

Effects of COVID-19 on Family Caregivers

A Community Survey from the University of Pittsburgh

The COVID-19 pandemic has caused massive disruptions to society, with major impacts on employment, financial well-being and social relationships. The specific effects on family caregivers is unknown. Decades of research on family caregiving has shown that long-term and complex caregiving tasks often result in chronic stress for family caregivers which can lead to negative health outcomes for both the caregiver and care recipient. The COVID-19 pandemic has the potential to add to the complexity of caregiving given the stay-at-home requirements, reduced access to health care services, and the vulnerability of individuals at higher risk for severe side effects.

A team of researchers from the University Center for Social and Urban Research and the National Rehabilitation Research and Training Center on Family Support at the University of Pittsburgh set out to identify the specific effects of the pandemic on families. This report highlights the effects of COVID-19 on family caregivers. These results can inform the work of practitioners and policy makers as they design programs to help family caregivers and care recipients cope with this serious public health crisis and its aftermath.

Who are family caregivers?

Anyone who provides unpaid care to a spouse, partner, parent, child, other relative or a friend to help them take care of themselves because of a chronic illness or disability.

OUR SURVEY

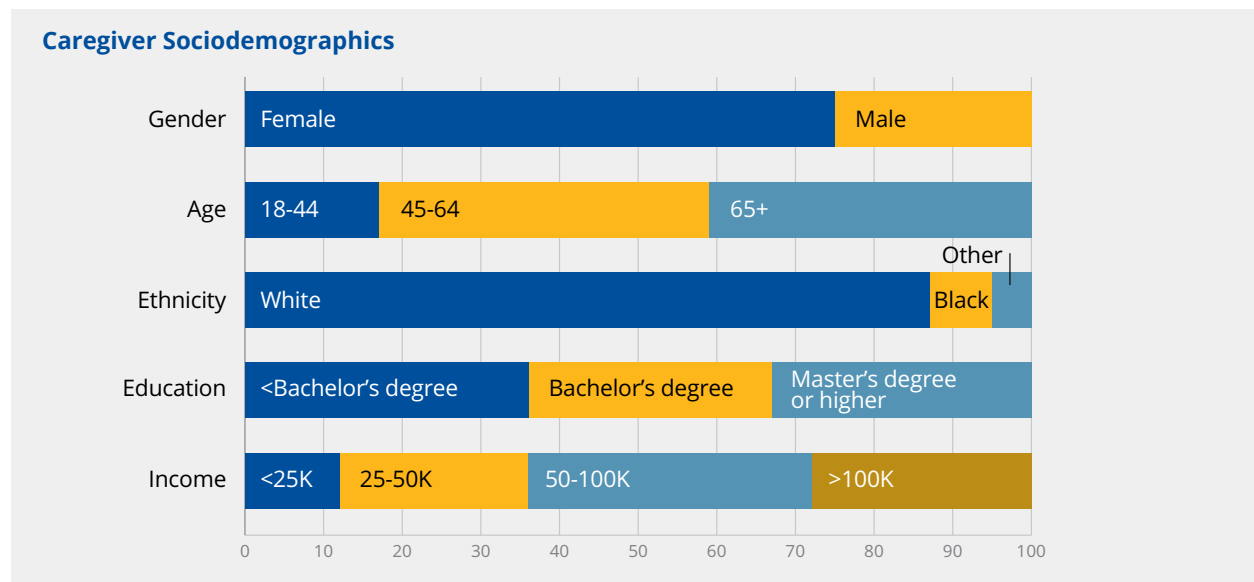
The survey was disseminated through a local area research registry, national disability and caregiving-related organizations, and a small-sample telephone survey of previously identified Pittsburgh area caregivers between April 15 and May 27, 2020. Responses were received from

