring for a year or longer (37 percent vs. 22 percent caring for less than a year)
  - — Primary caregivers (34 percent vs. 25 percent not)
  - — Those caring for someone with a long-term physical condition (35 percent vs. 22 percent not)
- *Use of assistive devices* for the recipient is more common when caregivers are caring for someone age 65 or older (20 percent vs. 11 percent with younger recipients), providing care for more than a year (22 percent vs. 11 percent less than a year), and caring for someone with a long-term physical condition (22 percent vs. 9 percent not).
- Creating electronic lists or spreadsheets to *track caregiving activities* is more common for caregivers who feel they had no choice (17 percent vs. 12 percent who had a choice), younger caregivers (15 percent of caregivers ages 18 to 64 vs. 11 percent of those ages 65 and older), and those caring for someone with a long-term physical condition (17 percent vs. 12 percent not). This is less common among Hispanic caregivers (8 percent) than all others (17 percent).
- *Checking up on the recipient with an app, video, wearable device, or other remote technology* is most commonly done by younger caregivers (16 percent among caregivers ages 18 to 49 and 12 percent ages 50 to 64 vs. 6 percent ages 65 and older) and student caregivers (24 percent vs. 11 percent not).

Online Solutions

Six in 10 caregivers have done at least one of a variety of tasks online to help with caregiving (60 percent, see Figure 82). Most commonly, caregivers rely on the Internet for searches for services, aides, facilities or other help (32 percent). Roughly 1 in 4 caregivers go online for purchases for their recipient, like managing prescriptions on an app or website (26 percent) or online grocery or household supply ordering (22 percent). One in 5 has watched videos to learn how to do different care tasks for a recipient (19 percent).

Fewer caregivers have gone online to create an online or shared calendar to organize caregiving schedules (11 percent), to use a ride-share service like Uber or Lyft (10 percent), or to connect with other caregivers (8 percent). Very few have used virtual provider visits (also called telehealth or e-doctor visits) for their recipients (4 percent).

Figure 82. Caregiver Use of Online Solutions



M7. In your experience as a caregiver for your [relation], have you ever done the following things online?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Note: Respondents may select more than one response; results add to greater than 100 percent.

Subgroups: 2020

Several groups are especially likely to lean on online technology or tools to help with caregiving tasks. As the intensity of the care situation increases, so too does caregiver use of online solutions, with high-intensity situation caregivers doing 1.7 tasks online, medium-intensity caregivers doing 1.3 tasks, and low-intensity caregivers doing 0.9 tasks online. Similarly, higher-hour caregivers more often report going online to do tasks related to caregiving (1.7 on average vs. 1.1 among those providing 20 or fewer hours of care).

Caregivers of recipients with an emotional or mental health issue more often report using each of these eight things, as do caregivers who report higher financial strain. Caregivers who report feeling alone perform six of eight online tasks more often,[69] as do those caring for someone with memory problems.[70]

- Younger caregivers seem to show greater comfort with two particular online tasks: placing an online order for groceries or household supplies for the care recipient (24 percent when ages 18 to 64 vs. 14 percent ages 65 and older), and watching videos to learn how to do care tasks (25 percent when ages 18 to 49 vs. 17 percent ages 50 to 64 and 10 percent ages 65 and older).
- Co-residing caregivers more often report managing their recipient's prescriptions online (35 percent vs. 20 percent not living together), watching videos to learn care tasks (23 percent vs. 16 percent), and creating an online or shared calendar to organize caregiving schedules or activities (13 percent vs. 9 percent).
- Those who feel they had no choice more often searched online for support services, aides, facilities, or other help (37 percent vs. 25 percent who had a choice), managed prescriptions (28 percent vs. 23 percent), and created a caregiving calendar (13 percent vs. 9 percent).
- Caregivers who more often report going online to manage their recipient's prescriptions include primary caregivers (29 percent vs. 20 percent non-primary) and those who have been caring for a year or longer (29 percent vs. 21 percent for less than a year).
- Caregivers who more often go online to search for support services, aides, facilities, or other such help include those who say their recipient has paid help (42 percent vs. 26 percent without), those who have been caring for at least a year (36 percent vs. 26 percent), and higher-income caregivers (34 percent of those with $50,000 or more in household income vs. 27 percent with less).
- Those who have been caring for at least a year (27 percent vs. 17 percent for less than a year) and caregivers living in an urban or suburban setting (23 percent vs. 16 percent rural) more often report ordering groceries or household supplies online.
- Non-rural-dwelling caregivers also more often go online to create calendars or organize care activities (11 percent vs. 7 percent rural), and they more often report using ride-share services for their recipient (11 percent vs. 2 percent rural).

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[69] All except use of ride-share services like Lyft or Uber, and doing a telemedicine or e-visit for the recipient.

