

**2020 Companion Report**

# Caregiving in the U.S. 2020: A Focused Look at Family Caregivers of Adults Age 50+



Conducted by





## Acknowledgments

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## I. Introduction

This is the first of two companion reports to the full report of the study titled *Caregiving in the U.S. 2020*.<sup>1</sup> This companion report focuses on 1,204 unpaid family caregivers<sup>2</sup> who provide care to an adult age 50 or older with trend comparisons to the 2015 study. Herein, this report presents a more thorough analysis of this group of caregivers, including not-yet-published data on caregivers caring for the oldest-old. The other companion report—*Caregiving in the U.S. 2020: A Focused Look at Family Caregivers of Adults Age 18 to 49*—provides detail on caregivers of younger adults (forthcoming).

### OVERVIEW OF METHODOLOGY

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As with the 2015 wave, all caregivers here were interviewed using Ipsos' (formerly Gfk) national, probability-based, online KnowledgePanel®; surveys were conducted between May 29, 2019, and July 27, 2019, prior to the current COVID-19 pandemic. To see the complete study results, or for more information about the questionnaires or the methodology, please reference the full *Caregiving in the U.S. 2020* report and its appendices A and B.

### READING THIS REPORT

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The sample sizes (*n* sizes) shown throughout represent the unweighted number of people who answered each question. All substantive results (means, medians, percentages) have been weighted and rounded. In addition, “don't know” or “refused” responses are not always presented in charts and tables. For these reasons, some charts and tables will not add to 100 percent; the results for multiple-response questions may also add to greater than 100 percent.

To signal statistically significant differences between subgroup findings, the report uses up or down arrows to highlight any numerical result that is significantly higher or lower than the comparison group, at the 95 percent confidence level. 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.

When more than two groups are being compared in the 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.

Throughout this report, the terms “caregiver of someone age 50+,” “50+ caregivers” or “caregivers of recipients 50+” refer to the focal group of this report: caregivers who provide care to an adult age 50 or older.

## II. Executive Summary

Although caregiving spans across ages, caregivers of recipients 50 years of age or older constitute the majority of caregivers: 79 percent of the estimated 53 million unpaid caregivers in the U.S. care for an adult in this age group. The prevalence of those caregiving for older adults (defined as those ages 50 or older) has increased by 7.6 million caregivers since 2015, with 1 in 6 Americans now providing care to someone age 50 or older. This equates to nearly 42 million adults caring for someone age 50 or older and is a trend that is only expected to persist as one of the largest demographic groups—baby boomers—continues to age. In just six years (2026), boomers will begin turning 80 years old, the age

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1 National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2020*. Washington, DC: May 2020. <https://doi.org/10.26419/ppi.00103.001> or <https://www.caregiving.org/caregiving-in-the-us-2020/>.

2 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.

when many individuals often start to most need long-term services and supports (LTSS) and help from others to carry out daily living tasks.<sup>3</sup>

Not only are there more caregivers of adults ages 50 or older in the U.S. now, but also more of these caregivers are providing care to two or more people (24 percent vs. 18 percent in 2015).

Caregivers of adults ages 50 or older are a diverse group. Sixty-one percent are non-Hispanic White, 17 percent are Hispanic/Latinx, 14 percent are African American, 5 percent are Asian American and Pacific Islander, and 3 percent are some other race/ethnicity. Six in 10 caregivers of those ages 50 or older are women (61 percent) and 62 percent of caregivers of older adults also work while providing care.

Caregivers of older adults are themselves 50.1 years old, on average. Over half are ages 50 or older (56 percent), with 20 percent ages 65 or older—the life stage of the vast majority of care recipients (76 percent of recipients are ages 65 or older). These caregivers are typically providing care to a relative, namely a parent, who is 74.8 years old, on average, and who more often has multiple conditions (45 percent of these recipients have multiple conditions in 2020 vs. 38 percent in 2015). Most recipients ages 50 or older require care due to a long-term physical condition (66 percent), and more recipients are requiring care in 2020 due to an emotional or mental health problem (24 percent vs. 19 percent in 2015) or a memory problem (35 percent vs. 29 percent in 2015). Perhaps because of the increasing comorbidity of conditions among their recipients, caregivers of adults ages 50+ more often report difficulty coordinating care among their recipients' various providers and services (26 percent vs. 19 percent in 2015).

As in 2015, caregivers of older adults continue to handle multiple care tasks and activities in their role, helping, on average, with 1.7 Activities of Daily Living (ADLs) and 4.4 Instrumental Activities of Daily Living (IADLs), while 59 percent also help with medical/nursing tasks. An increasing proportion of caregivers of adults ages 50 or older report taking on the role of advocate for their care recipient with health care providers, community services, government agencies (56 percent vs. 51 percent in 2015). These caregivers are also providing care for longer—significantly more of them have provided care for five years or more (28 percent vs. 24 percent in 2015).

Not only are 50+ caregivers providing care for longer periods of time and for more conditions than in 2015, but they also are increasingly doing so while living together with their recipient in the same home: 37 percent of caregivers report their recipient lives in their household (up from 32 percent in 2015), while fewer report their recipient lives in their own home (46 percent down from 51 percent in 2015). When the recipient lives in the caregiver's home, the caregiver often takes on more tasks and hours of care, resulting in declining health and financial impacts.

Caregivers of those ages 50+ are not a uniform group; there are many variations in experience, including by the age of the care recipient. Over half of caregivers of recipients ages 50+ are providing care to someone age 75 or older (53 percent), with 25 percent caring for someone age 85 years or older (known as the oldest-old). Caregivers of the oldest-old are more likely to report their recipient is living alone<sup>4</sup> (41 percent) compared with those caring for someone age 50 to 74 years old (23 percent). When they do not live alone, oldest-old care recipients live either with their caregiver (27 percent) or in a facility (10 percent in an assisted living facility, 8 percent in an independent living or retirement community, and 5 percent in a nursing care or long-term care facility).

Three in 10 caregivers of adults ages 50+ are providing care completely alone, with no help from anyone else (paid or unpaid); however, caregivers of the oldest-old more often report “many hands”—that is, they are more likely to report the presence of other unpaid caregivers and of paid help. In contrast, caregivers of recipients ages 50 to 64 are often the sole care provider—either paid or unpaid—

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3 D. Redfoot, L. Feinberg, and Ari. 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>.

4 The percentage who live alone is calculated among those who do not live in a facility of some sort.

and report increased financial strain and worse health for caregivers. Caregivers of recipients ages 50 to 64 more often are providing care to a spouse or partner (19 percent) compared with those caring for adults ages 75+, perhaps helping explain both the sole care provider role and increased hours—and potentially pointing to a loss of a second income from a spouse or partner who cannot work.<sup>5</sup>

With complexity of care increasing and caregivers taking on more by caring for multiple people with multiple conditions, caregivers’ own health may suffer as a result. Caregivers’ health has been declining since 2015, with a decrease in those reporting their health as very good or excellent (42 percent vs. 48 percent in 2015). In addition, one in five caregivers of adults ages 50+ say that their role as a caregiver made their health worse (21 percent).

Caregiving can also ripple out and impact the financial security of caregivers: 42 percent of caregivers of an adult age 50+ have experienced a financial impact due to their role as a caregiver, with 31 percent having experienced two or more financial impacts. For example, 32 percent say caregiving has eroded their savings in some form, and 10 percent are experiencing the critical impact of being unable to afford basic expenses like food. Interestingly, caregivers seemingly downplay the financial repercussions of caregiving—two in three caregivers report low financial strain (65 percent rating a 1 or 2 on a 5-point scale) despite many of them experiencing these financial impacts. Although the data for this report were collected before the onset of COVID-19, the heightened uncertainty and skyrocketing joblessness of the pandemic reinforces that we need to be acutely aware of the implications the findings in this report may have for caregivers of adults ages 50+ who were already being pulled in many directions—at the cost of their own health and finances.

### III. Detailed Findings

#### A. PREVALENCE OF CAREGIVING

The prevalence<sup>6</sup> of caregiving for someone age 50 or older is up significantly—estimated at 16.8 percent compared to 14.3 percent in 2015 (see Figure 1). This means that one in six Americans are caregivers of someone 50 years old or older.

Using a 2019 estimate of 249,193,093 Americans ages 18 and older, the study estimates 41.8 million adults have been caregivers to an adult 50+ years in the 12 months prior to the study; this equates to an increase of 7.6 million caregivers of someone age 50 or older over the past five years and accounts for most of the increase in caregiving for adults generally.<sup>7</sup>

**Figure 1. Prevalence of Caregiving for an Adult Age 50+, 2020 and 2015**

	2020 Prevalence	Estimated Number of U.S. Adults Who Are Caregivers	2015 Prevalence	Estimated Number of U.S. Adults Who Are Caregivers
<b>Caregivers of recipients ages 50+</b>	16.8%↑	41.8 million	14.3%	34.2 million

↑↓ Significantly higher or lower than in 2015.

5 Further research is needed.

6 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.

7 The estimated prevalence of caregiving for an adult age 18 or older is 19.2 percent in 2020, or approximately 47.9 million Americans, up from 16.6 percent in 2015; this represents an increase of 8.2 million caregivers of adults who are age 18 or older. Over the same time period, the estimated number of caregivers of adults ages 50 or older increased by 7.6 million. For full detailed calculations of prevalence estimates, see National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2020*.

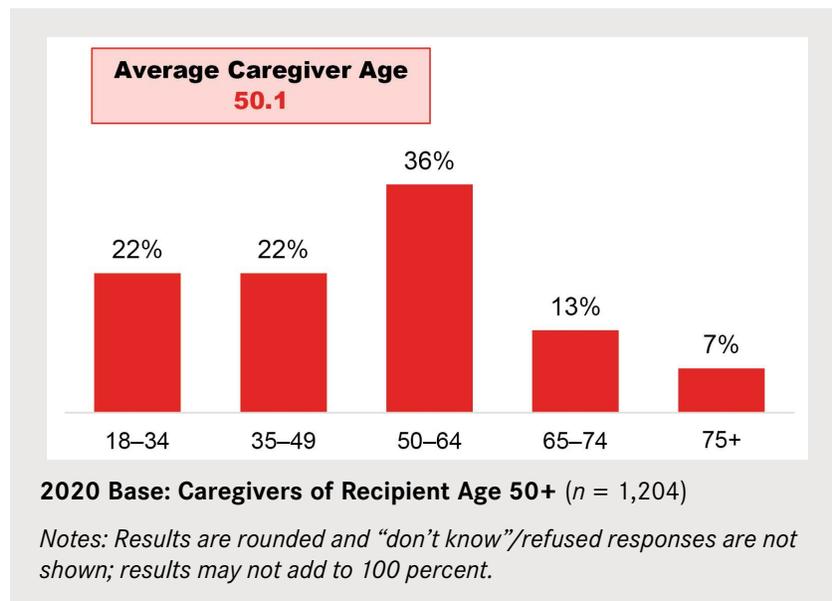
## B. BASICS OF THE CAREGIVING SITUATION

### WHO ARE CAREGIVERS OF SOMEONE 50+ YEARS OF AGE?

Six in 10 caregivers of someone age 50+ are women (61 percent), and 4 in 10 are men (39 percent).<sup>8</sup> Additionally, 6 in 10 caregivers of someone age 50+ report being non-Hispanic White (61 percent), 17 percent are Latinx/Hispanic, 14 percent are non-Hispanic African American or Black, 5 percent are Asian American<sup>9</sup> and Pacific Islander, and 3 percent are some other race/ethnicity, including multiracial. About 1 in 3 report having a household income of \$50,000 or less. For more detail on caregivers of someone 50+ demographics, see this report section M: Respondent profile.

On average, 50+ caregivers are 50.1 years old on average, with a median age of 52.0 years (see Figure 2), and 20 percent of caregivers are themselves 65 years of age or older.<sup>10</sup>

**Figure 2. Age of Caregivers of Someone Age 50+**



#### SUBGROUPS: 2020

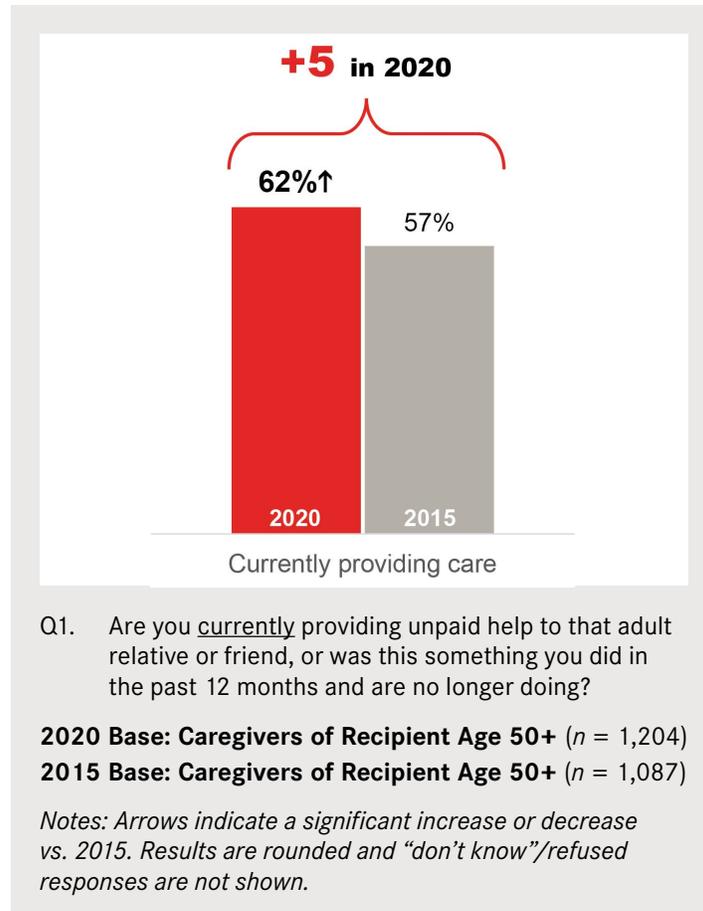
Caregivers of someone 50 or older reflect the changing demographics of the United States: White caregivers are the oldest (52.5 years, on average), older than either African American (49.0 years, on average) or Hispanic/Latinx (43.2 years, on average) caregivers.

- 8 Data about caregivers of adults generally (that is, those caring for an adult age 18 or older) are summarized in the report *Caregiving in the U.S. 2020*. Caregivers of adults ages 50 or older comprise the majority of caregivers of adults generally (age 18 or older) and as such, many findings presented in this paper echo findings from that broader look at caregivers of adults shown in *Caregiving in the U.S. 2020*.
- 9 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, the Indian subcontinent, and east Asia, as well as the Pacific Islands.
- 10 Six percent of caregivers are ages 75 to 84, and 1 percent are ages 85 or older.

## CURRENT VERSUS PAST CARE

Just over 6 in 10 caregivers of adults ages 50+ (62 percent; see Figure 3) are currently providing care to their 50+ recipient, up significantly compared with 2015 data (57 percent). Another 38 percent of caregivers have provided care to someone age 50+ in the past 12 months but are no longer doing so.

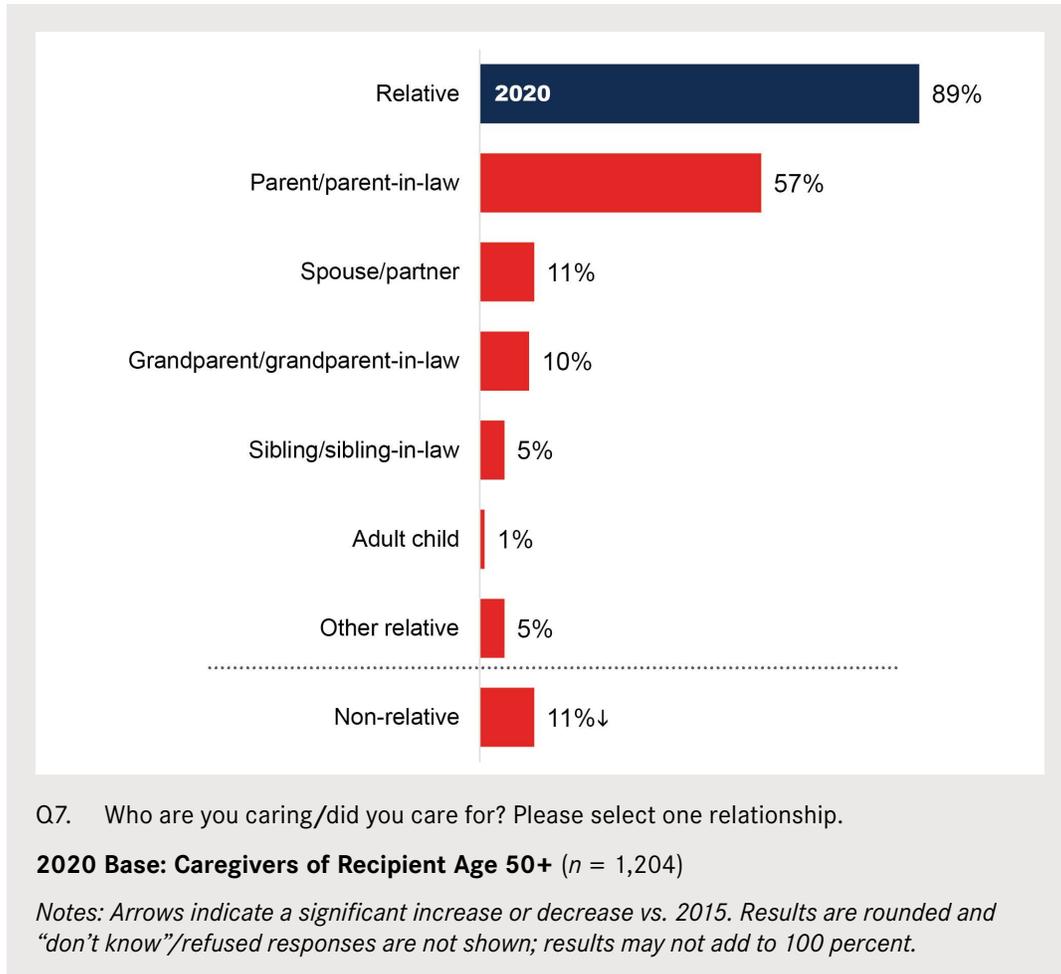
**Figure 3. Current Versus Past Care**



## CARE RECIPIENT RELATION TO CAREGIVER

The majority of 50+ caregivers take care of a relative (89 percent), while just 11 percent provide care to a friend, neighbor, or other non-relative which is down from 14 percent in 2015. Most are providing care to a parent (48 percent) or parent-in-law (9 percent), or for a spouse or partner (11 percent; see Figure 4).

**Figure 4. Care Recipient Relation to Caregiver**



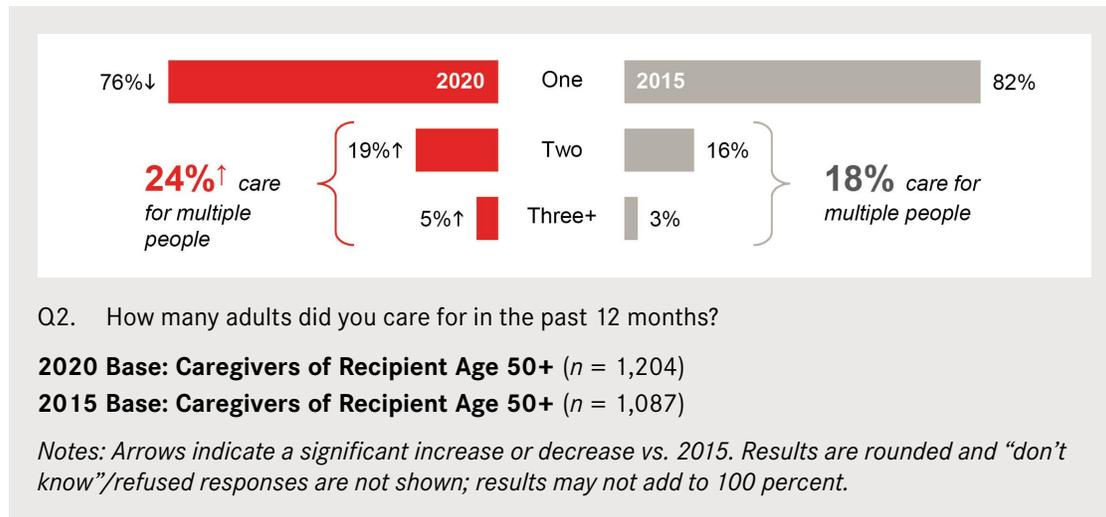
### SUBGROUPS: 2020

Asian American caregivers (62 percent) are more likely to be providing care to a parent than are White (49 percent), African American (39 percent), or Hispanic/Latinx (48 percent) caregivers.

## NUMBER OF CARE RECIPIENTS

Although most 50+ caregivers provide care to one person (76 percent), one in four (24 percent) care for two or more adults—up significantly from 2015 (18 percent; see Figure 5).

**Figure 5. Number of Care Recipients**



### CHANGE FOCUS: 2020 vs. 2015

Groups of 50+ caregivers show a significant increase in caregiving for two or more people in 2020 than in 2015, including white caregivers (24 percent vs. 17 percent in 2015) and caregivers whose recipient lives in a rural area (29 percent vs. 20 percent in 2015).

### SUBGROUPS: 2020

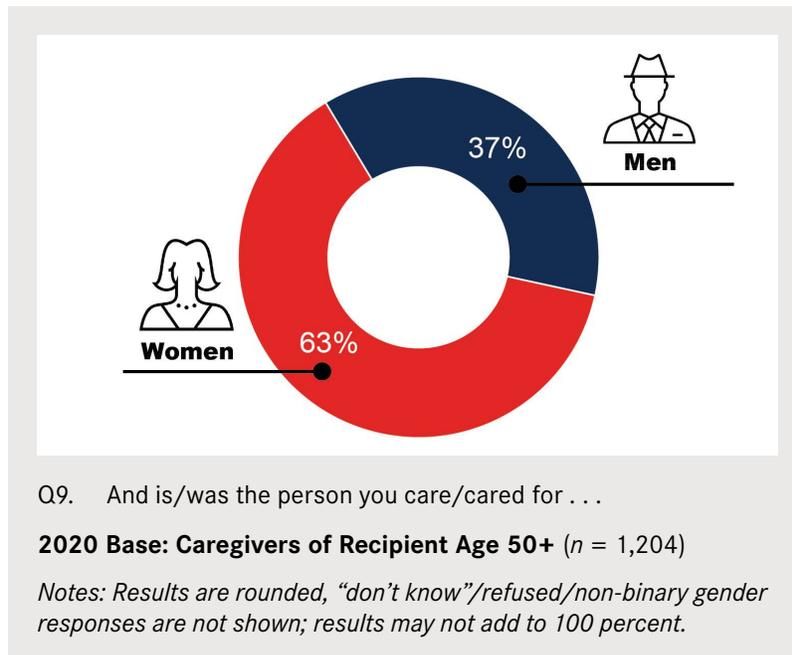
- Those providing care to a spouse/partner more often are solely focused on their spouse’s/partner’s care (92 percent provide care to just that spouse/partner), while those caregiving for a parent/parent-in-law, some other relative, or non-relatives more often provide care to multiple people (26 percent provide care for two or more people).
- Women (27 percent provide care for two or more people vs. 20 percent of men) and caregivers under the age of 65 (26 percent vs. 18 percent of caregivers ages 65+) more often provide care to multiple people.

Although some caregivers of older adults do provide care for multiple recipients, 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 who is age 50 or older.

## CARE RECIPIENT GENDER AND AGE

Similar to the gender profile of 50+ caregivers themselves, 2 out of 3 care recipients 50+ years of age are women (63 percent; see Figure 6) and about 4 in 10 are men (37 percent).

**Figure 6. Gender of Care Recipient Age 50+**



### CHANGE FOCUS: 2020 vs. 2015

Fifty percent of those providing care to someone 50 to 64 years old are providing care to a man; this is up from 32 percent in 2015.

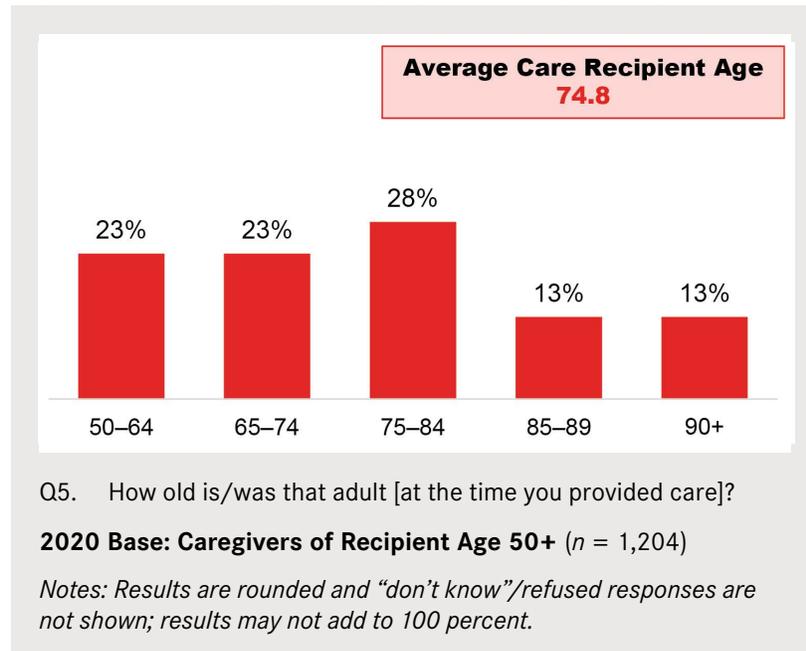
### SUBGROUPS: 2020

- Older care recipients are more often women: 49 percent of recipients ages 50 to 64 are women, rising to 64 percent among recipients ages 65 to 84 and 74 percent among those ages 85+.
- Caregivers of a spouse/partner are more often providing care to a man (60 percent) than those providing care to someone else (34 percent).<sup>11</sup>

<sup>11</sup> This encompasses those providing care to a parent/parent-in-law, some other relative, or a non-relative.

On average, the recipient is 74.8 years old, with a median age of 76.0 years old, as shown in Figure 7. Over half of caregivers of recipients ages 50+ are providing care for someone age 75 or older (53 percent), with 25 percent caring for someone age 85 years or older.

**Figure 7. Care Recipient Age (of Those Ages 50+)**



**SUBGROUPS: 2020**

White and Asian American caregivers of someone age 50+ are more often providing care to someone older (76.2 and 76.6 years old, on average, respectively) than African American (72.1, on average) or Hispanic/Latinx (72.0, on average) caregivers.

## CAREGIVER AGE, CARE RECIPIENT AGE, AND RELATIONSHIP

It is important to note that older caregivers tend to be providing care to someone similar in age to themselves, usually a spouse/partner or a non-relative (like a friend or neighbor); younger caregivers tend to provide care to someone older, more often a parent or grandparent (Figure 8).

**Figure 8. Age and Relationship of Care Recipient by Caregiver Age**

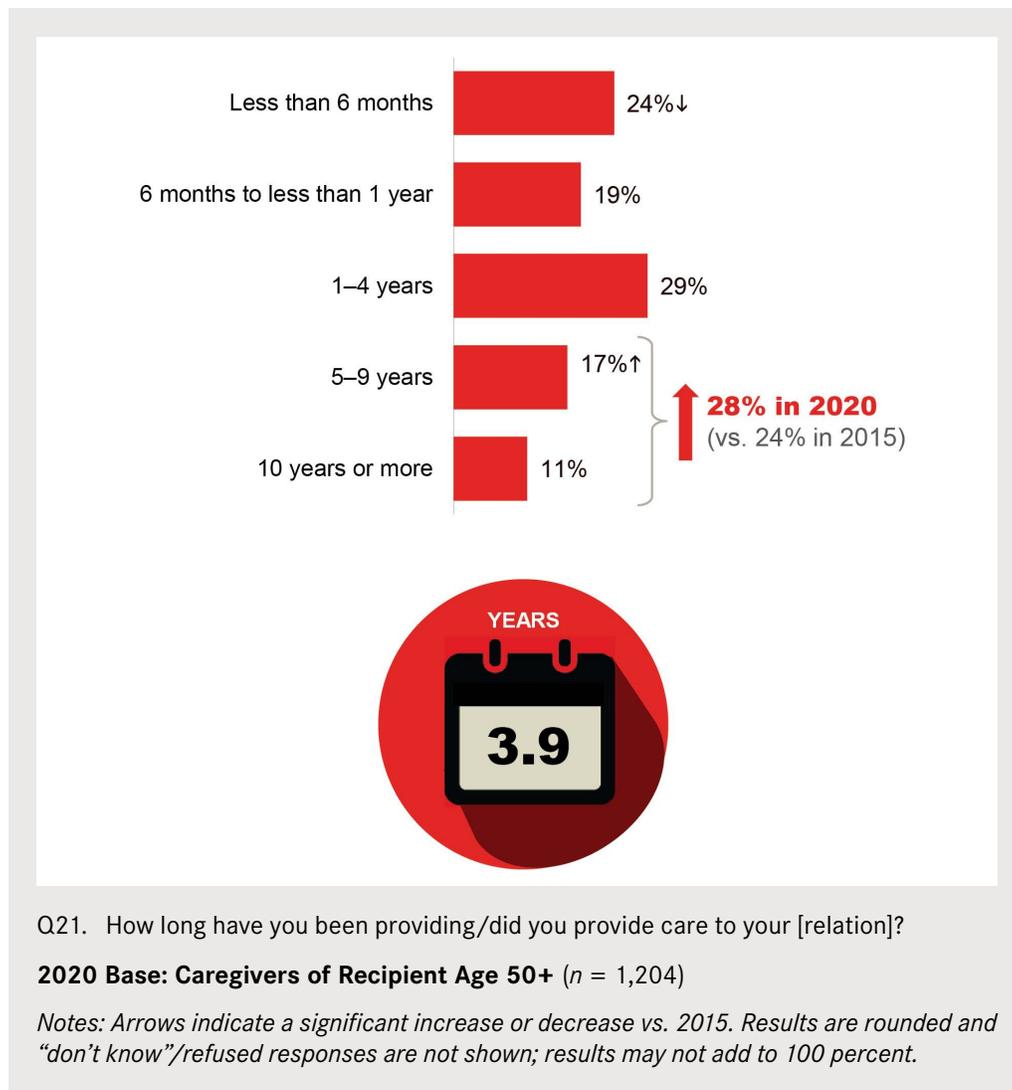
	Caregiver Age			
	18-49 (n = 448) A	50-64 (n = 488) B	65-74 (n = 199) C	75+ (n = 223) D
<b>Average Care Recipient Age</b>	69.4	78.9 <sup>A</sup>	78.7 <sup>A</sup>	80.3 <sup>A</sup>
<b>Recipient age 50-74</b>	68% <sup>BCD</sup>	26%	42% <sup>BD</sup>	22%
<b>Recipient age 75-84</b>	21%	37% <sup>AC</sup>	16%	43% <sup>AC</sup>
<b>Recipient age 85-89</b>	6%	20% <sup>AC</sup>	14% <sup>A</sup>	15% <sup>A</sup>
<b>Recipient age 90+</b>	4%	16% <sup>A</sup>	29% <sup>AB</sup>	21% <sup>A</sup>
<b>Relationship</b>				
<b>Parent/parent-in-law</b>	62% <sup>CD</sup>	67% <sup>CD</sup>	37% <sup>D</sup>	8%
<b>Spouse/partner</b>	3%	11% <sup>A</sup>	22% <sup>AB</sup>	43% <sup>ABC</sup>
<b>Grandparent/grandparent-in-law</b>	21% <sup>BCD</sup>	2% <sup>CD</sup>	--	--
<b>Sibling/sibling-in-Law</b>	1%	5% <sup>A</sup>	13% <sup>AB</sup>	10% <sup>A</sup>
<b>Other relatives</b>	5%	5%	11% <sup>AB</sup>	16% <sup>AB</sup>
<b>Non-relatives</b>	8%	10%	16% <sup>AB</sup>	24% <sup>AB</sup>

*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.*

## DURATION OF CARE FOR RECIPIENT

The average duration of caregiving is 3.9 years. Nearly 3 out of 10 caregivers of someone age 50+ have provided care for 5 years or longer (28 percent), significantly more than in 2015 (24 percent; see Figure 9). This difference paints an even more complicated picture of caregiving when taking into account the increase in prevalence of caregiving for adults ages 50+: not only are an increasing number of Americans providing care to older adults, more of them are doing so for a long period of time.

