

Caregiving in the U.S. 2020

A closer look at the experiences of caregivers today



National Alliance for Caregiving



Made Possible By

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About This Report



AVAILABLE TO DOWNLOAD AT:

<https://www.caregiving.org/research/caregiving-in-the-us/caregiving-in-the-us-2020/>

AARP
Family Caregiving™

nac
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Methodology

Caregiving in the U.S. 2020 Study Methodology

- Nationally representative, quantitative online surveys
- Utilized Ipsos' (formerly Gfk) national, probability-based, online KnowledgePanel® as was used in the 2015 wave
- Gathered full online survey responses from 1,392 caregivers of adults and 107 caregivers of children with special needs under age 18.

This Report & Presentation of Data

- Summarizes data from 1,392 caregivers age 18+ caring for an adult (age 18+)
- Margin of error for the data presented here (for caregivers of adults only) is +/- 2.6 percentage points at the 95% confidence level.
 - This means that 95 times out of 100, a difference of greater than roughly 2.6 percentage points would have occurred by chance.
- Significant increases or decreases are displayed in the graphics as the percentage point change from 2015 to 2020 and with arrows

The number of Americans providing unpaid care has increased over the last five years

Number of caregivers of
someone of any age

43.5
million
2015



53
million
2020



Percent providing care to
someone of any age

18%
2015



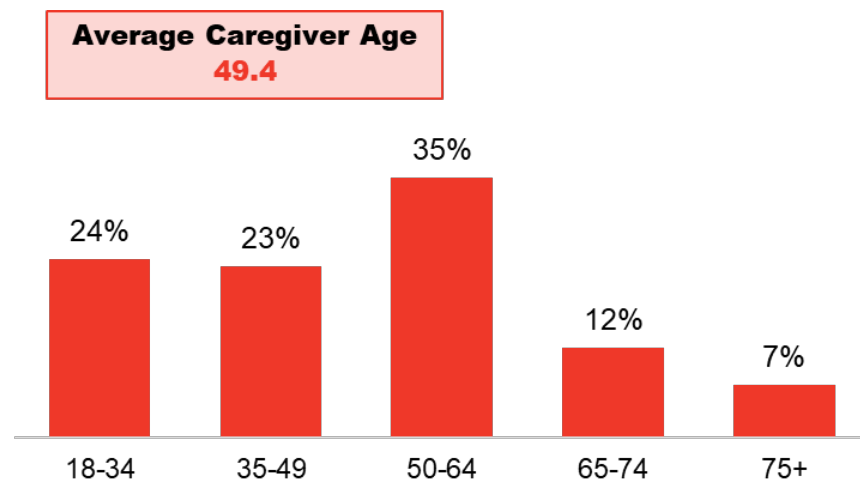
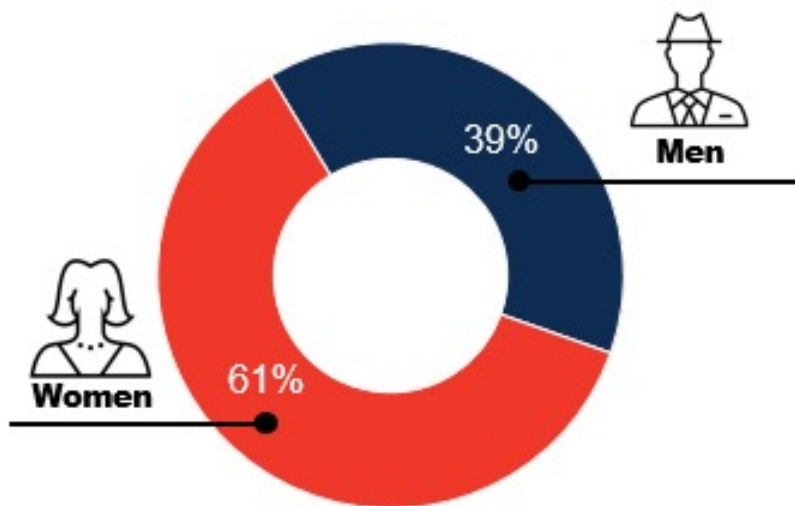
21%
2020

↑ **More are caring in general**, with 9.5 million new caregivers compared to 2015

↑ **21%** refers to the prevalence of caregiving for adults and children with special needs.

Demographics of caregivers: Age and gender

- On average, caregivers of adults are 49.4 years old, with a median age of 51.0 years.

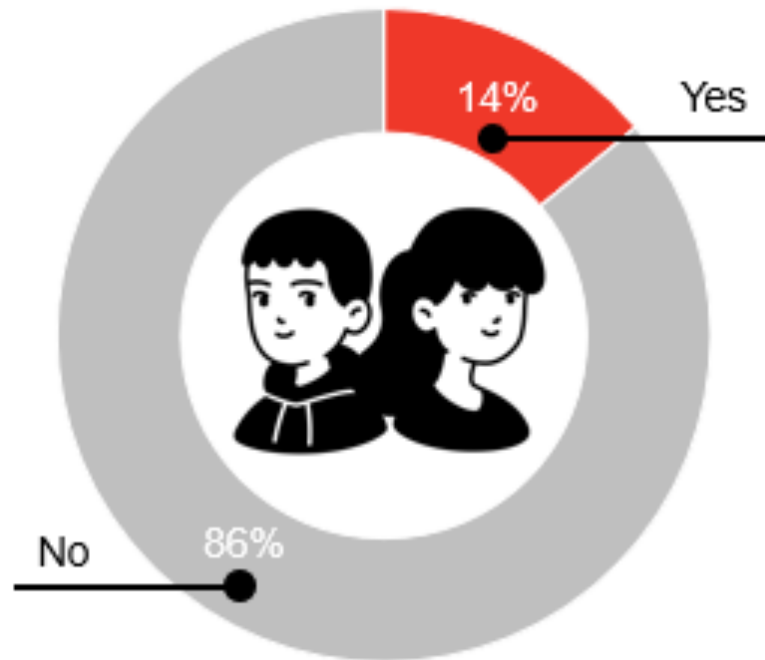


2020 Base: Caregivers of Recipient Age 18+ (n=1,392)

Our nation of caregivers now includes at least 3.4 million youth caregivers

Among those who report the presence of other unpaid help, 14% say *at least* one of those unpaid caregivers is a child under age 18 – *of all caregivers of adults, 7% report the presence of a child caregiver.*

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



New question. Not comparable to 2015.

