Alone Together: Understanding Social Isolation in Caregiving in the U.S. 2020

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National Alliance for Caregiving
July 20, 2020
Webinar Instructions

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  o Dial in to the conference call
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• **Technical issues**
  o Due to increased demand on tele-work platforms, we may experience technical issues during the webinar. We assure you we are working to mitigate and correct any possible interference.
Presenter

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Alone Together: 
Understanding Social Isolation 
and Loneliness in 
Caregiving in the U.S. 2020

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Presentation for: 
engAGED: The National Resource Center for 
Engaging Older Adults, National Association of 
Area Agencies on Aging (n4a)

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visit caregiving.org/caregiving-in-the-us-2020/aarp.org/caregiving; and 
aarp.org/ppi/info-2020/caregiving-in-the-united-states.html
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)
About This Report

Caregiving in the U.S.

Available to download at:
aarp.org/caregiving
caregiving.org/caregiving-in-the-us-2020

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Made Possible By

Independent Advisory Panel

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

  - Data collected for *Caregiving in the U.S. 2020* allowed **full online survey responses** from caregivers of adults and caregivers of children with special needs under age 18
  
  > However, the main study summarizes the findings for those caring for adults (age 18+) only

- **Margin of error is +/- 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
The Big Picture

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

↑ 21% refers to the prevalence of caregiving for all ages

↑ 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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Figure 25. Care Recipient’s Main Problem or Illness

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

2020 Base: Caregivers of Recipient Age 18+ (n=1,392)
Trends in Caregiving: Longer Care Journeys

• On average, caregivers spend **4.5 years** caring for their recipient

• **Most are caring longer**, with nearly a third (29%) caring for more than 5 years, up from 24% in 2015

• Caregivers spend **23.7 hours** per week providing care
  → One in five (21%) caregivers care 40+ each week

• Caring because of **chronic conditions**:
  
  ↑ Memory problem, such as dementia  
  (32% of caregivers, up 6% from 2015)

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

  ↑ Multiple conditions  
  (45%, up 8% from 2015)
Trends in Caregiving: High Intensity Care

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

- Very difficult: 6%
- Somewhat difficult: 24%
- Somewhat easy: 42%
- Very easy: 27%

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

- Very difficult: 5%
- Somewhat difficult: 18%
- Somewhat easy: 45%
- Very easy: 31%
Trends in Caregiving:
Caregiver Health and Wellbeing

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
• Half of caregivers feel their role gives them a sense of purpose in life (51%)
Trends in Caregiving: Feeling Alone

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

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

- One out of five caregivers of adults feel alone
- 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)

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The “Typical” Isolated Caregiver

• 49.6 years old, on average

• More often a woman, and less often married/partnered (than those who do not feel alone)

• Typically cares for a 68-year-old relative; about half the time their own parent

• The recipient typically has multiple conditions:
  → A long-term physical condition
  → An emotional/mental health condition
  → A behavioral problem.

• They are usually the sole unpaid caregiver (60% vs 43% who do not feel alone)

• Few report having paid help (23% vs 34% who do not feel alone).
The Isolated Caregiver: A Day in the Life

- **Caring for nearly six years** (5.9) on average
  - Compared to an average of 3.9 for those who do not feel alone

- More than half **live in the same house** as the person who needs care (54%)
  - Compared to 34% who do not feel alone

- Most are in a “**high-intensity**” care situation:
  - Average of 33 hours a week
  - Helping with 1.9 ADLs and 4.9 IADLs

- Care can be **challenging**
  - 4 out of 10 (39%) report difficulty helping with those ADLs
  - Compared to 14% who do not feel alone

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The Isolated Caregiver: Work and Finance

• **Most work in addition to caring**, an average of 37 hours each week

• More likely to experience **job-related impacts** than those who do not feel alone, such as:
  - taking time off work
  - cutting back work hours
  - receiving a warning for attendance

• Most have had at least one **financial impact**:
  - Stopping saving
  - Taking on more debt
  - Leaving bills unpaid or paying them late

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The Isolated Caregiver: Challenges to Health and Wellbeing

- Nearly three out of four have high stress (72%)
  - Compared to 24% of those who do not feel alone
- Nearly forty percent reported physical strain (37% high strain vs. 11%)
- Many had worsening health (30% rate their health fair/poor vs. 16%)
  - Challenges to taking care of their own health (58% vs. 11%)
  - Feeling health has declined as a result of caregiving (50% vs. 13%)
- More likely to anticipate caregiving for the next 5 years (62% vs. 52%)
- Most feel they had no choice in taking on this responsibility
  - 73% vs. 44% who do not feel alone
The Isolated Caregiver: Service and Supports