**Figure 9. Duration of Care**



**CHANGE FOCUS: 2020 vs. 2015**

29 percent of caregivers of recipients living in an urban or suburban setting report providing care for five years or longer (up from 24 percent in 2015).

**SUBGROUPS: 2020**

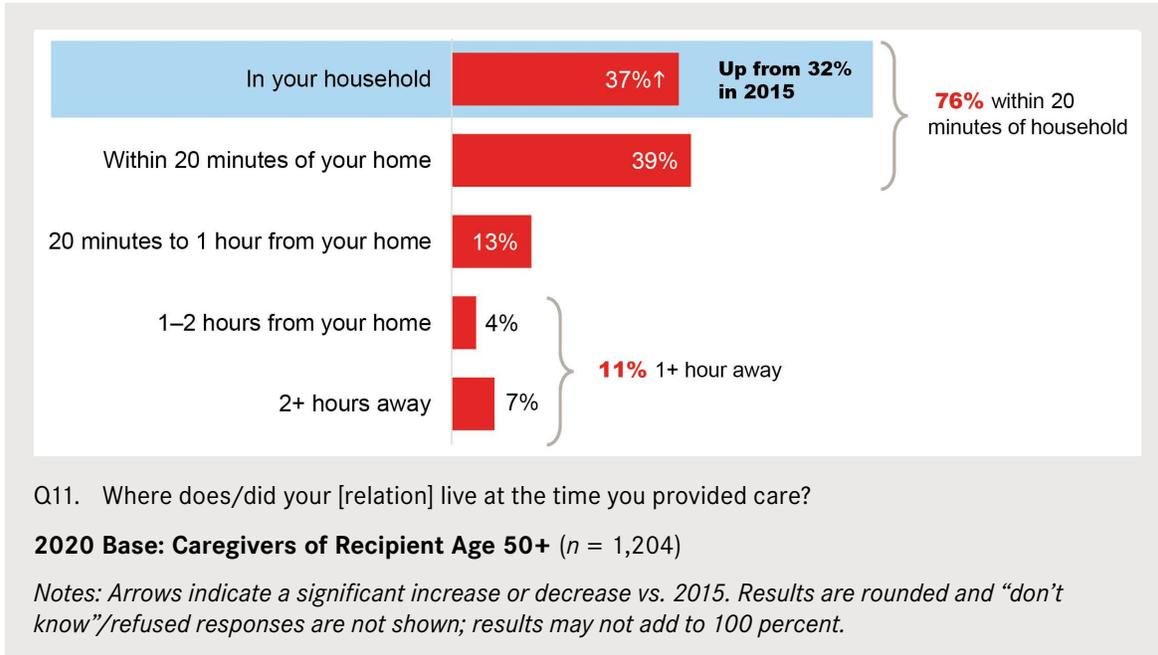
- Caregivers of older recipients more often provide care longer. Among those caring for someone age 50 to 74, 22 percent have provided care for five years or longer; this rises to 30 percent among those caring for someone age 75 to 84 and 36 percent among those providing care to someone age 85+.
- Caregivers of a spouse/partner (4.8 years, on average) or a parent/parent-in-law (4.0 years, on average) have been caring longer than those caring for a non-relative (2.4 years, on average).

## C. CARE RECIPIENT LIVING SITUATION

### CAREGIVER DISTANCE FROM CARE RECIPIENT

Most 50+ caregivers live within 20 minutes of their care recipient (76 percent; see Figure 10).

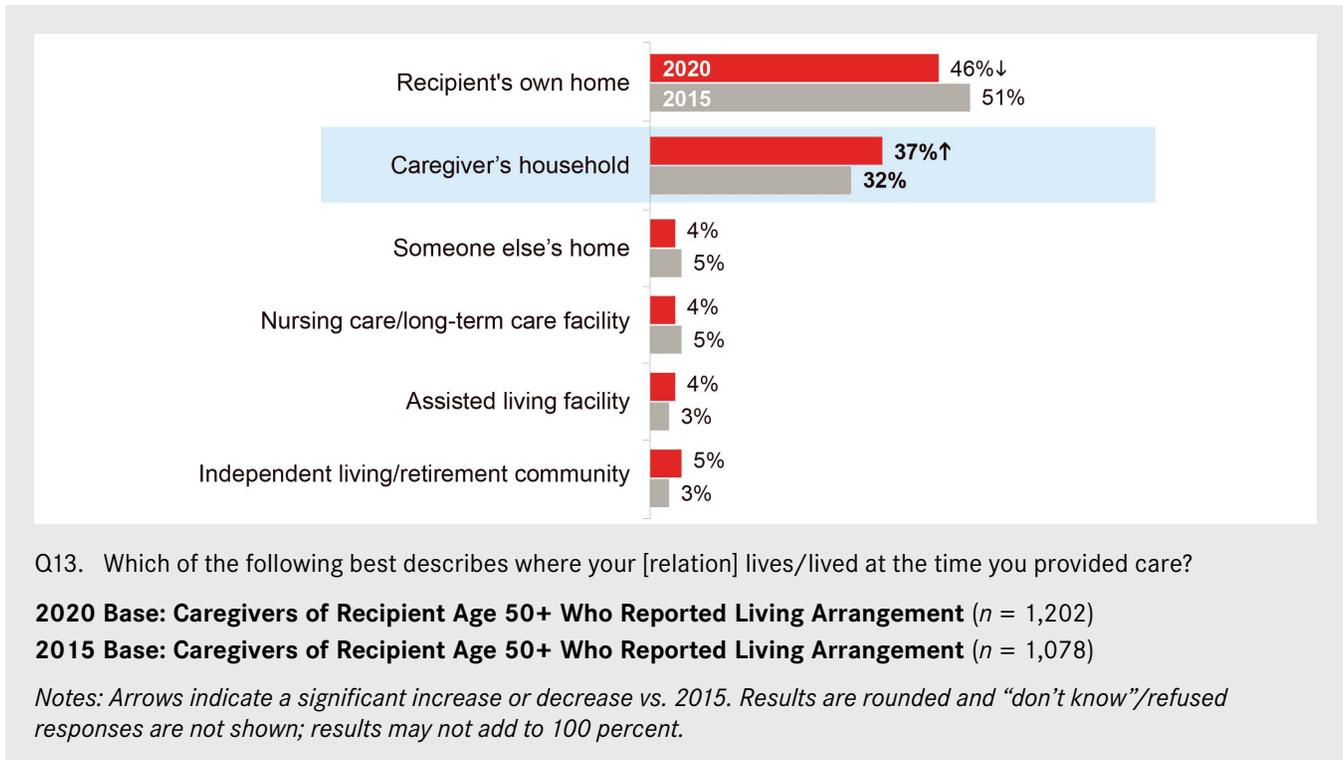
**Figure 10. Caregiver Distance from Care Recipient**



## WHERE CARE RECIPIENT LIVES

A shift in recipient residence has occurred over the past five years: more caregivers report their recipient age 50+ lives with them, the caregiver, instead of living in their (the recipient's) own home. Thirty-seven percent say their recipient lives in the caregiver's household, significantly more than in 2015 (32 percent) while less than half of caregivers report their recipient lives in the recipient's own home (46 percent; see Figure 11), significantly fewer than in 2015 (51 percent). Although they make up the minority, 4 percent of recipients live in someone else's home (not the caregiver's), 5 percent live in an independent living or retirement community, 4 percent live in an assisted living facility, and 4 percent live in a nursing care or long-term care facility.

**Figure 11. Where Care Recipient Age 50+ Lives**



### SUBGROUPS: 2020

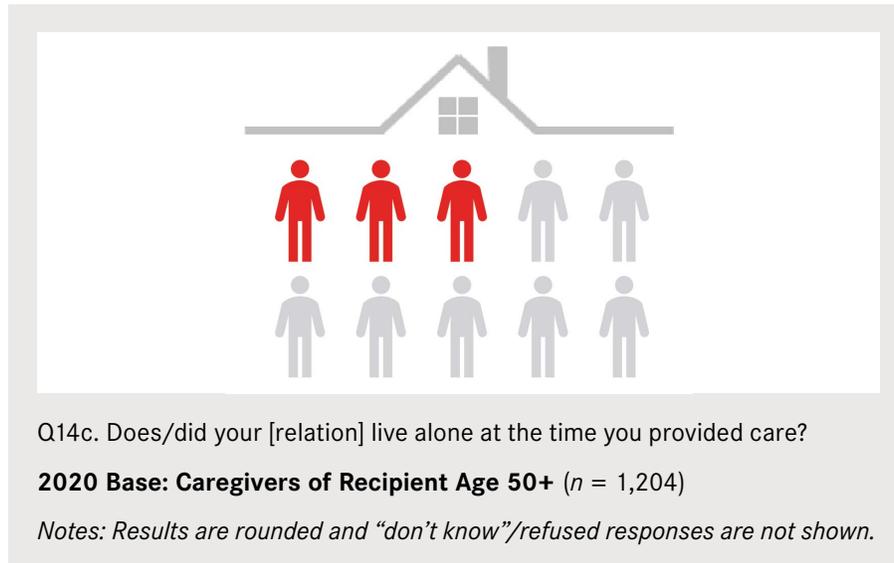
- Caregivers of color are more likely to report their recipient lives with them (42 percent African American, 46 percent Hispanic/Latinx, and 51 percent Asian American) than are White caregivers (33 percent).<sup>12</sup>
- As might be expected, most caregivers of a spouse/partner live with their care recipient (93 percent). Those providing care to a parent/parent-in-law are more likely to say their recipient lives with them (34 percent), compared to 26 percent of those providing care to other relatives and 15 percent for non-relatives.
- Caregivers with an annual household income of less than \$50,000 are more likely to have their recipient living in their home with them (44 percent vs. 33 percent of caregivers with \$50,000 or more), while those with \$50,000 or more in annual household income more often report their care recipient lives in a facility of some sort (16 percent vs. 7 percent of caregivers with less than \$50,000 in annual household income). Following a similar pattern, those caregivers experiencing moderate-to-high financial strain are more likely to have their recipient living with them in their home (46 percent vs. 31 percent of those with low financial strain).

12 *Living alone* refers specifically to those recipients who live by themselves—excluding those who live in an assisted living or skilled nursing facility.

## CARE RECIPIENT LIVING ALONE

Three in 10 care recipients live alone (29 percent; see Figure 12).<sup>13</sup>

**Figure 12. Care Recipient Age 50+ Living Alone**



Living situation seems to depend on the health and functional needs of the care recipient—with the oldest-old (those 85 years or older) care recipients more often living in a facility than their younger counterparts (see Figure 13). Younger recipients ages 50 to 64 tend to live in the caregiver’s home, while those ages 65 to 84 more often live in their own home. It is important to note that, among those not living in a facility, older recipients more often live alone (15 percent among recipients ages 50 to 64, rising to 35 percent among those ages 65 to 84 and up to 41 percent among those age 85+). Relatedly, caregivers of those living with Alzheimer’s or dementia more often report their care recipient lives in a facility of some sort (19 percent vs. 10 percent of those recipients who do not have these conditions).

**Figure 13. Care Recipient Living Situation by Care Recipient Age**

	Care Recipient Age			
	50–64 (n = 254) A	65–74 (n = 274) B	75–84 (n = 334) C	85+ (n = 336) D
Lives with caregiver	58% <sup>BCD</sup>	35% <sup>D</sup>	29%	27%
Lives in recipient’s own household	32%	55% <sup>AD</sup>	51% <sup>A</sup>	44% <sup>A</sup>
Lives in someone else’s household	5%	2%	4%	5% <sup>B</sup>
Lives in independent living or retirement community	1%	4% <sup>A</sup>	6% <sup>A</sup>	8% <sup>AB</sup>
Lives in assisted living facility	1%	1%	4%	10% <sup>ABC</sup>
Lives in nursing care or long-term care facility	2%	3%	5%	5% <sup>A</sup>

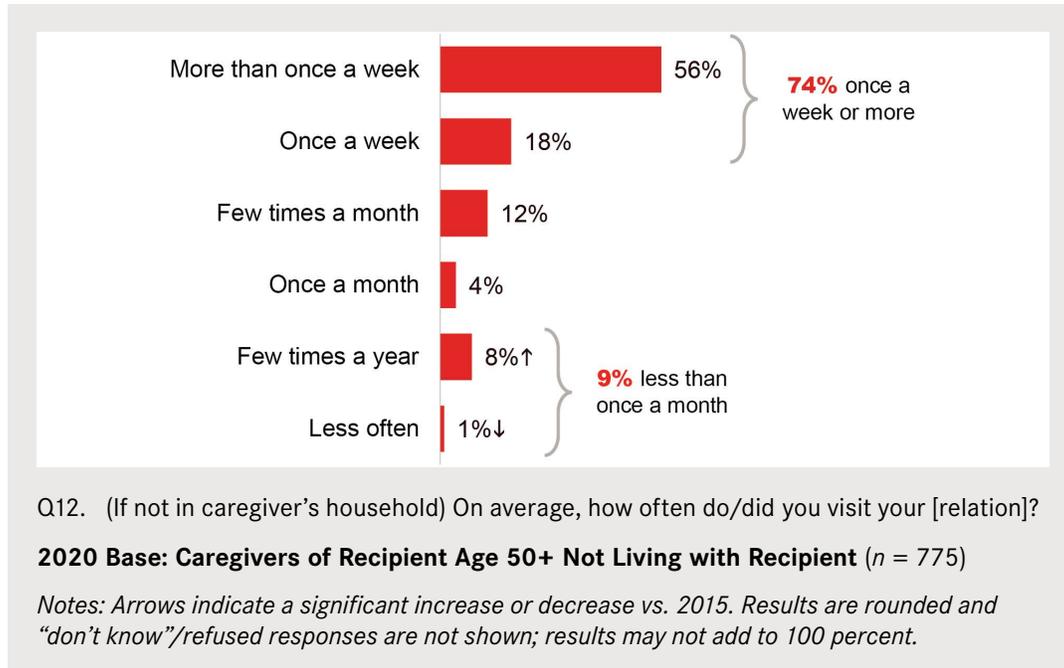
*Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded, and “don’t know”/refused responses are not shown; results may not add to 100 percent.*

<sup>13</sup> This is among all care recipients, where those who live in a care facility are counted as not living alone. If the data are rebased to look at only those who are not in an assisted living or skilled nursing facility, this amount rises to 31 percent who live alone.

## FREQUENCY OF VISITS

Of the 50+ 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 14), including more than half who say they visit multiple times a week (56 percent).

**Figure 14. Frequency of Caregiver Visits**



### SUBGROUPS: 2020

- Among those recipients and caregivers not living together, White (73 percent), African American (75 percent), and Hispanic/Latinx (81 percent) caregivers are more likely to say they visit their recipient once a week or more often (vs. 58 percent of Asian American caregivers).
- Caregivers with less than \$75,000 in annual household income more often visit their recipient once a week or more (80 percent vs. 69 percent of those with \$75,000 or higher household income).
- Caregivers who are 65 years of age or older are more likely to visit their recipient at least once a week or more often (81 percent vs. 72 percent of younger caregivers).<sup>14</sup>

14 There is no significant relationship between a caregiver working for pay at a job or career and frequency of visiting the care recipient to explain either the income or age differences in frequency of visitation.

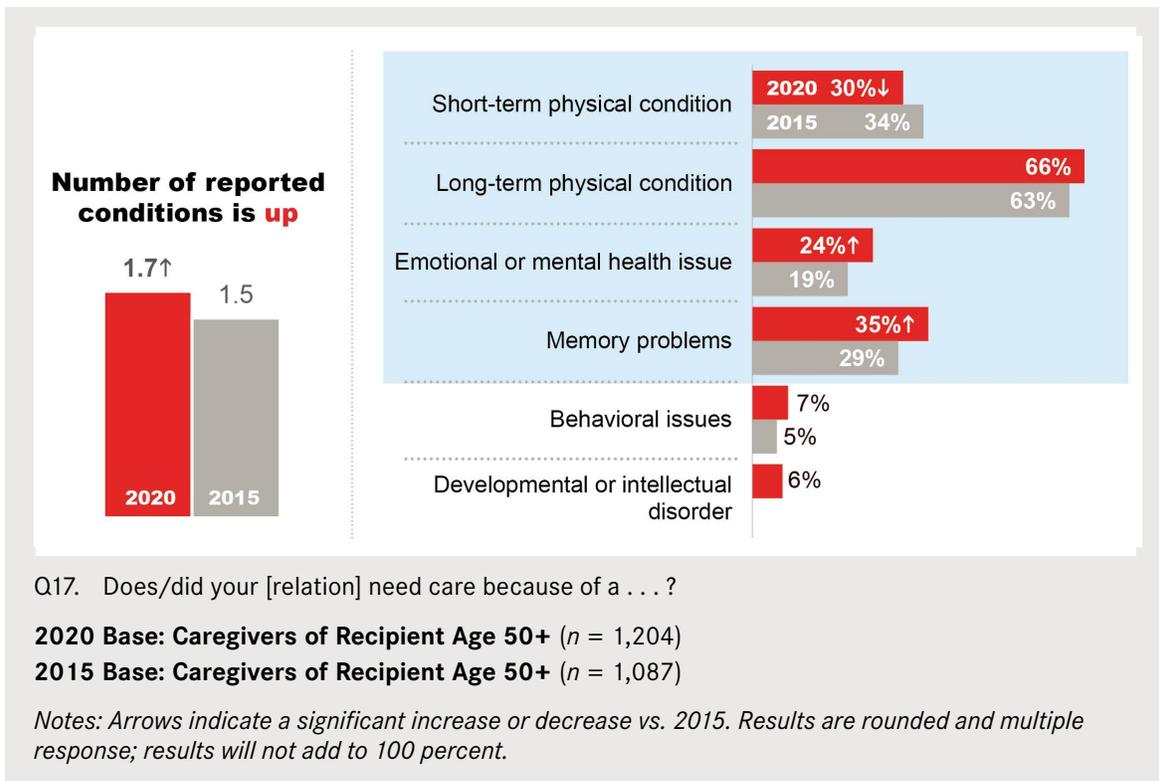
## D. CARE RECIPIENT'S CONDITION

### TYPES OF CARE RECIPIENT CONDITIONS

Caregivers in 2020 report their care recipients ages 50+ have greater health and functional needs than was reported in 2015 (see Figure 15). Two in three caregivers care for an adult age 50+ with a long-term physical condition (66 percent). Another 30 percent say their recipient has a short-term physical condition—significantly less commonly mentioned than in 2015 (34 percent).

More than one in three caregivers indicate their recipient has a memory problem (35 percent), up significantly from 2015 data (29 percent). In addition, caregivers of adults ages 50+ more often mention their recipient having emotional or mental health issues (24 percent) than did respondents in 2015 (19 percent). Smaller proportions indicate their care recipient has behavioral issues (7 percent) or a developmental or intellectual issue (6 percent).

**Figure 15. Types of Care Recipient Conditions for Those Ages 50+**



## COMORBIDITY OF CONDITIONS

A greater proportion of caregivers of adults ages 50+ report their recipient is dealing with multiple condition categories, with 45 percent of caregivers reporting their recipient has 2 or more conditions, compared to with 38 percent in 2015. On average, care recipients have 1.7 conditions, significantly higher than the 1.5 reported in 2015 (see data presented earlier, in Figure 15). This increasing comorbidity<sup>15</sup> 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 older adult recipients who may have increasingly complex medical or support needs.

### CHANGE FOCUS: 2020 vs. 2015

Comorbidity of conditions, as reported by caregivers, seems to be increasing for many recipients<sup>16</sup> of adults ages 50+, and is mostly driven by increases in reports of emotional or mental health issues and memory problems.<sup>17</sup>

- Caregivers who have provided care for five years or longer report their recipient has more conditions, on average, in 2020 (1.9) than in 2015 (1.6).
- Caregivers of recipients ages 50 to 64 report 1.7 conditions, higher than 2015 (1.5); more often they report the presence of an emotional or mental health problem (35 percent vs. 26 percent in 2015) or a behavioral issue (11 percent vs. 3 percent).
- Younger caregivers—those ages 18 to 49—report their 50+ recipient has, on average, 1.8 conditions (vs. 1.5 in 2015), driven by a slight increase in most conditions and a significant increase in reports of memory problems (31 percent vs. 24 percent in 2015).
- Caregivers with annual household incomes less than \$30,000 report their recipient has more conditions (1.9 vs. 1.6 in 2015),<sup>18</sup> with increases in emotional or mental health issues (37 percent vs. 22 percent in 2015) and behavioral issues (11 percent vs. 6 percent).

15 Comorbidity is when a person has more than one health issue or condition at the same time. These conditions are self-reports by caregivers about what they perceive to be their recipient's challenge or illness for which their recipient needs care.

16 Comorbidity is increasing regardless of caregiver gender, where the recipient lives, and living environment—specifically, for both men and women caregivers; for caregivers who live with their recipient and those who do not; and for those caring for someone living in a rural area and those who do not.

17 For each of these groups of caregivers, the recipients are of comparable age as they were in 2015, on average. This suggests that the care needs are becoming increasingly multifaceted and/or that caregivers are more clearly identifying the range of needs their recipient age 50+ may have. Further research is needed.

18 White (1.6 vs. 1.5 in 2015) and Hispanic/Latinx caregivers (1.8 vs. 1.5 in 2015) also report significant increases in the number of conditions their recipient has; however, examining these changes by income reveals this change is mostly among those caregivers with less than \$50,000 in annual household income.

It is important to note that the type of condition varies by the care recipient's age, such that older recipients are most likely to have a memory problem or a long-term health condition, while emotional or mental health issues or short-term physical conditions are more common among the youngest adult recipients, as shown in Figure 16.

**Figure 16. Types of Care Recipient Conditions by Care Recipient Age**

	Care Recipient Age			
	50-64 (n = 256) A	65-74 (n = 274) B	75-84 (n = 334) C	85+ (n = 336) D
Long-term physical condition	57%	66% <sup>A</sup>	68% <sup>A</sup>	72% <sup>A</sup>
Short-term physical condition	40% <sup>CD</sup>	36% <sup>CD</sup>	25%	20%
Emotional or mental health problem	35% <sup>CD</sup>	28% <sup>CD</sup>	18%	18%
Behavioral issue	11% <sup>CD</sup>	7%	4%	4%
Memory problem	19%	25%	44% <sup>AB</sup>	48% <sup>AB</sup>
Developmental or intellectual disorder or delay	9% <sup>C</sup>	5%	4%	5%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and multiple response; results will not add to 100 percent.

#### SUBGROUPS: 2020

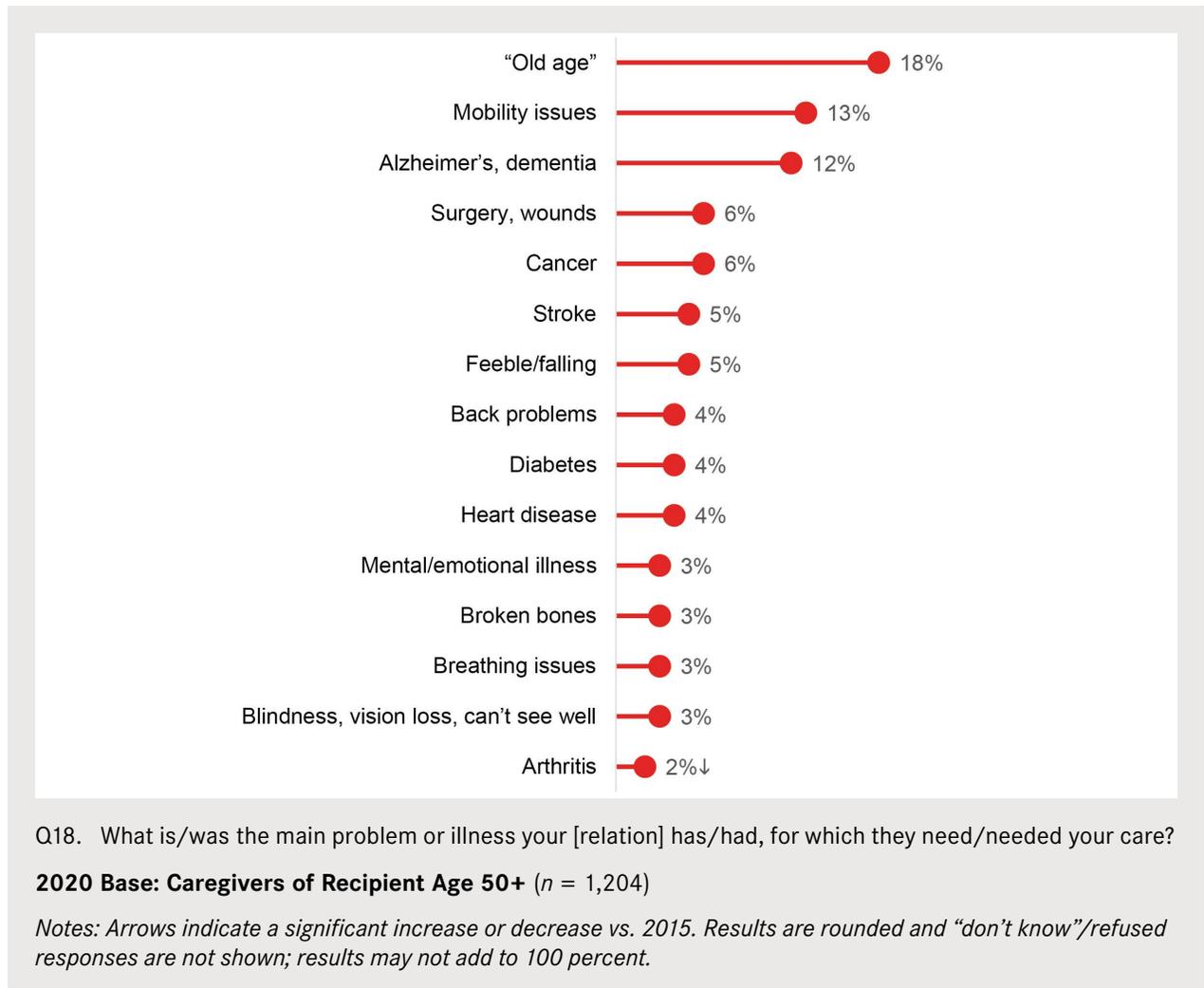
- Those providing care for a year or longer are more likely to be dealing with multiple conditions (53 percent vs. 35 percent of those who have been caregiving less than a year). Caregivers who have been in their role a year or longer are more likely providing care due to a long-term physical condition (80 percent vs. 47 percent when caregiving less than a year) and memory problems (41 percent vs. 26 percent).
- Hispanic/Latinx (40 percent) and Asian American (35 percent) caregivers more often report their recipient has a short-term physical condition than do African American caregivers (23 percent). Asian American caregivers (13 percent) are also more likely than either White (6 percent) or African American (5 percent) caregivers to report their recipient has a behavioral issue.

## CARE RECIPIENT'S MAIN CHALLENGE OR ILLNESS

Caregivers of those ages 50+ were asked to identify their recipient's main challenge or illness for which they require care. The three most common challenge or illnesses for care recipients ages 50+ cited by caregivers include "old age" (18 percent), mobility issues (13 percent), and Alzheimer's or dementia (12 percent; see Figure 17). Note that these perceptions may not mirror independent health statistics.<sup>19</sup>

<sup>19</sup> These are self-reports by caregivers about what they perceive to be the challenge or illness for which their recipient needs unpaid care.

**Figure 17. Care Recipient's Main Problem or Illness**



## PRESENCE OF ALZHEIMER’S OR DEMENTIA

Although Alzheimer’s or dementia is cited by only 12 percent of caregivers as the main condition for which the care recipient needs help, 28 percent of caregivers say their recipient has Alzheimer’s or dementia, comparable to the 24 percent who reported the presence of Alzheimer’s or dementia in 2015.

### CHANGE FOCUS: 2020 vs. 2015

- Caregivers of a parent/parent-in-law who is 50 or older more often report their parent/parent-in-law has Alzheimer’s or dementia (30 percent) than in 2015 (24 percent).
- Caregivers ages 18 to 49 more often say their care recipient age 50+ has Alzheimer’s or dementia (25 percent vs. 18 percent in 2015).

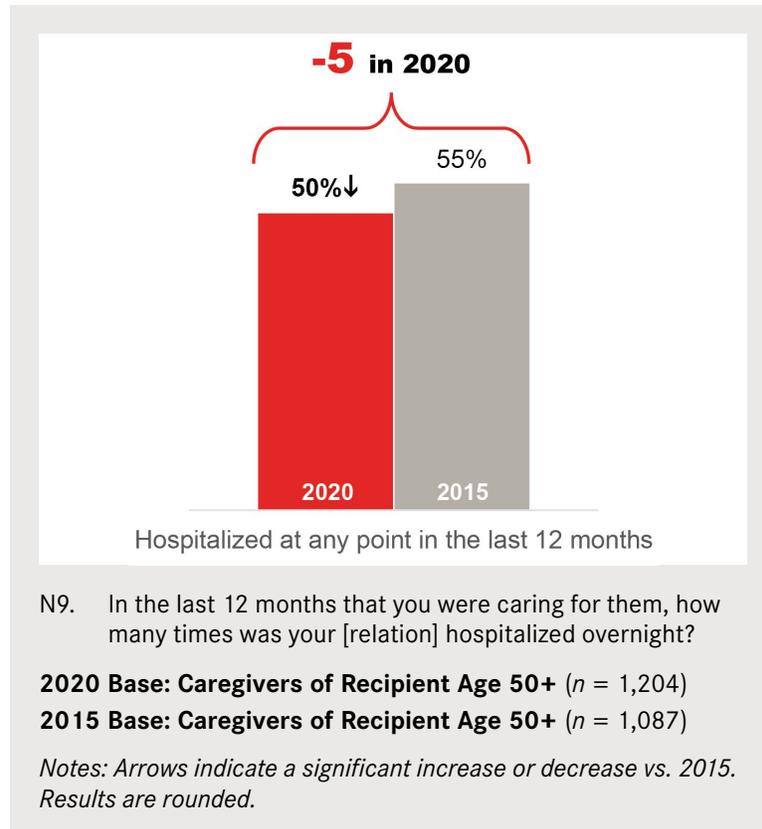
### SUBGROUPS: 2020

Caregivers of older recipients more often report the presence of Alzheimer’s or dementia (32 percent among caregivers of someone age 65+ vs. 12 percent when the recipient is age 50 to 64).

## FREQUENCY OF CARE RECIPIENT HOSPITALIZATION

Despite the increasing comorbidity of conditions, fewer caregivers of adults ages 50+ report their care recipient was hospitalized at least once over the past 12 months (50 percent; see Figure 18), down from 55 percent in 2015.<sup>20</sup>

**Figure 18. Frequency of Care Recipient Hospitalization**



### CHANGE FOCUS: 2020 vs. 2015

Fewer White caregivers reported that their care recipient was hospitalized in the past 12 months (50 percent vs. 56 percent in 2015).

### SUBGROUPS: 2020

Those providing care to someone living with Alzheimer's or dementia more often report their recipient age 50+ has been hospitalized overnight in the past year (54 percent vs. 47 percent of those caring for someone without Alzheimer's or dementia).

