FREE WEBINAR
Oct. 15, 2020
12:00 - 1:15 pm CDT

Caregiving Research 2020: Eye-Opening National and Minnesota Findings and Trends

By:
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Caregiving in the U.S. 2020
A closer look at the experiences of caregivers today

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

About This Report

AVAILABLE TO DOWNLOAD AT:

aarp.org/caregiving
caregiving.org/caregiving-in-the-us-2020
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

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>43.5 million</td>
</tr>
<tr>
<td>2020</td>
<td>53 million</td>
</tr>
</tbody>
</table>

Percent providing care to someone of any age

<table>
<thead>
<tr>
<th>Year</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>18%</td>
</tr>
<tr>
<td>2020</td>
<td>21%</td>
</tr>
</tbody>
</table>

↑ 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.

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.

Demographics of caregivers

**Race/Ethnicity**
- Six in 10 caregivers report being non-Hispanic White (61 percent),
- 17 percent are Latinx/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)
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)
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

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

- Excellent: 10%
- Very good: 31%
- Good: 38%
- Fair: 18%
- Poor: 3%

21% in 2020
(fair/poor)
vs. 17% in 2015
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 Chart]

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)

- 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)

29%

13%

Had a doctor, nurse, or social worker ask you about what you need/needed to help care for yourself

Had a doctor, nurse or social worker ask about what you need/needed to help care for your care recipient

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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)

Financial impact by household income

*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)

% Yes

- Go in late, leave early, take time off
- Went from working full to part-time/reduce work hours
- Leave of absence
- Receive warning about performance/attendance
- Turn down promotion
- Give up working entirely
- Retired early
- Lose job benefits
- None of these

Working caregivers who left their position, either sometime in the past year or ever, most commonly do so because:

- They needed to **care for their recipient (49%)**
- Their job didn’t **allow flexible work hours (15%)**
- They could not afford paid help (13%)
- They retired (12%)
- Their job did not allow time off with pay (12%)
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)

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 subgroups 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)
Half of caregivers have used technology or software in their role as caregiver

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

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

- Tracked recipient’s finances: 35%
- Tracked recipient’s personal health records: 30%
- Got or used assistive devices: 17%
- Created electronic lists/spreadsheets to track caregiving activities: 14%
- Checked up on recipient using app, video, wearable device, or other remote monitoring: 13%

Comparisons to 2015 are unavailable because this is the first time questions on technology have been asked for this report.
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)

- An income tax credit to caregivers, to help offset the cost of care: 68%
- A program where caregivers could be paid for at least some of the hours they provide care: 65%
- A partially paid leave of absence from work, for caregivers who are employed: 54%

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

<table>
<thead>
<tr>
<th>Information</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keeping recipient safe at home</td>
<td>26%</td>
</tr>
<tr>
<td>Managing emotional/physical stress</td>
<td>26%</td>
</tr>
<tr>
<td>Managing recipient’s paperwork/eligibility for services*</td>
<td>25%</td>
</tr>
<tr>
<td>Activities you can do with recipient*</td>
<td>20%</td>
</tr>
<tr>
<td>Making end-of-life decisions</td>
<td>13%</td>
</tr>
<tr>
<td>Managing your own personal finances*</td>
<td>13%</td>
</tr>
<tr>
<td>Choosing a home care agency, assisted living facility, or nursing home*</td>
<td>13%</td>
</tr>
<tr>
<td>Using technology to care for recipient*</td>
<td>12%</td>
</tr>
<tr>
<td>Managing recipient’s challenging behaviors</td>
<td>11%</td>
</tr>
<tr>
<td>Finding non-English language materials</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
</tr>
<tr>
<td>None</td>
<td>38%</td>
</tr>
</tbody>
</table>

* 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?

<table>
<thead>
<tr>
<th>Benefit</th>
<th>% Yes</th>
<th>Change 2020-2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paid sick days</td>
<td>58%†</td>
<td>Up from 52% in 2015</td>
</tr>
<tr>
<td>Flexible work hours</td>
<td>56%</td>
<td></td>
</tr>
<tr>
<td>Unpaid family leave*</td>
<td>53%</td>
<td></td>
</tr>
<tr>
<td>Paid family leave</td>
<td>39%†</td>
<td>Up from 32% in 2015</td>
</tr>
<tr>
<td>Programs to help caregivers</td>
<td>26%</td>
<td></td>
</tr>
<tr>
<td>(Information, referral, Employee Assistance Programs)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telecommuting</td>
<td>25%</td>
<td></td>
</tr>
</tbody>
</table>

*New in 2020

2020 Base: Working and Not Self-Employed Caregivers of Recipient Age 18+ (n=707)
There is an opportunity for public health experts, policy makers, health and social providers, researchers, employers, financial institutions, and other stakeholders, as well as workplaces, to work together to improve the health care and LTSS systems so they better address the needs of caregivers. Together, we can develop and enact solutions to support family caregivers and to improve their well-being and the well-being of those for whom they provide care.

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