- 619 family caregivers
- 2,933 noncaregivers

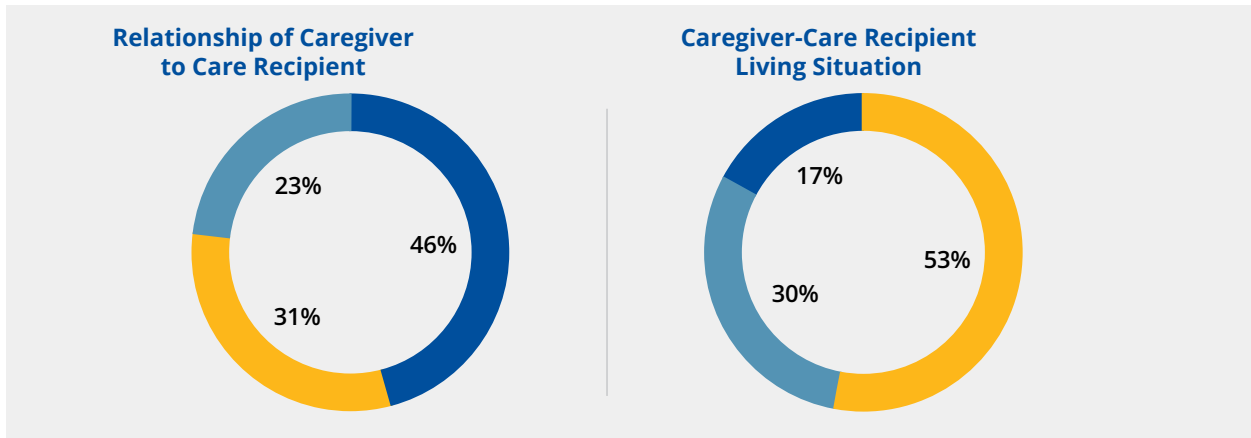
The survey assessed the impacts of the pandemic on employment, financial well-being, social interactions, health behaviors, and physical and mental health.

I. WHO ARE THE FAMILY CAREGIVERS IN OUR STUDY?

Family caregivers tended to be female, white/non-hispanic, married and college educated.



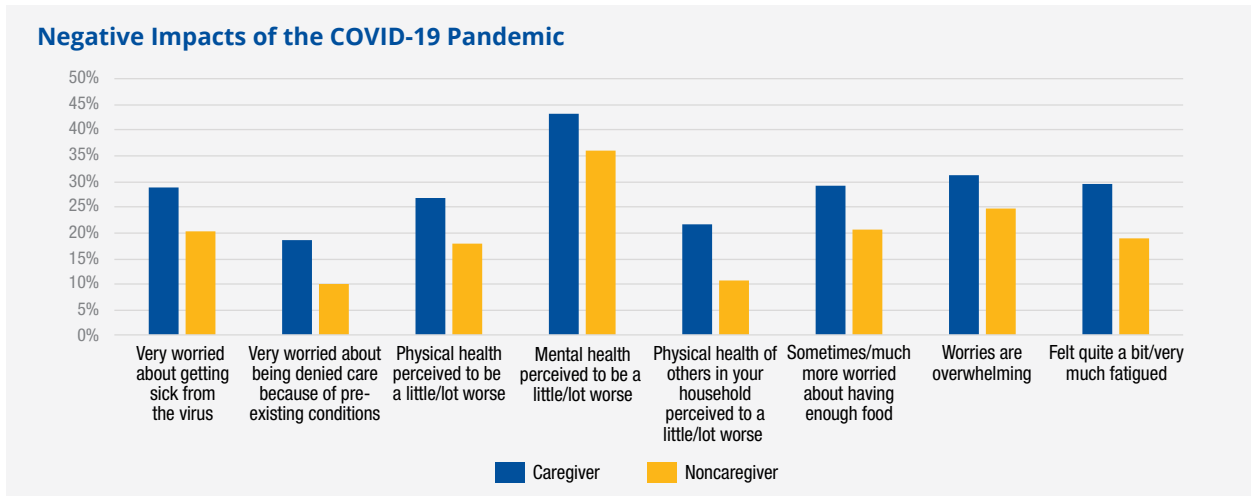
Most of the caregivers in this study were adult children, spouses or parents and approximately half of the caregivers were living with the care recipient.



These family caregivers helped with household tasks (e.g., shopping, managing finances, providing transportation); personal care tasks (e.g., bathing, dressing, eating); and medical tasks (managing medications, changing dressings, monitoring equipment).

II. HOW IS COVID-19 AFFECTING FAMILY CAREGIVERS COMPARED TO NONCAREGIVERS?

Caregivers consistently reported more negative impacts of the COVID-19 pandemic compared to noncaregivers across a wide range of categories.



As a result of COVID-19, caregivers were more likely than noncaregivers to report:

- worries about getting sick from the virus or being denied care due to pre-existing conditions;
- taking precautions such as wearing masks, postponing activities, and avoiding contact with high-risk individuals;
- negative impacts on their own physical and emotional health, function, and access to health care.

Caregivers were also more likely than noncaregivers to be experiencing:

- social isolation;
- financial hardship and food insecurity;
- anxiety and depression;
- fatigue and poor sleep; and
- pain that interfered with usual activities.