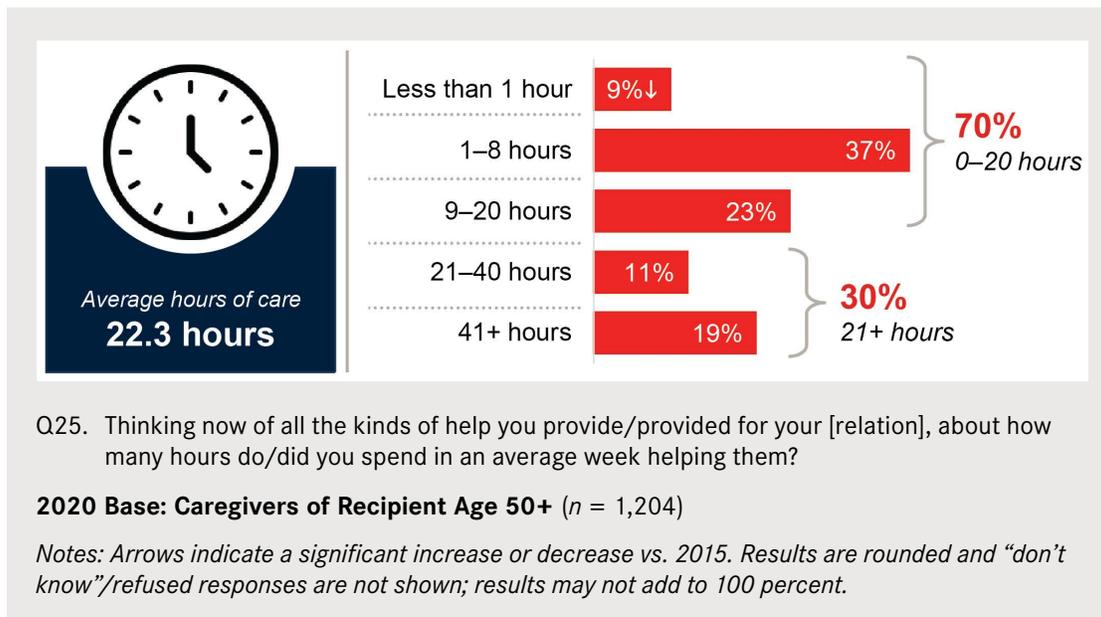
20 This trend may be due to trends toward increasing home-based care or to an avoidance of care due to the rising cost of health care and hospitalization; however, more research is needed. For data on the rising cost of hospitalization, see Moore BJ (IBM Watson Health), Liang L (AHRQ). Medicare Advantage Versus the Traditional Medicare Program: Costs of Inpatient Stays, 2009-2017. HCUP Statistical Brief #262. August 2020. Agency for Healthcare Research and Quality, Rockville, MD. [www.hcup-us.ahrq.gov/reports/statbriefs/sb262-Medicare-Advantage-Costs-2009-2017.pdf](http://www.hcup-us.ahrq.gov/reports/statbriefs/sb262-Medicare-Advantage-Costs-2009-2017.pdf); or Liang L (AHRQ), Moore B (IBM Watson Health), Soni A (AHRQ). National Inpatient Hospital Costs: The Most Expensive Conditions by Payer, 2017. HCUP Statistical Brief #261. Month 2020. Agency for Healthcare Research and Quality, Rockville, MD. [www.hcup-us.ahrq.gov/reports/statbriefs/sb261-Most-Expensive-Hospital-Conditions-2017.pdf](http://www.hcup-us.ahrq.gov/reports/statbriefs/sb261-Most-Expensive-Hospital-Conditions-2017.pdf).

## E. CAREGIVING ACTIVITIES AND LEVEL OF CARE

### HOURS OF CARE PROVIDED

On average, 50+ caregivers spend 22.3 hours per week providing care (see Figure 19), with a median of 10 hours.<sup>21</sup> Three in 10 provide care for 21 hours or more each week (30 percent), and 19 percent perform 41 or more hours of care each week.

**Figure 19. Hours of Care Provided for Care Recipients Ages 50+**



#### SUBGROUPS: 2020

- Caregivers with annual household incomes less than \$50,000 provide 26.4 hours of care a week—more than those with annual household incomes of \$50,000 or more (20.1 hours, on average).<sup>22</sup>
- As might be expected, caregivers in demanding care situations provide more hours of care weekly, including:
  - Caregivers whose recipient lives with them (35.7 hours vs. 14.5 hours for those not living with their recipient); and
  - Those providing care to a spouse/partner<sup>23</sup> (35.3 hours vs. 20.9 hours when providing care to a parent/parent-in-law, 24.0 hours for another relative, and 12.1 hours for a non-relative).

Caregivers of color are more likely than White caregivers to provide 21 or more hours of care weekly to their age 50+ recipients and report higher average hours of care (see Figure 20).

21 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 in the full report *Caregiving in the U.S. 2020*.

22 A similar pattern emerges by education as well.

23 Those caring for a spouse often are the primary caregiver and living with their care recipient.

**Figure 20. Hours of Care Provided Weekly by Caregiver Race/Ethnicity**

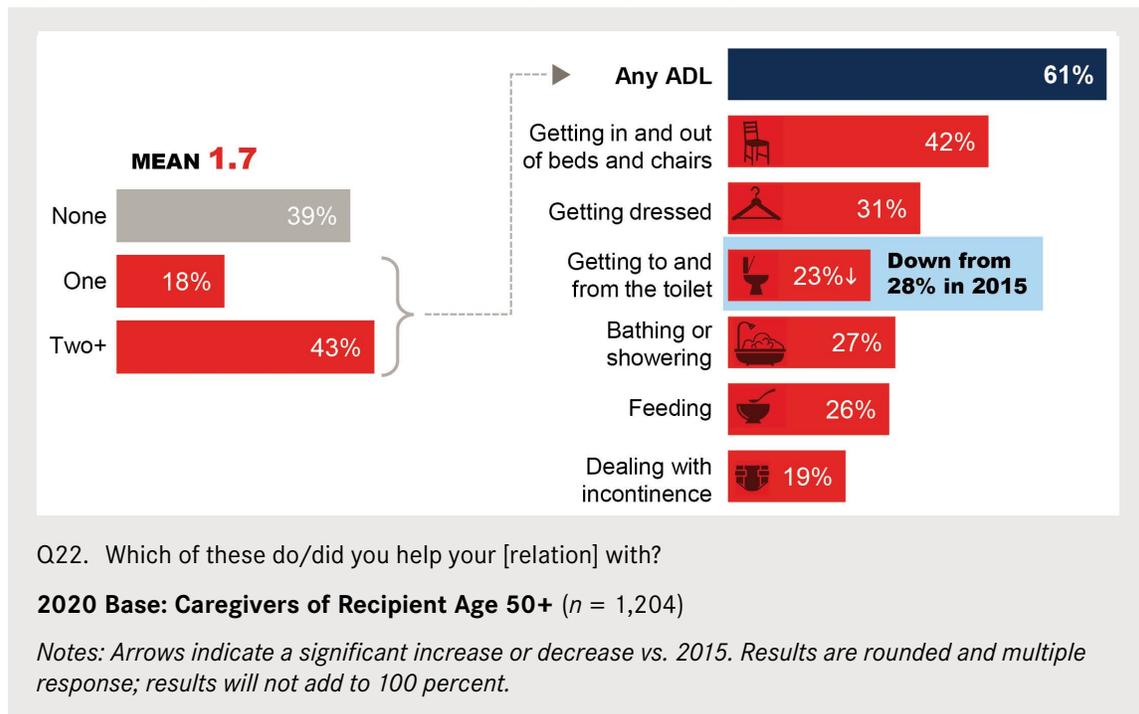
	White (n = 698) A	African American (n = 162) B	Hispanic (n = 178) C	Asian American (n = 177) D
<b>20 or fewer hours</b>	74% <sup>BD</sup>	55%	66% <sup>B</sup>	62%
<b>21 or more hours</b>	25%	45% <sup>AC</sup>	34% <sup>A</sup>	34% <sup>A</sup>
<b>Average hours per week</b>	19.7	29.9 <sup>A</sup>	24.2 <sup>A</sup>	26.1 <sup>A</sup>

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.

## HELP WITH ACTIVITIES OF DAILY LIVING (ADLs)

Six in 10 caregivers of someone age 50+ help their care recipient with at least 1 Activity of Daily Living (ADL)<sup>24</sup>, with 43 percent helping with 2 or more ADLs (see Figure 21). On average, caregivers help with 1.7 of the 6 ADLs. Most commonly, caregivers help their recipient get in and out of beds and chairs (42 percent).

**Figure 21. Help with Activities of Daily Living (ADLs)**



### CHANGE FOCUS: 2020 vs. 2015

A few groups of caregivers of adults ages 50+ are more likely than caregivers in 2015 to report helping with at least one ADL, including:

- African American caregivers (73 percent vs. 59 percent in 2015); and
- Long-term caregivers (58 percent of those providing care for five years or longer vs. 48 percent in 2015).

24 Activities of daily living (ADLs) include getting in and out of beds and chairs, getting dressed, getting to and from the toilet, bathing or showering, feeding, and dealing with incontinence.

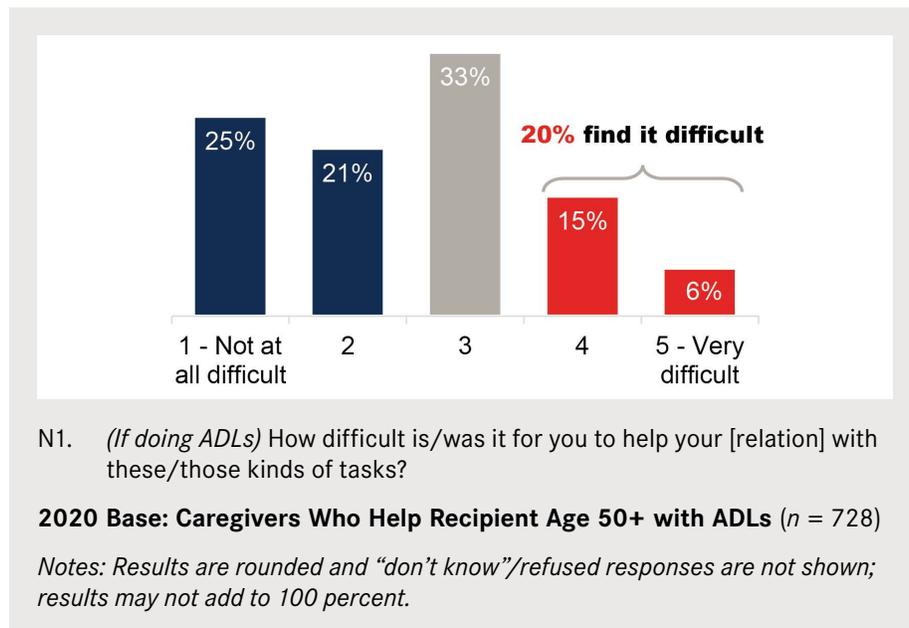
## SUBGROUPS: 2020

- Higher-hour caregivers help with 2.9 ADLs, on average, and more often help with each of the 6 ADLs than do lower-hour caregivers (1.2 ADLs, on average). Similarly, caregivers whose recipient lives with them in their household perform more ADLs (2.0 vs. 1.5 among caregivers not living with their recipient).<sup>25</sup>
- Those providing care to someone living with Alzheimer’s or dementia help with 2.2 ADLs, on average—significantly more than caregivers of someone without Alzheimer’s or dementia (1.4).
- African American<sup>26</sup> and Hispanic/Latinx caregivers help with an average of 2.2 and 1.9 ADLs, respectively—significantly more than White caregivers (1.5 ADLs) caregivers.

## DIFFICULTY WITH ACTIVITIES OF DAILY LIVING (ADLs)

Among 50+ caregivers performing ADLs, one in five indicates it is difficult to assist their recipient with these tasks (20 percent rating 4 or 5 on a 5-point scale; see Figure 22).

**Figure 22. Difficulty of Helping with ADLs**



## SUBGROUPS: 2020

- Caregivers for an adult age 50 or older living with Alzheimer’s or dementia (32 percent) are more likely to say helping with ADLs is difficult (vs. 15 percent of those who provide care to someone without Alzheimer’s).
- Those who provide care to a parent/parent-in-law (24 percent) are more likely to find it difficult to help with ADLs than are those providing care to a spouse/partner (14 percent).

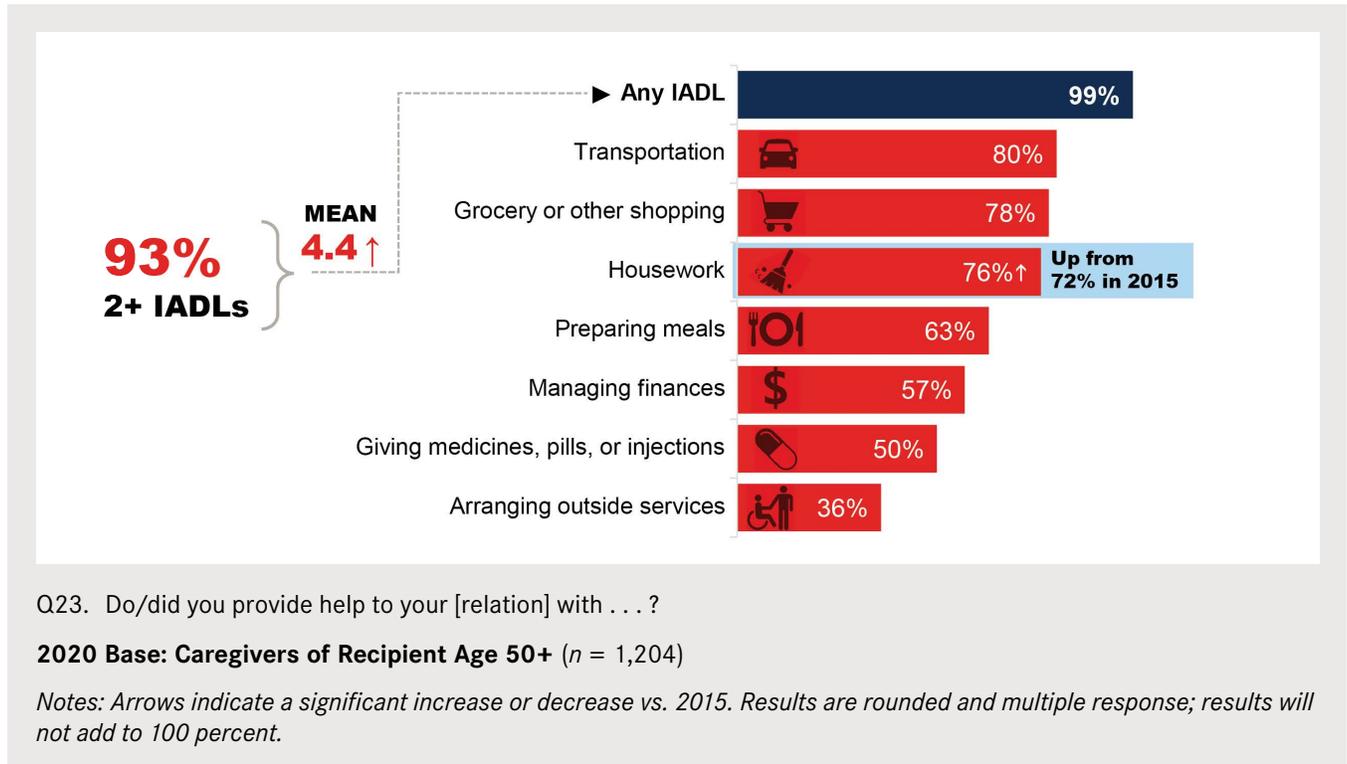
25 Those caring for a spouse/partner (nearly all of whom live with their recipient) help with 2.1 ADLs, on average—more than those who care for a parent/parent-in-law (1.5) or non-relative (1.5).

26 African American caregivers also help with significantly more ADLs than do Asian American caregivers (2.2 ADLs, on average, vs. 1.5 ADLs, on average).

## 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.<sup>27</sup> On average, 50+ caregivers help their recipient with 4.4 IADLs (significantly more than in 2015, at 4.2; see Figure 23). The performance of IADLs is fairly consistent with 2015 data; the most common IADLs include helping with transportation (80 percent), grocery or other shopping (78 percent), and housework (76 percent)—which is the only IADL that has seen a significant increase (up from 72 percent in 2015).

**Figure 23. Help with Instrumental Activities of Daily Living (IADLs)**



### CHANGE FOCUS: 2020 vs. 2015

Those providing care to the oldest adults age 85+ are more likely in 2020 to report helping with managing finances, paying bills, or filling out insurance claims (64 percent vs. 55 percent in 2015).

### SUBGROUPS: 2020

- Caregivers of color on average perform a higher number of IADLs (4.8 among Asian American, 4.7 among African American, and 4.6 among Hispanic/Latinx vs. 4.3 among White caregivers).
- Those in more demanding care situations also tend to help with more IADLs than their counterparts<sup>28</sup>:
  - Higher-hour caregivers are more likely to help with all 7 IADLs (5.5 IADLs, on average for those caring 21+ hours per week) compared to 3.9 IADLs, on average, for those providing 20 or fewer hours of care per week.

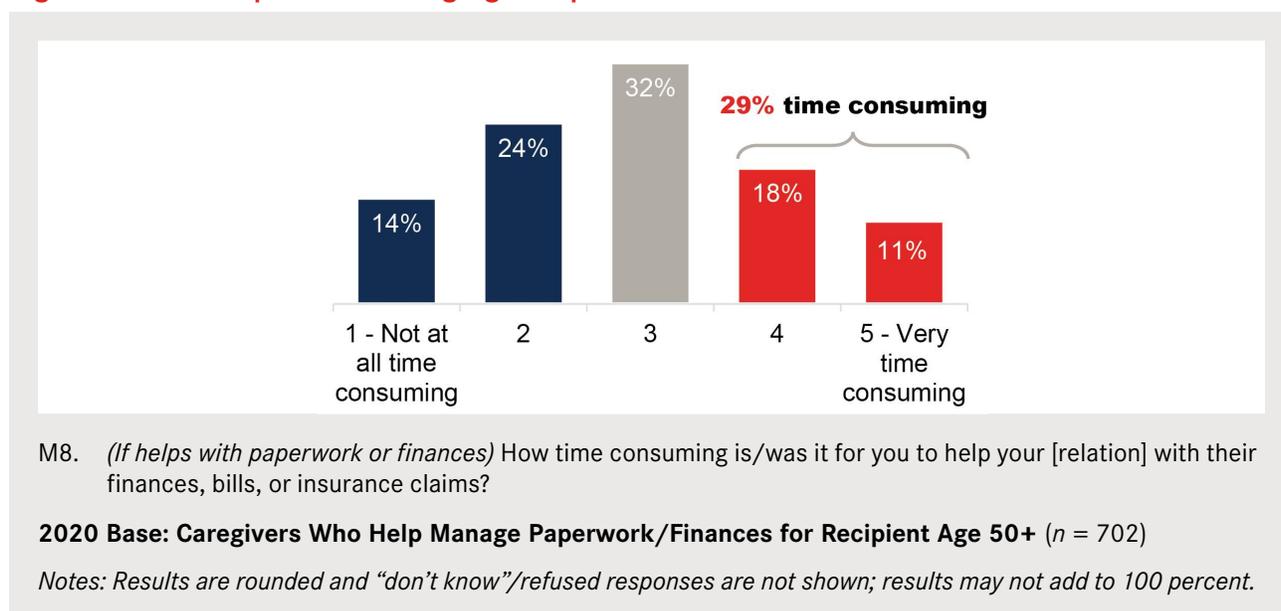
27 Instrumental Activities of Daily Living (IADLs) include transportation, grocery or other shopping, housework, preparing meals, managing finances, giving medications or injections, or arranging for outside services.  
28 Many caregivers who care for a spouse or partner are their care recipient's primary caregiver and live with their care recipient; thus, this finding also holds for those providing care to a spouse or partner.

- Those caregivers whose recipient lives with them help with more IADLs, on average, than do those whose care recipient does not live with them (5.1 IADLs, on average, compared to 4.0 IADLs, on average).
- Caregivers of someone living with Alzheimer’s or dementia help with an average of 4.8 IADLs—more than those who provide care to someone without these conditions (4.2).
- Caregivers with annual household incomes less than \$50,000 are more likely to help with grocery or other shopping (82 percent vs. 76 percent of those with \$50,000 or more in household income), housework (81 percent vs. 73 percent), and preparing meals (69 percent vs. 59 percent).
- Caregivers of the oldest recipients age 85+ more often help with managing finances (64 percent) than those who provide care to someone age 50 to 74 (51 percent).

## TIME SPENT ON MANAGING RECIPIENT’S FINANCES

Of those caregivers who help manage their recipient’s paperwork or finances, 29 percent report this task is time consuming (rating a 4 or 5 on a 5-point scale; see Figure 24).

**Figure 24. Time Spent on Managing Recipient’s Finances**



### SUBGROUPS: 2020

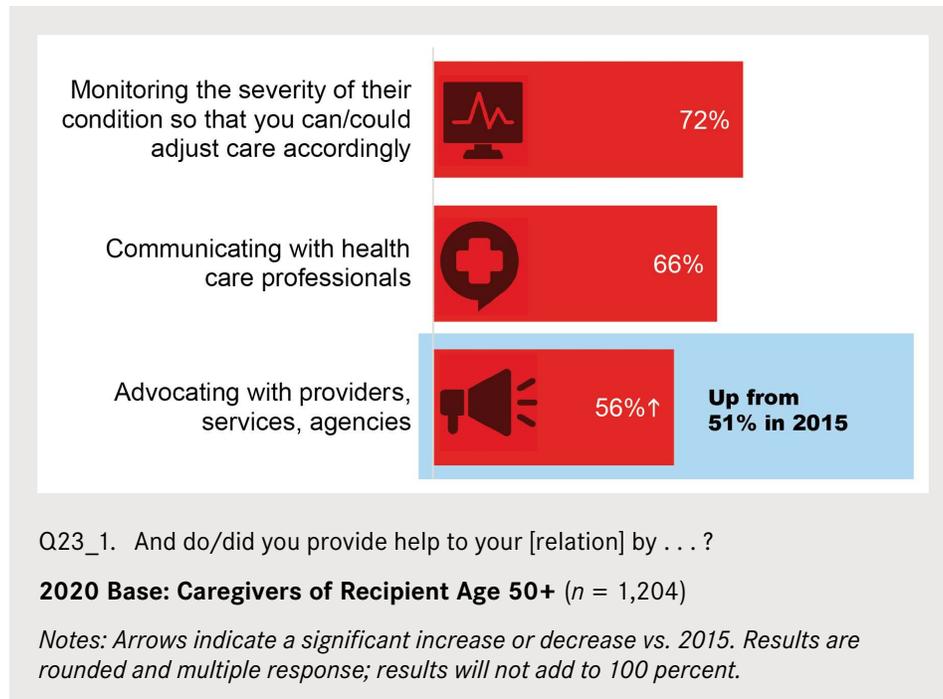
- High-hour caregivers more often find managing their recipient’s finances highly time consuming (44 percent vs. 21 percent of those providing 20 hours or less of care weekly).
- Those providing care to someone living with Alzheimer’s or dementia are more likely to find managing finances time consuming (38 percent vs. 24 percent of caregivers of someone without Alzheimer’s or dementia).
- Younger caregivers, lower-income caregivers, and caregivers with less education also find managing their recipient’s finances time consuming: 35 percent of caregivers ages 18 to 49 describe this task as time consuming (vs. 26 percent of caregivers ages 50+); 42 percent of those with annual household incomes less than \$30,000 find managing finances time consuming (vs. 27 percent of those with \$30,000 or more in household income<sup>29</sup>); and 36 percent of those with a high school degree or less education find managing their recipient’s finances time consuming (vs. 24 percent of those with a college degree or higher).

<sup>29</sup> As the report notes later, higher-income caregivers more often report the presence of other help, potentially contributing to this group finding managing their recipient’s finances less time consuming than do lower-income caregivers.

## 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. Seven in 10 caregivers of adults ages 50+ monitor the severity of their recipient's condition so they can adjust care accordingly (72 percent; see Figure 25). Many caregivers also assume the responsibility of being the voice for their care recipient: 66 percent communicate with health care professionals like doctors, nurses, or social workers about their recipient's care, while 56 percent advocate for their recipient with health care providers, community services, or government agencies, taking on this responsibility more than in 2015 (51 percent).

**Figure 25. Help with Other Key Activities**



### CHANGE FOCUS: 2020 vs. 2015

- Particular racial/ethnic groups of caregivers have seen shifts in the past five years in these kinds of support activities, with African American caregivers more often advocating for (63 percent vs. 49 percent in 2015) and communicating on behalf of (72 percent vs. 60 percent in 2015) their recipient age 50+, while Asian American caregivers are more often advocating for (66 percent vs. 55 percent in 2015) and monitoring their recipient's condition (79 percent vs. 70 percent in 2015).
- Those whose care recipient lives in a rural setting are more often advocating for their recipient in 2020 (58 percent) than in 2015 (44 percent).

**SUBGROUPS: 2020**

- Caregivers whose care situation is more intense or longer term more often help with these kinds of support activities, including:
  - Those who provide care for 21+ hours a week (68 percent advocate, 83 percent communicate, 88 percent monitor);
  - Those who have been providing care for at least a year (63 percent advocate, 72 percent communicate, 76 percent monitor); and
  - Caregivers of someone living with Alzheimer’s or dementia (68 percent advocate, 82 percent communicate, 82 percent monitor).
- Caregivers of the oldest adults age 85+ are more likely to advocate for their recipient (65 percent vs. 48 percent of those whose recipient is 50 to 74 years old) and communicate with health care professionals on their behalf (75 percent vs. 58 percent of those whose recipient is 50 to 74 years old).
- African American caregivers are more likely to advocate (63 percent) than White caregivers (53 percent). Asian American caregivers are more likely than White caregivers to do all three tasks: advocate (66 percent vs. 53 percent White), monitor (79 percent vs. 71 percent), and communicate (82 percent vs. 64 percent). Additionally, Asian American caregivers are more likely than Hispanic/Latinx caregivers to advocate for their recipient (66 percent vs. 55 percent, respectively) and communicate with health care professionals (82 percent vs. 66 percent, respectively).
- Women are more likely to report communicating with care professionals (69 percent vs. 62 percent of men).

Performing these tasks, like advocating for the care recipient or communicating with care professionals, varies by the relationship between the caregiver and care recipient. When caregivers are providing care to a close family member (like a spouse/partner or parent), they more often perform each of these three tasks than do caregivers of other relatives or non-relatives (see Figure 26).

**Figure 26. Help with Other Key Activities by Caregiver and Care Recipient Relationship**

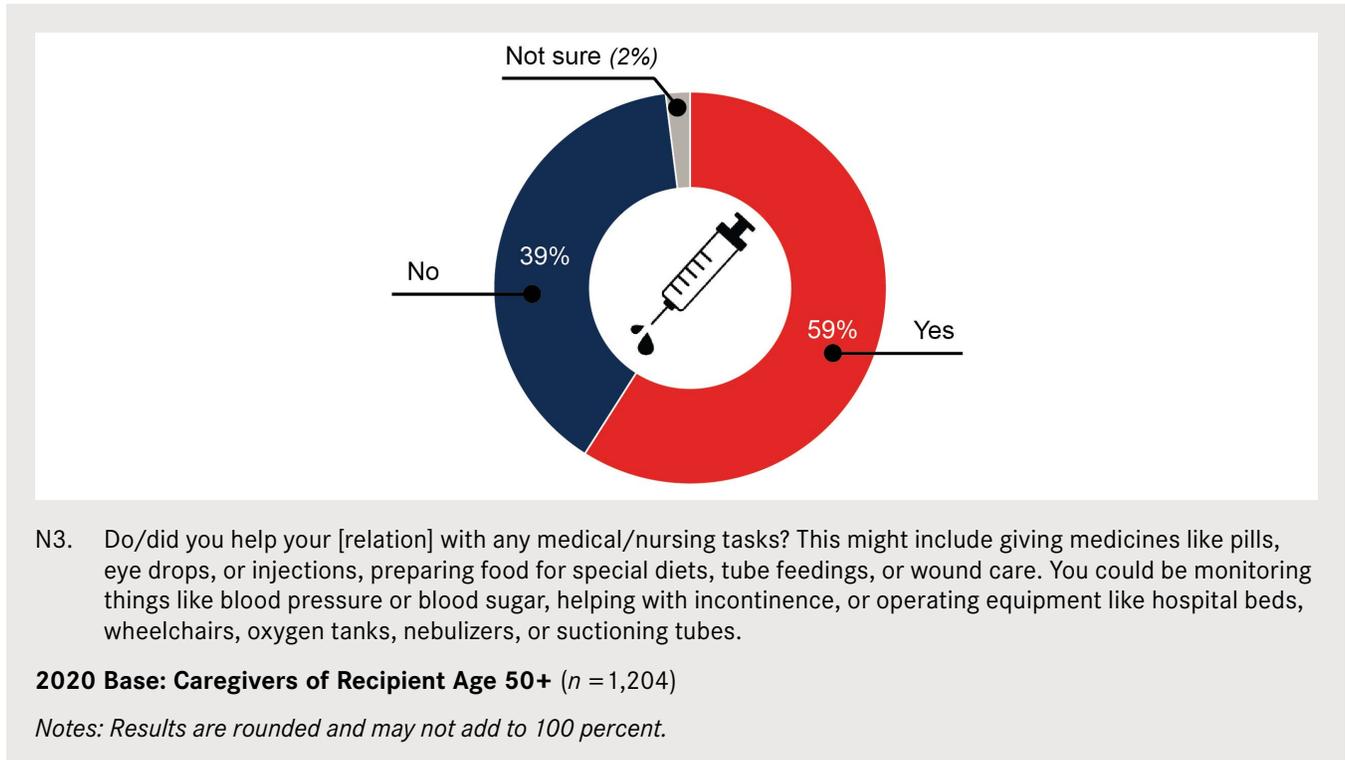
	Care Recipient Relationship to Caregiver			
	Spouse/ Partner (n = 143) A	Parent/ Parent-in-law (n = 693) B	Other Relative (n = 229) C	Non-Relative (n = 133) D
<b>Communicating with health care professionals like doctors, nurses, or social workers about recipient’s care</b>	83% <sup>BCD</sup>	68% <sup>CD</sup>	60%	49%
<b>Monitoring the severity of their recipient’s condition so that they can adjust care accordingly</b>	78% <sup>D</sup>	74% <sup>D</sup>	70% <sup>D</sup>	55%
<b>Advocating for their recipient with health care providers, community services, and government agencies</b>	62% <sup>CD</sup>	60% <sup>CD</sup>	49%	38%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and multiple response; results will not add to 100 percent.

## ASSISTANCE WITH MEDICAL/NURSING TASKS

Recent research revealed that, in addition to ADLs and IADLs,<sup>30</sup> family caregivers in general are increasingly performing tasks that nurses typically perform. Known now as medical/nursing tasks, these skilled activities include injections, tube feedings, catheter and colostomy care, and many other complex care responsibilities.<sup>31</sup> About 6 in 10 caregivers assist with medical/nursing tasks (59 percent; see Figure 27).

**Figure 27. Assistance with Medical/Nursing Tasks**



### CHANGE FOCUS: 2020 vs. 2015

- Long-term caregivers more often report helping with medical/nursing tasks for their recipient age 50+ (62 percent when providing care for five years or longer vs. 53 percent in 2015).

### SUBGROUPS: 2020

- Caregivers of color (71 percent African American, 68 percent Hispanic/Latinx, and 66 percent Asian American) are each more likely than are White caregivers (53 percent) to help with medical/nursing tasks for their age 50+ recipient.
- Again, those caregivers who are in more intensive or demanding care situations help with medical/nursing tasks more often, including:
  - High-hour caregivers (86 percent of those providing 21+ hours of care weekly vs. 47 percent when providing 20 hours or less);
  - Those caregivers whose 50+ recipient lives with them (73 percent vs. 51 percent of those whose recipient does not live with them); and
  - Caregivers of recipients living with Alzheimer's or dementia (70 percent vs. 54 percent of those whose recipient does not have Alzheimer's or dementia).

