



# Highlights: *Caregiving in the U.S. 2020*

LEAD Coalition

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June 3, 2020

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# TODAY'S DISCUSSION



- I. About the National Alliance for Caregiving
- II. Highlights from *Caregiving in the U.S. 2020*
- III. Action Items

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# ABOUT THE NATIONAL ALLIANCE FOR CAREGIVING

- Established in 1996, NAC is a 501(c)(3) non-profit organization dedicated to advancing family caregiving through research, innovation, and advocacy
- National coalition of 60 organizational members, including non-profits, corporations, and federal agencies
- Advocacy network representing approximately 30 states/local grassroots communities
- Global leadership as founder of the International Alliance of Carer Organizations (IACO)



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# REPORT HIGHLIGHTS



Available at

[aarp.org/caregiving](http://aarp.org/caregiving)

[caregiving.org/caregiving-in-the-us-2020](http://caregiving.org/caregiving-in-the-us-2020)



# MADE POSSIBLE BY



## *Independent Advisory Panel*

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

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**Feylyn Lewis, PhD**, Research Fellow, University of Sussex

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

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

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

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

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# METHODOLOGY



- Nationally representative, quantitative online surveys
- Captures perspectives from 1,392 caregivers age 18+
- Utilized Ipsos' (formerly Gfk) national, probability-based, online KnowledgePanel® as was used in the 2015 wave
- Margin of error for the overall 2020 results +/- 2.5 percentage points at the 95% confidence level.
  - This means that 95 times out of 100, a difference of greater than roughly 2.5 percentage points would not have occurred by chance.
- Significant increases or decreases are displayed in the graphics as the percentage point change from 2015 to 2020 and with arrows

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# THE BIG PICTURE

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



- ↑ **More are caring for 2 or more people** (up to 24% from 18% in 2015)
- ↑ **More are caring longer, on average 4.5 years**, with nearly a third (29%) reporting that they're caring for someone 5 years or more (up 5% from 2015)
- ↑ **More are caring in general**, with 9.5 million new caregivers compared to 2015

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# WHAT CARE INVOLVES



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

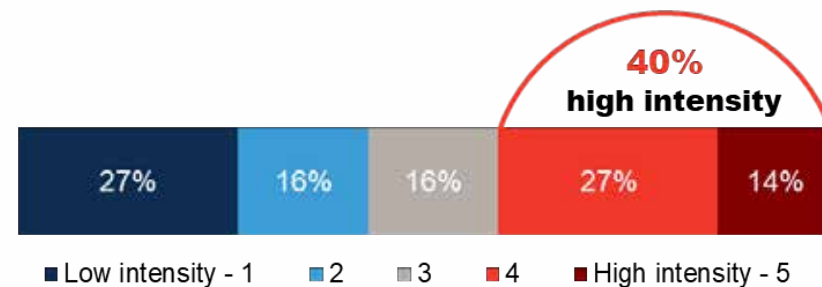
• Caring because of a:

↑ **Memory problems, such as Alzheimer's or related dementias**  
(32% of caregivers, up 6% from 2015)

↑ **Emotional/mental health issues**  
(27%, up 6% from 2015)

↑ **Multiple conditions**  
(45%, up 8% from 2015)

Level of Care Index



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# CAREGIVING: A “SECOND JOB”