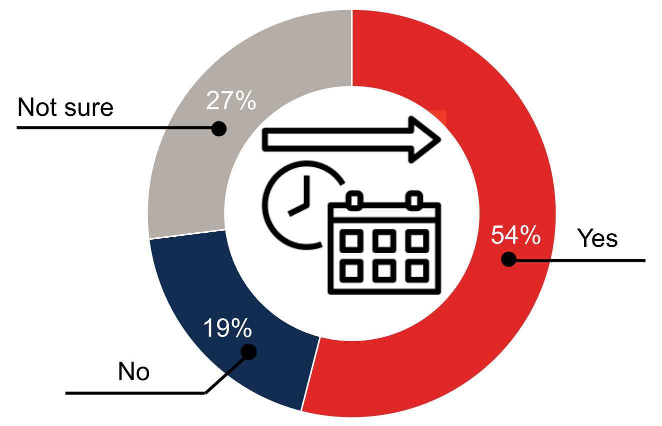
[70] All except ordering groceries or other household goods, and use of ride-share services like Lyft or Uber.

L. LONG-RANGE PLANNING

Expectations of Future Caregiving Role

Over half of caregivers expect they will be a caregiver for some adult (either their current recipient or someone else) during the next five years (54 percent, see Figure 83).

Figure 83. Expectations of Future Caregiving Role



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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Subgroups: 2020

- The expectation to continue being a caregiver five years in the future varies by caregiver generation, such that generation X caregivers most often have this future caregiving expectation *and* more often report this expectation than in 2015, as shown in Figure 84.

Figure 84. Expectations of Future Caregiving Role by Caregiver Generation

	Generation Z (n = 34) A	Millennial (n = 283) B	Generation X (n = 392) C	Baby Boomer (n = 594) D	Silent (n = 89) E
Expects to care in future	34%	46%	60%^{*AB}	58%^{AB}	54%^{A}

** Significantly higher than in 2015.*

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

- White (58 percent), Asian American (54 percent), and Hispanic (53 percent) caregivers are more likely to expect to be caregivers in the future than are African American caregivers (42 percent).
- Caregivers who feel they had no choice in taking on their role expect caregiving to continue five years into the future (61 percent vs. 46 percent with a choice).
- Those caring for a parent/parent-in-law (63 percent) or spouse/partner (59 percent) are more likely than those caring for other relatives (44 percent) or non-relatives (33 percent) to expect their role to continue.

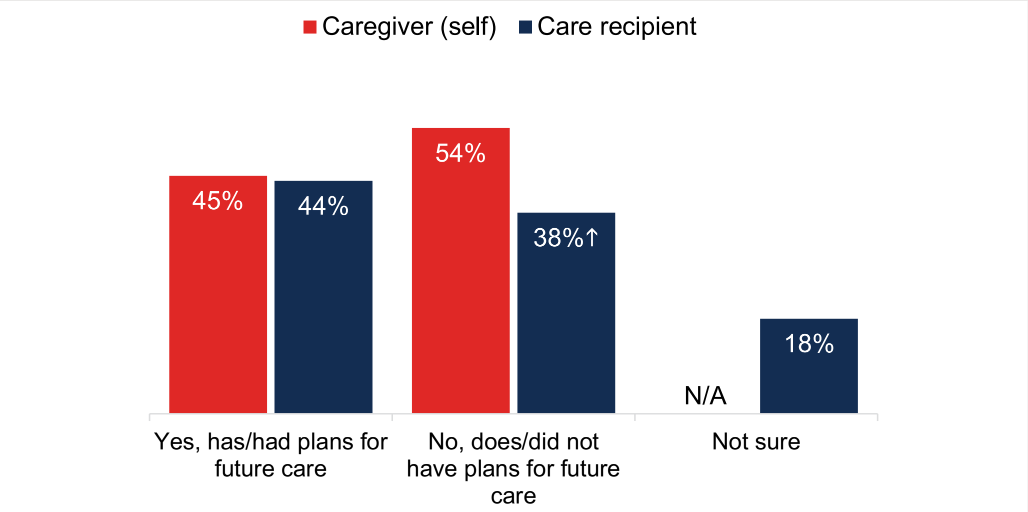
- Those caring for a recipient with memory problems (62 percent vs. 50 percent not) or someone with a long-term physical condition (60 percent vs. 45 percent not) more often expect their care role to continue into the future.
- Caregivers with a college degree or higher more often expect to continue providing care (62 percent vs. 50 percent with less education), as do those with higher household incomes (60 percent with $50,000 or more vs. 43 percent with less).
- Once caregivers have been providing care for at least a year, they more often expect their role to continue five years into the future (64 percent vs. 41 percent of those caring for less than a year).
- Those who feel alone more often expect caregiving to continue (62 percent vs. 52 percent not feeling alone).