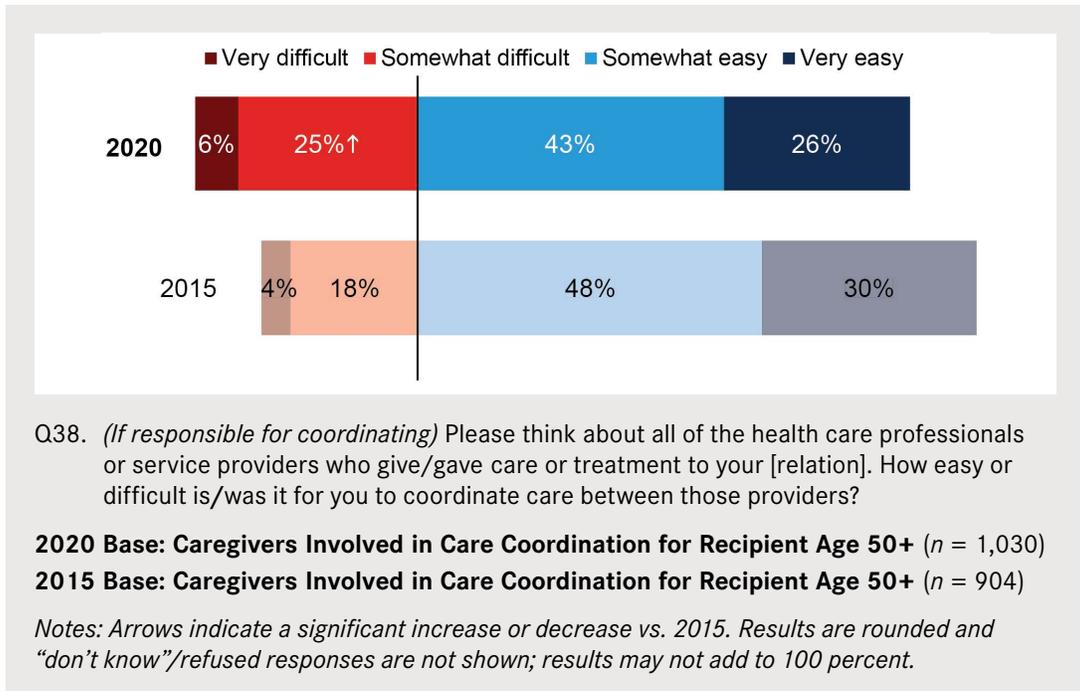
30 Of note: there are no significant differences in performance of ADLs, IADLs, or medical/nursing tasks among caregivers of older adults ages 50 or older by recipient age range of 50 to 64, 65 to 74, 75 to 84, and 85+.

31 See S. C. Reinhard et al., *Home Alone Revisited: Family Caregivers Doing Complex Care* (Washington, DC: AARP Public Policy Institute, 2019).

## EASE OF COORDINATING CARE

The challenges individuals face in navigating the health care and long-term services and supports (LTSS)<sup>32</sup> systems are often amplified for their caregivers, who are acting on their behalf.<sup>33</sup> Among those who coordinate care, a greater proportion of caregivers of someone age 50 or older report having at least some difficulty in coordinating care among their care recipient’s providers (31 percent vs. 22 percent in 2015; shown in Figure 28).

**Figure 28. Ease of Coordinating Care**



### CHANGE FOCUS: 2020 vs. 2015

This increased difficulty in coordinating care seems to be universal for caregivers regardless of hours of care provided (increasing significantly for both lower- and higher-hour caregivers).

Some groups of caregivers<sup>34</sup> who in 2020 report significantly greater difficulty with care coordination for their recipients ages 50+ include:

- Those providing care to a parent/parent-in-law (32 percent vs. 22 percent in 2015) or non-relative (29 percent vs. 16 percent in 2015);
- Caregivers ages 18 to 49 (33 percent vs. 22 percent in 2015);
- Those whose care recipient is between the ages of 65 and 84 (30 percent vs. 21 percent in 2015);
- Those providing care for at least a year (32 percent vs. 20 percent in 2015); and
- White caregivers (30 percent vs. 21 percent in 2015).

32 Per the Office of the Assistant Secretary for Planning and Evaluation: “Long-term services and supports (LTSS) encompass a variety of health, health-related, and social services that assist individuals with functional limitations due to physical, cognitive, or mental conditions or disabilities. LTSS includes assistance with activities of daily living (ADLs, such as eating, bathing, and dressing) and instrumental activities of daily living (IADLs, such as housekeeping and managing money) over an extended period of time. The goal of LTSS is to facilitate optimal functioning among people with disabilities.” See “An Overview of Long-Term Services and Supports and Medicaid: Final Report.” ASPE, 13 Aug. 2018, [aspe.hhs.gov/basic-report/overview-long-term-services-and-supports-and-medicare-final-report](https://aspe.hhs.gov/basic-report/overview-long-term-services-and-supports-and-medicare-final-report).

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

34 These are groups for whom a significantly higher proportion report difficulty in coordinating care in 2020 than in 2015, but for whom their respective comparison groups did not show a significant increase.

## SUBGROUPS: 2020

- Higher-hour caregivers are more likely to find care coordination difficult (37 percent of those who provide care for 21+ hours per week vs. 27 percent who provide care for fewer hours).
- Caregivers who are younger than 65 years old are more likely than those who are 75+ to find care coordination difficult (32 percent vs 23 percent, respectively).

Working caregivers<sup>35</sup> are more likely to report difficulty with care coordination than those not employed while providing care, perhaps because they are also more often living apart or farther from their recipient (see Figure 29).<sup>36</sup>

**Figure 29. Care Coordination and Location of Recipient by Employment**

	Employed while Caregiving (n = 621) A	Not Employed while Caregiving (n = 409) B
<b>Difficulty of coordinating care</b> (rating a 4 or 5 on a 5-point scale)	33% <sup>↑B</sup>	27%
<b>Recipient lives one hour or more away</b>	13% <sup>B</sup>	8%
<b>Recipient lives in own home</b>	51% <sup>B</sup>	37% <sup>↓</sup>

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Arrows indicate a significant increase or decrease vs. 2015. Results are rounded and “don’t know”/refused responses are not shown; results are from two different questions and will not add to 100 percent.

Base sizes for recipient living location by caregiver employment status are: employed while caregiving (n = 727) and not employed while caregiving (n = 477).

## 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,<sup>37</sup> is replicated in this study to convey in a simple measure 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.

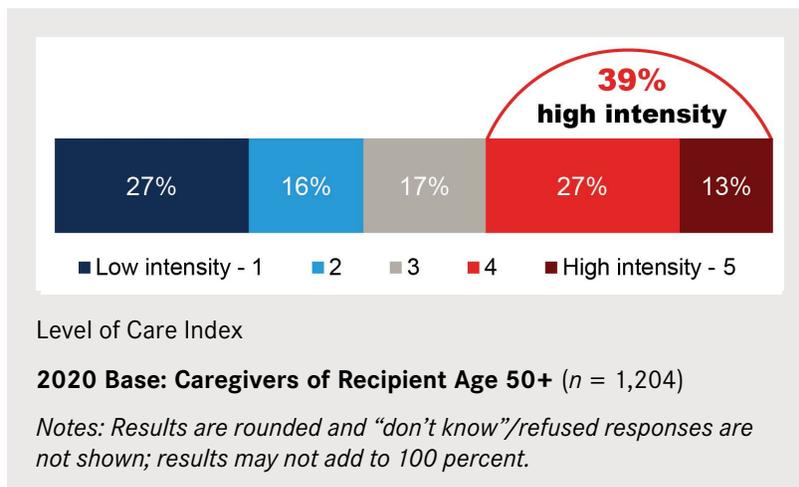
35 As shown in Section I below, 62 percent of 50+ caregivers were employed at some point in the past year while also caregiving. For additional information about caregivers who work while providing care, see Section I.

36 Of note, those with at least a college degree are more likely to find it difficult to coordinate care (vs. those with a high school degree or less), though those with at least a college degree are also more likely to be working while caregiving. Further research is needed to understand the relationship between caregiver education, employment, and distance to recipient to understand how these factors influence difficulty with care coordination.

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. For more information about the creation of the index, see appendix B of the *Caregiving in the U.S. 2020* full report.

Four in 10 caregivers of an adult age 50+ are in high-intensity situations (39 percent), 17 percent experience a moderate intensity, and 43 percent have a low intensity (see Figure 30). Similar to 2015, average level of intensity among caregivers is 2.8 on a 5-point scale.

**Figure 30. Level of Care Index**



For each intensity level of care, Figure 31 shows the components of the index among caregivers of adults ages 50 or older.

**Figure 31. Components of Level of Care Index by Intensity Category**

	Low Intensity (n = 518) A	Moderate Intensity (n = 209) B	High Intensity (n = 472) C
Hours of care per week (mean)	5.4	9.7 <sup>A</sup>	46.3 <sup>↓AB</sup>
Number of ADLs out of six total (mean)	0.2	2.1 <sup>A</sup>	3.1 <sup>AB</sup>
Number of IADLs out of seven total (mean)	3.5 <sup>↑</sup>	4.3 <sup>A</sup>	5.4 <sup>AB</sup>

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Arrows indicate a significant increase or decrease vs. 2015. Results are rounded.

**SUBGROUPS: 2020**

- African American (54 percent) and Hispanic/Latinx (47 percent) caregivers are more likely than White (34 percent) and Asian American (35 percent) caregivers to report high intensity.
- Those caregivers making less than \$30,000 in annual household income are more likely to report high intensity than those making \$30,000 or more (51 percent vs. 36 percent, respectively).
- Those who co-reside with their recipient are more likely to report being in high intensity care situations (61 percent vs. 27 percent of those who do not co-reside with their recipient).
- Similarly, those who provide care to a spouse/partner are more likely to report high intensity (62 percent vs. 36 percent when providing care to a parent/parent-in-law, 41 percent another relative, or 32 percent non-relative).

## F. PRESENCE OF OTHER HELP

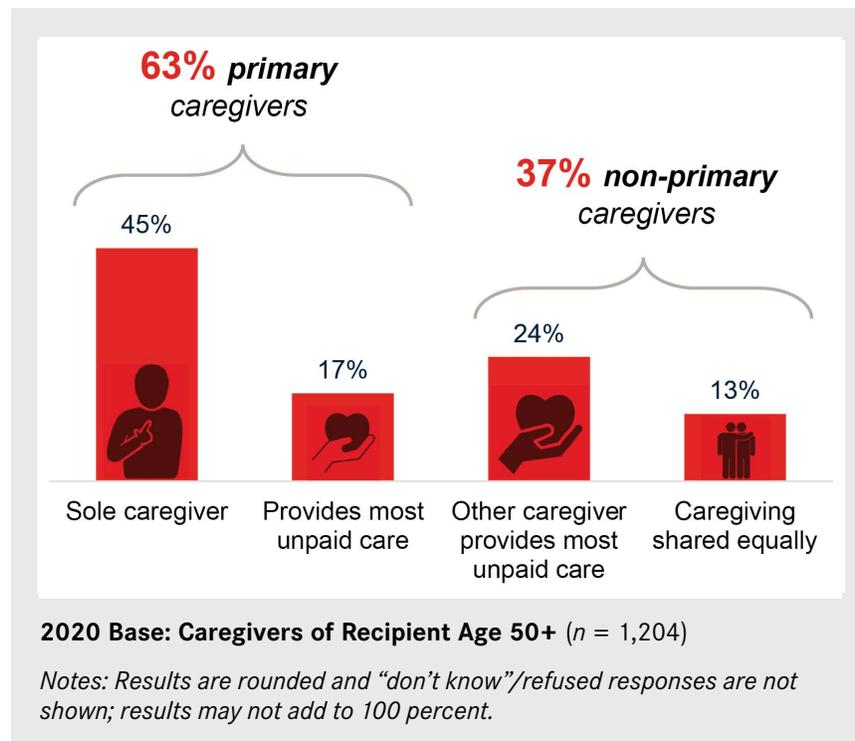
### PRESENCE OF OTHER UNPAID CAREGIVERS

More than half of caregivers of adults 50+ report someone else also provided unpaid care to their care recipient over the past year (55 percent), while 45 percent report having no other unpaid help.

### PRIMARY CAREGIVER STATUS

Over 6 in 10 caregivers of people ages 50+ perceive themselves to be the primary unpaid caregiver, meaning either they are sole caregivers (45 percent; see Figure 32) or there are other unpaid caregivers but they themselves provide the majority of unpaid care (17 percent). The 37 percent who are non-primary caregivers includes 13 percent who share caregiving equally with someone else and 24 percent who say another caregiver provides most of the unpaid care.

Figure 32. Primary Caregiver Status



#### CHANGE FOCUS: 2020 vs. 2015

Those whose care recipient lives in a rural setting more often are the primary caregiver (64 percent vs. 55 percent in 2015).

**SUBGROUPS: 2020**

- African American and Hispanic/Latinx caregivers (52 percent, each) are more likely than White caregivers (42 percent) to be the sole caregiver.<sup>38</sup>
- Those making less than \$50,000 in annual household income are more likely to be the primary caregiver than those with household incomes of \$50,000 or more (69 percent vs. 59 percent, respectively).
- Women are more likely to be primary caregivers (65 percent vs. 59 percent of men).
- Those providing care to a spouse/partner are more likely to be the primary caregiver (97 percent vs. 61 percent when caregiving for a parent/parent-in-law, 53 percent for another relative, or 54 percent for non-relative).<sup>39</sup>

Caregivers of younger recipients more often are the sole unpaid caregiver, doing so typically without any paid help in a high-intensity care situation, while caregivers of the oldest recipients are more often sharing care with both unpaid and paid help, perhaps helping buffer the intensity of the care situation for these caregivers of the oldest recipients (see Figure 33).

**Figure 33. Intensity, Caregiver Status, and Presence of Paid Help by Recipient Age**

	Care Recipient Age			
	50-64 (n = 256) A	65-74 (n = 274) B	75-84 (n = 334) C	85+ (n = 336) D
<b>High intensity</b> (percent rating 4 or 5 on a 5-pt scale)	42% <sup>D</sup>	44% <sup>D</sup>	39%	34%
<b>Sole unpaid caregiver</b>	60% <sup>BCD</sup>	48% <sup>CD</sup>	38%	37%
<b>Presence of paid help</b> *	17%	33% <sup>A</sup>	39% <sup>A</sup>	43% <sup>AB</sup>

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and reported from multiple questions; results will not add to 100 percent.

\*N size for this row excludes those who live in a facility of some sort, with base sizes by care recipient age: 50 to 64 (n = 246), 65 to 74 (n = 264), 75 to 84 (n = 305), and 85+ (n = 283).

38 Forty-two percent of Asian American caregivers report being the sole unpaid caregiver—a percentage not significantly different from that of any other racial/ethnic group listed.

39 As to be expected, those caring for a spouse/partner more often report co-residing with their recipient, so this trend is also seen in those co-residing with their care recipient (79 percent vs. 53 percent of those whose care recipient does not live with them).

## CAREGIVERS WHO ARE CHILDREN

Children may be among those called on to carry out care tasks for an adult age 50 or older. Among caregivers of adults ages 50+ who report having unpaid help, 12 percent say at least one of these unpaid caregivers is a child under age 18.

### SUBGROUPS: 2020

- Caregivers who are younger than 50 years old are more likely to report children as caregivers (19 percent vs. 7 percent of caregivers who are themselves 50 years old or older).

For Hispanic/Latinx caregivers, caregiving seems to be an intergenerational phenomenon.<sup>40</sup> Although White caregivers more often report any kind of help, paid or unpaid, Hispanic/Latinx caregivers are more likely to report a child providing caregiving support (see Figure 34).<sup>41</sup>

**Figure 34. Children Providing Care, Other Care Provided by Race/Ethnicity**

	Caregiver Race			
	White (n = 698) A	African American (n = 162) B	Hispanic (n = 178) C	Asian American (n = 177) D
<b>Caregiver has any kind of help</b>	74% <sup>BC</sup>	61%	61%	69%
<b>Other unpaid help</b>	58% <sup>BC</sup>	48%	48%	58%
<b>At least one child caregiver</b>	5%	9%	10% <sup>A</sup>	9%
<b>Paid help*</b>	36% <sup>C</sup>	32%	26%	34%
<b>Recipient lives in caregiver's household</b>	33%	42% <sup>A</sup>	46% <sup>A</sup>	51% <sup>A</sup>

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 are from multiple questions and will not add to 100 percent.

\* N size for this row excludes those who live in a facility of some sort, with base sizes by caregiver race/ethnicity: White (n = 618), African American (n = 150), Hispanic/Latinx (n = 176), and Asian American (n = 165).

40 When examining the percentage of all 50+ caregivers who report that at least one unpaid caregiver is a child, only Hispanic/Latinx caregivers are significantly more likely to report the presence of at least one child caregiver (at the 95 percent confidence level: 10 percent compared to 5 percent for White caregivers); while African American and Asian American caregivers are directionally higher but not significant (result is significant at a lesser threshold of 90 percent confidence level). However, when examining the same result *among* caregivers who report unpaid help, African American caregivers are significantly more likely to report the presence of at least one child caregiver. It may be that these caregivers are more often living in multigenerational housing, which may lend itself to children being more accessible or present to provide care. Further research is needed, as our data do not contain full household rosters to examine this hypothesis.

41 This finding seems to indicate that African American and Hispanic/Latinx caregivers are introduced to family caregiving from a young age; however, more research is needed.

## USE OF PAID HELP

Despite the increasing complexity or comorbidity of conditions that adult care recipients are dealing with—and the many hours their caregivers dedicate to care—the majority of 50+ caregivers have no paid help in taking care of their recipient (67 percent). Among caregivers whose recipient was not living in a nursing home or assisted living facility, only a third report their recipient received paid help from aides, housekeepers, or others in the past year (33 percent).

### SUBGROUPS: 2020

- Those providing care to someone age 65+ are more likely to have paid help (38 percent vs. 17 percent of those providing care to someone 50 to 64 years old)
- Those making \$75,000 or more in annual household income are more likely to have paid help than those making less than \$75,000 (38 percent vs. 28 percent, respectively).<sup>42</sup>
- Those who care for another relative (other than a parent/parent-in-law or spouse/partner; 37 percent) or a non-relative (42 percent) are more likely than those providing care to a spouse/partner (24 percent) to report paid help.
- Those who are in moderate- to high-intensity care situations are more likely to report other paid help (38 percent vs. 26 percent of those in low-intensity care situations).
- Caregivers of someone living with Alzheimer's or dementia are more likely to report the presence of paid help (45 percent vs. 29 percent of those providing care to someone without Alzheimer's or dementia).

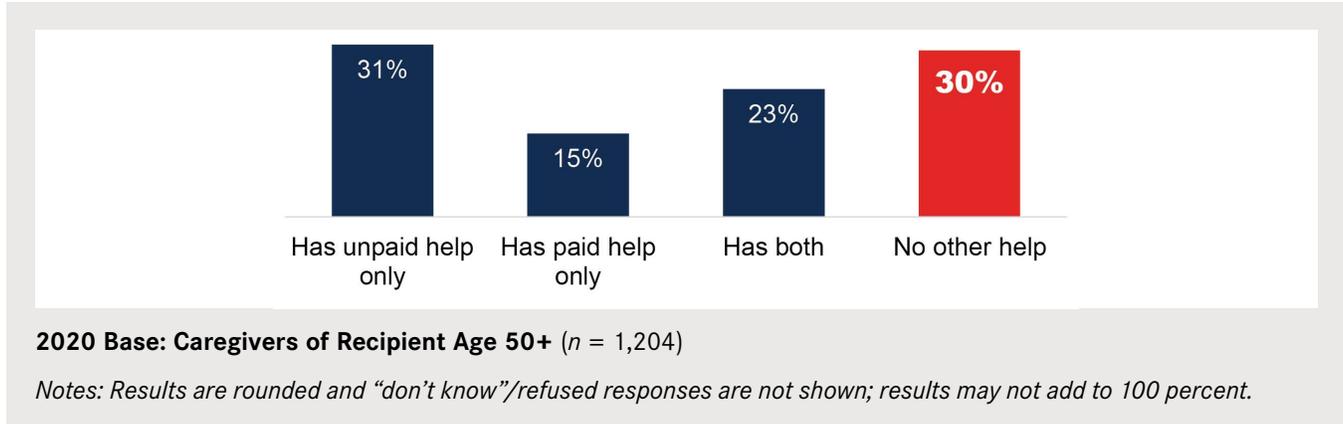
Interestingly, caregivers whose 50+ recipient lives with them are *less* likely to report having paid help (25 percent vs. 38 percent of caregivers whose recipient does not live with them, in the caregiver's home). Caregivers who co-reside with their recipient have lower household incomes and higher financial impacts due to caregiving than their counterparts. It is unclear whether the financial situation of caregivers leads them to move their age 50+ recipient into their home to be able to provide care in absence of paid help or whether living together creates the financial strain that precludes the use of paid help. Further research is needed.

<sup>42</sup> White caregivers report significantly higher household incomes than caregivers of color, likely driving the fact that White caregivers more often than Hispanic/Latinx caregivers report paid help (36 percent vs. 26 percent, respectively).

## COMBINATION OF PAID OR UNPAID HELP

One in three caregivers of adults ages 50+ is providing care completely alone, with no help from anyone else (paid or unpaid; 30 percent, as shown in Figure 35). Another 23 percent are at the other end of the help spectrum—reporting the presence of both paid and unpaid help.

**Figure 35. Combination of Paid or Unpaid Help**



Caregivers who “do it alone” without any other help (paid or unpaid) report being in worse health and are more often living with their recipient, as shown in Figure 36.

**Figure 36. Caregiving Situation by Presence of Paid and Unpaid Help**

	Has Both Paid and Unpaid Help (n = 295) A	Has Unpaid Help but No Paid (n = 365) B	Has Paid Help but No Unpaid (n = 182) C	Has No Other Help (n = 359) D
<b>Self-reported health status</b> (percent rating fair or poor)	16%	19%	15%	27% <sup>ABC</sup>
<b>Average hours of care provided weekly</b>	22.1	18.6	21.5	26.5 <sup>B</sup>
<b>Average ADLs performed</b>	2.3 <sup>BD</sup>	1.3	1.9 <sup>BD</sup>	1.5
<b>Average IADLs performed</b>	4.4 <sup>B</sup>	4.1	4.8 <sup>B</sup>	4.5 <sup>B</sup>
<b>Recipient condition categories</b> (average)	1.8 <sup>BD</sup>	1.6	1.9 <sup>BD</sup>	1.5
<b>High-intensity care situation</b> (rating 4 or 5 on a 5-point scale)	41% <sup>B</sup>	33%	42%	44% <sup>B</sup>
<b>Recipient lives with caregiver</b>	21%	31% <sup>A</sup>	30% <sup>A</sup>	58% <sup>ABC</sup>
<b>Caregiver feels alone</b>	16%	15%	27% <sup>AB</sup>	28% <sup>AB</sup>
<b>Caregiver’s median household income</b>	\$80,000	\$67,500	\$80,000	\$55,000

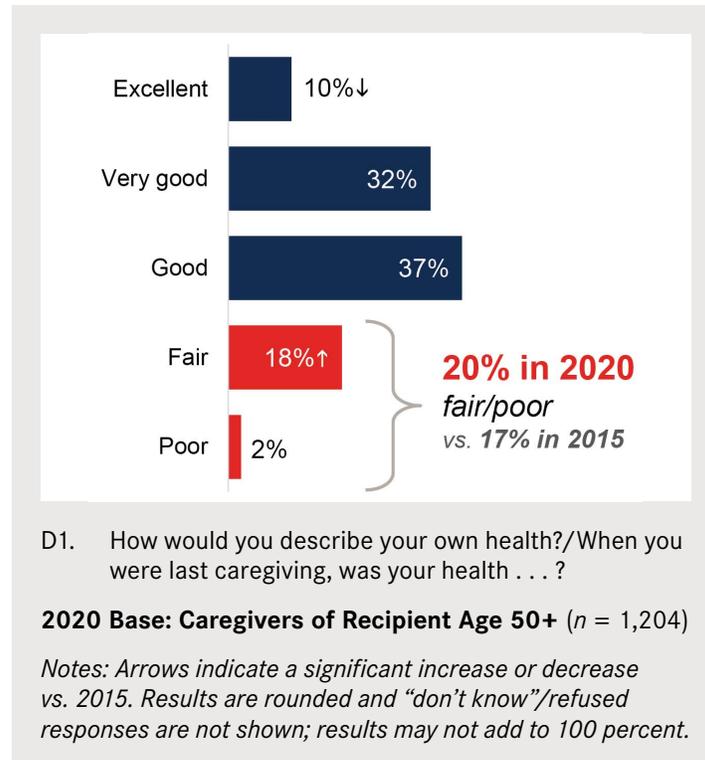
Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and “don’t know”/refused responses are not shown; results are from multiple questions and will not add to 100 percent.

## 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 of people ages 50+ (42 percent; see Figure 37) consider their health to be *excellent* or *very good*, down significantly from 2015 (48 percent), while 1 in 5 say it is *fair* or *poor* (20 percent), up significantly from 2015 (17 percent)<sup>43</sup>

**Figure 37. Caregiver Self-Rated Health**



#### CHANGE FOCUS: 2020 vs. 2015

The following groups of 50+ caregivers report worse health than in 2015:

- The youngest caregivers—those ages 18 to 49 (22 percent in fair or poor health vs. 15 percent in 2015); and
- Sole caregivers—those with neither paid nor other unpaid help (27 percent fair/poor vs. 17 percent in 2015).

43 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*, vol. 38, no. 1, 1997, pp. 21–37. For more information about self-rated health in the general adult population over the same time period, see National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2020*. Washington, DC: May 2020. <https://doi.org/10.26419/ppi.00103.001> or <https://www.caregiving.org/caregiving-in-the-us-2020/>

## SUBGROUPS: 2020

- Those who provide care to a spouse/partner age 50+ (28 percent) are more likely to say they are in fair or poor health than those providing care to a parent/parent-in-law age 50+ (18 percent).
- Caregivers of someone age 50+ who are in demanding care situations are more prone than their counterparts to say they are in worse health, as measured by the percentage rating their health as fair or poor:
  - Those providing 21+ hours of care weekly (28 percent vs. 17 percent of those providing 20 or fewer hours);
  - Caregivers who have no other help (27 percent vs. 17 percent of those who have any kind of help);
  - Those in high-intensity care situations (27 percent vs. 14 percent in low-intensity situations); and
  - Those who co-reside with their recipient (26 percent vs. 17 percent of those not living with their recipient).
- Caregivers from diverse communities also more often report worse health than their peers:
  - White caregivers (46 percent) are more likely than African American (36 percent) and Hispanic/Latinx (34 percent) caregivers to be in excellent or very good health.
  - Those caregivers with annual household incomes less than \$50,000 are more likely to say they are in fair/poor health (28 percent vs. 16 percent of those making \$50,000 or more), as are those with a high school degree or less (27 percent vs. 17 percent of those with at least some college education).

## CAREGIVER HEALTH CHANGES

Although three out of four 50+ caregivers feel that providing care has not affected their own health (74 percent), nearly one out of five feel caregiving has made their health worse (21 percent), while 5 percent feel caregiving has made their health better.

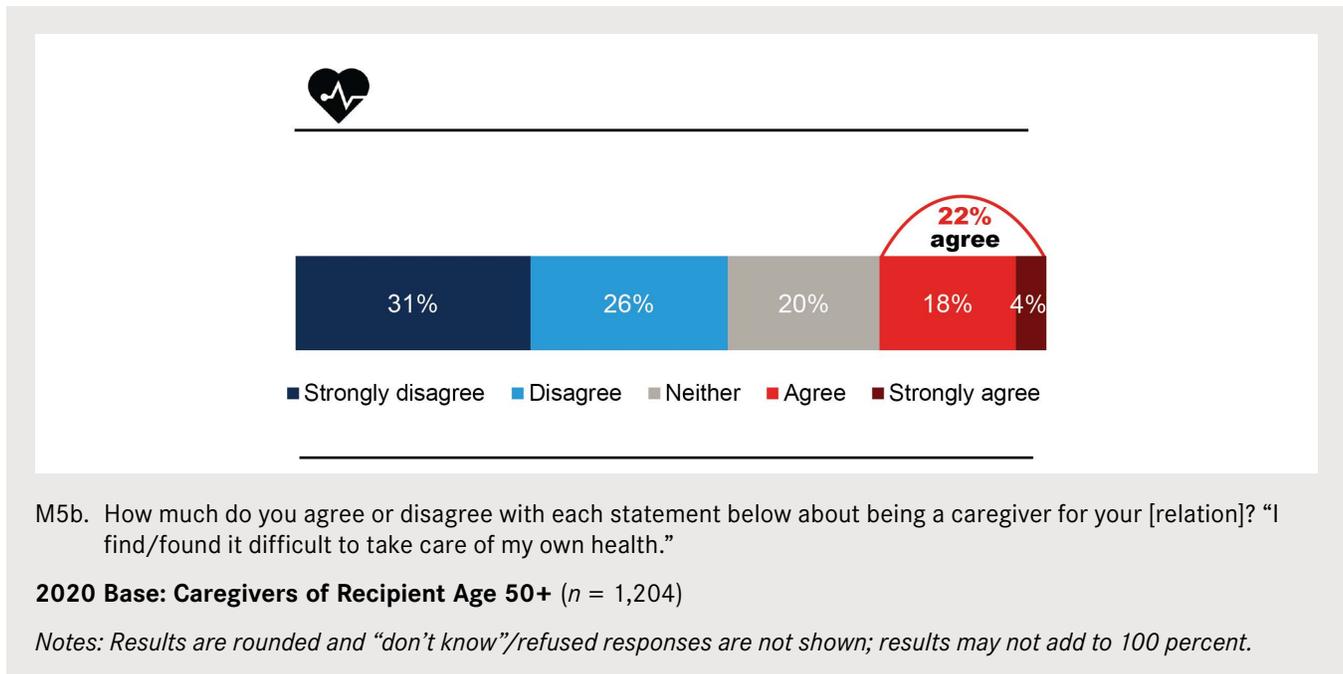
## SUBGROUPS: 2020

- Similar to patterns observed in those with poorer health status, those in more demanding care situations more often report that their role as a caregiver made their health worse:
  - Those who are in high-intensity care situations are more likely to say caregiving made their health worse (31 percent vs. 15 percent of those in low- to moderate-care situations).
  - Those who provide care for 21+ hours per week are more likely to say caregiving made their health worse (31 percent vs. 17 percent who provide 20 or fewer hours of care).
  - Those who provide care for a year or more are more likely to say that caregiving made their health worse (25 percent vs. 16 percent when providing care for less than a year).
  - Those who co-reside with their recipient are more likely to say caregiving made their health worse (27 percent vs. 18 percent of those not co-residing with their recipient).
- The following groups are also more likely than their peers to report that their role as a caregiver made their health worse:
  - Those providing care to a spouse/partner (34 percent) are more likely to say caregiving made their health worse than those providing care to a parent/parent-in-law (22 percent), some other relative (13 percent), or a non-relative (18 percent).
  - Caregivers of someone living with Alzheimer's or dementia are more likely to report that caregiving made their health worse (31 percent vs. 17 percent of those caring for someone without Alzheimer's or dementia).

## DIFFICULTY CARING FOR OWN HEALTH

Over one in five 50+ caregivers say it is difficult to take care of their own health (22 percent), while 57 percent disagree (see Figure 38).

**Figure 38. Difficulty Caring for Own Health**



### SUBGROUPS: 2020

Nearly across the board, caregivers in higher-intensity or demanding care situations say caregiving has made it difficult to take care of their own health. This includes:

- Those who are in high-intensity care situations (31 percent vs. 16 percent of those in low- to moderate-intensity situations);<sup>44</sup> and
- Those who provide care for longer periods of time (26 percent of those providing care for at least a year vs. 17 percent less than a year).

Additionally, the following groups more often than their peers report difficulty caring for their own health:

- White (24 percent) and Asian American (27 percent) caregivers vs. African American caregivers (17 percent);
- Those providing care to a spouse/partner (33 percent vs. 23 percent providing care to a parent/parent-in-law, 15 percent to some other relative, and 17 percent to non-relative); and
- Caregivers of someone living with Alzheimer’s or dementia (28 percent vs. 18 percent of those providing care to someone without these conditions).