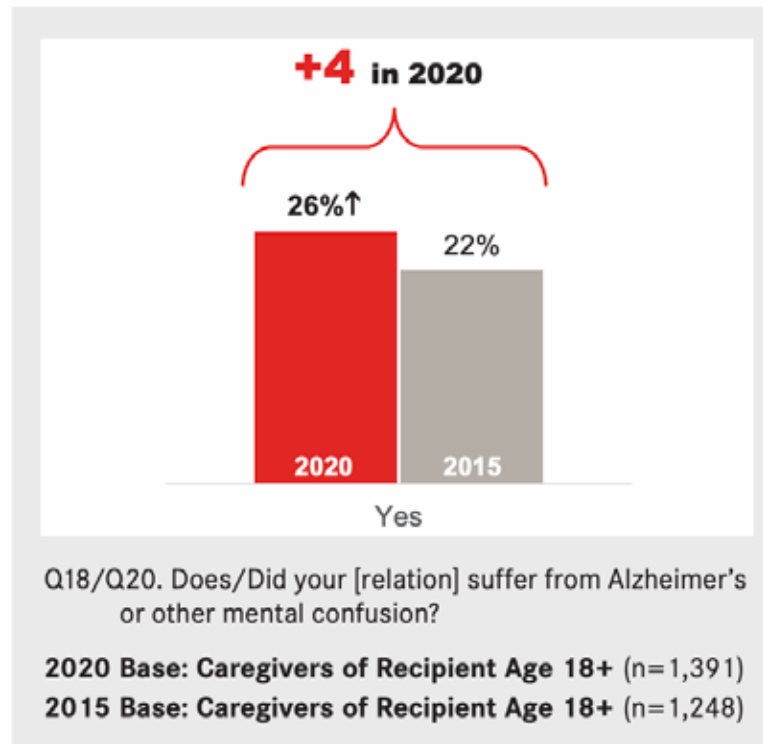
- On average, caregivers spend **23.7 hours** per week providing care
  - One in five (21%) caregivers provide more than 40 hours each week
- Most caregivers (61%) are also working:
  - 61% have no paid leave
  - Those working near full-time (30+ hours) often report that they had “no choice”
  - Men more likely to be employed while caregiving (67%) than women



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# DEMENTIA CARE

**Figure 27. Presence of Alzheimer's or Dementia**



- One in ten (11%) indicate that Alzheimer's disease or a related condition is the main problem or illness
- In total, 26% say that dementia is present, whether it's the main problem or co-existing with another condition

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# CAREGIVING NEEDS BY AGE



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

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

\* Significantly higher than in 2015.

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

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# CAREGIVING NEEDS BY LENGTH OF CARE



**Figure 24. Types of Care Recipient Conditions by Caregiver Tenure**

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

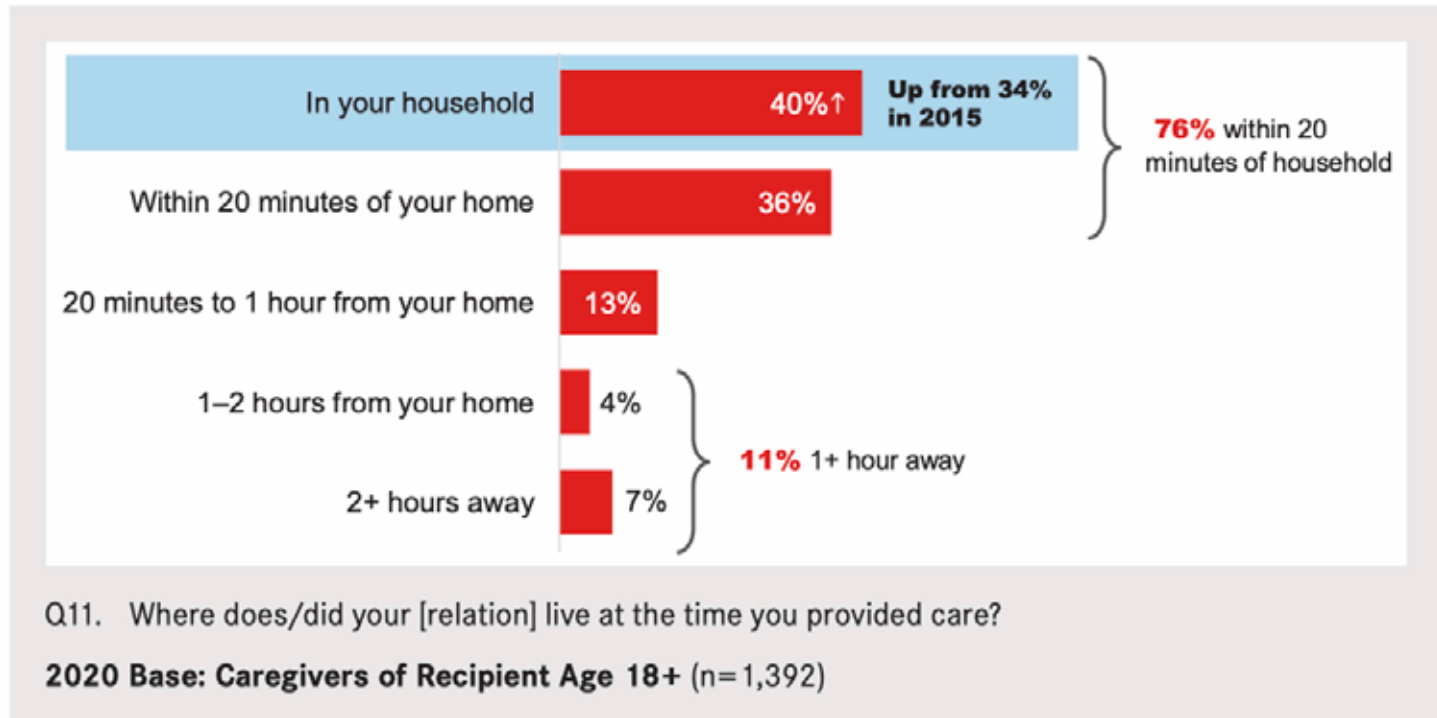
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# NEAR OR FAR, CARE HAPPENS