III. HOW IS COVID-19 AFFECTING FAMILY CAREGIVER DUTIES AND RESPONSIBILITIES?

Family caregivers report that COVID-19 has increased caregiving duties and responsibilities.

Sixty-three percent of caregivers reported increased caregiving efforts which were largely due to reduced access to their usual forms of support, increased needs of their care recipient, extra precautions being taken against COVID-19, and care recipient mental health issues. Additionally, 23% of family caregivers reported a change in who was providing care because of changes in access to services; social distancing/isolation; and family, friends and neighbors who stepped in to help.

“The fear of accepting help versus doing it alone is stressful. We weigh the risks and needs for our daughter as well as for ourselves. We are both working and trying to balance care and work is exhausting.”

Providing care became more difficult—emotionally, physically, and financially

For family caregivers, adapting to the pandemic has meant myriad lifestyle adjustments: loss of care resources, loss/reduction of income, increased need of care, increased expenses, and the inability to access usual care for both the caregiver and the care recipient. As a result, 56% of family caregivers reported that COVID-19 had made providing care more emotionally difficult, 22% reported it had made providing care more physically difficult, and 20% reported it had made providing care more financially difficult.

“She needs to be monitored more and make sure she is in a good place mentally and emotionally. She is now sleeping in my room for her safety.”

“He is not able to go to the outpatient clinic for monitoring and dressing change, or to acquire necessary supplies. Also, the therapist can't evaluate the wound status. I have to assess status and make changes in care based on my knowledge base and experience.”

Access to health care was interrupted

Because of cancellations, postponements, and lack of access to usual health care services, 37% reported that the pandemic had interfered with doctors' appointments or treatments for the care recipient, noting that some care recipients resisted technology-based methods like telehealth video appointments. Additionally, 21% of family caregivers reported that the pandemic had interfered with their own health care, partially due to increased mental health issues because of the pandemic.

Lifestyle adjustments led to caregiver and care recipient changes

The lifestyle adjustments required by the pandemic led to a reported 43% increase in worry, fear, depression and sleep problems among caregivers and concerns about declines in the mental health of the person they were caring for. Lifestyle adjustments also led to family disagreements or conflict over caring for the care recipient in 17% of respondents.

“I am exhausted at the end of the day. I feel like I am stuck in a box without an outlet. I don't have any energy or time to play with my son.”

IV. WHICH FAMILY CAREGIVERS ARE AT GREATEST RISK FOR NEGATIVE IMPACTS OF COVID-19?

The following family caregivers tended to report greater negative impacts of the pandemic:

- Female
- Younger (age 18-44 vs other)
- Minority vs. non-Hispanic White
- Those without college education
- Lower Income
- Caregivers for those with emotional/behavioral issues
- Caregivers of younger care recipients
- Caregivers who live with the care recipient

It is critical that these at-risk caregivers be targeted when developing and implementing interventions, policies, and other forms of assistance. These sub-groups are presented individually here, but, caregivers often fell into multiple risk categories. These intersections will exacerbate a caregiver's risk and should be considered in future intervention and policy development.

V. CONCLUSIONS AND IMPLICATIONS

Under ordinary circumstances, caregiving is an intense, complex and potentially stressful undertaking. Our work shows that the pandemic has made an already challenging situation even more so. Family caregivers reported consistently more negative impacts of COVID-19 compared to those not providing care. These differences were seen in multiple areas, and were particularly striking in terms of financial strains and mental health impacts. We also found increases in caregiving duties and responsibilities, along with specific pandemic-related challenges to providing care.

Certain family caregivers were at higher risk for negative impacts, including female caregivers, minority caregivers, caregivers with less education, caregivers with lower income, and caregivers who live with the care recipient. While these findings mirror the broader caregiving risk literature, we also found that younger caregivers, caregivers of younger care recipients, and those providing care for emotional / behavioral problems were also at increased risk. These findings are not reflected in the broader literature, and combined with the other effects reported here, provide additional insight into the impacts of COVID-19 on family caregivers.

Our results confirm the widely believed notion that COVID-19 has made family caregiving more difficult. During this public health crisis, family caregivers should receive increased support and assistance, and be specifically targeted in policy discussions and intervention/program planning.

This survey was conducted through a collaboration between the University Center for Social and Urban Research and The National Rehabilitation Research and Training Center on Family Support, both at the University of Pittsburgh.

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