Demographics of caregivers

Race/Ethnicity

- Six in 10 caregivers report being non-Hispanic White (61 percent),
- 17 percent are Latino/Hispanic
- 14 percent non-Hispanic African American or Black
- 5 percent Asian American and Pacific Islander
- 3 percent some other race/ethnicity, including multiracial

Other Key Demographics

- One in 10 is a student enrolled in college or other classes was also student at some point in the past year while caregiving
- 9 percent have served on active duty in the U.S. Armed Forces
- Eight percent self-identify as lesbian, gay, bisexual, and/or transgender (LGBTQ)



Complexity of Care

(C) 2020 National Alliance for Caregiving and AARP

Basics of the caregiving situation

- More caregivers of adults are providing care to **multiple people**, with **24%** caring for two or more recipients (up from 18% in 2015)
- Caregivers of adults find themselves providing **care for 4.5 years**. A greater proportion of caregivers report having provided care for 5 years or longer
- On average, caregivers spend **23.7 hours** per week providing care
 - 21% perform over 40 hours of care weekly – the equivalent of a full-time job

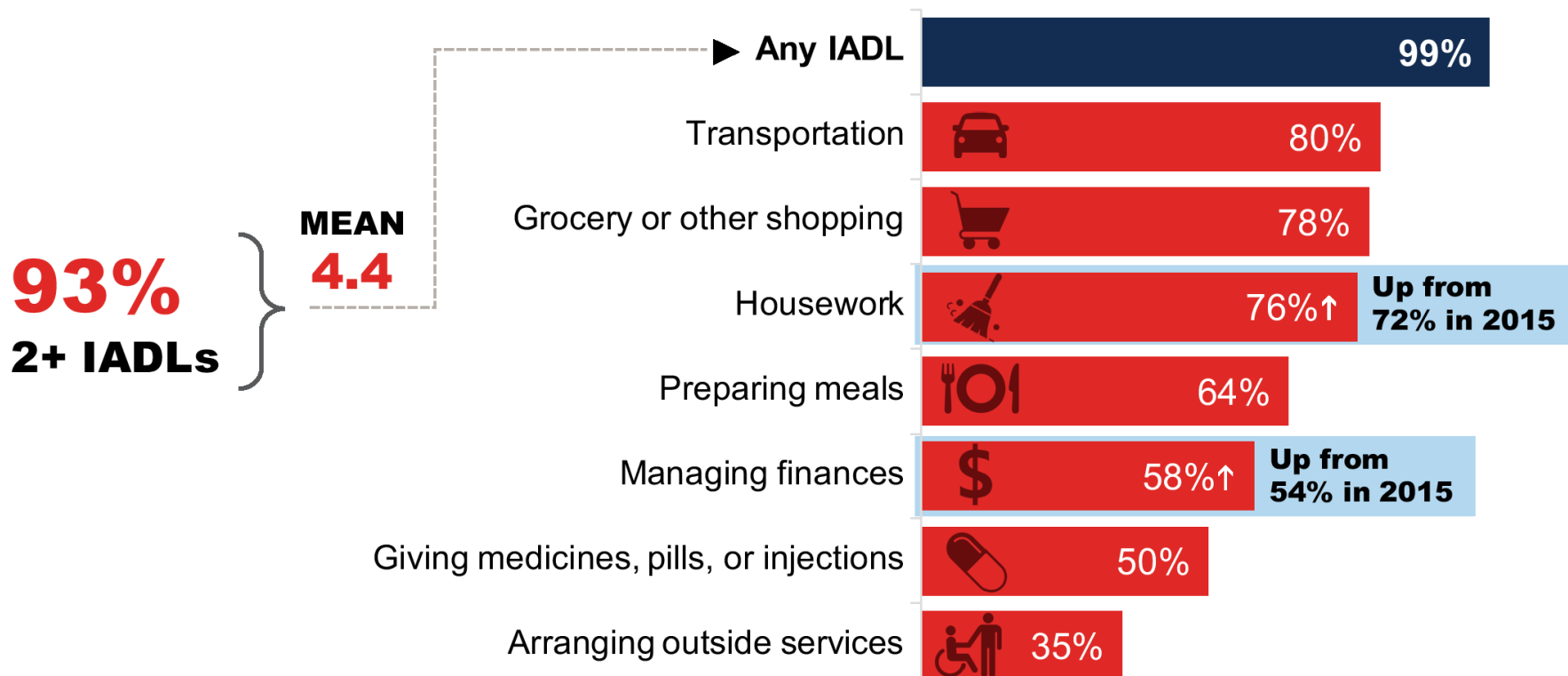


Caregivers more often report their recipient has multiple conditions



- A greater proportion of caregivers of adults report their recipient is dealing with multiple condition categories, with **45% reporting two or more condition categories**, compared to 37% in 2015
- 32% of caregivers indicate their recipient has a **memory problem** (up from 26% in 2015)
- 27% of caregivers say their recipient has **emotional/mental health** issues (up from 21%)
- **Long-term physical conditions** are more common in 2020 among the youngest recipients (46% when caring for someone age 18-49 vs. 32% in 2015)

Juggling multiple Activities of Daily Living (ADLs)



Integral to the Care Team

Monitoring the severity of their condition so that you can/could adjust care accordingly



71%↑

**Up from
66% in 2015**

Communicating with health care professionals



65%

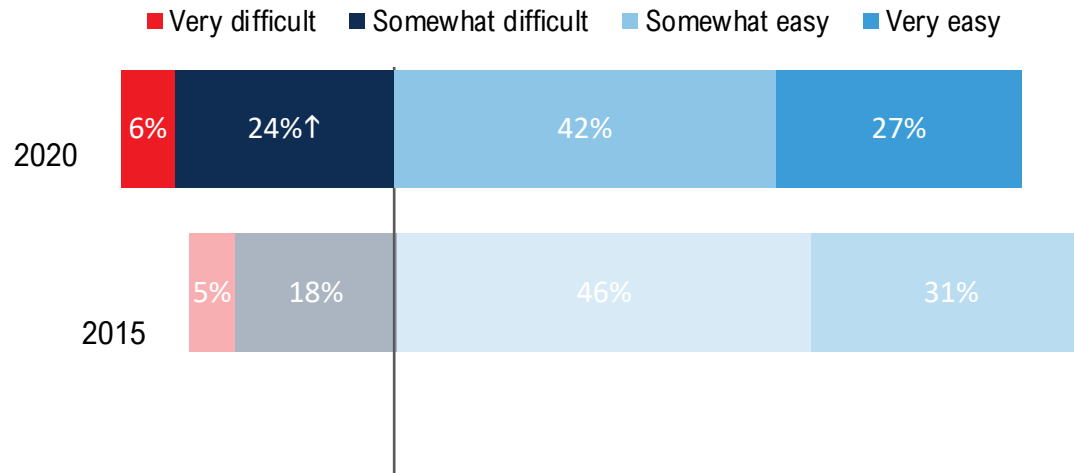
Advocating with providers, services, agencies