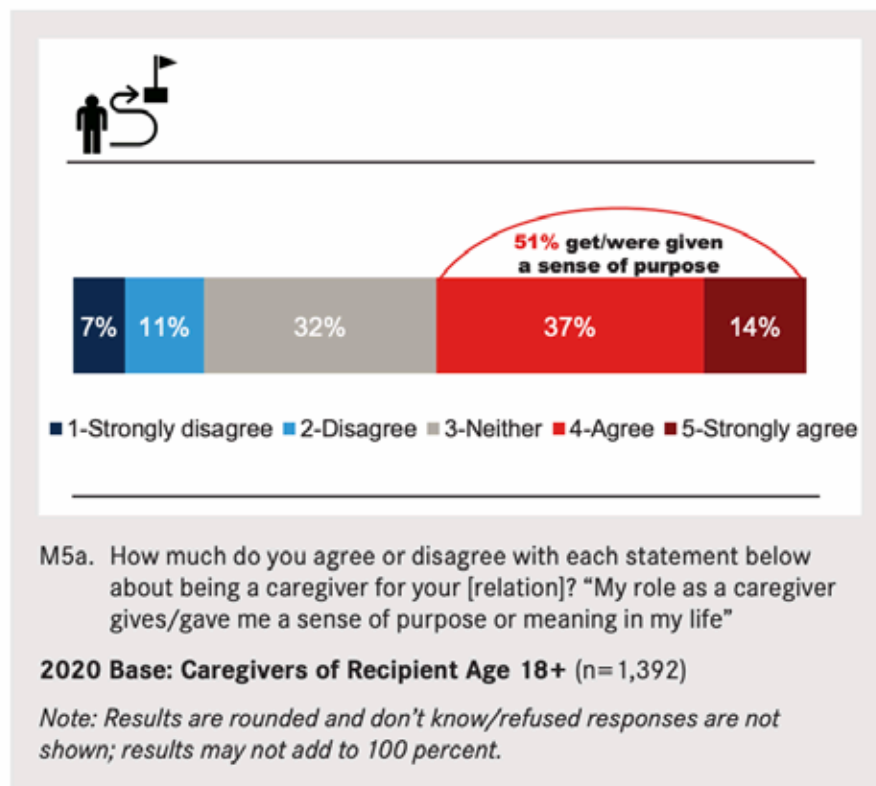
**Figure 18. Caregiver Distance from Care Recipient**