- More often want help managing their own emotional and physical stress and their own personal finances.
- Find it more difficult to coordinate care between their recipient’s providers (40% vs. 21% who do not feel alone)
- Find it difficult to get affordable services in their care recipient’s community (46% vs. 21% who do not feel alone)
- They often reach out for help:
  → Searching online for support services, aides, facilities, or other assistance for their care recipient
  → More often using technology to help them with tasks like tracking their recipient’s finances and personal health records.
The Isolated Caregiver: Helpful Policies

- They would appreciate **any kind of financial support policies**
  - Income tax credits
  - Payment for some hours of care
  - Partially paid leave from work

- **Nearly half (47%) want access to respite**, and they’re **more likely to want respite** than others
  - 47% compared to 35% of those who do not feel alone

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Hot Topic: Understanding Social Isolation in a Time of Physical Distance
COVID-19: Often Little Support for “Typical” Challenges

**Typical* Caregiving Challenges**

- Living together vs. long-distance or facility-based care
- Helping with activities of daily living, care coordination, medical/nursing tasks
- Emotional strain on relationships with the person receiving care, other family or friends
- Financial strain, deferred career or educational goals
- Worsening physical health of the caregiver
COVID-19: A Disruptive Influence

- Uncertainty of disease impact and timeline, which increases caregiver stress
- Quarantine/limits on visiting family members, especially in advanced illness
- Closure of dependent care and childcare supports
- Potential job loss, long-term career and income security damage
- Restricted access to medicine, equipment, and care providers
- Increased concern about self-care and health, worry, anger, anticipatory anxiety and grief
COVID-19: The “Typical” Caregiving Journey

*This is for illustration only. While generally this principle may hold true in chronic conditions such as diabetes or dementia, the main problem or illness requiring care may change over time or coexist with other chronic conditions, injury, or disease. In conditions that are relapsing/remitting condition (such as cancer, autoimmune disorders), or conditions where the disease journey is unclear (such as rare and orphan disorders).
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COVID-19: The Pandemic Creates **New Uncertainty** in the Caregiving Journey and **New Caregivers**
COVID-19: Even Before COVID-19, We Faced Siloed Systems of Support

**Health Care Paradigm**
(Support Caregiver as “Provider”, Services via the Beneficiary)
- Medicaid HCBS Waivers, such as 1915(i) Program
- Managed Care, Medicare Advantage, Managed LTSS, etc.
- Physician billing codes to support services to caregivers

**Hybrid**
- VA Caregiver Support Program
- Patient Advocacy and other Non-Profit Supports
- E.g., Chronic Disease Self-Management Program
- E.g., American Cancer Society Caregiving Supports

**Social Care Paradigm**
(Support Families and Family Responsibilities)
- Older Americans Act National Family Caregiver Support Program
- Lifespan Respite Act
- Community-based supports
- Workplace accommodations
COVID-19: Supply/Demand Challenges

- Dependent care supports become unavailable (e.g., school closures, adult care providers) requiring more time from the caregiver.
- Economic pressures amplify (layoffs, rise in unemployment, pressures in balancing work and care responsibilities) threatening financial security of the family unit.
- Caregiver fatigue, potential exposure to COVID-19 puts the person needing care at risk especially when health systems are overwhelmed.
COVID-19: 
Developing a New Framework for Caregivers

• Describe the **impact of COVID-19 on family caregivers**

  ➢ Who are co-resident but cannot go to a facility for risk of contagion

  ➢ Who are physically distant and should be incentivized to stay at home

• Push people of influence to **include caregivers as partners** – and to provided support when other help is needed

  ➢ Federal, state, and local policymakers

  ➢ Innovators and private enterprise

  ➢ Professionals who work with caregivers

[caregiving.org] [https://twitter.com/NA4Caregiving] [https://facebook.com/NA4Caregiving]
engAGED National Resource Center

- National effort to increase social engagement among older adults
- Administered by the National Association of Area Agencies on Aging (n4a)
- Project partners:
  - Generations United,
  - National Center for Osher Lifelong Learning Institutes
  - Older Adults Technology Services
- Funded by the U.S. Administration on Aging, which is part of the Administration for Community Living
COVID-19 Innovations from the Field
- Caregiver Social Isolation
- Telephone Reassurance and Wellness Checks
- Remote Connectedness
- Virtual Wellness Programming
- Engaging Older Adults at Home
- Transportation and Social Isolation
- Caregiver Social Isolation

Other Recent resources:
- Staying Connected At Home During COVID-19 (flyer)
- New additions to blog, social media, newsletter

https://www.engagingolderadults.org/
Coming Soon!

Blog post templates to engage older adults and caregiver during COVID-19 (sample language for AAAs and other providers)
Find us here:

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– Facebook: @engAGEDCenter
– Twitter: @engAGEDCenter
Questions?

Please use the questions tab in your Go To Webinar module to submit your question.
Thank you for attending today’s webinar!

The recording will be available on: https://www.engagingolderadults.org