Long-Range Planning

Fewer than half of caregivers report that their care recipient has or had plans in place for future care (44 percent, see Figure 85), which includes instructions for things like handling financial matters, health care decisions, or living arrangements. Nearly two in five report there are no such plans in place (38 percent, up from 32 percent in 2015), while one in five are not sure (18 percent, down from 22 percent in 2015).

About two in five caregivers indicate they have plans in place for their own future care (45 percent).

Figure 85. Long-Range Planning



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

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?

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Subgroups: 2020

- As caregivers' reported financial strain increases, they are less likely to report their care recipient having future care plans in place, suggesting that a lack of long-range plans may cause financial stress for caregivers (see Figure 86). In addition, caregivers with high financial strain are less often reporting their recipient has plans in place than in 2015.

Figure 86. Percent with Long-Term Plans in Place by Financial Strain of Caregiver

	High Financial Strain (n = 255) A	Moderate Financial Strain (n = 260) B	Low Financial Strain (n = 871) C
Care recipient has plans in place	27%*	41%^{A}	50%^{AB}
Caregiver has plans in place	39%	44%	48%^{A}

** Significantly lower than in 2015*

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

Groups of caregivers that are likely to report their care recipient has or had plans for their future care in place include:

- Caregivers who report the presence of both paid and unpaid help (57 percent vs. 41 percent of those with one or no source of help)
- Those caring for adults ages 65 and older (52 percent vs. 29 percent when recipient is age 18 to 64)
- Caregivers whose recipient has a memory problem (51 percent vs. 40 percent not)
- Those who expect to be caring in the future (50 percent vs. 37 percent of those who do not or are not sure)
- Those who have been caring for at least a year (49 percent vs. 38 percent for less than a year)
- Higher-income caregivers (48 percent with $50,000 or more vs. 37 percent with less)
- More educated caregivers (48 percent with at least some college vs. 35 percent high school diploma or less)
- Those caring for a parent/parent-in-law (47 percent vs. 37 percent of those caring for a non-relative)
- Those not living with their care recipient (47 percent vs. 39 percent of those who co-reside)

Of note, caregivers of recipients with an emotional or mental health issue are *less likely* to report their recipient has plans in place (38 percent with plans vs. 46 percent of those caring for someone without emotional or mental health issues).

Caregivers who more often report having their own plans for future care include higher-income caregivers (49 percent vs. 38 percent less than $50,000); those with at least some college education (49 percent vs. 38 percent high school diploma or less); non-Hispanics (46 percent compared to 37 percent of Hispanics); and older caregivers (63 percent ages 65 and older vs. 50 percent ages 50 to 64 and 34 percent ages 18 to 49).

M. RESPONDENT PROFILE

Caregivers reflect the general U.S. population and on the whole look similar to caregivers in 2015 (see Figure 87). Six in 10 are women and 4 in 10 are men; the average age is 49.4 years old, 6 in 10 are White, and about half are married.

Figure 87. Demographic Summary of Caregivers of Adults, 2020 and 2015

	2020 (n = 1,392)	2015 (n = 1,248)
Caregiver Gender		
Man	39%	40%
Woman	61%	60%
Age of Caregiver		
18–34	24%	24%
35–49	23%	23%
50–64	35%	34%
65–74	12%	12%
75+	7%	7%
Mean age	49.4	*49.2*
Race/Ethnicity of Caregiver		
White	61%	62%
African American	14%	13%
Hispanic	17%	17%
Asian American	5%	6%
Other	3%	2%
Caregiver Education		
Less than high school	6%	8%
High school graduate	26%	28%
Some college	22%	22%
Technical school	11%*	8%
College graduate	21%	20%
Graduate school	14%	15%
Caregiver Marital Status		
Married	54%	57%
Living with a partner	7%	8%
Widowed	4%	5%
Separated	3%*	1%
Divorced	8%	8%
Single, never married	21%	19%

** Result is significantly higher or lower than in 2015.*

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Household incomes for caregivers are higher in 2020 than in 2015, though this change may be due to both changed measurement and general wage change over the past five years.[71] Three in 10 caregivers have a child or grandchild living in their home at the time of care and just 12 percent live in a rural area, down from 2015 (16 percent). Six in 10 are employed while providing care, while 1 in 10 is a student while caregiving.