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# MIXED EMOTIONS

Figure 55. Sense of Purpose



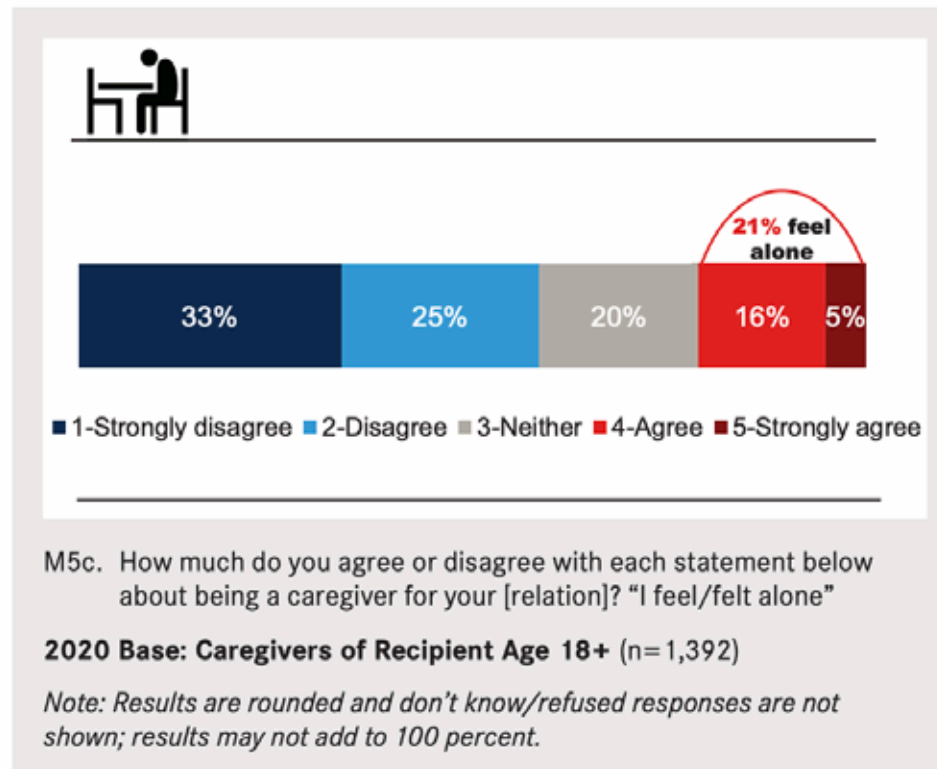
- Notably, Latino (61%) and African American (59%) caregivers more often report a sense of purpose, compared to White (46%) or Asian American (48%) caregivers
- Despite higher-intensity care situations, Latino and African American caregivers often report less emotional stress