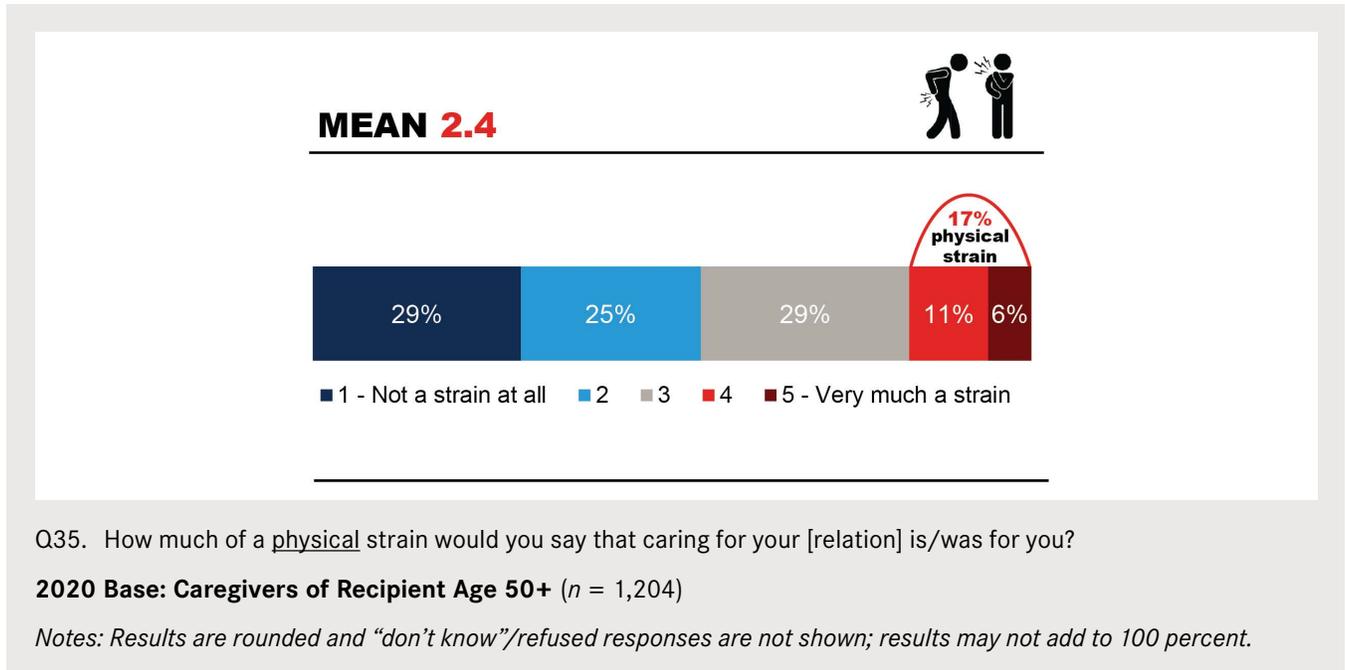
Caregivers of someone age 65 to 84 are more likely than those providing care to the oldest recipients (85+) to find it difficult to take care of their own health. Additionally, caregivers providing care to the younger recipients also report higher intensity with less help (paid or unpaid), suggesting these caregivers of younger recipients may be stretched too thin to focus on their own well-being.

44 A similar pattern emerges by hours of care, which is used when creating the Level of Care or intensity index: 33 percent of those providing 21+ hours of care per week say caregiving made it difficult to take care of their own health vs. 17 percent of those providing 20 or fewer hours.

## PHYSICAL STRAIN OF CAREGIVING

Nearly one in five 50+ caregivers report high physical strain as a result of caregiving (17 percent rating a 4 or 5 on a 5-point scale; see Figure 39). On average, caregivers of adults age 50+ report a physical strain of 2.4 (out of 5).

**Figure 39. Physical Strain of Caregiving**



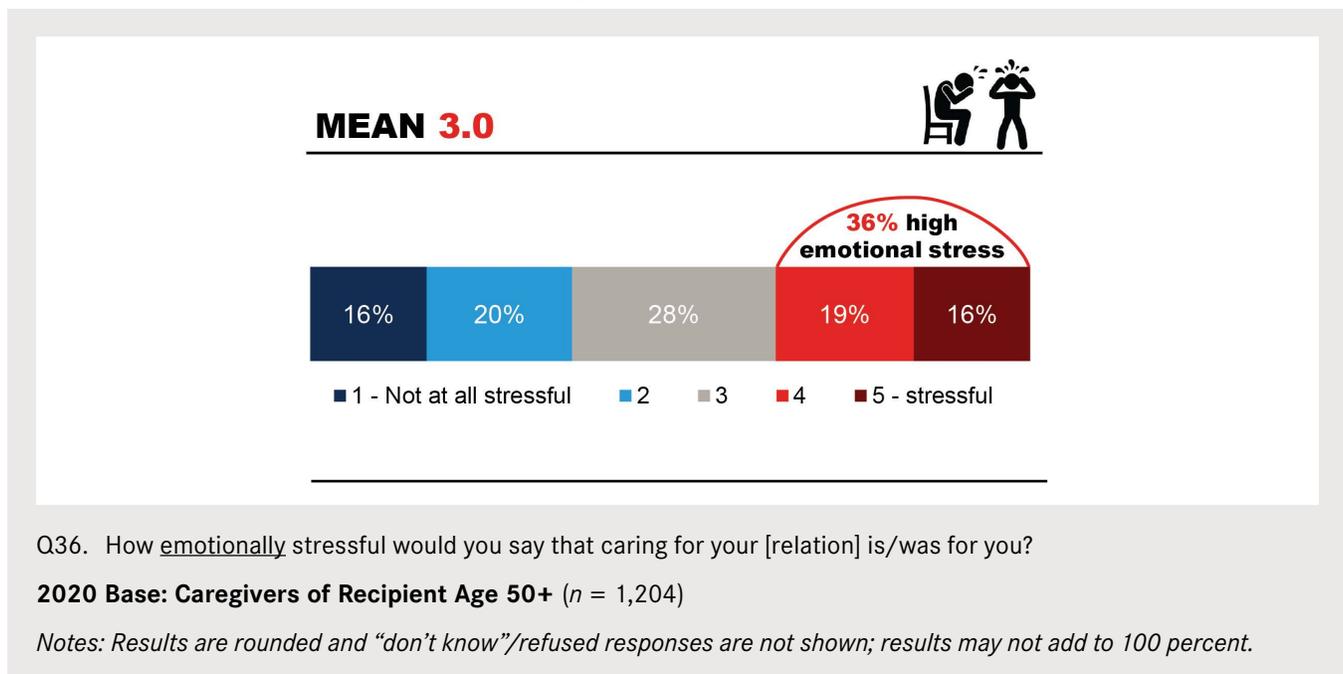
### SUBGROUPS: 2020

High physical strain is especially prevalent among caregivers in moderate- to high-intensity care situations (24 percent vs. 8 percent of those in low-intensity care situations), suggesting that the higher hours of care provided and higher number of ADLs/IADLs used to calculate the index are related to high physical strain. In fact, those who provide care for 21+ hours per week are more likely to say caregiving was a physical strain (28 percent vs. 12 percent when providing care for 20 or fewer hours).

## EMOTIONAL STRESS OF CAREGIVING

Nearly 4 in 10 caregivers of an adult age 50+ consider their caregiving situation to be highly emotionally stressful (36 percent rating stress a 4 or 5 on a 5-point scale, shown in Figure 40), while an additional 28 percent report moderate emotional stress.<sup>45</sup> On average, caregivers of adults report emotional stress level of 3.0 (out of 5).

**Figure 40. Emotional Stress of Caregiving**



### CHANGE FOCUS: 2020 vs. 2015

Asian American caregivers report higher emotional stress in 2020 (47 percent vs. 34 percent in 2015).

### SUBGROUPS: 2020

Not surprisingly, emotional stress seems to be related to amount of time and length of time providing care—emotional stress is higher among those who provide care for 21+ hours per week (49 percent vs. 30 percent of those who provide care for 20 or fewer hours), those who are in moderate- to high-intensity care situations (46 percent vs. 23 percent of those in low-intensity care situations), and those who have been providing care for a year or longer (41 percent vs. 29 percent of those who have been providing care for less than a year).

Other caregivers experiencing high emotional stress more often than their counterparts include:

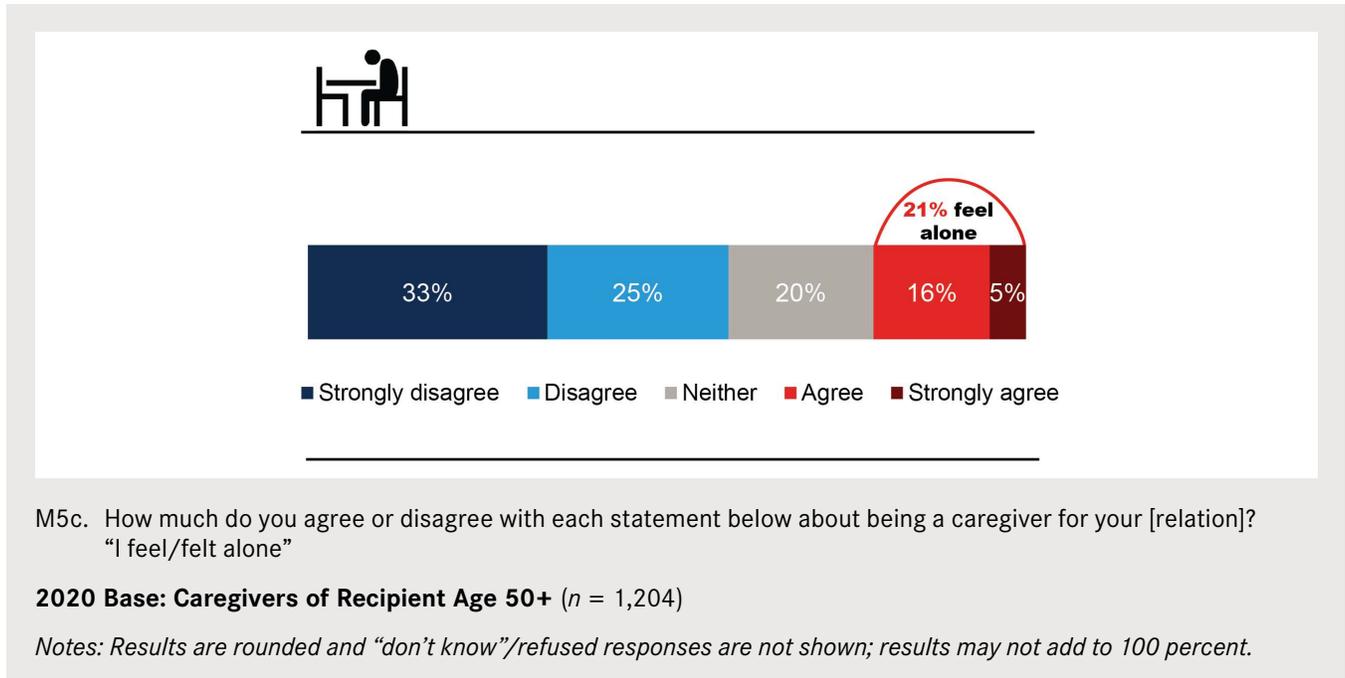
- Asian American caregivers (47 percent vs. 38 percent of White, 30 percent of African American, or 31 percent of Hispanic/Latinx caregivers); and
- Those providing care to someone living with Alzheimer’s or dementia (53 percent vs. 28 percent of caregivers of recipients without these conditions).

45 Physical strain and emotional stress seemingly impact caregiver health—31 percent of caregivers with high physical strain self-report having fair or poor health (higher than the 15 percent of caregivers with low physical strain), while 26 percent of caregivers with high emotional stress self-report having fair or poor health (higher than the 15 percent of caregivers with low emotional stress).

## FEELING ALONE

One out of five caregivers of adults ages 50+ feels alone (21 percent strongly agree or agree with the statement “I feel alone,” as shown in Figure 41), while 58 percent disagree. Feelings of loneliness are associated with strong feelings of stress and strain as well as decreased health for caregivers.<sup>46</sup>

**Figure 41. Feeling Alone**



### SUBGROUPS: 2020

Caregivers in more intensive or demanding situations more often say they feel alone, including:

- Primary caregivers (27 percent vs. 11 percent of non-primary caregivers);
- Those in high-intensity care situations (29 percent vs. 16 percent of those in low- to moderate-care situations) and higher-hour caregivers (30 percent who provide care 21+ hours weekly vs. 18 percent for those who provide fewer hours);<sup>47</sup>
- Caregivers whose recipient lives with them (30 percent vs. 17 percent of those not co-residing); and
- Caregivers of a 50+ recipient who is living with Alzheimer’s or dementia (27 percent vs. 18 percent of those providing care to someone without these conditions).

Many of these same groups listed above also report their 50+ recipient has multiple conditions. As the reported number of conditions increases, so does the 50+ caregivers report of feeling alone, suggesting perhaps that as the complexity of the recipient’s care needs increase, so too does the caregiver’s level of loneliness. Among those providing care to a 50+ recipient with one condition, 16 percent feel alone. This rises to 25 percent when providing care to someone with two conditions and rises again to 36 percent when providing care to someone with three or more conditions.

46 Caregivers who report feeling alone more often suffer from the negative effects of their caregiving role; for full breakdown, see National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2020*. Washington, DC: May 2020. <https://doi.org/10.26419/ppi.00103.001> or <https://www.caregiving.org/caregiving-in-the-us-2020/>. Similar patterns emerge when looking at just caregivers of those ages 50+.

47 To frame it another way, caregivers who feel alone provide more hours of care (31.2 hours per week, on average, vs. 19.5 hours per week on average for those who do not feel alone).

## CHOICE IN TAKING ON CAREGIVER ROLE

Having a choice to take on care is an important aspect of caregiving: those who reported having no choice were found to more often face complex care situations and increased stress and strain.<sup>48</sup>

When asked if they had a choice in taking on the responsibility to provide care for their recipient, 53 percent of 50+ caregivers felt they had no choice in taking on this role, while 47 percent feel they did have a choice.

### CHANGE FOCUS: 2020 vs. 2015

Among caregivers of adults age 50+, particular groups show significant increases in feeling that they did not have a choice in taking on their role as a caregiver, including:

- Those providing care to a recipient age 65 to 84 (57 percent in 2020 vs. 48 percent in 2015);
- Asian American caregivers (64 percent vs. 48 percent in 2015);
- Those caring for someone living in a rural area (52 percent vs. 43 percent in 2015), and
- Lower-hour caregivers (52 percent of those providing 20 or fewer hours of care weekly vs. 45 percent in 2015).

### SUBGROUPS: 2020

- Those providing care to a recipient age 65 to 84 are more likely than those caring for someone younger to feel they did not have a choice (57 percent vs. 45 percent of those caring for someone 50 to 64 years old).
- Asian American caregivers (64 percent) are more likely than both White (53 percent) and Hispanic/Latinx (49 percent) caregivers to feel that they had no choice.<sup>49</sup>
- Those providing care to a parent/parent-in-law (61 percent) or spouse/partner (66 percent) more often report feeling they had no choice in taking on their role (vs. 39 percent of those providing care to some other relative and 21 percent providing care to a non-relative).

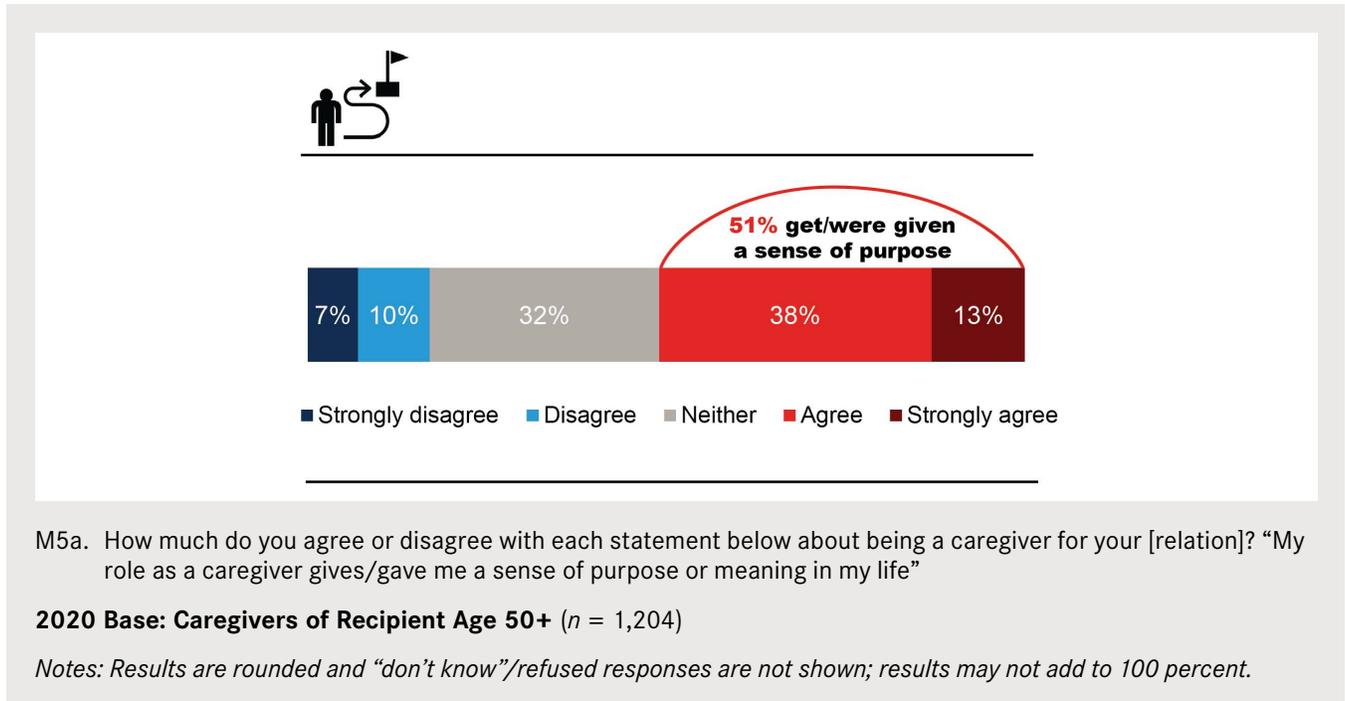
48 See National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2020*. See also National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2015*. Washington, DC: June 2015. <https://www.caregiving.org/research/caregivingusa/>.

49 There is no significant difference when comparing African American caregivers (55 percent feel they had no choice) to White, Hispanic/Latinx, or Asian American caregivers.

## SENSE OF PURPOSE

For caregivers, positive emotions often coexist with feelings of isolation, stress, or strain. Half of caregivers of adults ages 50 or older feel their role as a caregiver gives them a sense of purpose or meaning in life (51 percent; see Figure 42).

**Figure 42. Sense of Purpose**



### SUBGROUPS: 2020

- African American and Hispanic/Latinx caregivers (61 percent, each) are more likely than White caregivers (46 percent) to feel like their role gave them a sense of purpose.
- Those who are in moderate- to high-intensity care situations are more likely to agree that their role gave them a sense of purpose (56 percent vs. 45 percent of those in low-intensity care situations).
- Primary caregivers are more likely to agree their role gave them a sense of purpose (54 percent vs. 46 percent of non-primary caregivers).
- Those caregivers making less than \$50,000 in annual household income are more likely to agree their role gave them a sense of purpose (61 percent vs. 46 percent of those making \$50,000 or more).<sup>50</sup>

50 As are those with a high school degree or less compared with those with at least some college (62 percent vs. 47 percent).

Providing care to one’s spouse/partner seems to have both emotional and physical challenges that impact the caregiver’s health, while providing care to a parent/parent-in-law is more emotionally stressful (as shown in Figure 43).

**Figure 43. Impacts on Caregiver by Relationship of Caregiver and Recipient**

	Care Recipient Relationship to Caregiver			
	Spouse/ Partner (n = 143) A	Parent/ Parent-in-law (n = 693) B	Other Relative (n = 229) C	Non-Relative (n = 133) D
Average emotional stress	3.1 <sup>CD</sup>	3.2 <sup>CD</sup>	2.8	2.5
Average physical strain	2.7 <sup>BCD</sup>	2.4	2.3	2.3
Self-reported health: fair or poor	28% <sup>B</sup>	18%	20%	24%
Caregiving made health worse	34% <sup>BCD</sup>	22% <sup>C</sup>	13%	18%
Agree role provides purpose or meaning	46%	47%	61% <sup>AB</sup>	61% <sup>AB</sup>

*Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and are from multiple questions; results will not add to 100 percent.*

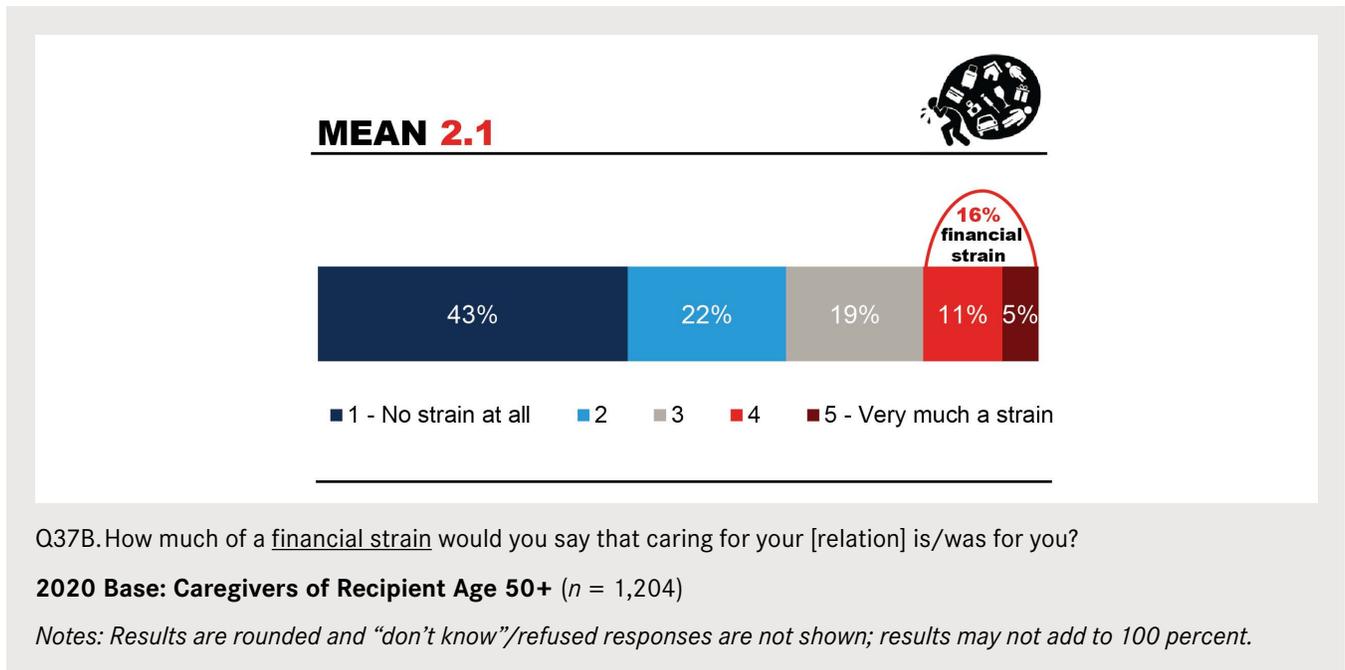
## H. THE FINANCIAL SITUATION OF CAREGIVERS

### 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 six caregivers of recipients ages 50+ report experiencing high financial strain as a result of providing care (16 percent rating a 4 or 5 on a 5-point scale; see Figure 44). On average, caregivers of adults ages 50+ report a financial strain of 2.1 (out of 5). While caregivers and their recipients face numerous challenges, the financial hardships due to caregiving are likely only being exacerbated by the economic implications of COVID-19.<sup>51</sup>

51 See M. Lopez, L. Rainie, and A. Budiman, “Financial and Health Impacts of COVID-19 Vary Widely by Race and Ethnicity,” Pew Research Center, Washington, DC, May 2020, <https://www.pewresearch.org/fact-tank/2020/05/05/financial-and-health-impacts-of-covid-19-vary-widely-by-race-and-ethnicity/>.

**Figure 44. Financial Strain of Caregiving**



**SUBGROUPS: 2020**

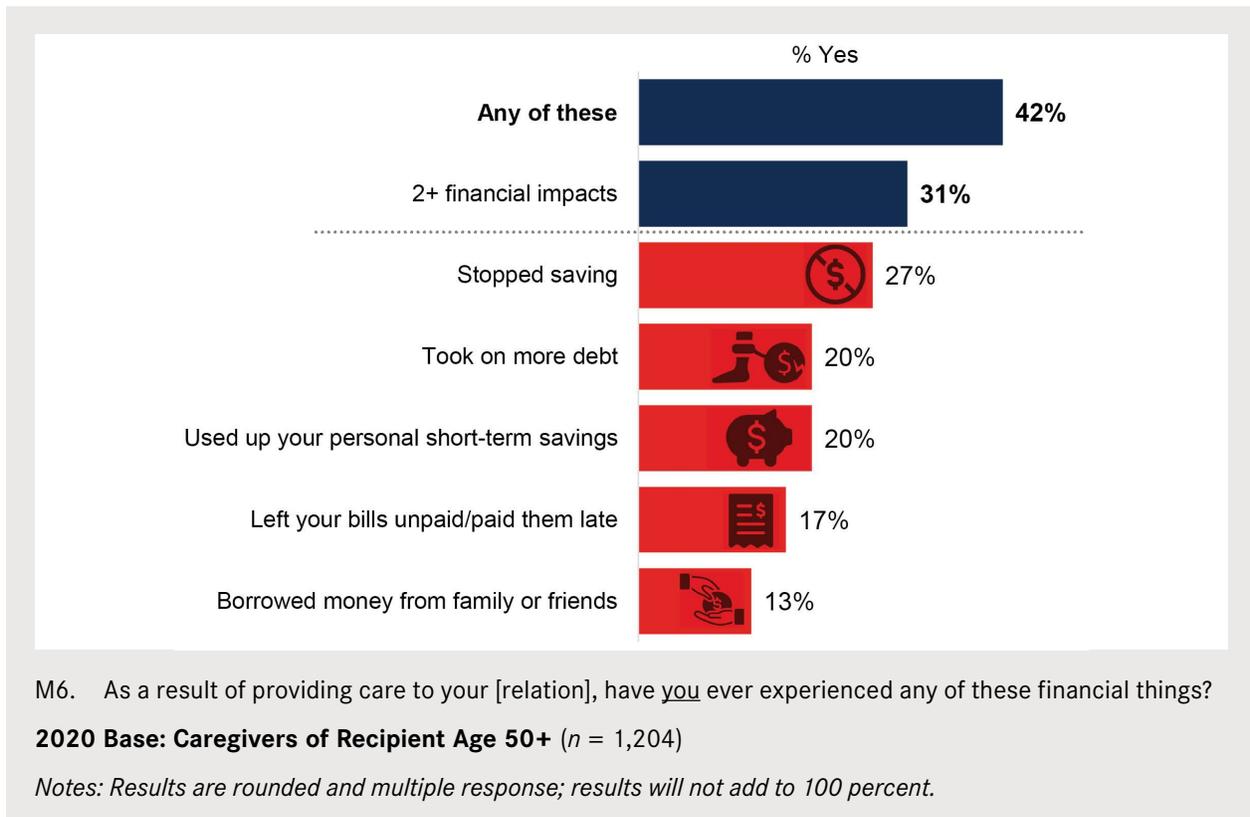
- As might be expected, caregivers with an annual household income less than \$30,000 are more likely than those with a household income of \$75,000 or more to rate their financial strain as high (21 percent vs. 14 percent, respectively).<sup>52</sup>
- Atop their other concerns, caregivers who are in more intense and more demanding care situations more often report high financial strain than do their peers. This includes:
  - Those who are in moderate- to high-intensity care situations (22 percent report high financial strain vs. 8 percent of those in low-intensity care situations);
  - Those who provide care for 21+ hours per week (25 percent vs. 12 percent of those who provide 20 or fewer hours of care); and
  - Those who feel alone (34 percent vs. 8 percent who do not feel alone).
- Financial strain seems to also be affected by not only the age of care recipient but also the age of the caregiver:
  - Those providing care to someone in the younger bracket of ages 50 to 64 are more likely to report high financial strain (22 percent vs. 13 percent of those providing care to someone 75+ years old).
  - Caregivers who themselves are younger than 50 years old are more likely to rate their financial strain as high (20 percent vs. 13 percent of those who themselves are age 50 or older).

<sup>52</sup> Level of education follows a similar pattern, with those who have at most some college reporting higher financial strain than those with a college degree or higher (18 percent vs. 12 percent).

## FINANCIAL IMPACTS

Caregivers' perception of financial strain is seemingly incongruent with actual financial challenges experienced due to caregiving. While 2 in 3 caregivers of recipients ages 50+ report low financial strain (65 percent rating a 1 or 2 on a 5-point scale; see Figure 44 above), more than 4 in 10 caregivers of recipients ages 50+ have experienced at least one financial impact as a result of caregiving (42 percent). Even further, 31 percent who have experienced two or more financial impacts (see Figure 45), suggesting that caregivers may be more impacted than they indicate.

**Figure 45. Financial Impacts as Result of Caregiving**



In terms of savings, 27 percent of caregivers have stopped saving, 20 percent have used up their personal short-term savings, and 11 percent have used long-term savings (like retirement or education accounts) to pay for other things. With regard to debt, one in five has taken on more (20 percent), while 13 percent have borrowed money from friends or family. Very few report they have missed or were late paying student loans (4 percent), while 2 percent have filed for bankruptcy (medical or personal).

In terms of bills and living expenses, 1 in 6 caregivers has left bills unpaid or paid them late (17 percent), and 1 in 10 has been unable to afford basic expenses like food (10 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 (9 percent), while 8 percent put off when they planned to retire or decided never to retire.

- Lower-income caregivers are particularly affected by the financial implications of caregiving—they experience nearly twice the amount of financial impacts as caregivers with higher household incomes (2.1 impacts, on average, for caregivers with annual household incomes lower than \$50,000 vs. 1.2 impacts for caregivers with annual household incomes of \$50,000 or higher). Most commonly, they experience impacts related to saving (42 percent vs. 27 percent), debt (36 percent vs. 22 percent), and impacts related to bills or expenses (31 percent vs. 14 percent).
- As might be expected, those reporting higher financial strain also report a higher number of financial impacts (3.9 for those with high strain, 2.1 for those with moderate financial strain, and 0.7 for those with low financial strain). Additionally, groups that report higher financial strain, as seen above, also report experiencing a greater number of financial impacts. A large brunt is focused on caregivers in demanding situations, including primary caregivers, caregivers who provide care for longer periods of time, caregivers reporting higher intensity,<sup>53</sup> and caregivers who co-reside with their recipient.<sup>54</sup>
- Experience of financial impacts also spans across racial and ethnic groups: African American (2.1)<sup>55</sup> and Hispanic/Latinx (1.8) caregivers have experienced more financial impacts than have White caregivers (1.3).

53 High-intensity caregivers more often report lower annual household incomes (41 percent with less than \$50,000 vs. 31 percent among those in a lower-intensity care situation). There is a relationship between demanding care situations, household income, and financial impacts; however, additional research is needed to establish whether the financial strain and lower income come as a result of demanding care situations or whether financial strain and lower income (inability to afford additional help or services) result in unpaid caregivers taking on more—and therefore finding themselves in a more intense care situation.

54 Primary caregivers experience 1.6 impacts vs. 1.2 for non-primary caregivers. Those who provide care for 21+ hours per week experience 2.2 impacts vs. 1.2 impacts when providing 20 or fewer hours of care. Those who are in moderate- (1.3 impacts) and high- (2.2 impacts) intensity care situations experience greater impacts than those in low-intensity care situations (0.9 impacts). Those caregiving for five or more years report 1.9 impacts on average, vs. 1.4 impacts for those providing care between one and four years and 1.2 for those who provide care for less than a year. Those who co-reside with their recipient experience 2.2 impacts vs. 1.1 impacts for those who do not co-reside with their recipient, and those providing care to a spouse/partner experience 1.9 impacts, on average, vs. 1.3 impacts each for those providing care to some other relative or a non-relative.

55 African American caregivers have also experienced more financial impacts than Asian American caregivers (2.1 vs. 1.5 impacts).

As seen in Figure 46, caregivers of younger recipients are disproportionately affected by financial strain and financial impacts compared to older recipients.