56%↑

**Up from
50% in 2015**

More caregivers have difficulty coordinating care



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

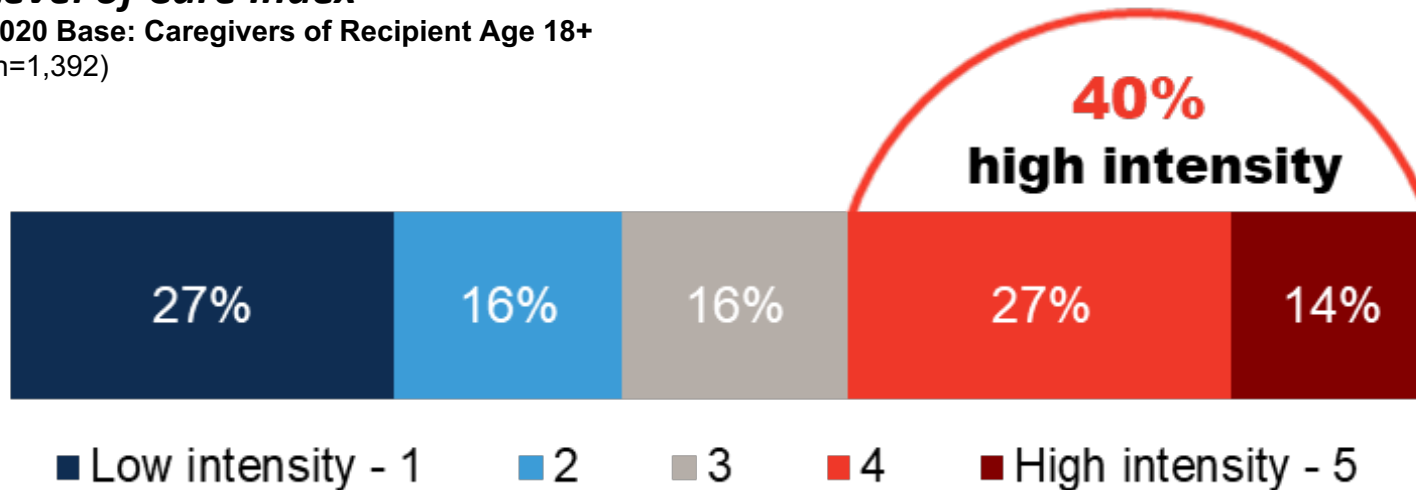
2020 Base: Caregivers Involved in Care Coordination for Recipient Age 18+
(n=1,200)

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

40% of caregivers are in a high intensity care situation

Level of Care Index

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



- Younger caregivers (ages 18 to 49) are more often in a high intensity care situation (43%) compared to 2015 (36%)



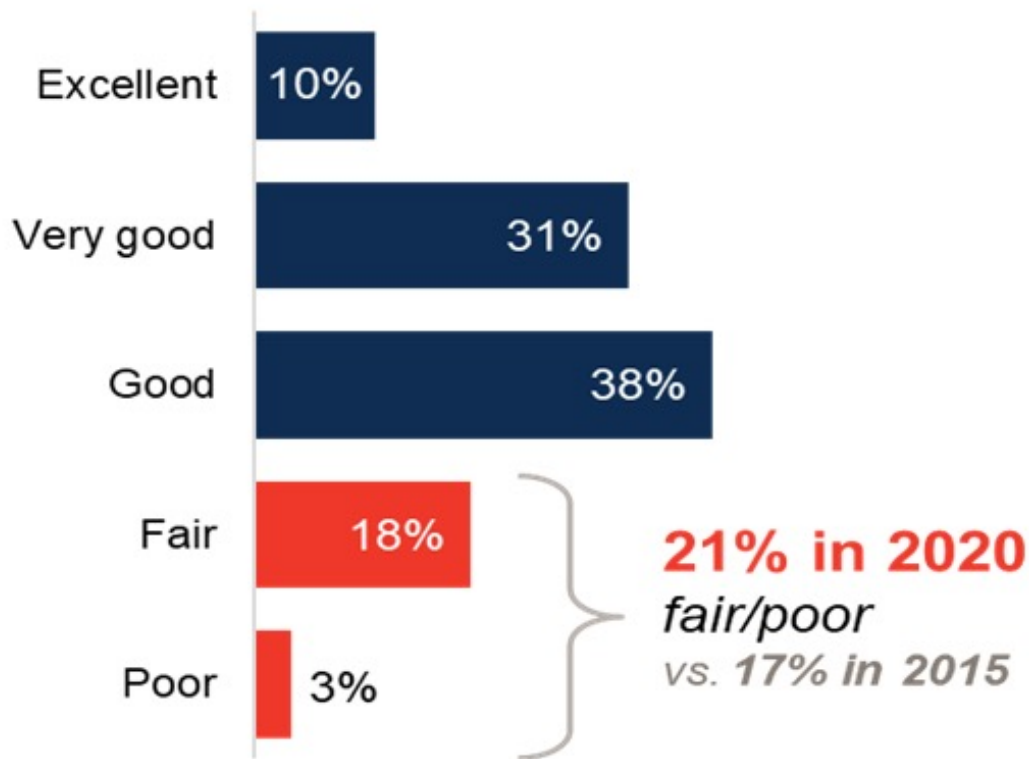
Healthcare Impacts

(C) 2020 National Alliance for Caregiving and AARP

The health status of caregivers has declined over the last five years

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

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



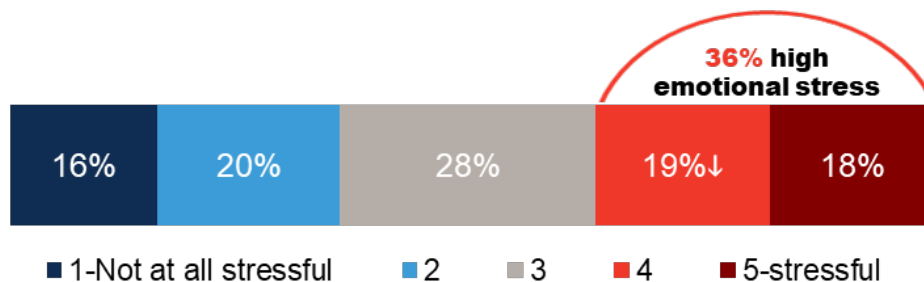
Caregivers are emotionally stressed, though half feel a sense of purpose from role

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

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

- Half of caregivers feel their role gives them a sense of purpose in life (51%)