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# A LONELY EXPERIENCE

Figure 54. Feeling Alone



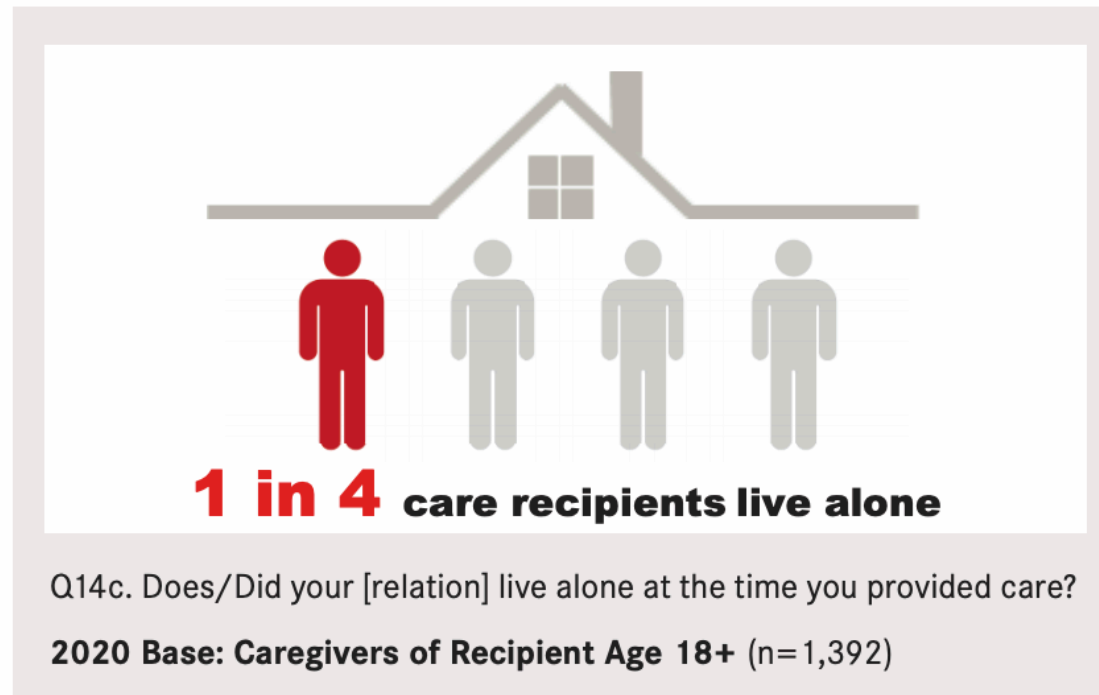
- Despite living together, caregivers who live with the person in their care more often report feeling lonely (29%), as do spouses (29%)
- Caregivers who use social media more often report feeling alone, suggesting that in-person interaction is key to addressing isolation

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# MORE OFTEN THAN OTHERS, FRIENDS, NEIGHBORS, AND OLDER ADULTS (65+) MAY LIVE ALONE



