CHRT

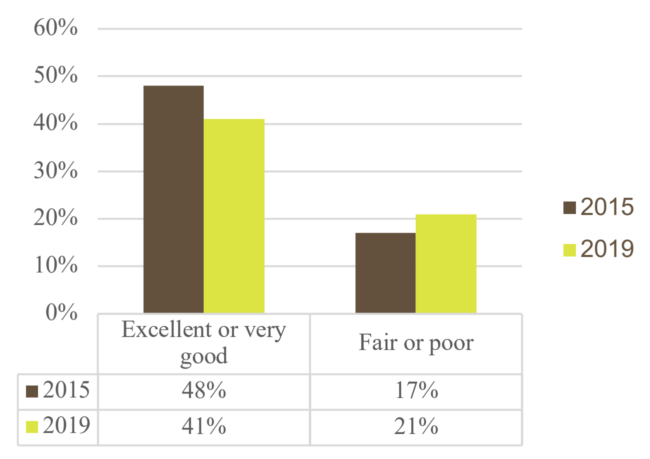
COVID-19 IMPACT – NOVEMBER 2021

COVID-19 adds stress for family caregivers – why that matters

Introduction

Nearly 40% of all family caregivers find their caregiving situation to be emotionally stressful.[i] When caregivers feel they have no choice in assuming their caregiving duties, this increases to 53%. Left unaddressed, caregiver stress[1] can worsen physical, mental, and emotional health, as well as social and financial well-being.[ii]

In recent years, caregivers' self-rated health has worsened



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[1] "Caregiver burden" is commonly used to describe stress, strain, or negative outcomes experienced by caregivers as a result of their caregiving duties. However, describing a caregiver's stress as a "burden" can imply that the care recipient is the burden and that they—rather than their condition--are personally to blame for the stress. Not only does this perpetuate negative feelings that dependent individuals may be experiencing as a result of their condition, but it may further stigmatize various conditions. In an effort to move away from "caregiver burden", this brief will use"caregiver stress."

CHRT is an independent 501(c)(3) impact organization with a mission to advance evidence-based care delivery, improve population health and expand access to care.

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A recent AARP report,[iii] comparing 2015 and 2019 data, found that:

- The proportion of caregivers reporting excellent or very good health decreased from 48% to 41%.
- The proportion reporting fair or poor health increased from 17% to 21%.
- In 2020, 21% of caregivers felt their health was fair or poor (compared to 10% in the general adult population).
- The longer a caregiver has been providing care, the more likely they are to report fair or poor health.
- More than 20% of caregivers feel their health has gotten worse as a result of caregiving.
- Worsening health is especially concerning for co-resident caregivers (30% report worse health), higher-hour caregivers (29% report worse health), caregivers who perform medical and nursing tasks (27% report worse health) and primary caregivers (25% report worse health).

Employment and financial status also have an impact on the stress that family caregivers experience.

- Most family caregivers are still full-time employees and must balance their caregiving duties with work duties to financially support themselves and their families.
- Family caregivers provide over $10,000 per person in unpaid hours of care each year.[iv]

Additionally, caregivers with less than $50,000 in household income are far less likely to rate themselves as having excellent or very good health compared to higher-income caregivers.[v]An October 2021 KFF Health Tracking Poll[vi] also examined

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stress, financial strain, and health among the 21% – or one in five – unpaid adult caregivers, and found that:

- 77% experience stress or worry about the individual's care.
- 42% experience financial strain, such as losing a job or working reduced hours.
- 50% experience a worsening of their own mental health, while 28 % experience a worsening of their own physical health.

The same poll[vii] also found that unpaid caregivers were disproportionately female, minority, lower income and less educated compared to the U.S. adult population:

- More likely to be female (55%, compared to 45% male).
- More likely to be minorities compared to overall adult population 21 vs. 17 % Hispanic, 14 vs. 12% Black, 55 vs. 57% white.[viii]
- More likely to be lower income (with 49% reporting less than $40,000 in household income, compared to 32% reporting $40,000 to $89,999 and 19% reporting $90,000 or higher).
- Less likely to have a college degree (with 40% reporting a high school education or less and 38% reporting some college, compared to 22% with a college degree).

The COVID-19 pandemic has only added to the difficulty of caregiving. This brief will examine how COVID-19 has impacted family caregivers, with special attention to working caregivers, caregivers with children, and caregivers of people who are aging with disabilities. The stories included in this brief were featured in a PBS NewsHour segment about COVID-19 and caregiving.

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Compounding factors on caregiver stress

COVID-19 impacts

> "[It] was really getting extremely difficult before. And then [with the pandemic], any help that I was getting, whether it was someone coming in, that stopped."

Deanna Ludwig is 50 years old. Her husband had a massive bilateral stroke about 25 years ago and she is now his caregiver. He does feed himself, but, other than that, he requires support for everything.