**Figure 46. Financial Impacts by Recipient Age**

	50-64 (n = 256) A	65-74 (n = 274) B	75-84 (n = 334) C	85+ (n = 336) D
<b>Financial impacts</b> (average)	2.1 <sup>BCD</sup>	1.7 <sup>D</sup>	1.4 <sup>D</sup>	0.8
<b>Financial strain</b> (percent rating a 4 or 5 on a 5-point scale)	22% <sup>CD</sup>	16%	15%	11%
<b>Experienced Change in At Least One Impact Related to . . .</b>				
<b>Saving</b>	44% <sup>BCD</sup>	33% <sup>D</sup>	34% <sup>D</sup>	20%
Stopped saving	36% <sup>BD</sup>	27% <sup>D</sup>	29% <sup>D</sup>	15%
Used up personal short-term savings	29% <sup>CD</sup>	22% <sup>D</sup>	19% <sup>D</sup>	11%
Used up long-term savings, like retirement or education, to pay for other things	15% <sup>D</sup>	10%	10%	8%
<b>Debt</b>	38% <sup>CD</sup>	33% <sup>CD</sup>	22%	16%
Took on more debt	30% <sup>CD</sup>	23% <sup>CD</sup>	16%	13%
Borrowed money from family or friends	20% <sup>CD</sup>	16% <sup>D</sup>	11% <sup>D</sup>	4%
Missed or was late paying student loan	5%	6%	4%	3%
Filed for bankruptcy	5% <sup>C</sup>	2%	1%	2%
<b>Bills or Expenses</b>	29% <sup>CD</sup>	24% <sup>D</sup>	17% <sup>D</sup>	12%
Left bills unpaid or paid late	23% <sup>CD</sup>	21% <sup>CD</sup>	15%	10%
Was unable to afford basic expenses like food	18% <sup>BCD</sup>	9% <sup>D</sup>	9% <sup>D</sup>	4%
<b>Work</b>	19% <sup>D</sup>	14%	14%	11%
Had to start working, work more, or find a second job	15% <sup>CD</sup>	11% <sup>D</sup>	8% <sup>D</sup>	4%
Put off retirement or decided to never retire	9%	8%	8%	8%
<b>Home</b>	12% <sup>D</sup>	8% <sup>D</sup>	7% <sup>D</sup>	3%
Moved to a less expensive home, apartment, or other living arrangement	11% <sup>D</sup>	7% <sup>D</sup>	7% <sup>D</sup>	3%
Was evicted or had home foreclosed	1%	3% <sup>D</sup>	1%	<0.5%

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and multiple response; results will not add to 100 percent.

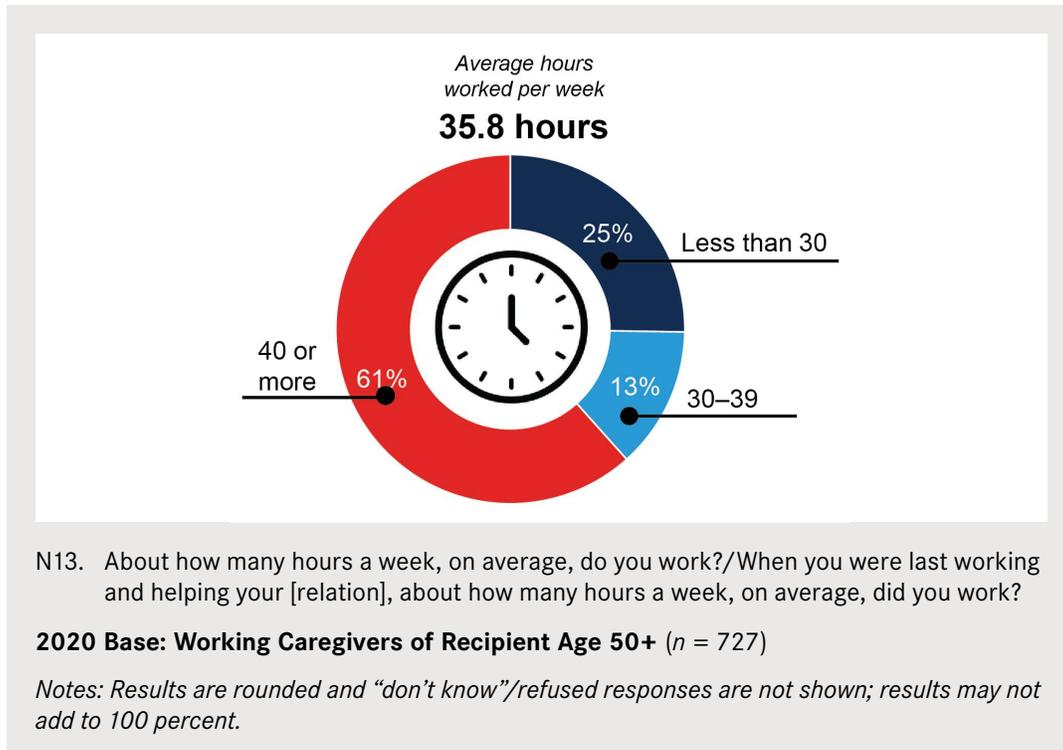
## I. IMPACT OF CAREGIVING ON WORK

### WORKING WHILE CARING

Sixty-two percent of 50+ caregivers were employed at some point in the past year while also caregiving, while 38 percent have not worked while caregiving during the past year.

Six in 10 employed<sup>56</sup> caregivers work full time (61 percent), and another 13 percent work between 30 and 39 hours per week. One in 4 work fewer than 30 hours a week (25 percent). On average, employed caregivers work 35.8 hours a week (see Figure 47).

**Figure 47. Hours Worked among Employed Caregivers**



#### CHANGE FOCUS: 2020 vs. 2015

- White caregivers more often report working while providing care (63 percent vs. 55 percent in 2015), while African American caregivers in 2020 work a higher average number of hours (37.0 hours on average vs. 33.0 hours on average in 2015).
- Caregivers in high-intensity care situations in 2020 more often report working while providing care (56 percent vs. 48 percent in 2015).

<sup>56</sup> The term *employed caregivers* refers to caregivers who were both working and providing care at the same time in the past 12 months and is used consistently in any reference to employment.

## SUBGROUPS: 2020

- Those caregivers with an annual household income of \$50,000 or more are more likely employed while caregiving (67 percent vs. 53 percent of those with a household income of less than \$50,000) and are more likely to work a higher average amount of hours (37.1 hours vs. 32.7 hours per week for those making less than \$50,000).<sup>57</sup>
- Those who provide care for 20 or fewer hours weekly are more likely to work while caregiving (66 percent vs. 53 percent of those providing 20 or fewer hours of care).
- Caregivers in low- to moderate-intensity care situations are more likely to work while providing care (66 percent vs. 56 percent in high-intensity care situations).
- Those providing care to a parent/parent-in-law (69 percent) are more likely to be employed while caregiving (vs. 47 percent of those providing care to a spouse/partner, 58 percent providing care to some other relative, or 46 percent of those providing care to a non-relative).
- As might be expected, caregivers who are younger than 65 years old are more likely to work while caregiving (71 percent vs. 25 percent of those who are older than 65 years old); on average, they work more hours (36.7 hours vs. 26.3 hours per week for those who are older than 65 years).
- Men are more likely to work while providing care (68 percent vs. 58 percent of women) and to work a higher average amount of hours per week (38.7 vs. 33.7 hours for women).

## TYPE OF EMPLOYMENT

More than half of employed caregivers of adults ages 50+ are paid hourly (54 percent), while 40 percent report being salaried. Thirteen percent of caregivers are self-employed or own their own business.

## SUBGROUPS: 2020

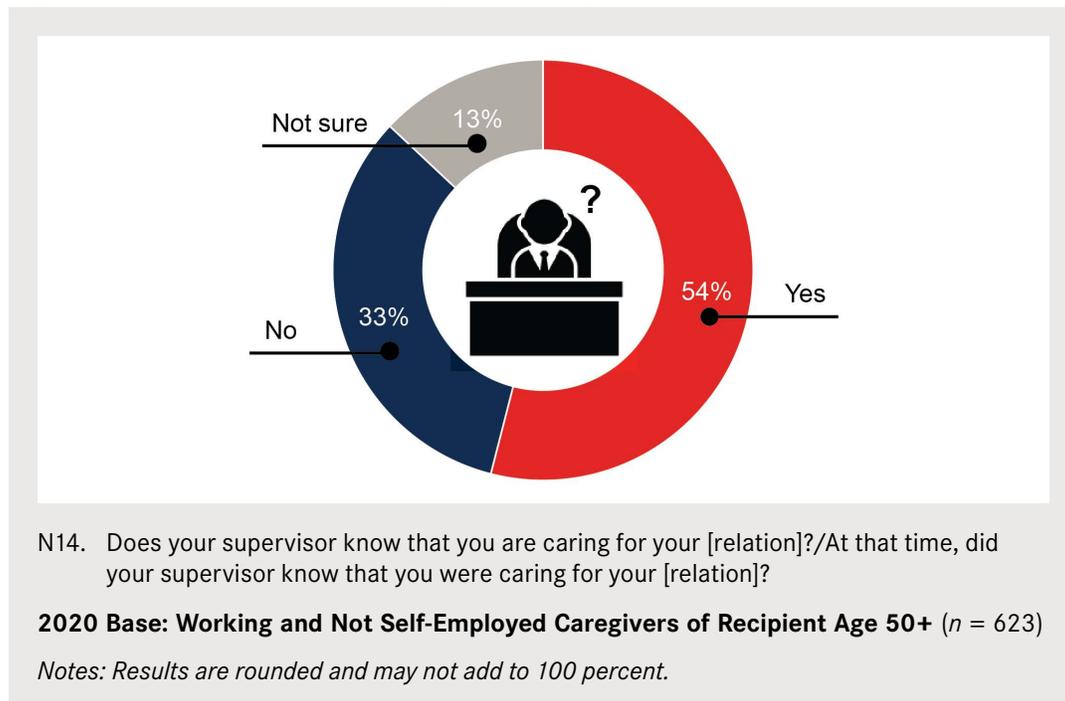
- White (52 percent), African American (56 percent), and Hispanic/Latinx (64 percent) caregivers are each more often working at a position that is paid hourly, while Asian American caregivers more often report having a salaried job (57 percent).
- Those who provide care for 21 hours or more weekly are more often working at a position that is paid hourly (61 percent vs. 52 percent of those who provide 20 or fewer hours of care).
- Those whose care recipient lives in a rural area are more likely to be paid hourly for the time they work than those whose care recipient does not live in a rural area (60 percent vs. 51 percent, respectively).
- Those with an annual household income of \$50,000 or more are more often in a salaried position (48 percent vs. 20 percent of those with a household income less than \$50,000).
- The youngest caregivers—those ages 18 to 49—more often work hourly (59 percent vs. 48 percent of those 50+ years old). 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 do salaried caregivers.

<sup>57</sup> The causal relationship between employment and income for caregivers is not clear. There is some evidence that caregivers in less intense or demanding care situations are more often working (see subgroups in this section) and have fewer impacts on their work due to caregiving (see subgroups below for workplace impacts), which may cause these caregivers to have higher household incomes due to their ability to work while providing care. However, it may also be that higher income caregivers are more able to afford support services or paid help (see subgroups above for paid help) that allow them to continue employment. Further research is needed.

## SUPERVISOR KNOWLEDGE OF CAREGIVER'S ROLE

Among employed 50+ caregivers who are not self-employed, about half report that their supervisor at work is aware of their caregiving responsibility (54 percent; see Figure 48).

**Figure 48. Supervisor Knowledge of Caregiver's Role**



### SUBGROUPS: 2020

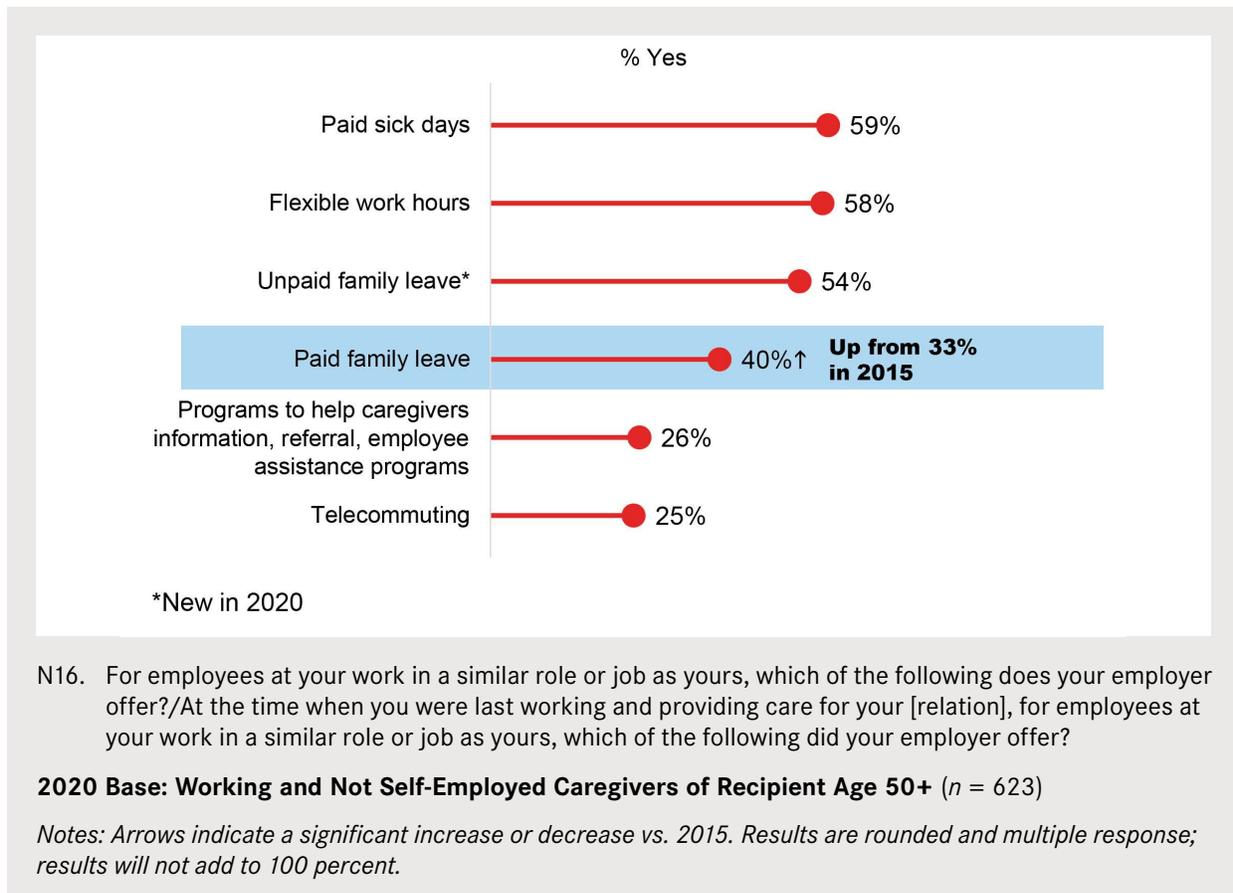
- It seems that the caregiving situation is what drives the need to share or alert the supervisor, as employed caregivers in more intensive care situations more often report their supervisor is aware of their caregiving role. This includes
  - Higher-hour caregivers (71 percent vs. 48 percent of those providing 20 hours or less of care per week);
  - Those who are in moderate- to high-intensity care situations (67 percent vs. 38 percent low-intensity situations);
  - Primary caregivers (58 percent vs. 49 percent non-primary); and
  - Caregivers of someone living with Alzheimer's or dementia (63 percent vs. 51 percent of those providing care to someone living without Alzheimer's or dementia).
- Both older caregivers (61 percent among those ages 50+ vs. 48 percent of caregivers ages 18 to 49) and those caring for an older recipient (59 percent when the recipient is age 75+ vs. 49 percent when the recipient is age 50 to 74) are more likely to say their supervisor is aware of their role as a caregiver.
- Those providing care to a relative are more likely to report that their supervisor is aware of their role as a caregiver than are those providing care to a non-relative (56 percent vs. 32 percent, respectively).
- White caregivers are more likely than Hispanic/Latinx caregivers to say their supervisor has knowledge of their role (59 percent vs. 41 percent, respectively).<sup>58</sup>

58 Half of African American and Asian American caregivers (53 percent and 49 percent, respectively) say their supervisor was aware of their role as a caregiver—not significantly different from White or Hispanic/Latinx caregivers.

## WORKPLACE BENEFITS FOR CAREGIVERS

Among working 50+ caregivers, 6 in 10 say their employer offers paid sick days<sup>59</sup> (59 percent), while 58 percent report having flexible work hours (see Figure 49). About half report having unpaid family leave (54 percent). Four in 10 say their employer offers paid family leave (40 percent, up from 33 percent in 2015),<sup>60</sup> but only a quarter say their employer offers employee assistance programs (EAPs; 26 percent) or telecommuting (25 percent).

**Figure 49. Workplace Benefits for Caregivers**



59 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>.

60 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, US 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>.

Caregivers working in a salaried position report higher household income (85 percent with \$50,000 or more in annual household income vs. 61 percent of those working in an hourly position) and are more likely to report nearly all benefits.<sup>61</sup> Even among higher-income caregivers (those with at least \$50,000 in annual household income), salaried workers more often report having each of these six benefits than do hourly workers, suggesting that caregivers who work in hourly positions less often have needed benefits that may help them maintain both their caregiving and employee roles.<sup>62</sup>

In recent years, some workplace supports for employed family caregivers have received increased attention from the public and private sectors, and several states and municipalities have moved forward to enact paid family leave programs and paid sick day 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.<sup>63</sup> 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.<sup>64</sup>

#### CHANGE FOCUS: 2020 vs. 2015

- Those who are providing care to someone age 85+ in 2020 are more likely to report having paid family leave (36 percent vs. 23 percent of those in 2015).
- Those who are providing care to someone age 50 to 64 in 2020 are more likely to report having flexible work hours (60 percent vs. 43 percent of those in 2015). Similarly, African American caregivers more often report flexible work hours (65 percent vs. 49 percent in 2015).
- Caregivers who are 50 years of age or older in 2020 are more likely to have paid sick days (64 percent vs. 55 percent in 2015) and paid family leave (42 percent vs. 31 percent in 2015).

## 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 caregiving responsibilities, sometimes caregivers choose to or are forced to make changes to their work situation. Six in 10 caregivers of recipients ages 50+ report having experienced at least 1 impact or change to their employment situation as a result of caregiving (60 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 working hours (14 percent), taking a leave of absence (13 percent), or receiving a warning about performance or attendance (7 percent; see Figure 50). On average, caregivers report having experienced 1.1 work impacts.

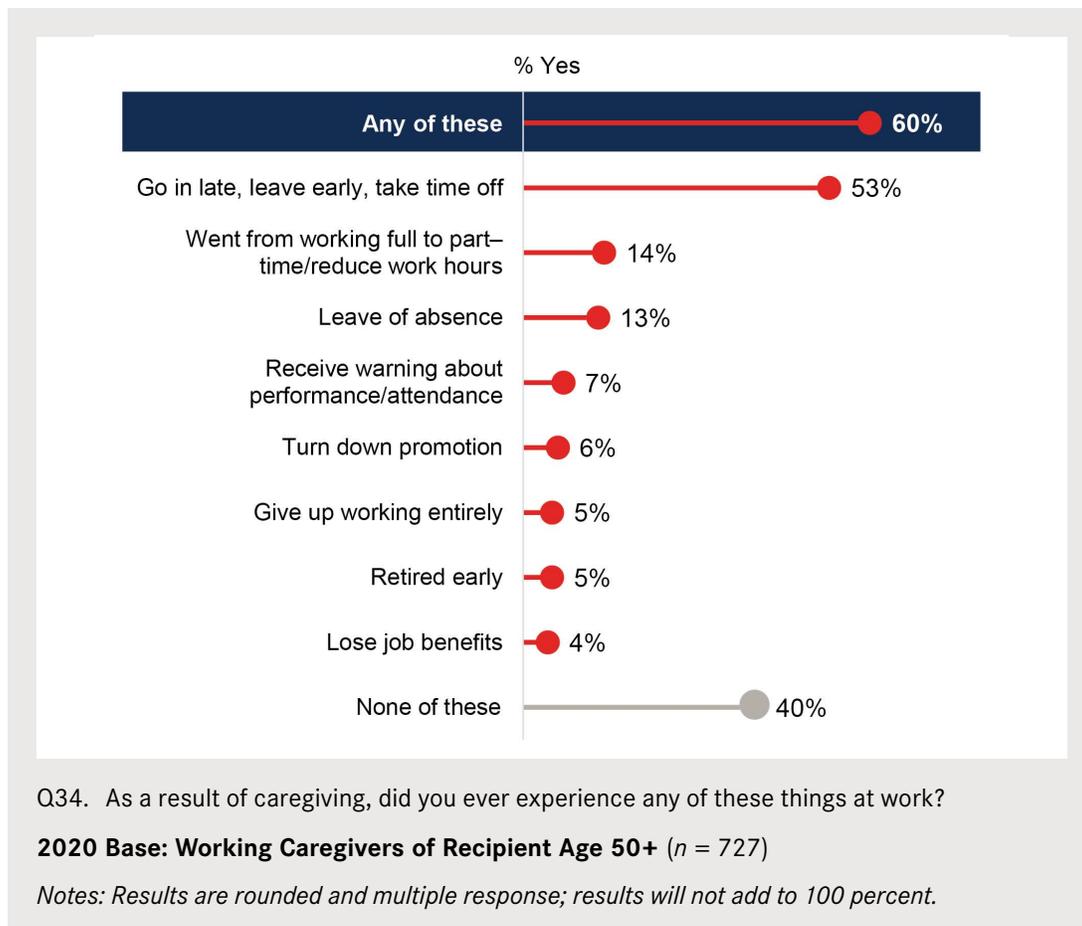
61 Salaried working caregivers more often report benefits than working caregivers who are paid by the hour: having telecommuting (42 percent vs. 13 percent hourly); programs like information, referrals, counseling, or EAP (36 percent vs. 18 percent); paid sick days (81 percent vs. 43 percent); paid family leave (52 percent vs. 32 percent); and unpaid family leave (65 percent vs. 46 percent). The only benefit that is not significantly more common for salaried working caregivers is flexible work hours (61 percent, not significantly different from 56 percent of those paid hourly for their employment).

62 Salaried working caregivers with higher annual household incomes (\$50,000 or more) more often report benefits than working caregivers who are paid hourly: having telecommuting (44 percent vs. 14 percent hourly); programs like information, referrals, counseling, or EAP (39 percent vs. 22 percent); paid sick days (83 percent vs. 49 percent); paid family leave (54 percent vs. 31 percent); unpaid family leave (70 percent vs. 50 percent); and flexible work hours (63 percent vs. 53 percent of those paid hourly for their employment).

63 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).

64 See National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2020*.

**Figure 50. Work Impacts as a Result of Caregiving**



**SUBGROUPS: 2020**

- Even though 50+ caregivers who are in more demanding situations are less likely to be employed while caregiving, they more often report a higher average number of work impacts due to providing care:
  - Primary caregivers (1.3 vs. 0.8 impacts for non-primary caregivers), notably more often going in late/leaving early, cutting back on hours, losing job benefits, or giving up work entirely;
  - Those who provide 21+ hours of care per week (1.6 vs. 0.9 impacts for those who provide 20 or fewer hours of care), notably more often taking a leave of absence, cutting back on hours, losing job benefits, giving up work entirely, or receiving a warning about their performance or attendance;
  - Those who are in high-intensity care situations (1.5 impacts vs. 0.7 for those in low-intensity and 0.9 impacts for those in moderate-intensity care situations), including more often taking a leave of absence, cutting back on hours, giving up work entirely, or receiving a warning about work performance/attendance;
  - Those caregivers with high financial strain (2.0 impacts vs. 0.8 and 1.1 impacts for those with low-to-moderate financial strain, respectively); and
  - Those with household incomes less than \$50,000 (1.3 impacts vs. 1.0 for those who make \$50,000 or more).
- Those who provide care to a spouse/partner report more work impacts (1.4 vs. 0.9 impacts for those providing care to a non-relative), including going in late/leaving early, taking a leave of absence, or giving up work entirely.

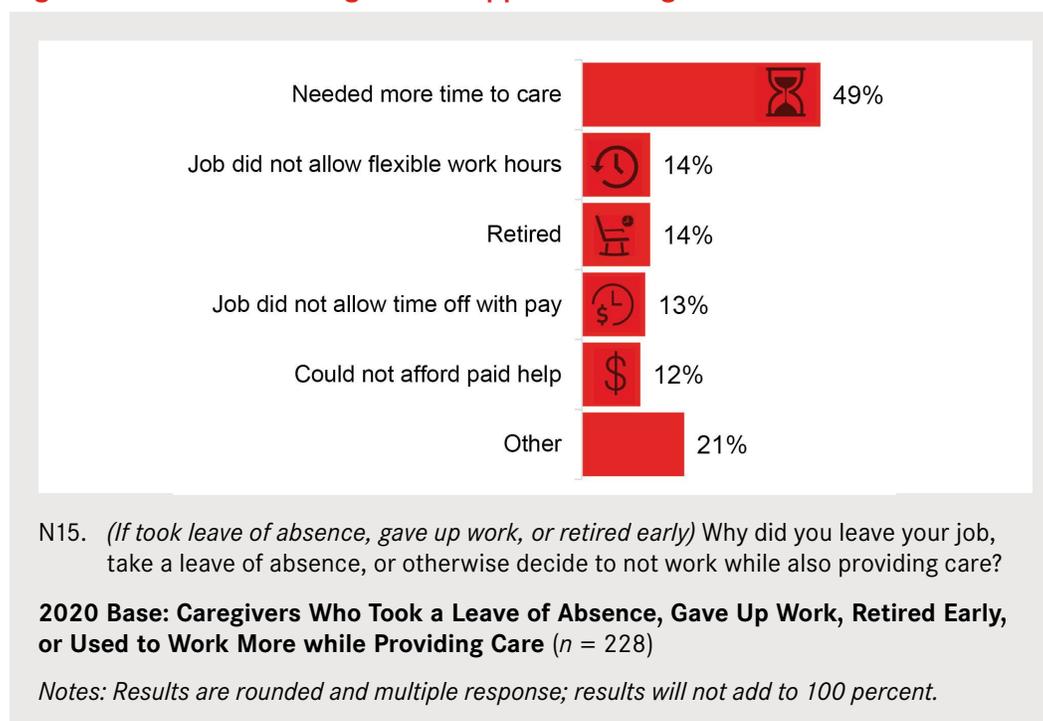
- Those providing care to someone living with Alzheimer’s or dementia are more likely to experience a higher average number of work impacts (1.3 vs. 0.9 impacts for those who provide care to someone without Alzheimer’s or dementia), including going in late/leaving early, retiring early, and receiving a warning about work performance or attendance.

## REASONS FOR LEAVING WORK

Among caregivers of adults ages 50+ who have not worked while providing care in the past 12 months, 22 percent worked at some point while providing care to their recipient.<sup>65</sup>

Caregivers of someone age 50+ who left their position, either sometime in the past year or ever while also caregiving, most commonly did so because they needed more time to care for their recipient (49 percent). Fewer said their job didn’t allow flexible work hours or that they retired (14 percent each). Similar shares of caregivers say their job did not allow time off with pay (13 percent), or they could not afford paid help (12 percent; see Figure 51).<sup>66</sup>

**Figure 51. Reasons Caregivers Stopped Working**



## DISCRIMINATION

Few caregivers of adults ages 50+ report feeling that their responsibilities as a caregiver led to them being penalized or discriminated against at work (6 percent).<sup>67</sup>

<sup>65</sup> This past working while providing care is more common among caregivers under age 65 (25 percent) than it is among caregivers already at retirement age or older (15 percent of those ages 65+).

<sup>66</sup> 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.

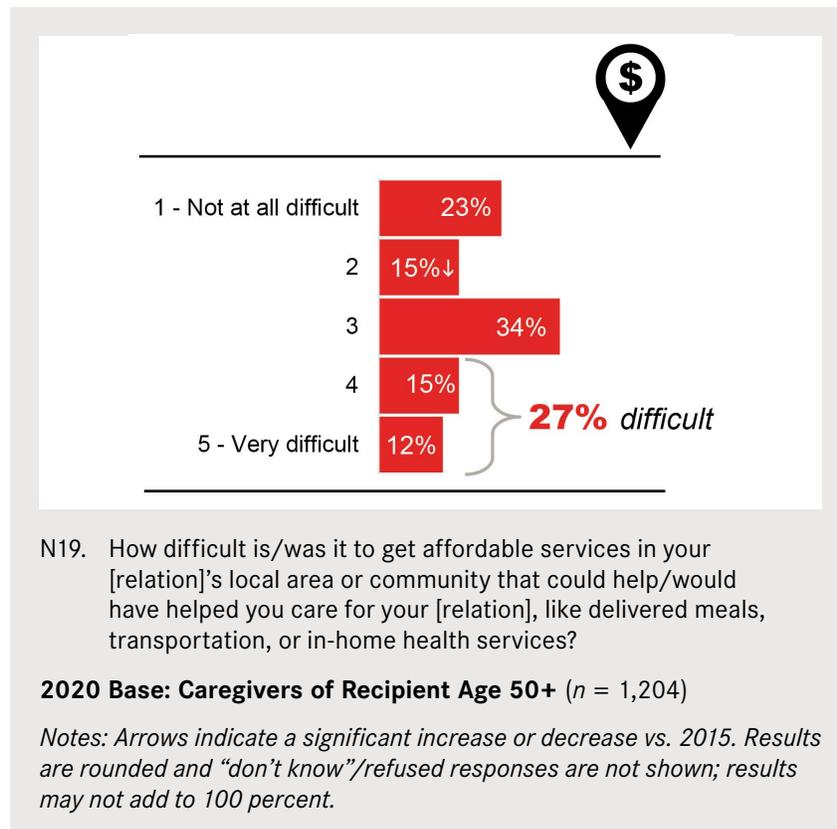
<sup>67</sup> As of 2016, at least 15 localities or states (including the District of Columbia) have laws to protect workers from employment discrimination; see <http://www.longtermcorecard.org/publications/fs-protecting-family-caregivers-from-employment-discrimination>.

## J. SERVICES, SUPPORT, AND INFORMATION

### AFFORDABILITY OF SERVICES

One in four caregivers of adults ages 50 or older say it is difficult to get affordable services in their recipient's community, like home-delivered meals, transportation, or in-home health services, that would help with the recipient's care (27 percent rating a 4 or 5 on a 5-point scale; see Figure 52), while another 34 percent feel it is moderately difficult.

**Figure 52. Affordability of Services in Recipient's Area**



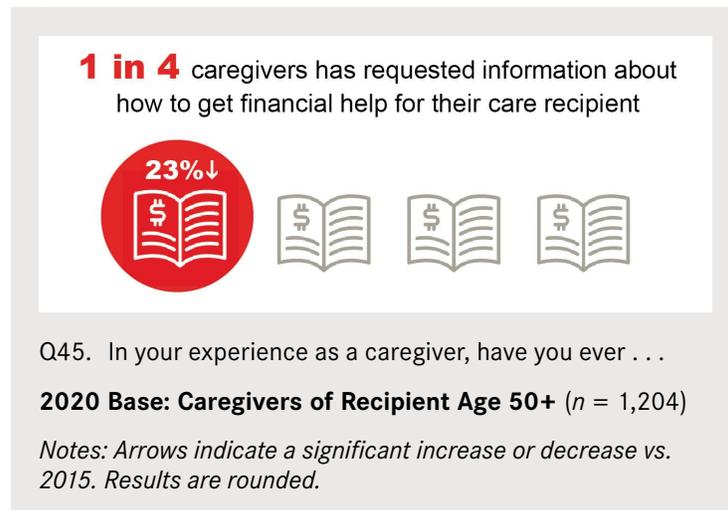
#### SUBGROUPS: 2020

- Those providing care to someone in the 65 to 84 age range are more likely to report difficulty finding affordable services (30 percent) compared with those caring for the oldest-old (21 percent when recipient is age 85+).
- Caregivers ages 18 to 49 are more likely to say it is difficult to find affordable services (31 percent vs. 23 percent of caregivers ages 50 or older).
- Again, those in the most intensive care situations more often report difficulty finding affordable services, including:
  - Those in a high-intensity care situations (36 percent vs. 21 percent of those in low- to moderate-intensity care situations); and
  - Those providing care to someone living with Alzheimer's or dementia (34 percent vs. 22 percent of those caring for someone not living with Alzheimer's or dementia).

## FINANCIAL HELP FOR RECIPIENT

Just one in four caregivers of an adult age 50 or older have requested information about how to get financial help for their recipient (23 percent, down significantly from 27 percent; see Figure 53).