Figure 87 (continued). Demographic Summary of Caregivers of Adults, 2020 and 2015

	2020 (n = 1,392)	2015 (n = 1,248)
Caregiver Household Income (unadjusted)		
Less than $50,000 (net)	36%*	47%
Less than $15,000	8%*	12%
$15,000–$29,999	13%*	16%
$30,000–$49,999	15%*	18%
$50,000 or more (net)	64%*	53%
$50,000–$74,999	18%	17%
$75,000–$99,999	14%	13%
$100,000+	33%*	23%
Median household income (2015 inflation adjusted)	*$67,500*	*$59,300*
Children/Grandchildren in Caregiver's Household		
Yes	30%	28%
No	68%	70%
Caregiver Living Location		
Urban/Suburban	88%*	84%
Rural	12%*	16%
Caregiver Employment Status		
Employed in past year while caregiving	61%	60%
Not employed	39%	40%
Caregiver Student Status		
Yes	11%	n/a
No	89%	n/a

** Result is significantly higher or lower than in 2015*

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

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[71] See appendix B: Methodology for documentation on inflation and the comparison of scales for household income used in 2020 and 2015. When these issues are corrected for, household income of caregivers in 2020 and caregivers in 2015 are comparable.

Most caregivers have health insurance, usually through an employer. National estimates of insurance coverage indicate that 12.5 percent of Americans ages 18 to 64 are without health insurance.[72] Among caregivers ages 18 to 64, 15.2 percent report they are without health insurance, suggesting that caregivers are more likely than general Americans to lack health insurance. About 1 in 10 have served in the U.S. Armed Forces and 8 percent self-identify as LGBTQ. Three in 10 report their recipient lives in a rural area and 14 percent say their recipient is a veteran.

Figure 87 (continued). Demographic Summary of Caregivers of Adults, 2020 and 2015

	2020 (n = 1,392)	2015 (n = 1,248)
Caregiver Has Health Insurance		
Yes	87%	n/a
No	13%	n/a
Caregiver Source of Health Insurance		
Employer-sponsored	56%	n/a
Medicare	20%	n/a
Medicaid	9%	n/a
Direct purchase	8%	n/a
Military/Veterans	4%	n/a
Caregiver Service in Armed Forces		
Served on active duty	9%	10%
Did not ever serve	91%	89%
Caregiver LGBTQ Status		
Yes	8%	9%
No	91%	91%
Care Recipient Living Location		
Urban/Suburban	69%	71%
Rural	31%	28%
Care Recipient Service in Armed Forces		
Served on active duty	14%	14%
Did not ever serve	83%	85%

** Result is significantly higher or lower than in 2015*

Note: Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

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[72] J. Tolbert et al., "Key Facts about the Uninsured Population," Appendix Table B, Issue Brief, Kaiser Family Foundation, December 13, 2019, https://www.kff.org/uninsured/issue-brief/key-facts-about-the-uninsured-population/.

Hispanic caregivers are the youngest at 43.3 years old, while White caregivers are the oldest at 51.7 (see Figure 88). Hispanic caregivers most often have a high school diploma or less (45 percent), while the majority of Asian American caregivers report having a college degree or higher (74 percent).

Figure 88. Demographic Summary—All Caregivers and by Race/Ethnicity

	Total (n = 1,392)	White (n = 801) A	African American (n = 199) B	Hispanic (n = 205) C	Asian American (n = 197) D
Caregiver Gender					
Man	39%	40%	34%	39%	42%
Woman	61%	60%	66%	61%	58%
Age of Caregiver					
18–34	24%	20%	26%	34%^{AD}	20%
35–49	23%	18%	27%^{A}	32%^{A}	32%^{A}
50–64	35%	40%^{BCD}	30%	23%	29%
65–74	12%	14%^{C}	9%	7%	12%
75+	7%	8%^{C}	7%	4%	7%
Mean age	*49.4*	*51.7*^{BC}	*47.7*^{C}	*43.3*	*49.3*^{C}
Caregiver Education					
Less than high school	6%	5%^{D}	6%^{D}	13%^{ABD}	0%
High school graduate	26%	26%^{D}	24%^{D}	32%^{D}	4%
Some college	22%	21%	24%^{D}	27%^{D}	15%
Technical school	11%	11%^{D}	17%^{ACD}	9%	6%
College graduate	21%	21%^{C}	16%	13%	50%^{ABC}
Graduate school	14%	16%^{C}	13%	6%	24%^{ABC}
Caregiver Marital Status					
Married	54%	62%^{BCD}	33%	46%^{B}	52%^{B}
Living with a partner	7%	6%	9%	10%	5%
Widowed	4%	4%	8%^{C}	2%	4%
Separated	3%	2%	3%	5%	2%
Divorced	8%	9%	11%	6%	6%
Single, never married	21%	16%	30%^{A}	29%^{A}	29%^{A}

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Hispanic and African American caregivers report lower household incomes than White or Asian American caregivers. Hispanic caregivers most often have children or grandchildren living in their home (47 percent). White caregivers more often report living in a rural area (16 percent). African American (19 percent), Hispanic (15 percent), and Asian American (17 percent) caregivers more often report attending school while providing care than White caregivers (7 percent).