Figure 17. Care Recipient Living Alone

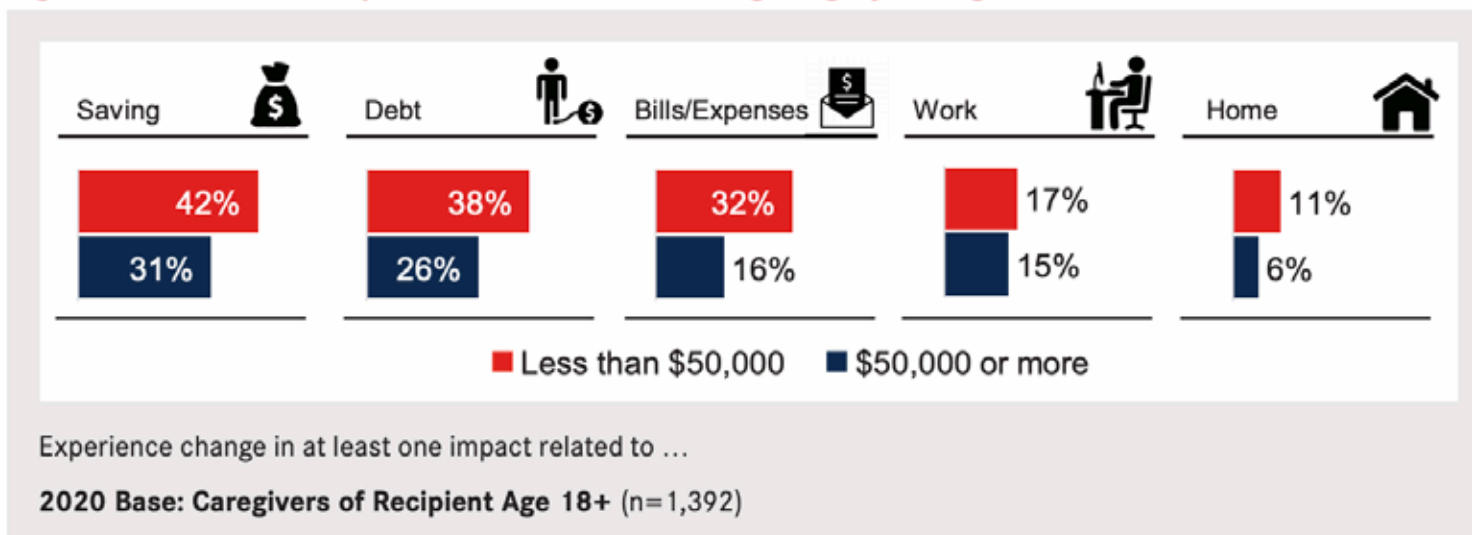


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# FINANCIAL IMPACT



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

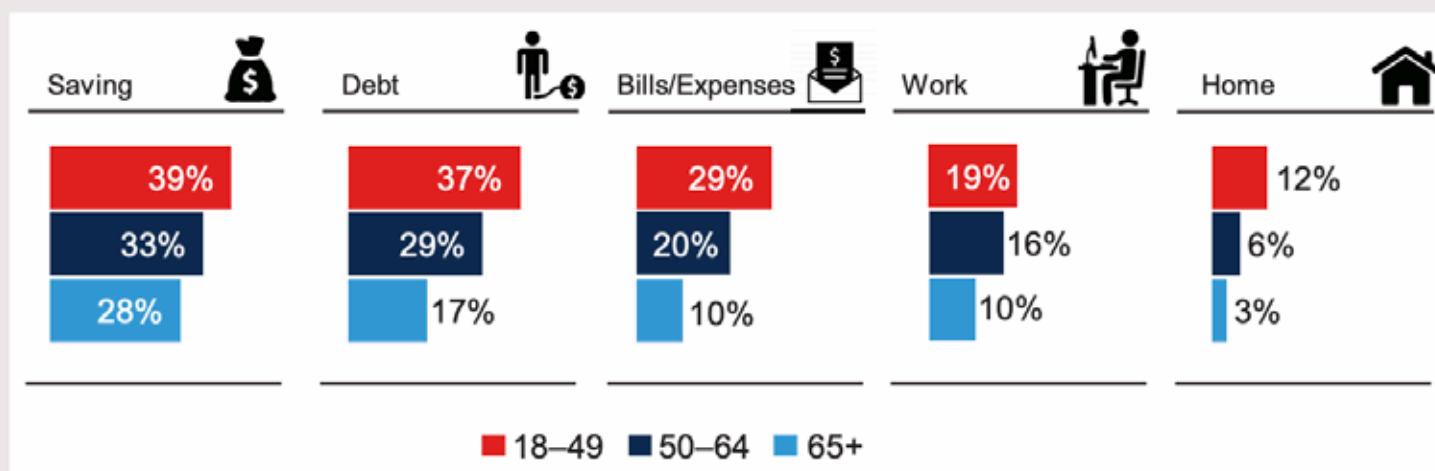


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# WHAT'S THE IMPACT ON FUTURE GENERATIONS?