"When they first started talking about the virus, I knew that I was going to guard him like Fort Knox. Nowhere, I said, he can't go to respite unless I'm laying here dead ... So, that's kind of changed over time. If they had an opening in a respite facility where there's [no] cases, but there's a chance, I'd be like, let's go."[ix]

The COVID-19 pandemic has created an incredibly challenging environment for caregivers. In addition to managing the health of their care recipient, caregivers had to manage risk to their own health—caregivers may have a heightened risk of infection, as research shows that more than one-third have medical conditions that make them more susceptible to contracting COVID-19.[x] And caregivers had to manage risks to their care recipient's health, as well. Many care recipients are aging or are living with a condition that makes them more susceptible to health complications from a COVID-19 infection.

For many caregivers, the pandemic has exacerbated existing challenges. Studies suggest that nearly one in five family caregivers already felt isolated prior to the pandemic.[xi] The stay-at-home orders led to increased isolation and lack of access to respite services. Caregiving stress is compounded by feelings of isolation that take a heavy, detrimental toll on a caregiver's mental and emotional well-being. This may

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affect multiple facets of the caregiving role, including their ability to serve as a caregiver for longer periods of time.

While caregiver support groups have been effective in mitigating feelings of isolation, caregivers have limited access to these groups. Caregivers need reliable internet access and technology skills to join virtual support groups. This means that rural caregivers and caregivers who are not adept at utilizing communication technology may have a hard time receiving this type of support.

A recent Wisconsin survey of nearly 500 older adults and individuals with disabilities found that every respondent experienced a disruption in their caregiving service during the early months of the pandemic.[xii] Ancillary supports, such as respite services, in-home care assistants, and adult day centers, shut down for long periods of time. Caregivers without these services can quickly experience feelings of burnout, which can lead to increased fatigue, irritability, changes in sleeping patterns, feelings of anxiety and depression, and even getting sick more often.[xiii]

Working from home

Vivian Geary is a senior event planner for a large entertainment attraction in Orlando, Florida. She was a caregiver for her mom, who was hemiplegic (paralysis of the muscles of the lower face, arm, and leg on one side of the body) and lived with her for ten years. Geary took it upon herself to educate her managers on her role as a family caregiver, explaining the challenges with a standard 9-5 schedule.

Geary's employers were understanding and tried to compare her caregiving duties with those of working parents in the company. But Geary disagreed with the comparison. While many parents only need childcare coverage before and after school, caregivers of aging parents need coverage around the clock.

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The distinction made a difference at night when Geary was asked to run an event onsite. “I did have to tell my management in a review once that I wanted (to work) more daytime events, because nighttime events cost me money.” Her regular home care coverage ended at 9 p.m. and she had to hire additional help when working late. “By using the childcare model, they thought that by nighttime I’d be taken care of. It was just kind of an aha for them.’”[xiv]

3 out of 5 family caregivers are employed outside of their caregiver role, the majority of whom work full-time

More than 60% of family caregivers are employed outside their caregiver role, the majority of whom work full-time.[xv] More than half of caregivers of someone with a long-term physical condition (58%) reported that their supervisors were aware of their caregiving duties. But without adequate workplace supports, employment can affect caregiving duties and vice versa.

Employed caregivers may be absent front work, reduce their hours, turn down a promotion, or leave the workplace entirely by retiring early or quitting. 61% of caregivers have experienced at least one of these changes to employment. Higher-hour and higher-intensity caregivers typically experience these impacts more often than others. There may also be considerable short-term and long-term economic consequences for those who reduce their working hours, retire early, or quit. These include lost salary, personal savings for retirement, Social Security and retirement benefits, career opportunities, and overall financial well-being.[xvi]

As schools and businesses turned to remote work, many caregivers had to juggle childcare and employment duties in the home while continuing to perform their

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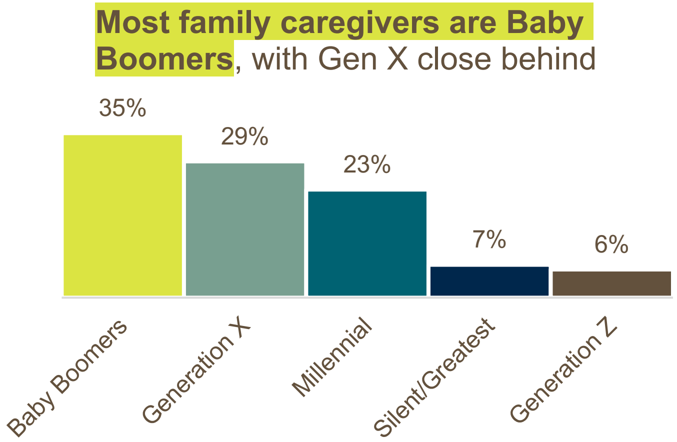
caregiving duties as well. Unfortunately, there aren't many ways to address the challenges of working at the same time as caregiving. Nursing home facilities had high rates of COVID-19 infections and deaths, so many families were reluctant to introduce their care recipients to this environment. Direct care workers have unknown exposure to COVID-19, so it's understandable that caregivers were reluctant to hire them. Nursing facilities and other community-based and institutional care options are also very costly, so there are significant financial barriers as well.