Figure 88 (continued). Demographic Summary—All Caregivers and by Race/Ethnicity

	Total (n = 1,392)	White (n = 801) A	African American (n = 199) B	Hispanic (n = 205) C	Asian American (n = 197) D
Caregiver Household Income (unadjusted)					
Less than $50,000 (net)	36%	32%	47%^{AD}	41%^{AD}	27%
Less than $15,000	8%	6%	15%^{AD}	11%^{AD}	5%
$15,000–$29,999	13%	11%	15%	17%	13%
$30,000–$49,999	15%	15%^{D}	17%^{D}	14%	9%
$50,000 or more (net)	64%	68%^{BC}	53%	59%	71%^{BC}
$50,000–$74,999	18%	18%	19%	19%	13%
$75,000–$99,999	14%	13%	14%	13%	19%
$100,000+	33%	37%^{BC}	19%	27%	37%^{B}
Median household income (2015 inflation adjusted)	*$67,500*	*$80,000*	*$55,000*	*$55,000*	*$87,500*
Children/Grandchildren in Caregiver's Household					
Yes	30%	25%	34%^{A}	47%^{ABD}	28%
No	68%	74%^{BC}	63%^{C}	50%	70%^{C}
Caregiver Living Location					
Urban/Suburban	88%	84%	93%^{A}	97%^{AD}	91%^{A}
Rural	12%	16%^{BCD}	7%	3%	8%
Caregiver Employment Status					
Employed in past year while caregiving	61%	62%	64%	60%	59%
Not employed	39%	38%	36%	40%	41%
Caregiver Student Status					
Yes	11%	7%	19%^{A}	15%^{A}	17%^{A}
No	89%	92%^{BCD}	81%	85%	83%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Hispanic caregivers less often report having health insurance (79 percent). White and African American caregivers are more often veterans. White caregivers more often report their recipient lives in a rural area (35 percent) than Hispanic or Asian American caregivers.

Figure 88 (continued). Demographic Summary—All Caregivers and by Race/Ethnicity

	Total (n = 1,392)	White (n = 801) A	African American (n = 199) B	Hispanic (n = 205) C	Asian American (n = 197) D
Caregiver Has Health Insurance					
Yes	87%	89%^{C}	87%^{C}	79%	89%^{C}
No	13%	11%	13%	21%^{ABD}	11%
Caregiver Source of Health Insurance					
Employer-sponsored	56%	58%	50%	56%	64%^{B}
Medicare	20%	22%^{C}	19%	14%	18%
Medicaid	9%	7%	13%^{AD}	15%^{AD}	6%
Direct purchase	8%	7%	9%	8%	10%
Military/Veterans	4%	5%^{CD}	4%^{C}	1%	1%
Caregiver Service in Armed Forces					
Served on active duty	9%	10%^{CD}	12%^{CD}	4%	5%
Did not ever serve	91%	90%	88%	96%^{AB}	95%^{AB}
Caregiver LGBTQ Status					
Yes	8%	7%	11%^{D}	6%	4%
No	91%	92%	89%	91%	88%
Care Recipient Living Location					
Urban/Suburban	69%	65%	70%	75%^{A}	70%
Rural	31%	35%^{CD}	30%^{D}	25%^{D}	11%
Care Recipient Service in Armed Forces					
Served on active duty	14%	18%^{CD}	11%	9%	8%
Did not ever serve	83%	81%	86%	89%^{A}	89%^{A}

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Caregivers of younger adults are 44.7 years old on average, younger than caregivers of adults ages 50 and older, see Figure 89.

Figure 89. Demographic Summary by Care Recipient Age

	Total (n = 1,392)	Caregivers of Younger Adults 18–49 (n = 188) A	Caregivers of Older Adults 50+ (n = 1,204) B
Caregiver Gender			
Man	39%	40%	39%
Woman	61%	60%	61%
Age of Caregiver			
18–34	24%	32%[B]	22%
35–49	23%	29%[B]	22%
50–64	35%	27%	36%[A]
65–74	12%	7%	13%[A]
75+	7%	4%	7%
Mean age	*49.4*	*44.7*	*50.1*[A]
Race/Ethnicity of Caregiver			
White	61%	58%	61%
African American	14%	19%	14%
Hispanic	17%	15%	17%
Asian American	5%	6%	5%
Other	3%	2%	3%
Caregiver Education			
Less than high school	6%	10%	6%
High school graduate	26%	32%[B]	25%
Some college	22%	17%	23%
Technical school	11%	12%	11%
College graduate	21%	19%	21%
Graduate school	14%	9%	15%[A]
Caregiver Marital Status			
Married	54%	53%	54%
Living with a partner	7%	14%[B]	6%
Widowed	4%	8%[B]	3%
Separated	3%	4%	2%
Divorced	8%	5%	9%
Single, never married	21%	13%	23%[A]

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Caregivers of younger adults more often report household income less than $50,000 (43 percent). Three in 10 caregivers—regardless of the age of the care recipient—have children living in their home.