**Figure 53. Financial Help for Recipient**



### SUBGROUPS: 2020

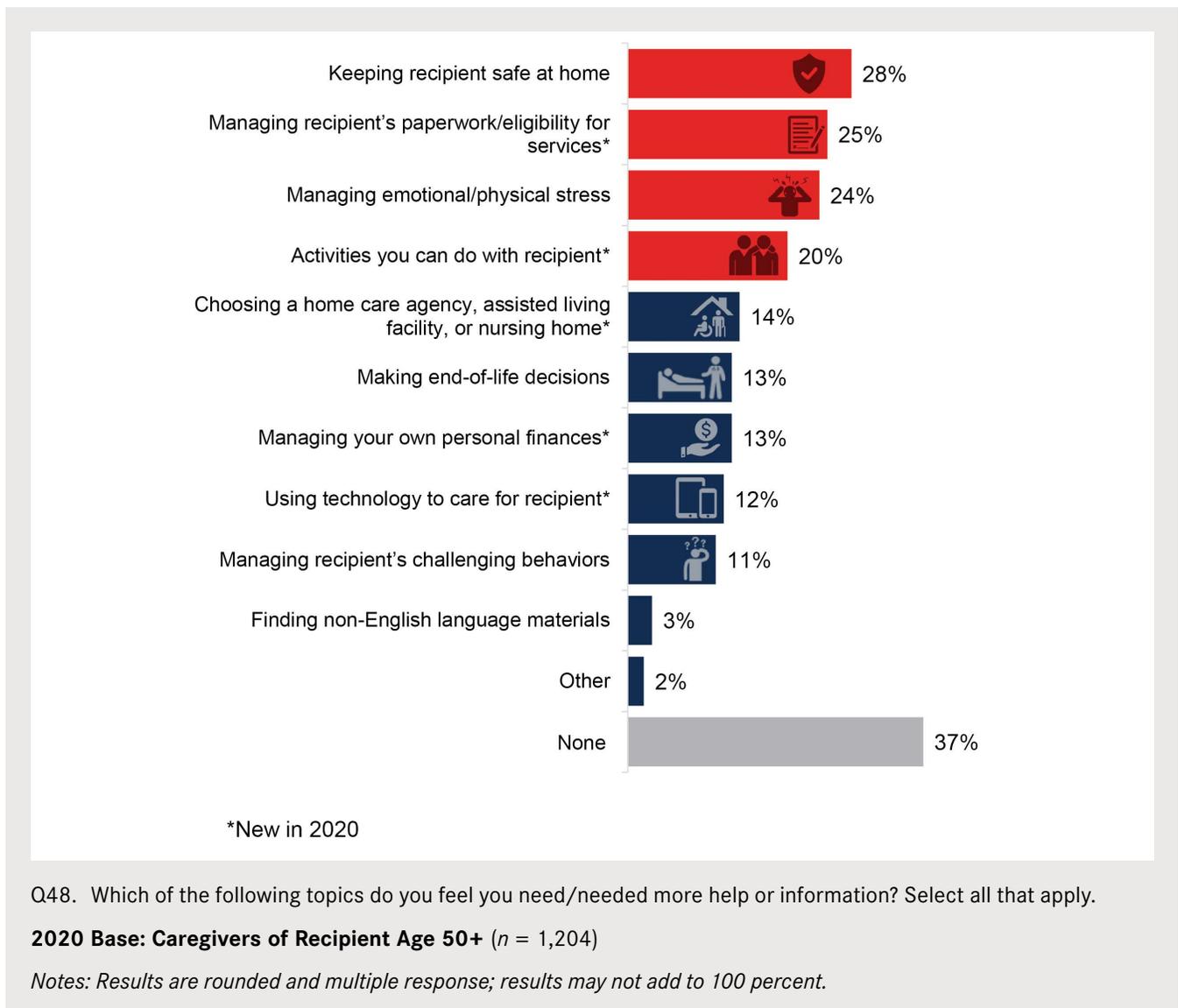
- As may be expected due to the financial pressures they report, those caregivers experiencing moderate-to-high financial strain are more likely to have requested information about how to get financial help for their recipient (34 percent vs. 17 percent of those with low financial strain).
- Those caregiving for a year or longer more often requested information (28 percent vs. 15 percent when caregiving less than a year).
- Those in high-intensity care situations are more likely to have requested information about how to get financial help for their care recipient (27 percent vs. 19 percent of those in low-intensity care situations).
- Those who feel alone are more likely to have requested information about how to get financial help for their recipient (31 percent vs. 20 percent of those who do not feel alone).
- Those providing care to someone living with Alzheimer's or dementia are more likely to have requested information (32 percent vs. 19 percent of those providing care to someone not living with Alzheimer's or dementia).

## CAREGIVER TRAINING AND INFORMATION NEEDS

Many caregivers of adults ages 50+ could use more information on or help with caregiving topics, with 63 percent needing help with at least one topic (see Figure 54).<sup>68</sup> Nearly 3 in 10 caregivers want information about keeping their recipient safe at home (28 percent), while 1 in 4 want help figuring out forms, paperwork, and eligibility for service and managing their own emotional or physical stress (25 percent and 24 percent, respectively). One in 5 also want information on activities they could do/have done with their recipient (20 percent).

About one in eight caregivers needs help with critical care decisions for their recipient, such as choosing home care, assisted living, or a nursing home (14 percent) or making end-of-life decisions (13 percent). 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). Few want non-English-language materials (3 percent). Few want non-English-language materials (3 percent).

**Figure 54. Caregiver Training and Information Needs**



68 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.

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.

A few groups of 50+ caregivers are especially likely to want help with many topics or tasks, including the following:

- Those who are in high-intensity care situations are more likely to feel they need information or help on nine topics (vs. than those in low-intensity care situations).<sup>69</sup>
- Those providing care to someone living with Alzheimer’s or dementia more often want help with six topics<sup>70</sup> (vs. those providing care to someone without Alzheimer’s or dementia).

Needing more help or information also varies by particular demographic groups:

- Those providing care to someone age 85+ are more likely than those caring for someone age 50 to 64 to feel they need help with managing their recipient’s challenging behaviors (15 percent vs. 8 percent, respectively), choosing a home care agency (19 percent vs. 6 percent, respectively), and making end-of-life decisions (16 percent vs. 10 percent, respectively), while those providing care to someone younger than 85 years old are more likely to feel they need help managing or handling their own personal finances (15 percent vs. 7 percent, respectively).
- Asian American caregivers are more likely than White, African American, and Hispanic caregivers to feel they need help or information on five topics.<sup>71</sup>

69 High-intensity caregivers would like more help or information about managing their own emotional or physical stress (32 percent); keeping their recipient safe at home (31 percent); activities they could do/have done with their recipient (25 percent); making end-of-life decisions (18 percent); choosing a home care agency, assisted living facility, or nursing home (17 percent); managing or handling their own personal finances (16 percent); managing their recipient’s challenging behaviors (14 percent); using technology to care for their recipient (14 percent); and finding non-English-language materials (5 percent).

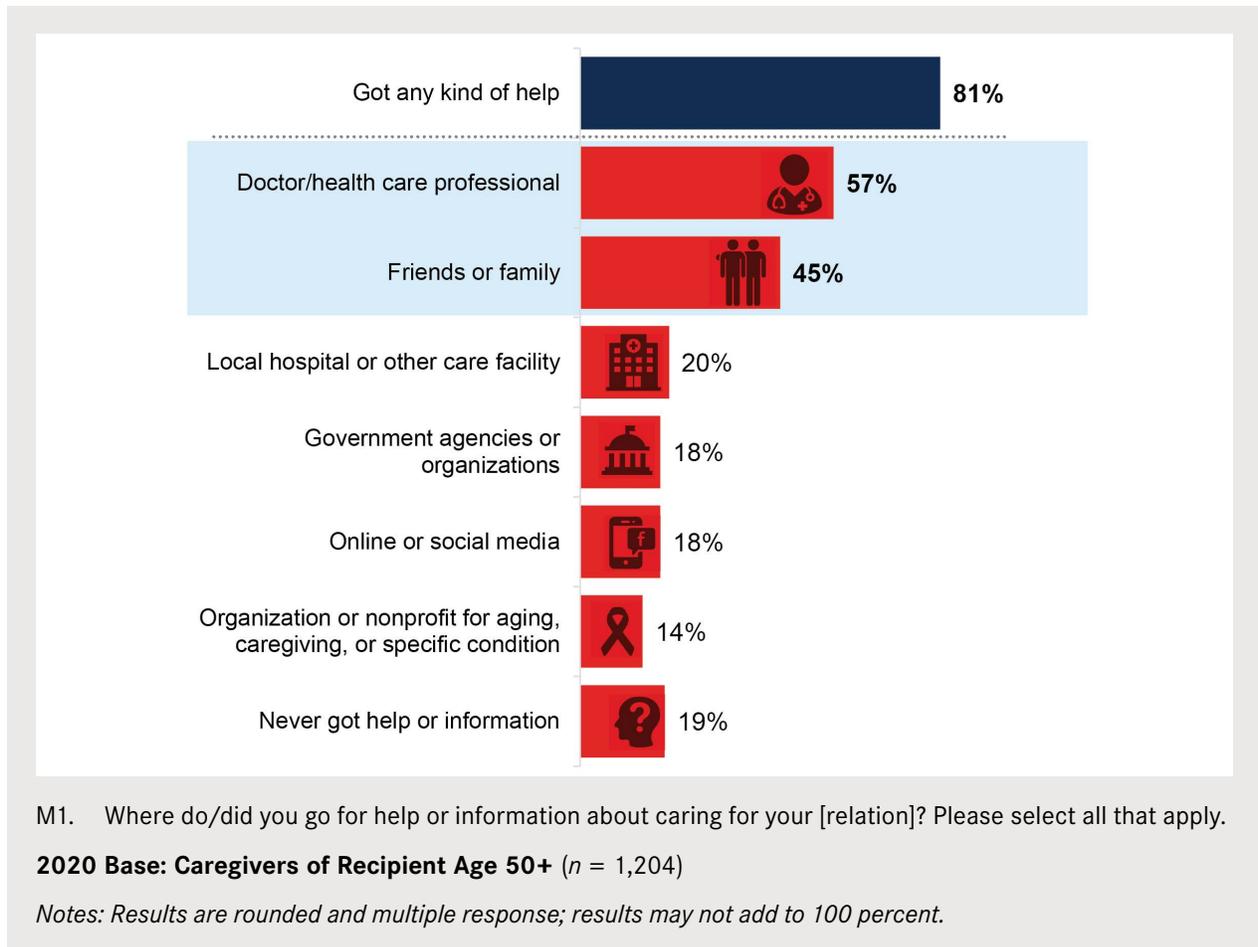
70 Caregivers of someone living with Alzheimer’s or dementia would like more help or information about managing their own emotional or physical stress (30 percent), figuring out forms (30 percent), managing challenging behaviors (26 percent), choosing a home care agency/assisted living/nursing home (24 percent), making end-of-life decisions (19 percent), and using technology to care for their recipient (16 percent).

71 Asian American caregivers would like more help or information about figuring out forms (44 percent), managing their own emotional or physical stress (38 percent), using technology to care for their recipient (30 percent), choosing a home care agency/assisted living/nursing home (24 percent), and finding non-English-language education materials (16 percent).

## SOURCES OF HELP OR INFORMATION

Most 50+ caregivers report having at least one source of help or information about providing care (81 percent), though 19 percent have never gotten any help or information. Most commonly, caregivers of someone age 50+ rely on health care professionals (57 percent; see Figure 55), followed by family and friends (45 percent). One in five relies on their local hospital or care facility (20 percent). Similar shares of caregivers rely on government agencies or organizations or online or social media (18 percent each). Seeking out help or information about providing care may be related to assistance with ADLs<sup>72</sup>—caregivers who help their recipient with any of the aforementioned ADLs report having turned to a higher average number of sources for help or information (1.9 sources vs. 1.5 sources when the caregiver performs no ADLs).

**Figure 55. Sources of Help or Information Used by Caregivers**



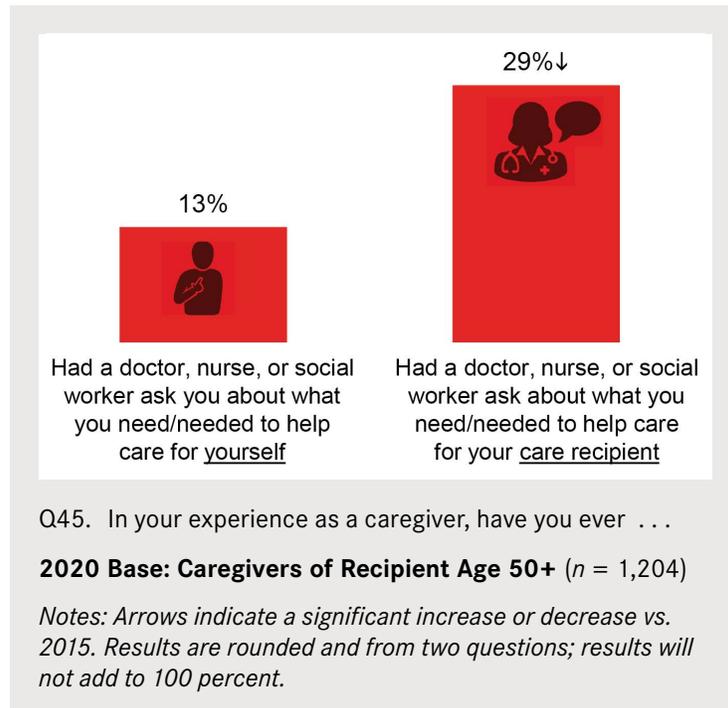
72 ADLs include helping a care recipient with getting in and out of beds and chairs, getting dressed, getting to and from the toilet, bathing or showering, feeding, or dealing with incontinence.

- Interestingly, those caregivers who feel alone do not report more use of help overall, but are more likely to have used a local hospital or other care facility (25 percent vs. 18 percent of those who do not feel alone); online or social media (25 percent vs. 17 percent); or an organization or nonprofit for aging, caregiving, or a specific condition (20 percent vs. 12 percent) for help or information, suggesting that caregivers who feel alone turn to more varied sources.
- Caregivers who are 50+ years old themselves are more likely to have gone to a doctor for help or information (63 percent vs. 49 percent of caregivers younger than 50 years old), while caregivers who are younger than 50 years old are more likely to have gone online or social media for help or information (23 percent vs. 15 percent of caregivers older than 50 years old).
- Women who provide care are more likely to have gone to friends or family for help or information (48 percent vs. 40 percent of men who provide care).
- Those whose care recipient lives in an urban or suburban setting are more likely than those whose care recipient lives in a rural setting to have gone to a doctor or health care professional for help or information (59 percent vs. 52 percent, respectively).
- Other groups of caregivers of someone 50+ years old more often report having at least one source for help or information than their counterparts, including:
  - Those who are providing care to someone age 85+ (83 percent vs. 75 percent of those providing care to someone 50 to 64 years old);
  - Asian American (90 percent) and African American (86 percent) caregivers in comparison to Hispanic/Latinx (74 percent) caregivers;
  - Caregivers with at least a college degree (85 percent vs. 76 percent of those with a high school degree or less);
  - Those in moderate- to high-intensity care situations (85 percent vs. 76 percent of low-intensity caregivers);
  - Caregivers of someone living with Alzheimer's or dementia (89 percent vs. 78 percent of those providing care to someone without these conditions); and
  - Long-term caregivers (88 percent of those providing care for five years or longer vs. 78 percent of those providing care for less than five years).

## CONVERSATIONS WITH HEALTH CARE PROVIDERS

While nearly 2 in 3 caregivers of adults ages 50+ reports needing help with at least one topic related to caregiving, fewer than 3 in 10 say a health care provider, such as a doctor, nurse, or social worker, has asked them about what they needed to care for their recipient (29 percent), down significantly from 33 percent in 2015 (see Figure 56). Despite experiencing health issues and having difficulty taking care of themselves, just 13 percent of 50+ caregivers say a health care provider has asked what they need to care for themselves.

**Figure 56. Conversations with Health Care Providers**



### CHANGE FOCUS: 2020 vs. 2015

- Some 50+ caregivers are less often having conversations with health care professionals about their care recipient's needs in 2020 than in 2015, including:
  - Caregivers of 50+ recipients who live in a rural area (27 percent vs. 36 percent in 2015);
  - Those providing care to a parent/parent-in-law (30 percent vs. 36 percent in 2015);
  - Caregivers whose recipient lives with them (30 percent vs. 38 percent in 2015); and
  - Low-income caregivers (25 percent of those with an annual household income less than \$30,000 vs. 34 percent in 2015).

**SUBGROUPS: 2020**

- Those providing care to a relative are more likely to have had a health care professional ask them what they needed to care for their recipient (31 percent vs. 17 percent of those providing care to a non-relative), while those providing care to a spouse/partner (21 percent) are more likely than those providing care to a parent/parent-in-law (12 percent) or a non-relative (10 percent) to have had a health care professional ask them what they needed to care for themselves.
- African American (37 percent) and Asian American <sup>73</sup> (37 percent) caregivers are more likely than White (28 percent) caregivers to have had a health care professional ask them what they needed to care for their recipient.<sup>74</sup>
- Primary caregivers are more likely to have had a health care professional ask them what they needed to provide care to their recipient (32 percent vs 26 percent of non-primary caregivers).
- Those providing care to someone living with Alzheimer’s or dementia are more likely to have had a health care professional ask them what they needed to take care of their recipient (38 percent vs. 27 percent of those caring for someone without these conditions) *and* what they needed to take care of themselves (21 percent vs. 10 percent).

As care situation intensity and hours of care increase, so too does the likelihood that caregivers have had conversations with health care professionals about needs, as shown in Figure 57. However, a majority still report *not* having these conversations.

**Figure 57. Discussion with Care Professionals by Level of Care Index (Intensity) and Hours of Care**

Had Conversation about . . .	Level of Care Index			Hours of Care	
	Low Intensity (n = 518) A	Moderate Intensity (n = 209) B	High Intensity (n = 472) C	0-20 Hours (n = 834) D	21+ Hours (n = 365) E
<b>What is needed to care for recipient</b>	19%	30% <sup>A</sup>	41% <sup>AB</sup>	25%	39% <sup>D</sup>
<b>Self-care needs</b>	8%	10%	21% <sup>AB</sup>	10%	21% <sup>D</sup>

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and from two questions; results will not add to 100 percent.

73 Asian American caregivers are also more likely than Hispanic/Latinx caregivers to have had a health care professional ask them what they needed to care for their recipient (37 percent vs. 26 percent, respectively).

74 White caregivers more often report providing care to a non-relative than both African American and Asian American caregivers, perhaps helping explain some of these differences. Further research is needed to understand the multicultural context of caregiver-provider interactions.

## DESIRED CONVERSATIONS WITH HEALTH CARE PROVIDERS

The majority of caregivers of adults ages 50+ are not having these conversations about their needs, though many would like to. When indicating if these kinds of conversations would be helpful, nearly a third (32 percent) say they would like to be asked about their needs to help care for their recipient and about one in four (23 percent) show interest in conversations about self-care.<sup>75</sup>

### 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. These groups include the following:

- Caregivers of recipients ages 50 to 64 are more likely than those caring for the oldest-old (those 85+ years old) to want conversations about what they need to take care of their recipient (37 percent vs. 29 percent, respectively) *and* themselves (29 percent vs. 18 percent, respectively).
- Caregivers who are younger than 50 years old are more likely to want conversations about recipient care (38 percent vs. 27 percent of caregivers ages 50+) and self-care (28 percent vs. 18 percent).
- Asian American caregivers (50 percent) are more likely than White (29 percent), African American (34 percent), and Hispanic/Latinx caregivers (36 percent) to want to have conversations about their recipient's care, while both Asian American (30 percent) and African American (30 percent) caregivers are more likely than Hispanic/Latinx caregivers (18 percent) to want to have self-care conversations.
- Caregivers facing higher-intensity care situations and higher financial strain as a result of providing care more often want both of these kinds of conversations.<sup>76</sup>

Other groups of caregivers who are more interested in conversations about caring for their recipient include those providing care to a parent/parent-in-law (36 percent vs. 24 percent caring for a spouse/partner and 26 percent caring for some other relative) and working caregivers (35 percent vs. 27 percent of caregivers who do not work).

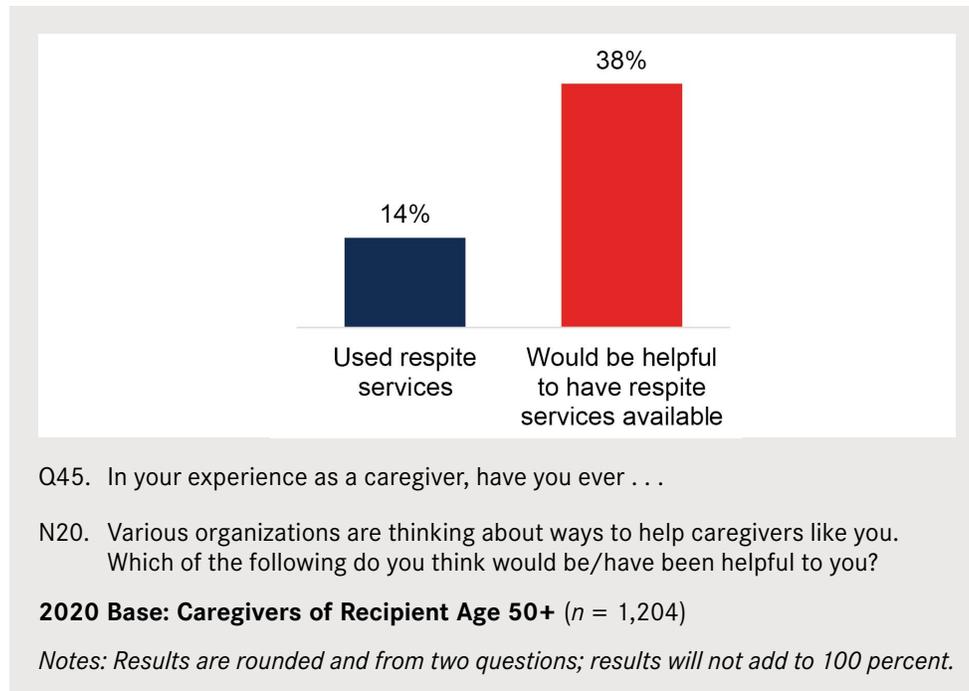
75 Data were not trended to 2015 as the structure of the question asked changed (from helpfulness of six policy options in 2015 to helpfulness of just three policy options in 2020), so results are not comparable.

76 Those in high-intensity care situations more often want recipient need conversations (35 percent vs. 28 percent of those in low-intensity care situations) and self-care conversations (29 percent vs. 17 percent of those in low-intensity care situations). Those with moderate-to-high financial strain are more likely to want to have conversations both about what they need to care for their recipient (39 percent vs. 28 percent of low financial strain) and about what they need to care for themselves (33 percent vs. 17 percent).

## RESPIRE SERVICES

Nearly 4 in 10 caregivers of recipients ages 50+ feel having respite services available would be helpful (38 percent, see Figure 58).<sup>77</sup> 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.<sup>78</sup>

**Figure 58. Respite Services**



### CHANGE FOCUS: 2020 vs. 2015

Particular groups of 50+ caregivers who, compared with in 2015, more often say having respite would be helpful to them include Asian American caregivers (49 percent vs. 16 percent in 2015), caregivers of rural-dwelling recipients (37 percent vs. 29 percent in 2015), and long-term caregivers (45 percent of those providing care for five or more years in 2020 vs. 37 percent in 2015).

### SUBGROUPS: 2020

- Those in high-intensity care situations are more likely to say respite would be helpful (48 percent of high intensity vs. 32 percent of low-to-moderate intensity) and to have used respite (19 percent vs. 8 percent of low-intensity caregivers).
- Groups more likely to say that respite services would be helpful include the following:
  - Those who feel alone (47 percent vs. 36 percent of those who do not feel alone);
  - Caregivers ages 18 to 64 (40 percent vs. 32 percent of caregivers 65 years of age or older);
  - Those providing care to someone living with Alzheimer's or dementia (48 percent vs. 35 percent of those providing care to someone without these conditions); and
  - Those caregiving for longer than a year (43 percent vs. 33 percent of those providing care for less than a year).

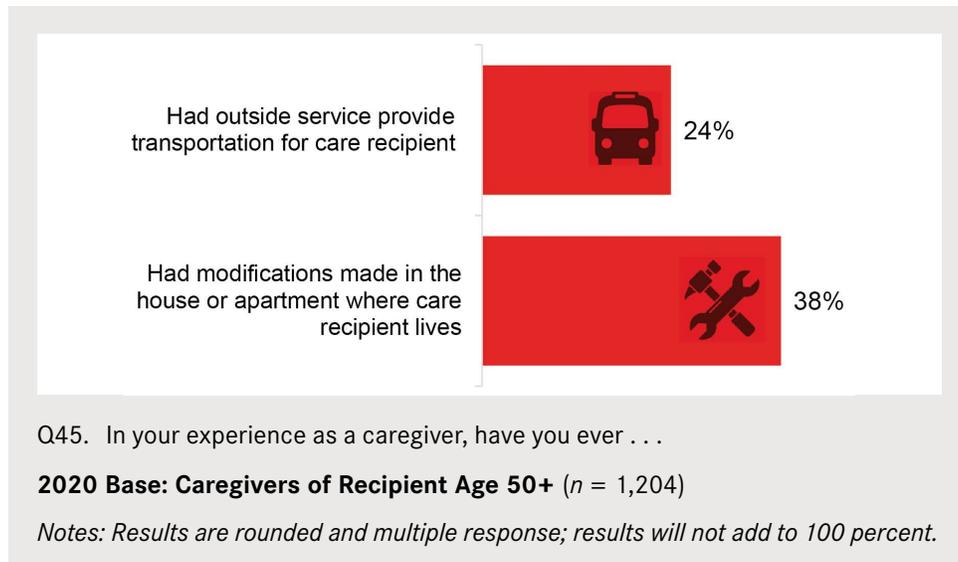
77 Data were not trended to 2015 as the structure of the question asked changed (from helpfulness of six policy options in 2015 to helpfulness of just three policy options in 2020), so results are not comparable.

78 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. In this study, use of respite care by family caregivers of older adults (ages 65+) was found to be 15.7 percent in 2015.

## USE OF CAREGIVER SUPPORT SERVICES

About two in five caregivers of recipients ages 50+ report they have had to make modifications to the home where their recipient lives in order to more easily provide care (38 percent; see Figure 59). One in four have used transportation services for their care recipient (24 percent).

**Figure 59. Use of Caregiver Support Services**



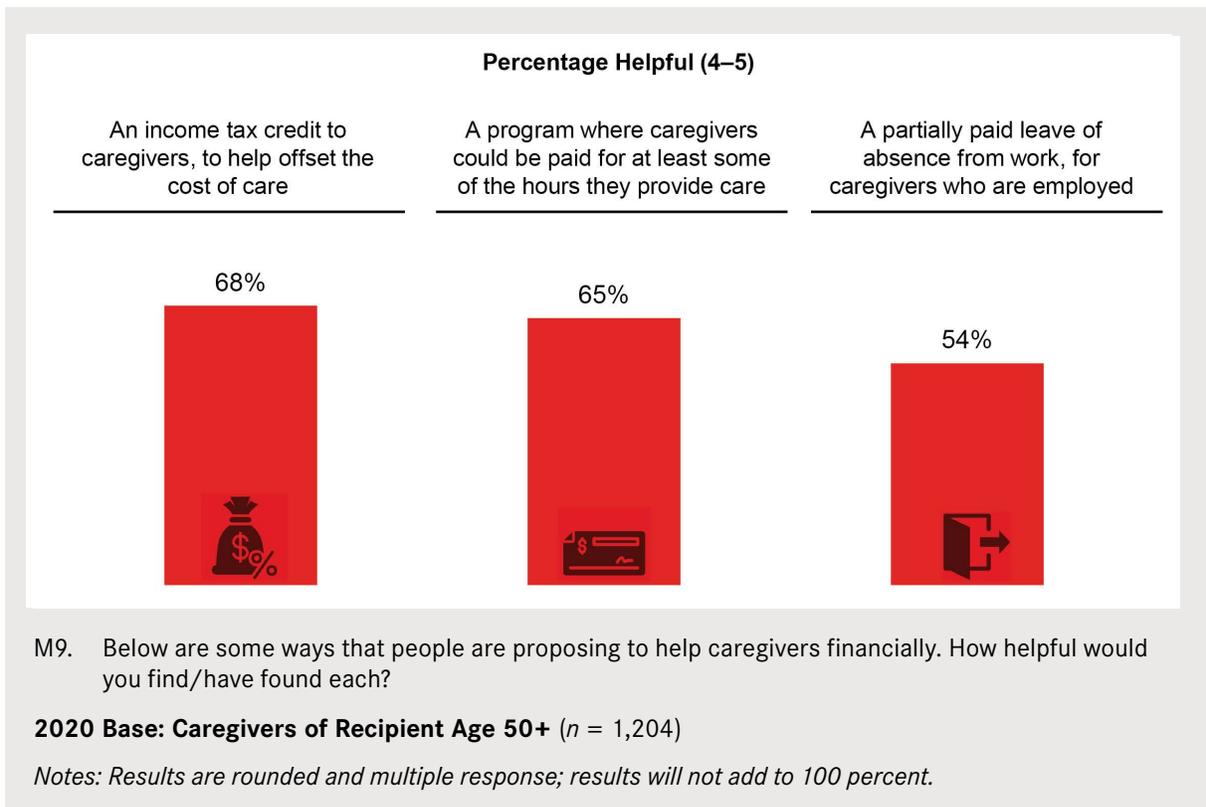
### SUBGROUPS: 2020

- Caregivers in longer-term or intensive care situations more often report both making modifications to their recipient's place of residence and using an outside transportation service, including:
  - Those who have been caregiving for five years or longer (44 percent made modifications vs. 33 percent of those providing less than a year of care; 30 percent used transportation services vs. 20 percent);
  - Caregivers who report their recipient is living with Alzheimer's or dementia (modifications: 46 percent vs. 35 percent of those providing care for someone without those conditions; transportation: 31 percent vs. 21 percent);
  - Caregivers of the oldest recipients age 85+ (modifications: 46 percent vs. 31 percent of those caring for someone 74 years or younger; transportation: 30 percent vs. 21 percent); and
  - Those in moderate- to high-intensity care situations (modifications: 48 percent vs. 26 percent of those in low-intensity care situations; transportation: 28 percent vs. 19 percent).
- Caregivers who more often make modifications to their recipient's residence include those whose recipient lives in an urban or suburban area (40 percent vs. 33 percent of caregivers of rural-dwelling recipients) and higher-income caregivers (43 percent of those with \$50,000 or more in annual household income vs. 29 percent of those with less).
- Caregivers who more often report use of transportation services for their age 50+ recipient include those who feel alone (29 percent vs. 21 percent of those not feeling alone) and those whose recipient does not live with them (26 percent vs. 20 percent of those co-residing with their recipient).

## 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 of recipients ages 50+ would find an income tax credit helpful (68 percent, shown in Figure 60), 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). These policies become even more important when looking at the employed population—60 percent of caregivers of recipients ages 50+ would find a partially paid leave of absence helpful (vs. 45 percent of those who did not work while caregiving).

**Figure 60. Policy Proposals for Caregiver Support**



### SUBGROUPS: 2020

- Groups especially interested in each of these three policy proposals include those who are in high-intensity care situations, caregivers ages 18 to 64, and women.<sup>79</sup>
- Caregivers who are more likely to say a program where they could be partially paid for their hours of care is helpful include those who feel alone (77 percent vs. 63 percent of those who do not feel alone) and African American (73 percent) and Hispanic/Latinx (74 percent) caregivers (vs. 60 percent of White caregivers).

<sup>79</sup> High-intensity caregivers are more likely to find the following helpful: an income tax credit (72 percent vs. 65 percent among low-intensity situation caregivers), a program to pay for hours of care (74 percent vs. 56 percent of low- and 63 percent of moderate-intensity caregivers), and a partially paid leave from work (60 percent vs. 48 percent of low-intensity). Caregivers ages 18 to 64 are more likely to find the following helpful: an income tax credit (69 percent vs. 59 percent of caregivers age 65+), a program to pay for hours of care (68 percent vs. 51 percent of caregivers age 65+), and a partially paid leave from work (58 percent vs. 36 percent of caregivers age 65+). Women are more likely to find the following helpful: an income tax credit (70 percent vs. 63 percent of men), a program to pay for hours of care (69 percent vs. 58 percent of men), and a partially paid leave from work (59 percent vs. 47 percent of men).