Caring for parents and children



Jessica Johnson is 45 years old and has been juggling caregiving responsibilities for her 12-year-old daughter, who suffers from mental illness, and her in-laws, who both have chronic health conditions.

Now Johnson is sheltering at home in New Jersey with her husband and two daughters and trying to figure out how to care for her in-laws in Texas. Her mother-in-law is recovering from back surgery, and her father-in-law struggles to treat his diabetes and heart disease.[xvii]

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Eleven million caregivers (28% of all caregivers) are part of the “sandwich generation,” caregivers who attend to aging parents while raising their own young children.[xviii] The majority of these caregivers are female, and between the ages of 40 and 59.

According to the Pew Research Center, almost half of adults in their 40s and 50s are raising young children (or financially supporting a child 18+) and have a parent aged 65 and older. About 15% of those middle-aged adults financially support both generations – children and parents. And 38% say that both parents and children rely on them for emotional support.[xix]

With this dual role of responsibility, these individuals are particularly prone to burnout as well as feeling stressed and overwhelmed[xx]:

- 85% of sandwich generation caregivers report needing more information on at least one caregiving related topic, including managing stress (44 %).
- More than 30% of sandwich generation caregivers report a high level of emotional stress.
- Nearly 20% report a high level of both financial strain and physical strain.
- Caregivers who live with their care recipient and those who care for a close relative are the most likely to report high levels of stress.

Family caregivers of adults who are aging with a physical disability have faced some of the greatest challenges during the COVID-19 pandemic.

When a care recipient is both aging and has a physical disability, the challenges imposed by each separate condition can compound and make caregiving duties more difficult. As these individuals age, they are at an increased risk for the development of multiple secondary health conditions such as increased fatigue, weakness, and further decreases in stability and mobility.[xxi] These primary and secondary conditions

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can require more intensive caregiving, especially in terms of hours spent caregiving and physical caregiving tasks.

Conclusion

Supporting an individual who is aging with a physical disability is not a one-person job. It requires a team of dedicated individuals, from health care professionals to community organization workers, to help aging and disabled individuals to live as well as they can. However, this duty often falls heaviest on a family caregiver.

Recent trends have made this task even greater, as caregivers are now managing their own health in addition to their recipient's health amid a global pandemic, while many are also caring for children and managing employment at the same time. To effectively help caregivers and alleviate caregiver stress, we need to better understand the stress and how it is exacerbated, then develop proactive programmatic and policy solutions.[xxii]

About the Authors

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[i] https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf
[ii] https://pubmed.ncbi.nlm.nih.gov/28637391/
[iii] https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf
[iv] https://chrt.org/wp-content/uploads/2021/03/TheHiddenCostOfUnpaidCaregiving_Final.pdf
[v] https://www.cdc.gov/mmwr/volumes/67/wr/mm6732a3.htm?s_cid=mm6732a3_w
[vi] https://www.kff.org/health-costs/poll-finding/kff-health-tracking-poll-october-2021/
[vii] Ibid.
[viii] https://datacenter.kidscount.org/data/tables/6539-adult-population-by-race#detailed/1/any/false/574,1729,37,871,870,573,869,36,868,867/68,69,67,12,70,66,71,2800/13517,13518
[ix] https://www.pbs.org/newshour/show/covid-19-has-made-life-much-harder-for-family-caregivers-here-are-some-of-their-stories
[x] https://www.healthaffairs.org/do/10.1377/hblog20200421.666035/full/
[xi] https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf
[xii] https://khn.org/news/pandemic-upends-the-lives-of-people-with-disabilities-and-of-their-caregivers
[xiii] https://my.clevelandclinic.org/health/diseases/9225-caregiver-burnout
[xiv] https://www.nextavenue.org/how-family-caregivers-make-career-and-elder-care-work
[xv] https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf
[xvi] https://www.aarp.org/content/dam/aarp/ppi/2018/08/breaking-new-ground-supporting-employed-family-caregivers-with-workplace-leave-policies.pdf
[xvii] https://www.aarp.org/caregiving/life-balance/info-2020/coronavirus-gen-x-caregivers.html
[xviii] https://caringacross.org/wp-content/uploads/2019/11/NAC_SandwichCaregiving_Report_digital112019.pdf
[xix] https://www.seniorlink.com/blog/sandwichgenerations
[xx] https://caringacross.org/wp-content/uploads/2019/11/NAC_SandwichCaregiving_Report_digital112019.pdf
[xxi] https://pubmed.ncbi.nlm.nih.gov/23887334/
[xxii] Center for Health and Research Transformation (2021). Family caregiver stress: state and federal policy and programmatic solutions

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