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



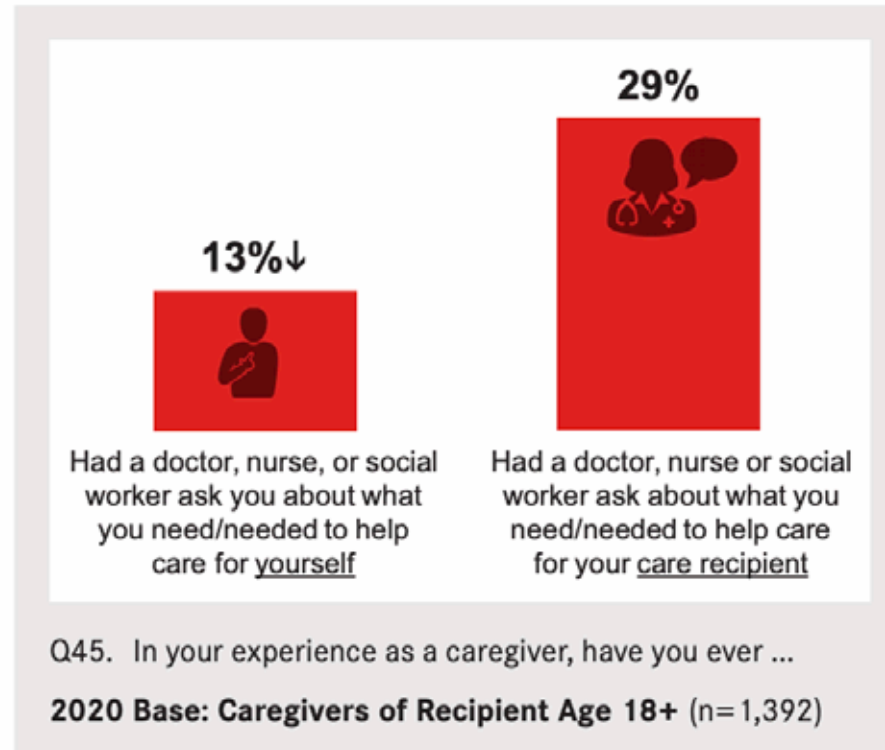
Experience change in at least one impact related to ...