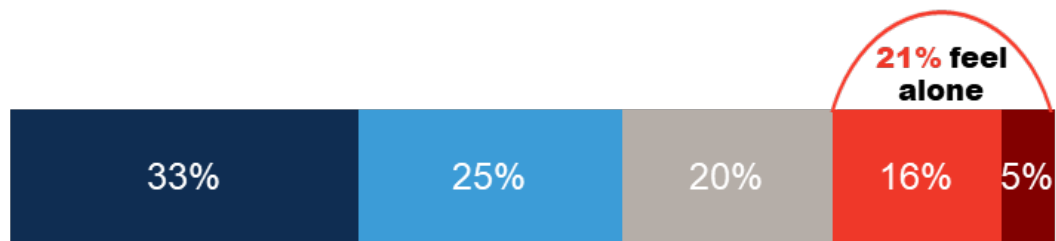
MEAN 3.0



One out of five caregivers of adults feel alone

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

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



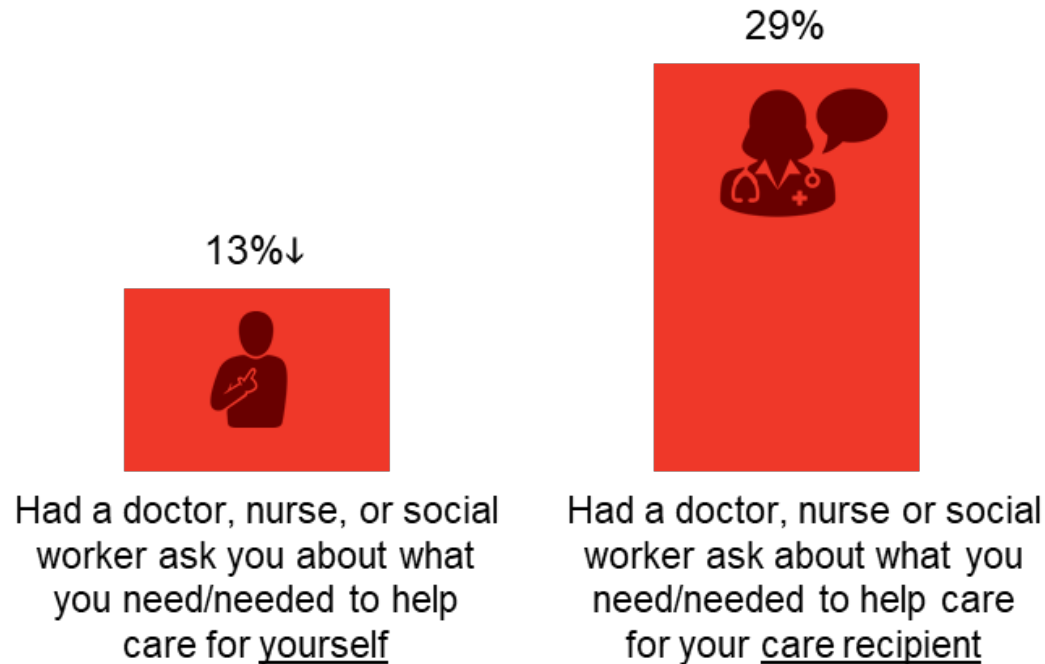
■ 1-Strongly disagree ■ 2-Disagree ■ 3-Neither ■ 4-Agree ■ 5-Strongly agree

- 22% of those caring one to four years and 32% of those caring five or more years feel alone (compared to 14% of those caring for less than a year)

Few caregivers report having been asked what they need to provide care

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

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



A photograph of two women sitting at a wooden table in a bright room with a large window. The woman on the left is an older Black woman with short grey hair, wearing a light beige sweater. The woman on the right is a younger white woman with dark curly hair tied back, wearing a brown sweater. They are both looking at a document on the table. A patterned mug is also on the table. The scene is brightly lit by natural light from the window.

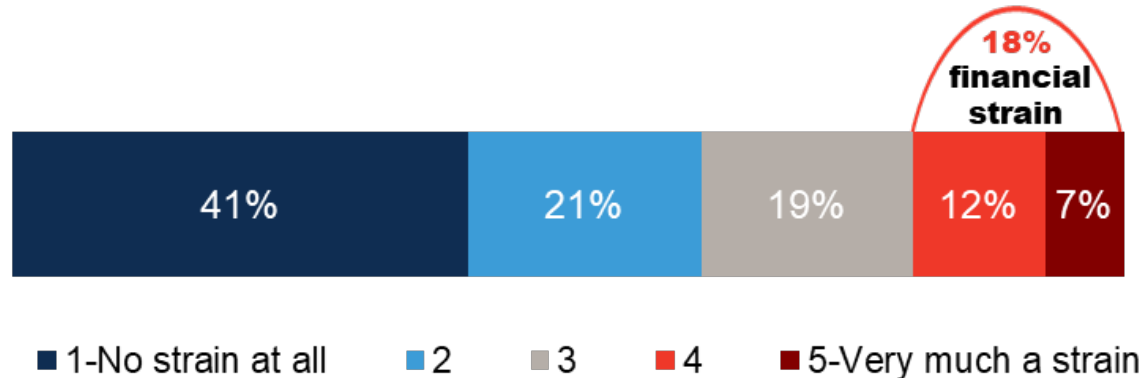
Financial Strain

(C) 2020 National Alliance for Caregiving and AARP

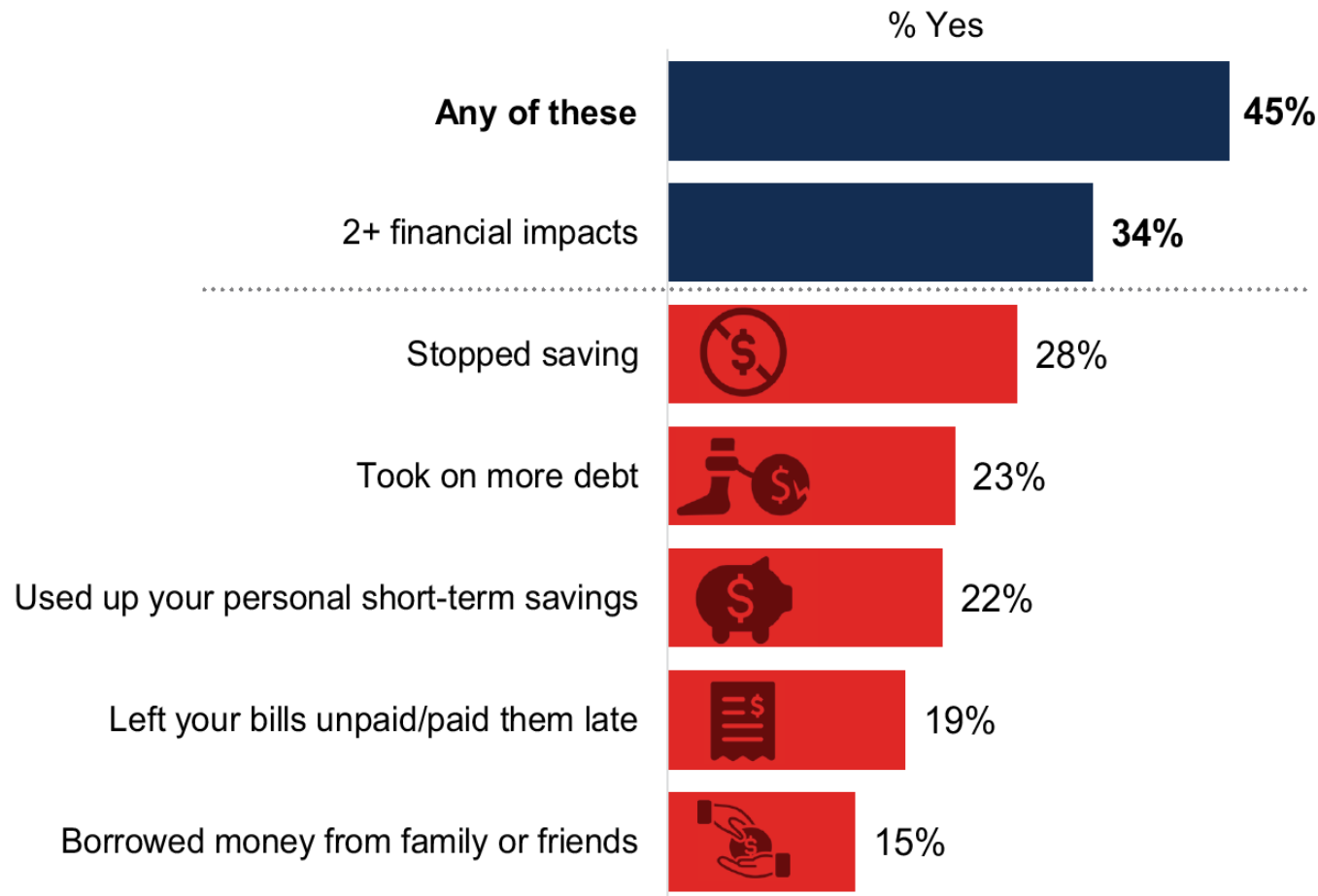
About one in five caregivers report experiencing financial strain as a result of providing care