Figure 89 (continued). Demographic Summary by Care Recipient Age

	Total (n = 1,392)	Caregivers of Younger Adults 18–49 (n = 188) A	Caregivers of Older Adults 50+ (n = 1,204) B
Caregiver Household Income (unadjusted)			
Less than $50,000 (net)	36%	43%^{B}	35%
Less than $15,000	8%	7%	8%
$15,000–$29,999	13%	17%	12%
$30,000–$49,999	15%	18%	15%
$50,000 or more (net)	64%	57%	65%^{A}
$50,000–$74,999	18%	19%	17%
$75,000–$99,999	14%	12%	14%
$100,000+	33%	26%	34%^{A}
Median household income (2015 inflation adjusted)	$67,500	*$55,000*	*$67,500*
Children/Grandchildren in Caregiver's Household			
Yes	30%	31%	30%
No	68%	65%	68%
Caregiver Living Location			
Urban/Suburban	88%	86%	89%
Rural	12%	14%	11%
Caregiver Employment Status			
Employed in past year while caregiving	61%	59%	62%
Not employed	39%	41%	38%
Caregiver Student Status			
Yes	11%	15%	10%
No	89%	84%	89%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

Caregivers of younger adults less often report having health insurance (80 percent vs. 88 percent of those caring for someone age 50 or older). They less often report their younger recipient is a veteran (6 percent), as compared to those caring for an older recipient (16 percent of recipients are veterans).

Figure 89 (continued). Demographic Summary by Care Recipient Age

	Total (n = 1,392)	Caregivers of Younger Adults 18–49 (n = 188) A	Caregivers of Older Adults 50+ (n = 1,204) B
Caregiver Has Health Insurance			
Yes	87%	80%	88%^{A}
No	13%	20%^{B}	11%
Caregiver Source of Health Insurance			
Employer-sponsored	56%	53%	57%
Medicare	20%	18%	21%
Medicaid	9%	11%	9%
Direct purchase	8%	10%	7%
Military/Veterans	4%	5%	4%
Caregiver Service in Armed Forces			
Served on active duty	9%	8%	10%
Did not ever serve	91%	92%	90%
Caregiver LGBTQ Status			
Yes	8%	10%	7%
No	91%	87%	92%
Care Recipient Living Location			
Urban/Suburban	69%	64%	69%
Rural	31%	36%	30%
Care Recipient Service in Armed Forces			
Served on active duty	14%	6%	16%^{A}
Did not ever serve	83%	90%^{B}	82%

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and don't know/refused responses are not shown; results may not add to 100 percent.

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April 5, 2022

The Honorable Mark Pearson
Chairman, House Health, Human Services and Elderly Affairs

The Honorable Erica Layon
Vice-Chairman, House Health, Human Services and Elderly Affairs

Thank you, Chairman Pearson and members of the committee. My name is MacKenzie Nicholson and I am the Public Policy Manager of the Alzheimer's Association, MA/NH chapter. I am here before you today asking for your support for SB414, an act relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders, and making an appropriation therefor.

As Senator Avard mentioned, In New Hampshire, there are an estimated 26,000 individuals living with Alzheimer's or other dementia and an estimated 57,000 caregivers providing care to them. Caregivers of those living with Alzheimer's and dementia have incredibly difficult jobs and often assist their loved ones with one or more activities of daily living (ADLs), including bathing, dressing, and eating as well as multiple instrumental activities of daily living (IADLs), such as paying bills, shopping and using transportation.

Eighty-three percent of the help provided to older adults in the United States comes from family members, friends or other unpaid caregivers and in 2020 alone, caregivers in New Hampshire provided more than 82 million hours of unpaid care to loved ones experiencing Alzheimer's or dementia at an estimated economic value of more than $1.4 billion.

In order to provide this care to their loved one, many caregivers report needing to cut back hours, take a leave of absence or leave the workforce entirely. They also experience depleted income and finances due to paying for healthcare or other services for themselves and those living with dementia. The total lifetime cost of care for someone with dementia was estimated at $373,527 in 2020. Seventy percent of the lifetime cost of care is borne by family caregivers in the forms of unpaid caregiving and out-of-pocket expenses for items ranging from medications to food for the person with dementia.

In addition to the economic burden placed on these caregivers, as the person with dementia's symptoms worsen, caregivers often experience increased emotional stress, depression and new or exacerbated health problems. Seventy-four percent of caregivers of people with Alzheimer's or other dementias reported that they were "somewhat concerned" to "very concerned" about maintaining their own health since becoming a caregiver. Evidence also suggests that the stress of providing dementia care increases caregivers' susceptibility to a multitude of disease and health complications.

All this to say that caregiving can be physically, emotionally and financially challenging.