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

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# Ask About Needs

Figure 76. Conversations with Health Care Providers

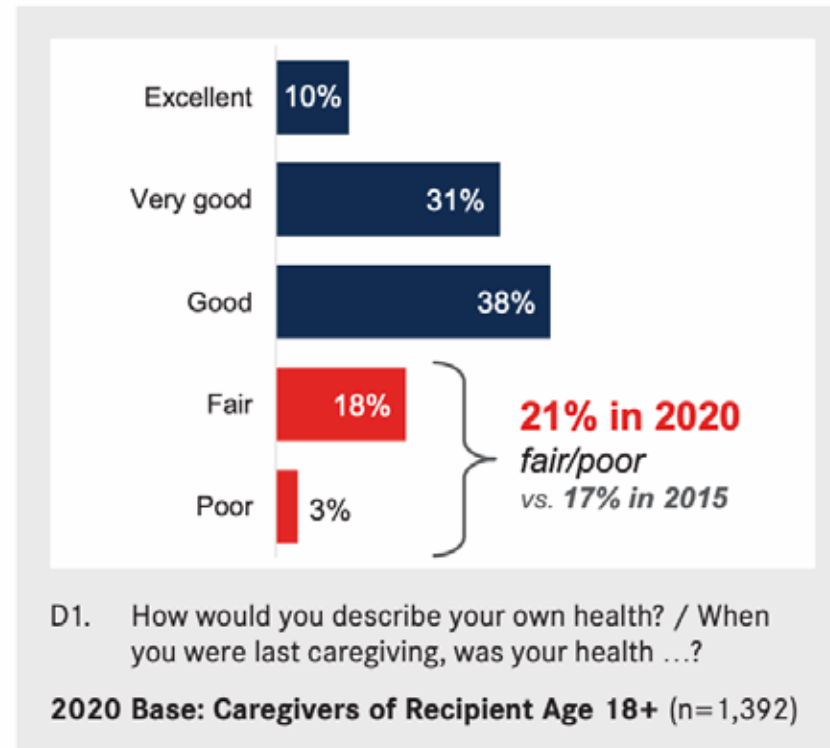


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# Encourage Self-Care



Figure 47. Caregiver Self-Rated Health



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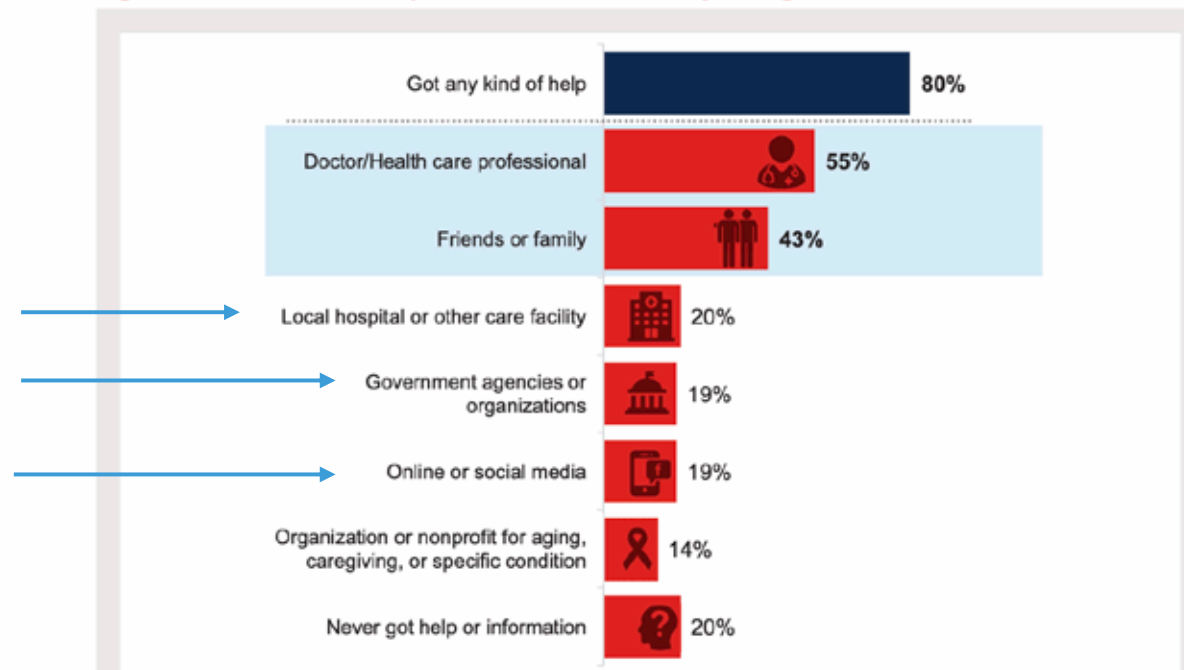


# TRANSLATING RESEARCH → ACTION

## LEVERAGE TRUSTED SOURCES OF INFORMATION



Figure 75. Sources of Help or Information used by Caregivers



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

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

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

visit [caregiving.org/caregiving-in-the-us-zuzu](https://caregiving.org/caregiving-in-the-us-zuzu); [aarp.org/caregiving](https://aarp.org/caregiving); and [aarp.org/ppi/info-2020/caregiving-in-the-united-states.html](https://aarp.org/ppi/info-2020/caregiving-in-the-united-states.html)

# ACTION ITEMS



## **MENTAL HEALTH: Support caregiver's role as a member of the care team**

- Identify, Assess, and Support
- Only 13% of caregivers were asked what they needed to take care of themselves by a doctor, nurse, or social worker

## **PHYSICAL HEALTH: Provide respite, especially in light of COVID-19**

- Only 14% of caregivers used respite, while 38% feel respite would be helpful

## **FINANCIAL HEALTH: Support paid family/medical leave, tax credits, funding for OAA programs, and Medicaid expansion**

- More than half (54%) of working caregivers would find partially paid leave helpful ; 6 out of 10 for those working 30+ hours each week
- Most (68%) said an income tax credit would be helpful
- Most (65%) would find it helpful to be part of a program where they are paid for part of the care provided (such as the Medicaid HCBS 1915 waiver programs)
- Close loopholes in Family First Coronavirus Response Act through new legislation like the HEROES Act

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