Q37. How much of a financial strain would you say that caring for your [relation] is/was for you?
2020 Base: Caregivers of Recipient Age 18+
(n=1,392)

MEAN 2.2

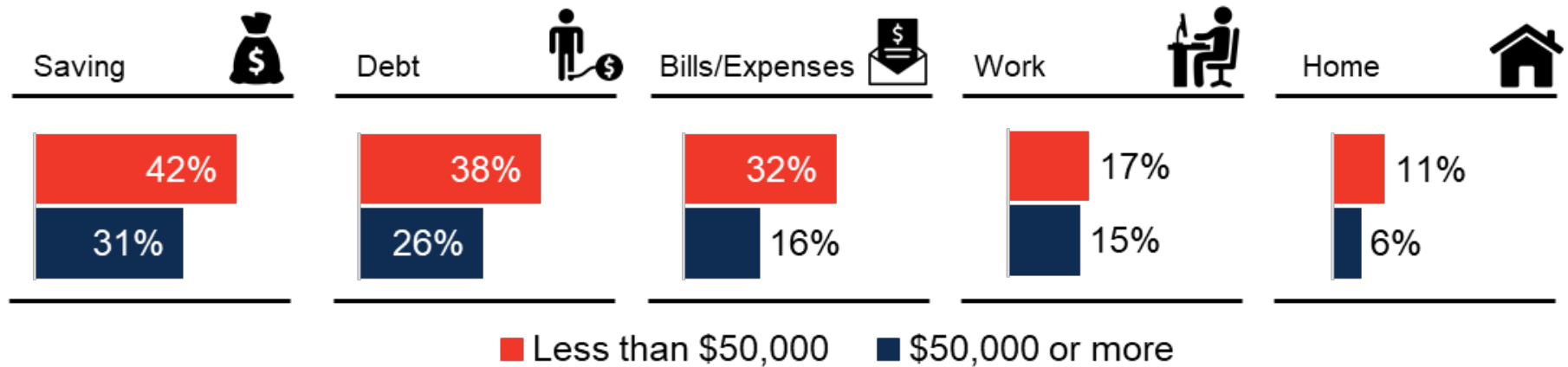


Top Financial Impacts as a Result of Caregiving

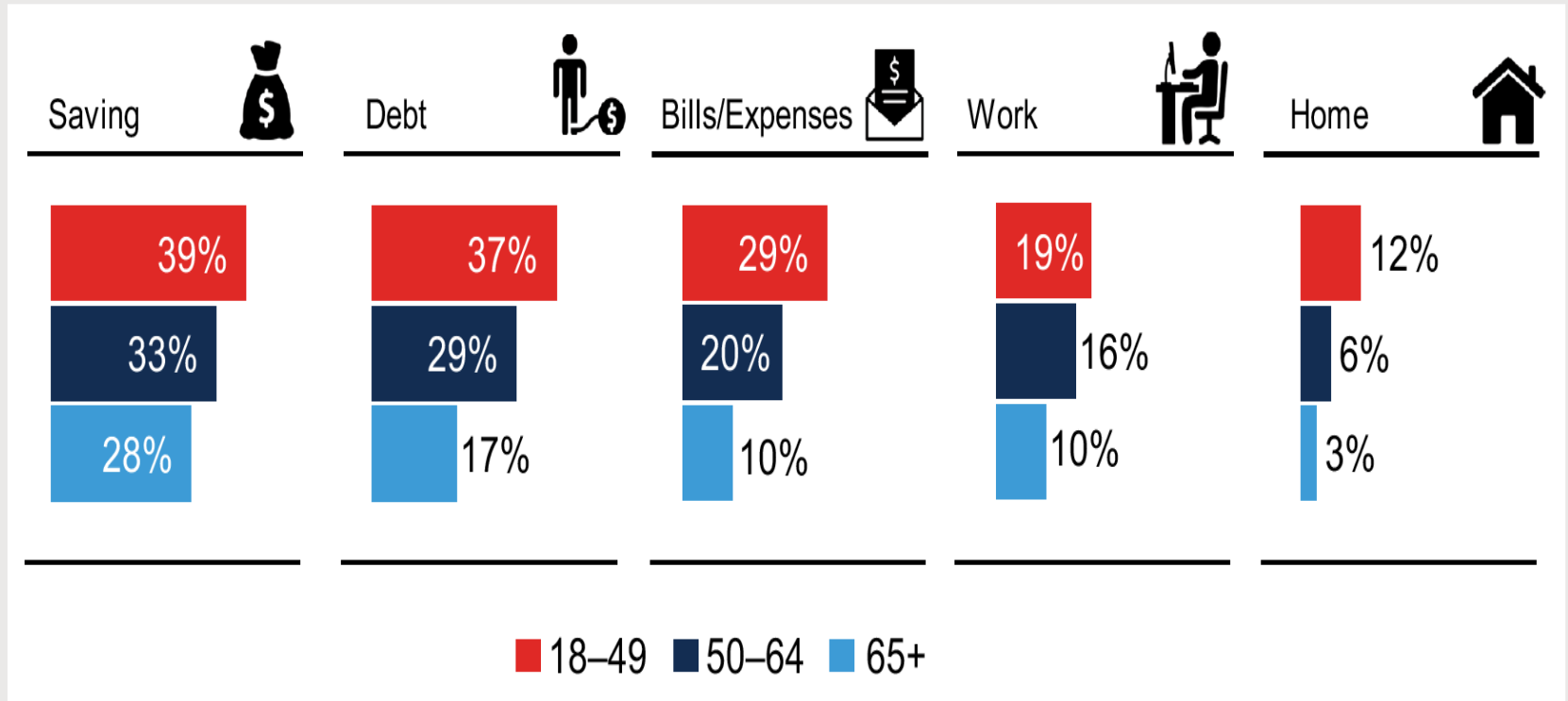


Financial impact by household income

Experience change in at least one impact related to ...
2020 Base: Caregivers of Recipient Age 18+ (n=1,392)