To help reduce the burden on caregivers, New Hampshire has a respite grant which, when received, can assist a caregiver in acquiring alternative care for their loved one so that they can take a break while knowing that their loved one is safely cared for. However, current law states that in order to access the respite grant, you must have Alzheimer's or other dementia thus preventing access for those without a formal diagnosis.

There are many reasons why someone may not have a formal diagnosis. For example:

- Some medical providers are resistant, for one reason or another, to make an official diagnosis;
- There is still a stigma around dementia and it may be easier to discuss that the patient is exhibiting signs of dementia rather than exploring a full diagnosis;
- In some areas, transportation is an issue and even getting someone to the medical provider's office can be difficult;
- Family members can have a hard time exploring a diagnosis, so the medical provider takes baby steps with them and discusses how the patient has symptoms of dementia; and
- Lastly, testing for a definitive Alzheimer's or dementia diagnosis can be incredibly time consuming and costly. Often it can take multiple specialists visits, cognitive tests, scans and even a lumbar puncture to make a diagnosis.

We know that having access to respite is more beneficial when started as soon as possible, not when someone is in the later stages of the dementia process – as the caregiver may be already burnt out. If we can provide respite early on, we have a better chance of helping the caregiver care for their loved one in the home for a longer period of time. In order to do this, we need to change the definition of Alzheimer's disease and related disorders to include those who are symptomatic, which is what SB414 seeks to do.

The fight against Alzheimer's and dementia is personal for me. Growing up and even until a few short years ago my mom was an outgoing, active and happy woman who loved to bake pies with her grandkids and hand out candy at Halloween. Now, 66, she is withdrawn, can hardly walk, has trouble finding words and recalling even something as simple as what she had for lunch. I know in my heart that my mom is likely in the middle stages of dementia.

I'm lucky that I live close enough to help my dad with her care. In fact, approximately one-quarter of dementia caregivers are in my situation and a part of the "sandwich generation" — meaning that we not only care for an aging parent, but also for our children. Because my dad is my mom's primary caregiver, I don't have a good insight as to what happens during my mom's medical appointments. Either out of love, denial, or fear, my dad has not pushed doctors to determine a reason for why my mom has slowly gotten worse over the past few years. My dad is in over his head with her care, something he will freely admit and I worry about them night and day. I worry that if something were to happen to my dad or if he needed to travel to attend to family elsewhere that my mom would forget to take medication or eat - something that has happened before! Unfortunately, my parents would not be eligible for an ADRD respite grant if they were to seek it because my mom lacks a formal diagnosis.

My mom's story is not unique, and although I have a personal connection, I know I am not alone. By 2025, the number of Granite Staters living with the disease is expected to increase to 32,000, and as our state continues to age, that number is only going to grow. Alzheimer's is an incurable, fatal disease that is incredibly heartbreaking to witness. I ask that you vote Ought to Pass on SB414 so that we can better support those living with Alzheimer's and other forms of dementia and their caregivers. Thank you.

MacKenzie Nicholson
Public Policy Manager
menicholson@alz.org
M: (603)969-9155

SB 414 INTRODUCTION April 5, 2022
Rep Jerry Knirk, MD, Carroll 3, introducing on behalf of Sen Kevin Avard

SB 414 broadens the definition of Alzheimer's Disease and Related Disorders (ADRD) in RSA 161-F:66 to include individuals who demonstrate ADRD to an extent that their symptoms interfere with activities of daily living, even if the formal diagnosis has not yet been made. Meeting this definition is necessary to be eligible for respite services under RSA 166-F:67. The related disorders include vascular disease, Lewy body dementia, frontotemporal dementia and Parkinson's related dementia.

The respite program is in place to support family caregivers, therefore supporting care in the less costly home setting rather than in institutions. Family caregivers suffer greatly caring for their loved one at home, leading to caregivers developing difficulties with their own mental and physical health. We need to get help to the caregivers before they burn out and are forced to place their loved one in a nursing home. The expansion of the definition is important to capture the situation in which individuals have become significantly symptomatic before receiving the formal diagnosis or when individuals have significant symptoms but do not go to a provider out of fear of the diagnosis or lack of access.

There is often a delay of 2-3 years between the onset of symptoms and the time of diagnosis. Clinical diagnosis of many disorders is not easy, especially when there is no clear simple test. Diagnosis can be particularly difficult in progressive disorders in which the early symptoms can be subtle and when there is a spectrum of disease. Whom amongst us has not had forgetfulness? Definitive diagnosis of Alzheimer's disease and related neurodegenerative disorders currently can only be made at autopsy but clinical diagnosis can reach a fairly high certainty if carefully done. But that takes time. Clinical diagnosis of Alzheimer's or related dementias require a careful history from the patient and family (taking into account the patient's and family's coping mechanisms which may hide some of the limitations), cognitive and mental status screening tests, perhaps advanced imaging such as MRI to rule out vascular disease and tumors and perhaps neuropsychiatric testing. Some providers may have a low bar for making a diagnosis while others may withhold diagnosis until confirmation by a specialist or advanced testing.