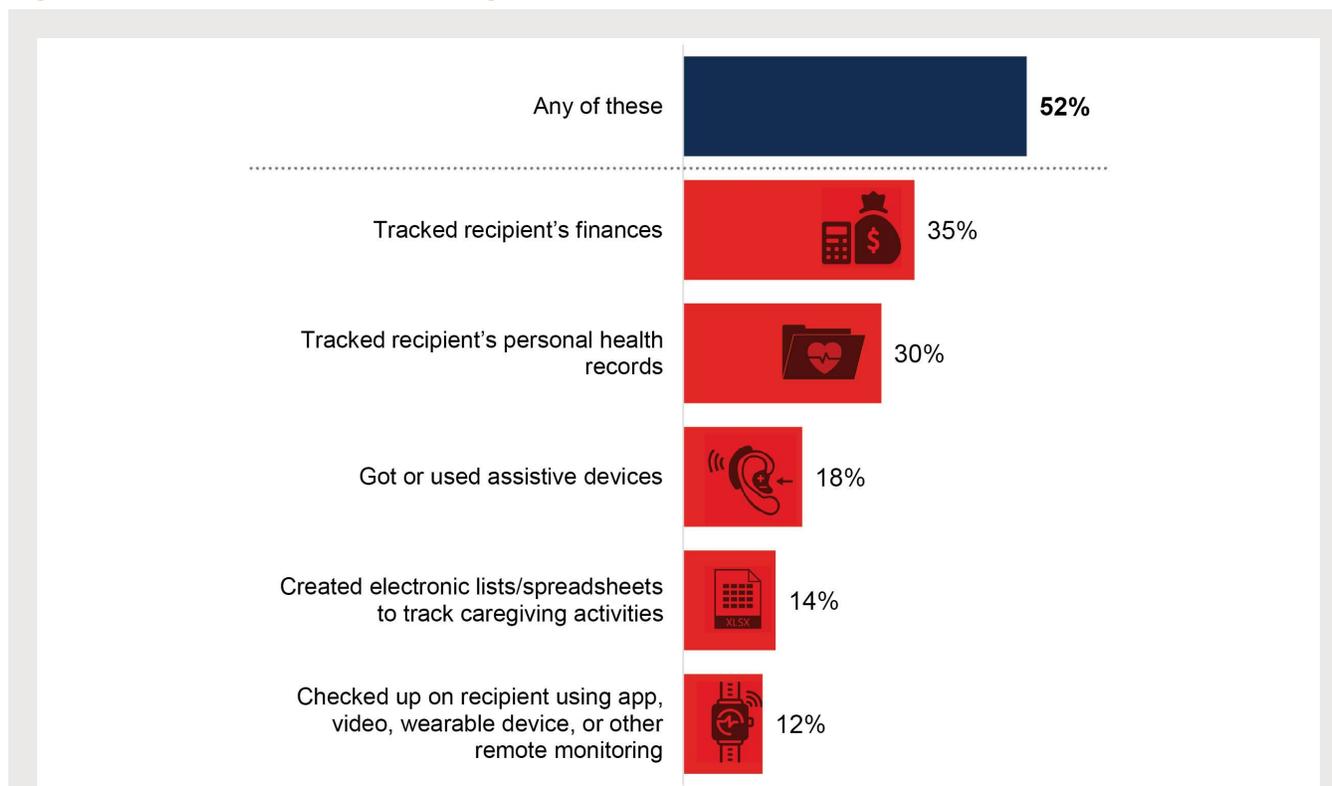
- Caregivers especially interested in a partially paid leave of absence from work include:
  - Caregivers of color (64 percent of African American, 67 percent of Hispanic/Latinx, and 64 percent of Asian American caregivers vs. 47 percent of White caregivers); and
  - Those providing care to a parent/parent-in-law (58 percent) or some other relative (54 percent vs. 39 percent of those providing care to a spouse/partner).
- Higher-income caregivers (70 percent vs. 63 percent of those with annual household incomes less than \$50,000) and employed caregivers (71 percent vs. 63 percent of caregivers who are not employed) are more interested in the income tax credit.

## K. TECHNOLOGY

### SOFTWARE AND MONITORING SOLUTIONS

Many experts feel that technology might help support caregivers. About half of 50+ caregivers have used at least one form of technology or software to help with caregiving (52 percent; see Figure 61). Most commonly, over 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 (18 percent) or apps, video, wearables, or other remote monitoring to check up on their recipient (12 percent). Fourteen percent have created electronic lists to track activities related to providing care.

**Figure 61. 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 50+ (n = 1,204)**

*Notes: Results are rounded and multiple response; results will not add to 100 percent.*

Caregivers of the oldest-old tend to use technology and software more often than those providing care to their younger counterparts: Those who are providing care to someone 85+ years of age (1.4 activities) more often have used at least one technology or software than those providing care to someone age 50 to 74 (0.8 activities for those 50 to 64 years old and 1.0 activities for those 65–74 years old), including tracking their recipient’s finances and using assistive devices.

Caregivers in more demanding care situations tend to lean on technology and software to help alleviate some of the intensity that goes along with their caregiving role:

- Primary caregivers more often use technology or software (1.2 activities vs. 0.9 activities for non-primary caregivers), including tracking their recipient’s finances and tracking their recipient’s personal health records.
- Those caregivers who feel alone more often use technology or software (1.6 activities vs. 1.0 activities for those who do not feel alone) and are more likely to have done nearly all activities with technology or software.<sup>80</sup>
- Those providing care to someone living with Alzheimer’s or dementia more often use technology and software (1.5 activities vs. 0.9 activities for those providing care for some other reason). They are also more likely to have done all 5 activities with technology or software.<sup>81</sup>

Other groups more often using technology and software include the following:

- African American (1.2 activities), Asian American (1.4 activities), and White caregivers (1.1 activities) more often use technology and software than do Hispanic/Latinx caregivers (0.9 activities), including creating electronic lists or spreadsheets to track activities related to caregiving and tracking their recipient’s personal health records.<sup>82</sup>
- Those providing care to a relative<sup>83</sup> more often use technology or software, including tracking their recipient’s finances (37 percent vs. 17 percent of those caregiving for a non-relative) and tracking their recipient’s personal health records (32 percent vs. 17 percent).
- Those with annual household incomes of \$50,000 or higher more often use technology and software (1.2 activities vs. 0.9 activities for those with household incomes less than \$50,000) and are more likely to have done nearly all activities with technology or software.<sup>84</sup>

80 This includes tracking their recipient’s finances (47% vs. 33% of those who do not feel alone); tracking their recipient’s personal health records (43% vs. 28%), getting or using assistive devices (25% vs. 16%); and creating electronic lists or spreadsheets to track activities relating to caregiving (24% vs. 13%). There are no differences in checking up on their recipient using an app, video, wearable device, or other remote monitoring (16% vs. 11%, not significant).

81 This includes tracking their recipient’s finances (47 percent); tracking their recipient’s personal health records (39 percent); gotten or used assistive devices (23 percent); creating online lists or spreadsheets to track activities relating to caregiving (19 percent); and checking up on their recipient using an app, video, wearable device, or other remote monitoring (19 percent).

82 Tracking a recipient’s health records is significant only for African American and Asian American caregivers when compared with Hispanic/Latinx caregivers.

83 On average, 1.2 activities when providing care to a parent/parent-in-law, 1.3 activities when providing care to a spouse/partner, and 1.1 activities when providing care to some other relative—each significantly higher than the 0.6 activities done by those providing care to a non-relative.

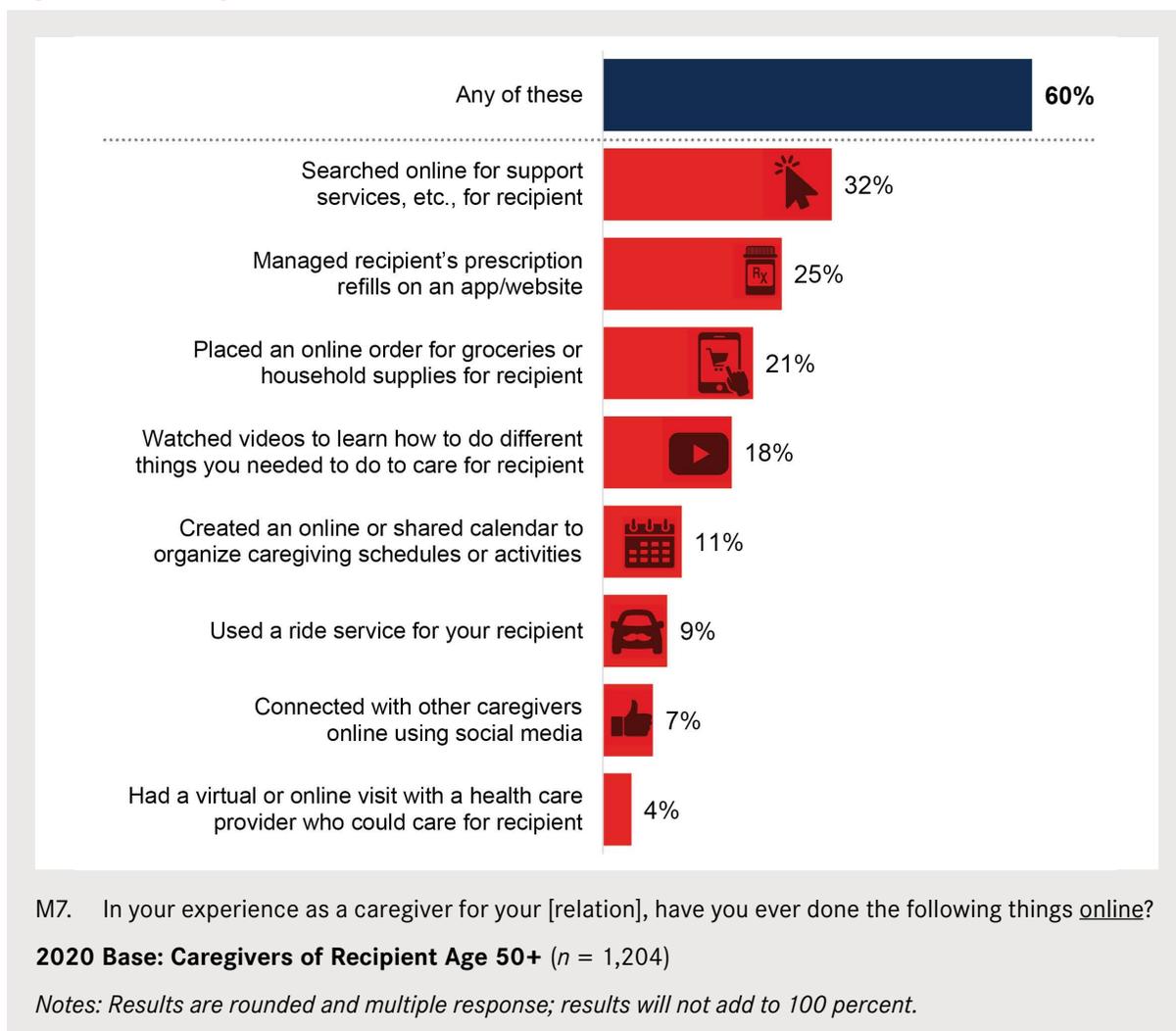
84 Excluding checking up on their recipient using an app, video, wearable device, or other remote monitoring.

## ONLINE SOLUTIONS

Six in 10 caregivers of adults ages 50+ have performed at least one of a variety of tasks online to help with caregiving (60 percent; see Figure 62), including over a third who have done multiple things online (35 percent). Most commonly, caregivers rely on the internet for searches for services, aides, facilities, or other help (32 percent). One in 4 caregivers goes online to manage prescriptions on an app or website (25 percent). Roughly 1 in 5 uses the internet to place an online order for groceries or household supplies or watched videos to learn how to do different care tasks for a recipient (21 percent and 18 percent, respectively).

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 (9 percent), or to connect with other caregivers (7 percent). Very few have used virtual provider visits (also called telehealth or e-doctor visits) for their recipients (4 percent).<sup>85</sup>

**Figure 62. Caregiver Use of Online Solutions**



85 Use of telehealth or e-doctor visits skyrocketed in early 2020, after fielding for this study was complete, due to the SARS-CoV-2 or coronavirus outbreak in the United States. See Ateev Mehrotra et al., *The Impact of the COVID-19 Pandemic on Outpatient Visits: Practices Are Adapting to the New Normal* (Commonwealth Fund, June 2020). <https://doi.org/10.26099/2v5t-9y63>. It is likely that telehealth or e-visits will become more commonplace even after the global pandemic ends—a trend that is likely to impact caregivers as well.

As the intensity of the care situation increases, so too does 50+ caregiver use of online solutions, with high-intensity situation caregivers doing 1.6 tasks online, moderate-intensity caregivers doing 1.3 tasks, and low-intensity caregivers doing 0.9 tasks online.<sup>86</sup> Similarly, higher-hour caregivers more often report going online to complete tasks related to caregiving (1.6 on average vs. 1.1 among those providing 20 or fewer hours of care per week).<sup>87</sup> Likewise, the following groups of caregivers in more demanding care situations more often go online to help with their caregiving tasks than do their peers:

- Caregivers who feel alone (1.8 vs. 1.1 activities for those who do not feel alone), who report more often completing nearly all of these activities online;<sup>88</sup>
- Caregivers of those living with Alzheimer's or dementia (1.6 vs. 1.1 for caregivers of those without these conditions), including searching online for support services, aides, facilities, or other help for their recipient (46 percent vs. 25 percent), managing their recipient's prescription refills or delivery on an app or website (31 percent vs. 23 percent), watching videos to learn how to do care tasks (23 percent vs. 16 percent), and connecting with other caregivers online using social media or support groups (10 percent vs. 5 percent); and
- Those who have been providing care for at least a year (1.4 vs. 1.1 activities for those caregiving less than a year), including searching online for support services, aides, facilities, or other help for their recipient (35 percent vs. 27 percent) and placing an online order for groceries or household supplies for their recipient (25 percent vs. 16 percent).

Use of online tools varies by demographic groups as well, with these groups more often using online solutions:

- Employed caregivers (1.4 vs. 1.1 activities for non-employed caregivers);<sup>89</sup>
- Asian American caregivers (1.7 activities),<sup>90</sup> more than either White (1.2) and Hispanic/Latinx (1.3) caregivers; and
- Younger caregivers ages 18 to 49 (1.4 vs. 1.2 activities when the caregiver is age 50 or older).<sup>91</sup>

86 Caregivers in high-intensity care situations more often are managing their recipient's prescription refills or delivery on an app or website (33 percent vs. 20 percent of those in low- to moderate-care situations) and watching videos to learn how to do different things they need to care for their recipient (27 percent vs. 13 percent of those in low- to moderate-care situations).

87 Higher-hour caregivers (those who provide 21+ hours of care per week) more often are searching online for support services, aides, facilities, or other help (38 percent vs. 29 percent of those who provide fewer hours of care); managing their recipient's prescription refills or delivery on an app or website (32 percent vs. 22 percent of those who provide fewer hours of care); watching videos to learn how to do different things they need to care for their recipient (27 percent vs. 15 percent of those who provide fewer hours of care); and having a virtual or online visit with a health care provider (6 percent vs. 3 percent of those who provide fewer hours of care).

88 Excluding using a ride service and having a virtual or online visit with a health care provider.

89 Driven by more searching for support services or aides, use of online videos, and telehealth.

90 Driven by more searching for support services or aides and online support group use.

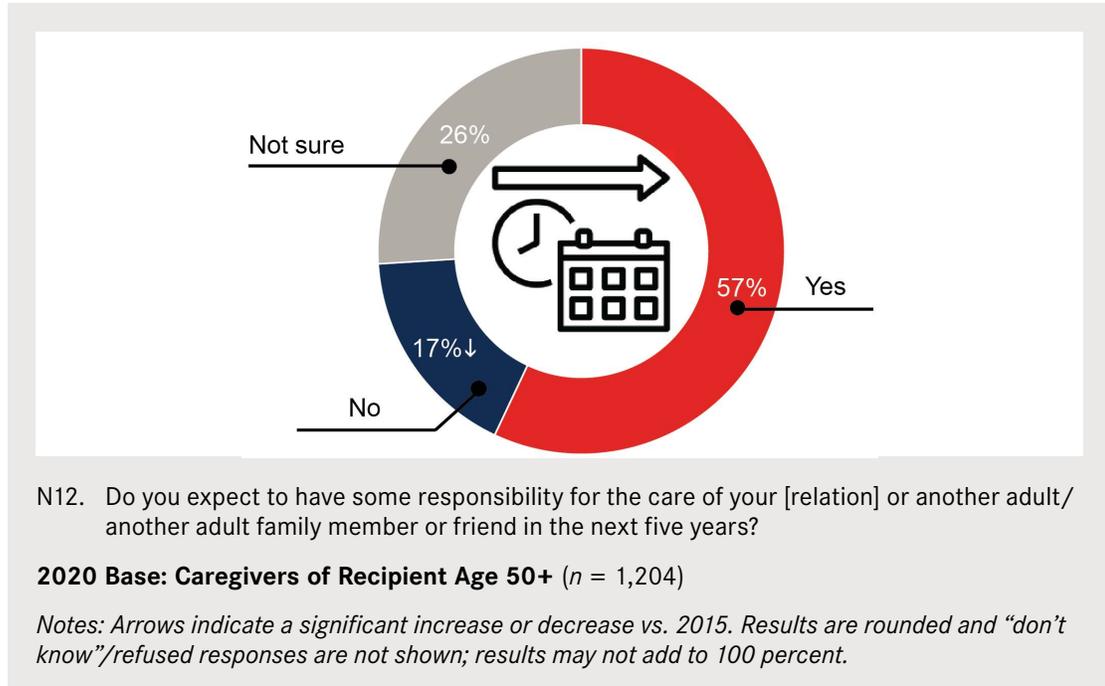
91 Driven by more use of online videos, online shopping for household needs/groceries, and ride-share services.

## L. LONG-RANGE PLANNING

### EXPECTATIONS OF FUTURE CAREGIVING ROLE

Nearly 6 in 10 caregivers of someone age 50 or older expect they will be a caregiver for some adult (either their current recipient or someone else) during the next five years (57 percent; see Figure 63).

**Figure 63. Expectations of Future Caregiving Role**



#### SUBGROUPS: 2020

- Expectation of future care also crosses racial/ethnic groups, income levels, and employment status:
  - White (60 percent), Hispanic/Latinx (57 percent), and Asian American (62 percent) caregivers are more likely than African American caregivers (45 percent) to expect to have some future responsibility.
  - Caregivers with annual household incomes of \$50,000 or more are more likely to expect to have some responsibility (62 percent vs. 47 percent of those with household incomes lower than \$50,000).<sup>92</sup>
  - Employed caregivers are more likely to expect their role to continue (61 percent vs. 51 percent of those not employed).
- Those providing care to close relatives, such as a parent/parent-in-law (64 percent) or spouse/partner (66 percent), more often expect their role to continue into the future (vs. 44 percent of those providing care to some other relative or 37 percent of those providing care to a non-relative).<sup>93</sup>
- Those who have provided care for a year or longer more often expect to have some responsibility in the future (66 percent vs. 45 percent of newer caregivers).
- Those who feel alone are more likely to expect to have some caregiving responsibility (65 percent vs. 55 percent of those who do not feel alone).

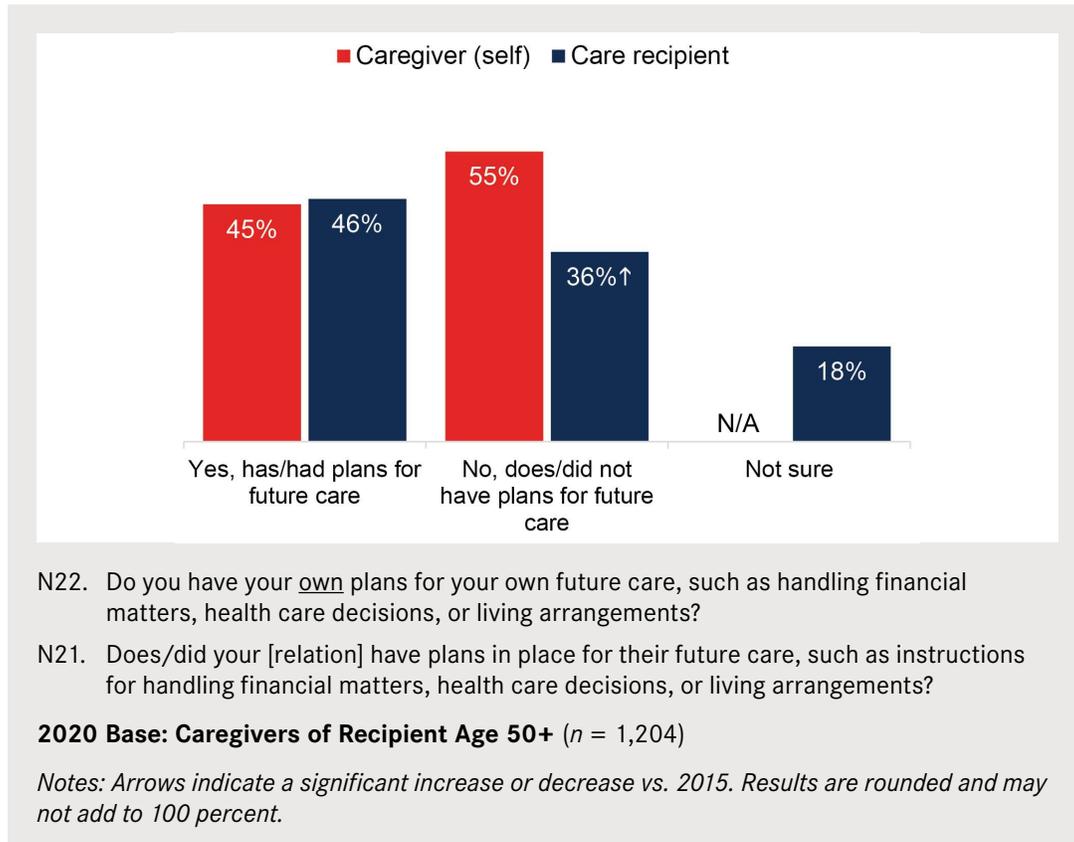
92 Education level follows suit: those with at least a college degree are more likely than those with less to expect to have some caregiving responsibility in the future (64 percent vs. 53 percent, respectively).

93 Generally, older caregivers (who more often care for a spouse/partner) and those caring for older recipients (who more often care for a parent/parent-in-law) also expect to continue to provide care into the future, though this is likely due to their relationship with their recipient, as opposed to age.

## LONG-RANGE PLANNING

Fewer than half of 50+ caregivers report that their care recipient has or had plans in place for future care (46 percent; see Figure 64), which includes instructions for things like handling financial matters, health care decisions, or living arrangements. Over a third report there are no such plans in place (36 percent, up from 29 percent in 2015), while nearly one in five are not sure (18 percent). Less than half indicate they have plans in place for their own future care (45 percent).

**Figure 64. Long-Range Planning**



### CHANGE FOCUS: 2020 vs. 2015

Caregivers of adults ages 50 to 64 more often report having their own plans in place in 2020 (45 percent vs. 35 percent in 2015).

### SUBGROUPS: 2020

- Several groups of caregivers more often report their recipient *does not* have a plan in place for their future care—and many of these caregivers are in highly time-consuming or intensive care situations, suggesting that the caregiver *is* the plan. This includes:
  - Primary caregivers (40 percent vs. 28 percent of non-primary caregivers);
  - Those who co-reside with their recipient (42 percent vs. 32 percent of those who do not co-reside with their recipient);
  - Those who feel alone (42 percent vs. 32 percent of those who do not feel alone); and
  - Those with annual household incomes lower than \$50,000 (40 percent vs. 33 percent).<sup>94</sup>

94 Those with household incomes lower than \$50,000 are also more likely to say they do not have their own plan in place for future care (62 percent vs. 51 percent of those with household incomes of \$50,000 or more).

- Planning for future care may be an activity that is more common with older age: caregivers of older recipients more often report their recipient has plans, with just 27 percent of those caring for someone age 50 to 64 reporting that the recipient has plans, climbing to 62 percent when providing care to someone age 85+. Similarly, older caregivers more often have plans in place for their own care, with just 33 percent of caregivers ages 18 to 49 having plans for their own future care, climbing to 75 percent among caregivers ages 75+.

Caregivers of color more often report their recipient does not have a plan in place, but this may be because they more often report living together in the same home and are the sole unpaid caregiver<sup>95</sup> (Figure 65).

**Figure 65. Future Plans, Caregiver Status, and Recipient Location by Race/Ethnicity**

Component	Caregiver Race			
	White (n = 698) A	African American (n = 162) B	Hispanic (n = 178) C	Asian American (n = 177) D
Recipient does not have plan in place	31%	43% <sup>A</sup>	45% <sup>A</sup>	45% <sup>A</sup>
Caregiver does not have plan in place	54%	49%	64% <sup>AB</sup>	54%
Sole caregiver	42%	52% <sup>A</sup>	52% <sup>A</sup>	42%
Recipient lives in caregiver's home	33%	42% <sup>A</sup>	46% <sup>A</sup>	51% <sup>A</sup>

Notes: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and from multiple questions; results will not add to 100 percent.

Both longer-term caregivers and caregivers of someone living with Alzheimer's or dementia are more likely to have a plan in place for their recipient's future care. This suggests that time may have a component when it comes to long-term care planning.<sup>96</sup> Longer-term caregivers (51 percent vs. 40 percent of those providing care for less than a year) and those caregiving for an adult age 50+ living with Alzheimer's or dementia (53 percent vs. 44 percent when providing care to someone without Alzheimer's or dementia) more often report that their recipient has a plan for future care.

95 Long-term care plans often are presumed to involve care facilities or paid caregivers, yet as our data show, Black and Hispanic/Latinx caregivers may be less likely to have the financial means to access this type of care. Although Asian American caregivers report higher household incomes, they also more often report that their recipient does not have a plan; this may mean that caregivers of color themselves *are* the plan for their recipient or that their cultural background may assume family is the plan for long-range care. Further research is needed.

96 Specifically, caregiving for longer periods of time and also the time associated with particular condition(s) like Alzheimer's may drive caregivers and families to create plans. Further research is needed.

## M. RESPONDENT PROFILE

On the whole, caregivers of someone age 50 or older look similar to caregivers in 2015 and caregivers of adults overall (see Figures 66 and 67). Six in 10 are women and 4 in 10 are men; the average age is 50.1 years old; 6 in 10 are White; and about half are married.

**Figure 66. Demographic Summary of Caregivers of Adults, 2020 and 2015**

	Recipient Age 50+ 2020 (n = 1,204)	Recipient Age 50+ 2015 (n = 1,087)
<b>Caregiver Gender</b>		
Man	39%	40%
Woman	61%	60%
<b>Age of Caregiver</b>		
18-34	22%	21%
35-49	22%	24%
50-64	36%	35%
65-74	13%	12%
75+	7%	8%
Mean age	50.1	50.3
<b>Race/Ethnicity of Caregiver</b>		
White	61%	62%
African American	14%	13%
Hispanic/Latinx	17%	16%
Asian American	5%	7%
Other	3%	2%
<b>Caregiver Education</b>		
Less than high school	6%	7%
High school graduate	25%	28%
Some college	23%	21%
Technical school	11%↑	7%
College graduate	21%	20%
Graduate school	15%	16%
<b>Caregiver Marital Status</b>		
Married	54%	57%
Living with a partner	6%	7%
Widowed	3%↓	5%
Separated	2%	2%
Divorced	9%	8%
Single, never married	23%	20%

↑↓ Result is significantly higher or lower than in 2015. Results are rounded and may not add to 100 percent

Household incomes for caregivers of adults ages 50+ are higher in 2020 than in 2015.<sup>97</sup> Three in 10 caregivers have a child or grandchild living in their home at the time of care and just 11 percent live in a rural area, down from 2015 (15 percent). Six in 10 are employed while providing care, while 1 in 10 is a student while caregiving.

**Figure 66. Demographic Summary of Caregivers of Adults, 2020 and 2015** *continued*

	Recipient Age 50+ 2020 (n = 1,204)	Recipient Age 50+ 2015 (n = 1,087)
<b>Caregiver Household Income (unadjusted)</b>		
<b>Less than \$50,000 (net)</b>	35%↓	46%
Less than \$15,000	8%↓	12%
\$15,000–\$29,999	12%↓	16%
\$30,000–\$49,999	15%↓	19%
<b>\$50,000 or more (net)</b>	65%↑	54%
\$50,000–\$74,999	17%	18%
\$75,000–\$99,999	14%	13%
\$100,000+	34%↑	23%
<b>Median household income (2015 inflation adjusted)</b>	\$67,500	\$59,300
<b>Children/Grandchildren in Caregiver’s Household</b>		
Yes	30%	28%
No	68%	71%
<b>Caregiver Living Location</b>		
Urban/suburban	89%↑	85%
Rural	11%↓	15%
<b>Caregiver Employment Status</b>		
Employed in past year while caregiving	62%	59%
Not employed	38%	41%
<b>Caregiver Student Status</b>		
Yes	10%	n/a
No	89%	n/a

↑↓ Result is significantly higher or lower than in 2015. Results are rounded and may not add to 100 percent.

97 See Appendix B: Methodology in National Alliance for Caregiving and AARP, *Caregiving in the U.S. 2020*.

Eighty-eight percent of 50+ caregivers have health insurance, usually through an employer. One in 10 has served in the U.S. Armed Forces and 7 percent self-identify as LGBTQ.<sup>98</sup> Three in 10 report their recipient lives in a rural area and 16 percent say their recipient is a veteran.

**Figure 66. Demographic Summary of Caregivers of Adults, 2020 and 2015** *continued*

	Recipient Age 50+ 2020 (n = 1,204)	Recipient Age 50+ 2015 (n = 1,087)
<b>Caregiver Has Health Insurance</b>		
Yes	88%	n/a
No	11%	n/a
<b>Caregiver Source of Health Insurance</b>		
Employer sponsored	57%	n/a
Medicare	21%	n/a
Medicaid	9%	n/a
Direct purchase	7%	n/a
Military/veterans	4%	n/a
<b>Caregiver Service in Armed Forces</b>		
Served on active duty	10%	10%
Did not ever serve	90%	89%
<b>Caregiver LGBTQ Status</b>		
Yes	7%	9%
No	92%	91%
<b>Care Recipient Living Location</b>		
Urban/suburban	69%	71%
Rural	30%	28%
<b>Care Recipient Service in Armed Forces</b>		
Served on active duty	16%	15%
Did not ever serve	82%	83%

↑↓ Result is significantly higher or lower than in 2015. Results are rounded and may not add to 100 percent.

98 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.”

Caregivers of adults ages 50+ are 50.1 years old, on average, significantly older than caregivers of younger adults—those ages 18 to 49 (see Figure 67).

**Figure 67. Demographic Summary by Care Recipient Age**

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

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and may not add to 100 percent.

Caregivers of adults ages 50+ more often report an annual household income of \$50,000 or more (65 percent vs. 57 percent of those providing care to someone between the ages of 18 and 49). Three in 10 caregivers—regardless of the age of the care recipient—have children living in their home.

**Figure 67. Demographic Summary by Care Recipient Age** *continued*

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

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and may not add to 100 percent

Caregivers of adults ages 50+ more often report having health insurance (88 percent vs. 80 percent of those providing care to someone between the ages of 18 and 49). They more often report their older recipient is a veteran (16 percent), as compared to those caring for a younger recipient (6 percent of recipients are veterans).

**Figure 67. Demographic Summary by Care Recipient Age** *continued*

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

*Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated. Results are rounded and may not add to 100 percent*

National Alliance for Caregiving and AARP. *Caregiving in the U.S. 2020: A Focused Look at Family Caregivers of Adults Age 50+.* Washington, DC: AARP. November 2020.  
<https://doi.org/10.26419/ppi.00103.022>

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