Financial impacts by caregiver age



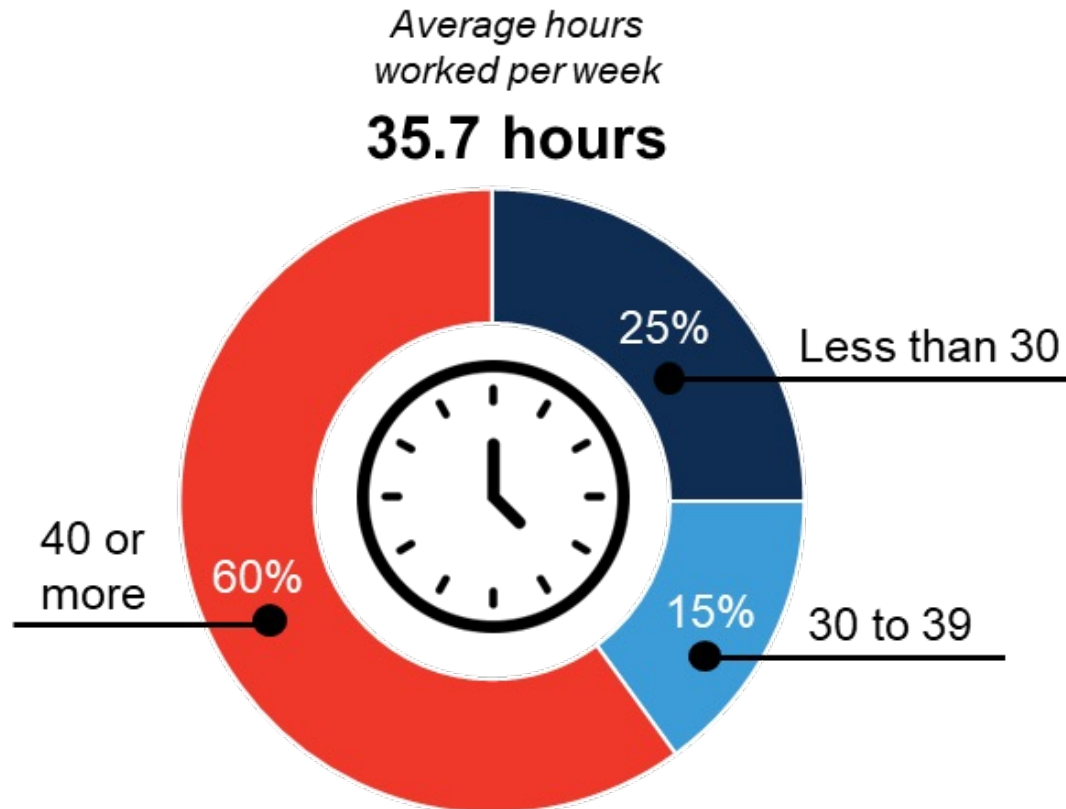
Experience change in at least one impact related to ...

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

61% of caregivers work while providing care, with most working full-time

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

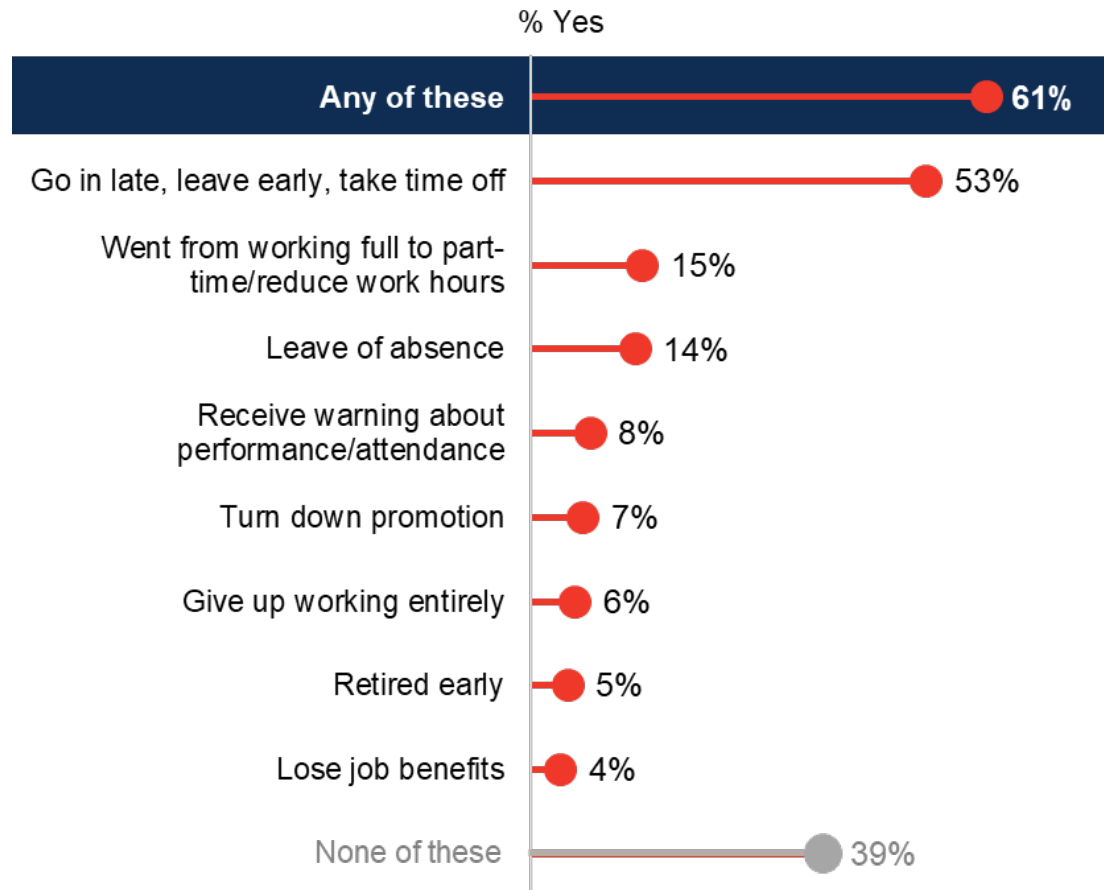
2020 Base: Working Caregivers of Recipient Age 18+ (n=837)



Many caregivers are forced to make changes to their work situation as a result of caregiving

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

2020 Base: Working and Not Self-Employed Caregivers of Recipient Age 18+ (n=837)



A hand holding a compass over a winding road in a desert landscape. The compass is held in the foreground, with the needle pointing towards the road. The road curves through a dry, hilly landscape under a clear sky. The background shows a winding road that disappears into the distance, flanked by dry, golden-brown hills and a small body of water on the left.

Navigating Services

(C) 2020 National Alliance for Caregiving and AARP

27% of caregivers say it is difficult to get affordable services in their recipient's area

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



1 - Not at all difficult

24%

2

15%

3

33%

4

15%

5 - Very difficult

12%

27% difficult

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



Some sub-groups more often report high difficulty finding services

- Caregivers of someone with an **emotional or mental health issue** (37% find it difficult vs. 23% of those without mental health issues)
- Caregivers of someone with **memory problems** (36% vs. 23% not)
- **Long-term physical conditions** (31% vs. 20% not)
- Caregivers of those living in **a rural area** (32% vs. 25% of those caring for someone who lives in a suburban or urban area)