Other barriers to early diagnosis include the stigma of the diagnosis on the part of the provider and the patient. The provider may be hesitant to make the diagnosis as they may be concerned that the diagnosis will be distressing to the patient or the family. The patient and family may be in denial. Systemic reasons for delays in diagnosis include the provider not having enough time to do a proper evaluation with the limited time in the office and the other medical problems which may need attention during that short time. It can be difficult for the family to discuss the situation in front of the patient at the office visit. There are also access problems due to lack of specialists in rural areas and cost barriers to obtaining care.

In summary, SB 414 will improve our respite program by increasing eligibility.

SB 414-FN-A - AS AMENDED BY THE SENATE

02/03/2022 0316s

2022 SESSION

22-2882
05/04

SENATE BILL ***414-FN-A***

AN ACT relative to the definition of Alzheimer's disease and related disorders.

SPONSORS: Sen. Avard, Dist 12; Sen. French, Dist 7; Sen. Gannon, Dist 23; Sen. Reagan, Dist 17; Sen. Carson, Dist 14; Sen. Rosenwald, Dist 13; Sen. Hennessey, Dist 1; Sen. Whitley, Dist 15; Sen. Watters, Dist 4; Sen. Soucy, Dist 18; Sen. Birdsell, Dist 19; Sen. Prentiss, Dist 5; Rep. Burt, Hills. 39; Rep. Ammon, Hills. 40; Rep. Hunt, Ches. 11; Rep. Knirk, Carr. 3

COMMITTEE: Health and Human Services

AMENDED ANALYSIS

This bill revises the definition of ADRD, Alzheimer's disease and related disorders.

- -

Explanation: Matter added to current law appears in ***bold italics.***
Matter removed from current law appears [~~in brackets and struckthrough.~~]
Matter which is either (a) all new or (b) repealed and reenacted appears in regular type.

SB 414-FN-A - AS AMENDED BY THE SENATE

02/03/2022 0316s

22-2882
05/04

STATE OF NEW HAMPSHIRE

In the Year of Our Lord Two Thousand Twenty Two

AN ACT relative to the definition of Alzheimer's disease and related disorders.

Be it Enacted by the Senate and House of Representatives in General Court convened:

1 Alzheimer's Disease and Related Disorders. Amend RSA 161-F:66, I to read as follows:

I. "ADRD", Alzheimer's disease and related disorders, means [~~a condition which~~] ***conditions for which an individual*** receives a differential diagnosis of Alzheimer's disease or a similar irreversible dementia***, or for which an individual demonstrates symptoms of Alzheimer's disease or a similar irreversible dementia to an extent such symptoms interfere with activities of daily living***.

2 Effective Date. This act shall take effect July 1, 2022.

LBA
22-2882
Revised 1/17/22

SB 414-FN-A- FISCAL NOTE
AS INTRODUCED

AN ACT relative to respite care services for persons caring for individuals with Alzheimer's disease and related disorders, and making an appropriation therefor.

FISCAL IMPACT: [X] State [ ] County [ ] Local [ ] None

	Estimated Increase / (Decrease)			
STATE:	**FY 2022**	**FY 2023**	**FY 2024**	**FY 2025**
Appropriation	$0	$1	$0	$0
Revenue	$0	$0	$0	$0
Expenditures	$0	Indeterminable Increase	Indeterminable Increase	Indeterminable Increase
Funding Source:	[X] General	[ ] Education	[ ] Highway	[ ] Other

METHODOLOGY:

This bill revises the definition of Alzheimer's disease and related disorders to include circumstances in which "an individual demonstrates symptoms of Alzheimer's disease or a similar irreversible dementia to an extent such symptoms interfere with activities of daily living." The Department of Health and Human Services states that the change is intended to capture situations in which individuals become symptomatic well before receiving a formal diagnosis, or in which individuals display symptoms but do not go to a doctor out of fear of a diagnosis. RSA 167-F:66 currently requires the Department to provide statewide respite care services to individuals, including those with Alzheimer's disease. The Department notes that it received $327,000 in FY 2021 and $302,508 each year of the FY 2022/23 biennium for the administration of respite care services. The Department further notes that 234 caregivers utilized respite funds in FY 2020, and 227 caregivers utilized such funds in FY 2021. The Department states that while it is unable to determine the number of additional caregivers who will seek funds as a result of the change contained in the bill, it expects that budgeted appropriations will be insufficient to fund care for all newly-eligible individuals.

This bill contains a nonlapsing appropriation of $1 for the biennium ending June 30, 2023. The bill has an effective date of July 1, 2022, so any fiscal impact will begin in FY 2023.

AGENCIES CONTACTED:

Department of Health and Human Services