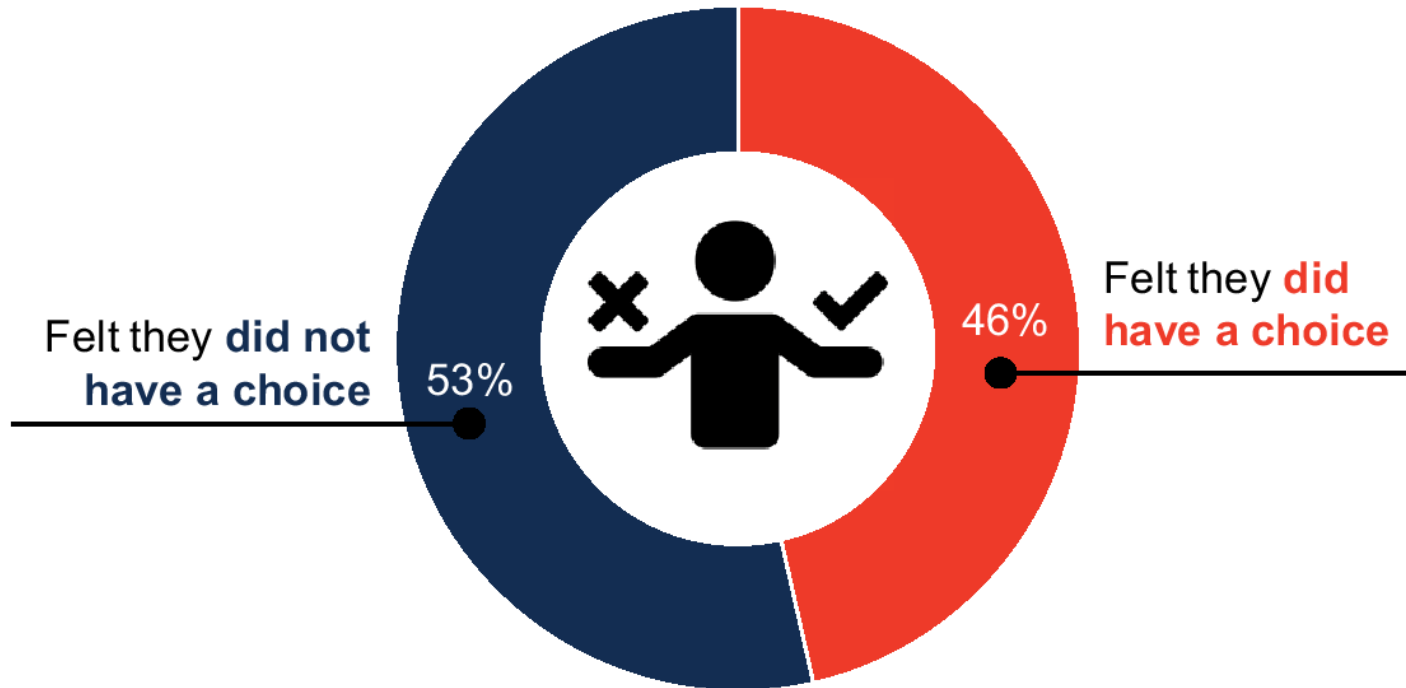
The background of the slide features a solid brown color with several raised fists of various skin tones (dark brown, medium brown, and light brown) visible. The fists are positioned at different heights and angles, creating a sense of collective strength and solidarity. The lighting is soft, highlighting the texture of the skin and the form of the fists.

Caregiver Resiliency

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More than half felt they didn't have a choice in providing care

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



More than half reported that caregiving gave them a sense of purpose

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



■ 1-Strongly disagree ■ 2-Disagree ■ 3-Neither ■ 4-Agree ■ 5-Strongly agree

A photograph of a man with short brown hair, wearing a dark blue shirt, smiling and assisting a young boy with dark hair and blue-rimmed glasses. The boy is wearing a teal t-shirt and is brushing his teeth with a blue and yellow toothbrush. The man is holding the boy's hand to guide him. The background is a plain, light-colored wall.

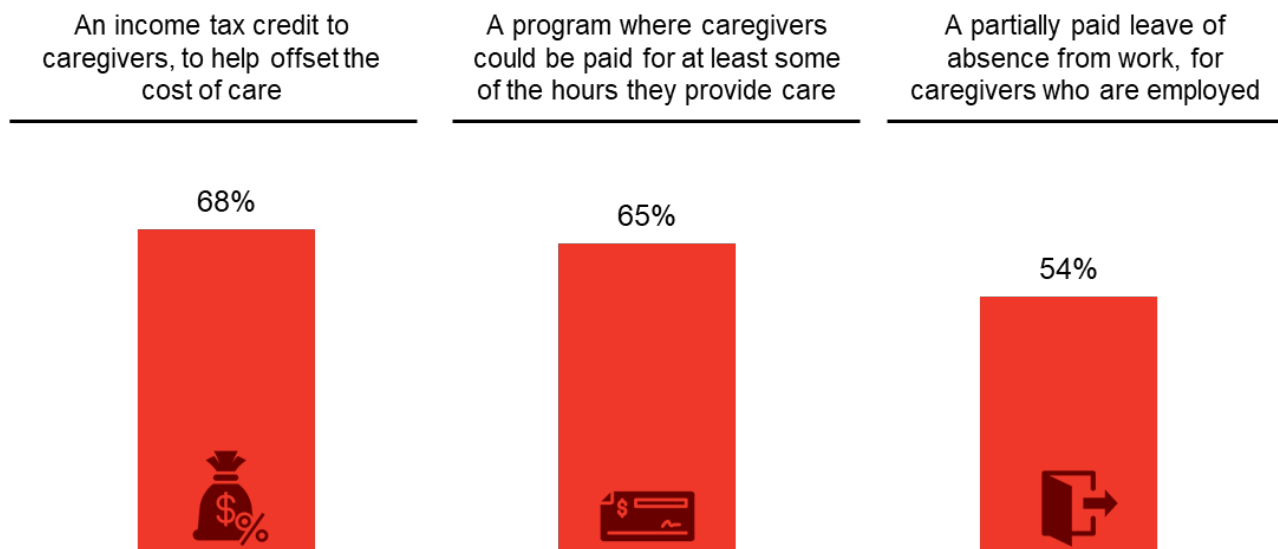
Policy Recommendations

(C) 2020 National Alliance for Caregiving and AARP

The majority of caregivers feel they would benefit from an income tax credit or program that pays for providing care

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

Percent Helpful (4–5)



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

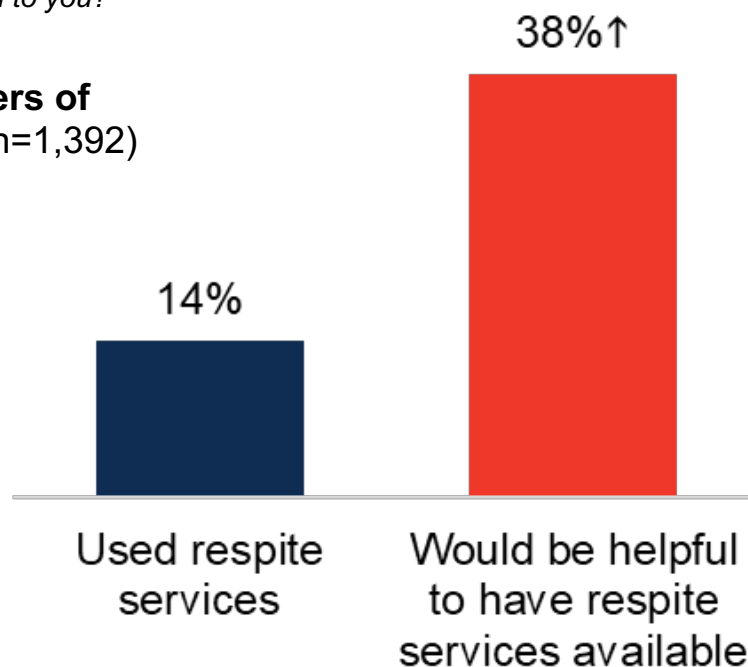
- More than half feel a partially paid leave of absence from work would be helpful (54 percent); **though this number rises to 62 percent among caregivers who work 30 hours or more each week.**

Few caregivers have used respite, despite nearly two in five feeling it would be helpful

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

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

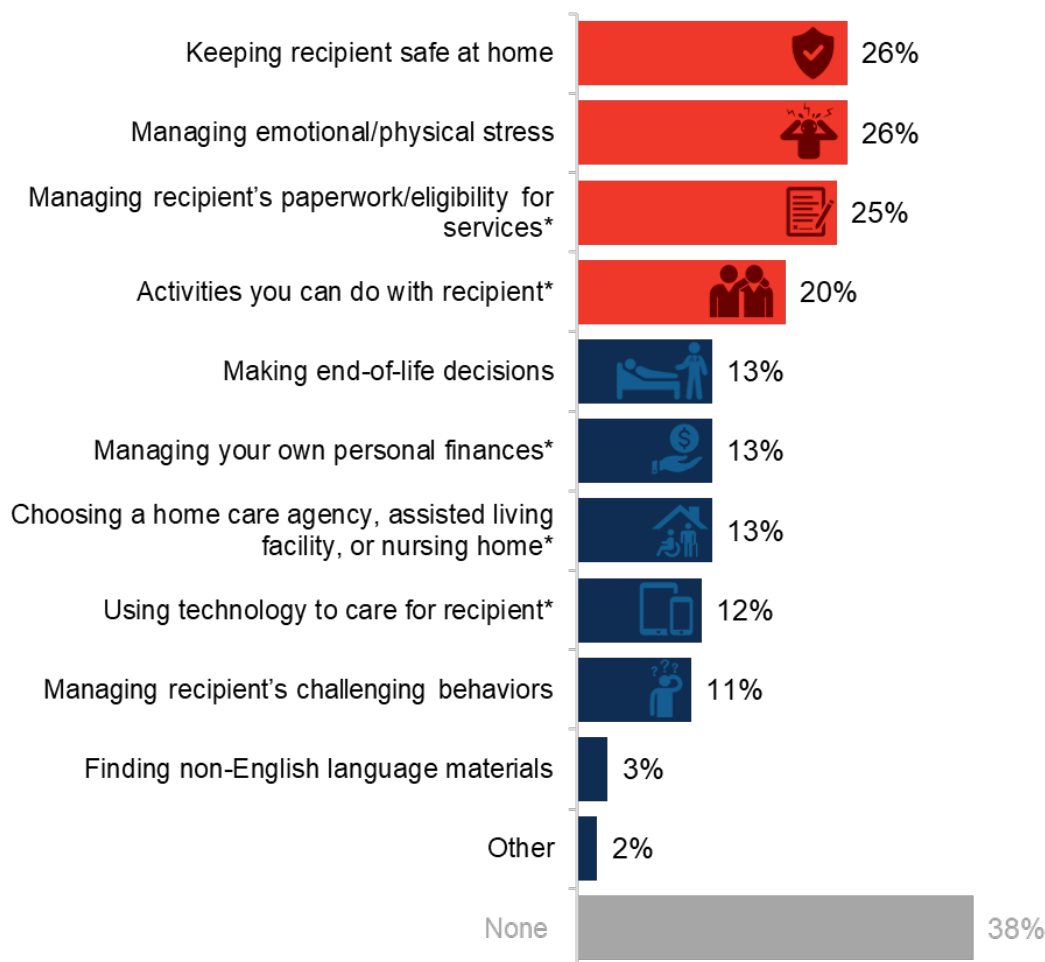
2020 Base: Caregivers of Recipient Age 18+ (n=1,392)



- Only 14% of caregivers report having used respite care service, despite nearly 38% feeling respite would be helpful.

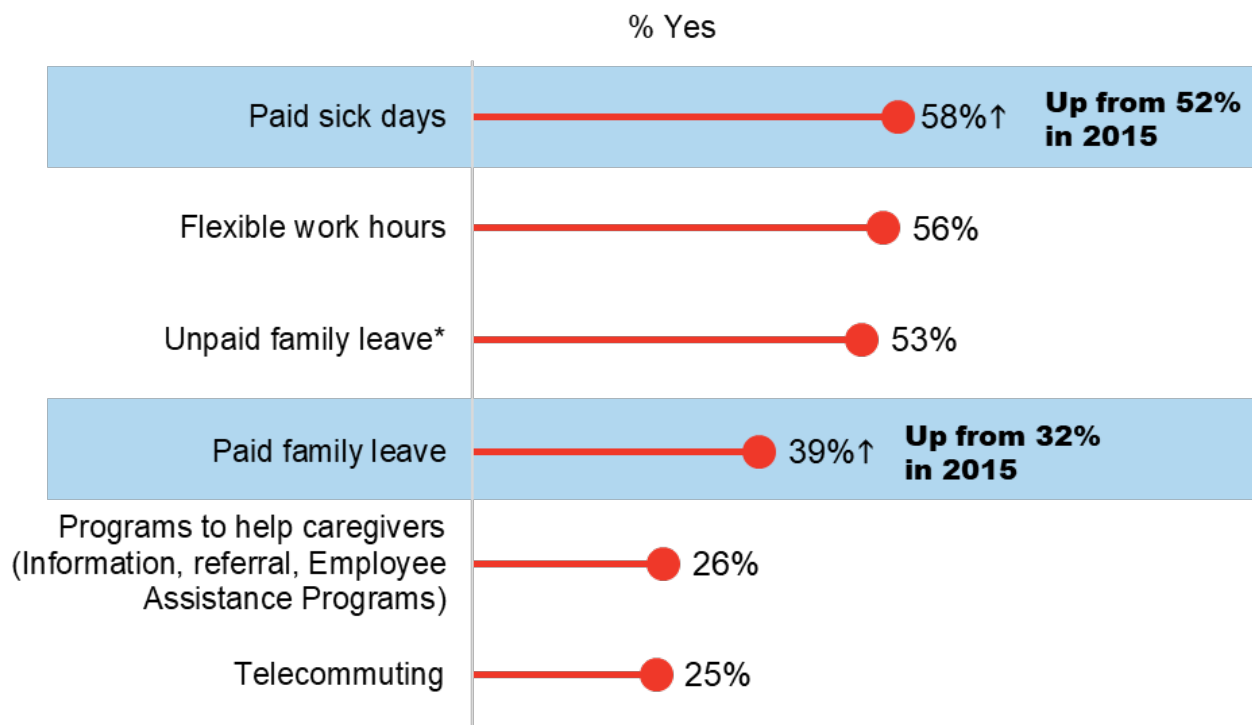
Caregivers want a variety of information depending on their care situation

* Indicates new in 2020



While more working caregivers report having paid leave benefits, most (61%) have no paid family leave

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



*New in 2020

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

We have a plan in place...

5 Priority Areas of the Recommendations

- Increased awareness of family caregiving.
- Increased emphasis on integrating the caregiver into processes and systems from which they have been traditionally excluded.
- Increased access to services and supports to assist family caregivers.
- Increased financial and workplace protections for caregivers.
- Better and more consistent research and data collection.

2022 National Strategy to Support Family Caregivers



Developed by:

The Recognize, Assist, Include, Support, and Engage (RAISE) Act
Family Caregiving Advisory Council

&

The Advisory Council to Support Grandparents Raising Grandchildren



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Thank You!