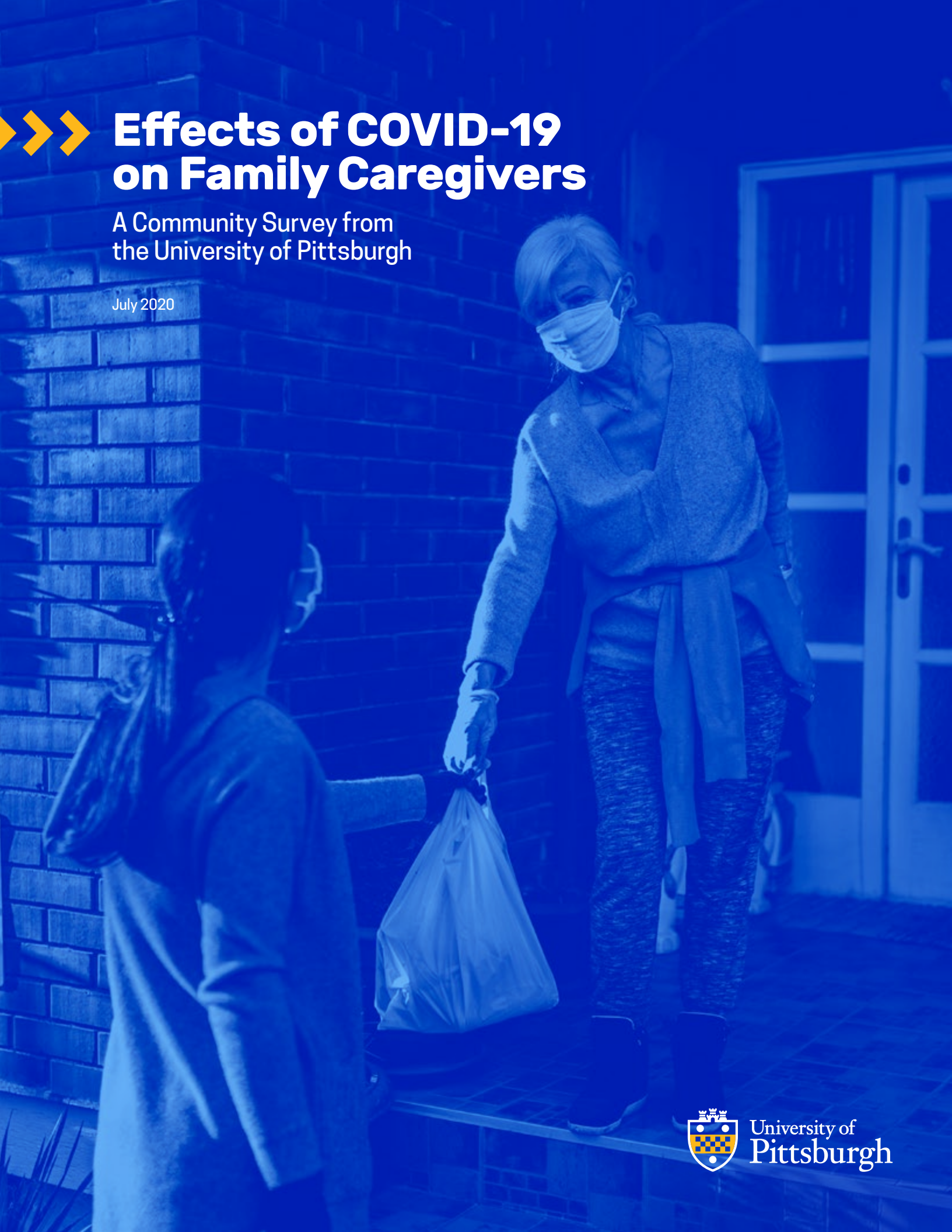
Effects of COVID-19 on Family Caregivers

A Community Survey from the University of Pittsburgh

July 2020



University of Pittsburgh

ABOUT THE NATIONAL REHABILITATION RESEARCH AND TRAINING CENTER ON FAMILY SUPPORT

The National Rehabilitation Research and Training Center on Family Support at the University of Pittsburgh partners with government, academia and the broad family support stakeholder community to translate state-of-the-art research and training into services and support programs to improve the care, health and quality of life of all persons with disabilities and the families who support them.

The center activities advance the science of caregiving for persons with disabilities while simultaneously disseminating existing evidence-based resources to increase access to state-of-the-art family caregiver support. The center operates with a philosophy of engagement science, in which the research is grounded in addressing practical care delivery challenges through the intensive input of diverse stakeholders.

The goals of the center include:

- advancing state-of-the-science research in caregiving, rehabilitation, and digital self-management support for persons with disabilities and their family caregivers;
- training health and rehabilitation providers and researchers in family caregiving science and practice;
- leveraging findings from Center research projects to advance the capacity of health care and public health systems to deliver high-quality, tailored support; and
- utilizing dynamic mechanisms to translate and disseminate knowledge to persons with disabilities, family caregivers, policymakers, service providers, researchers, and employers and other key stakeholders.

ABOUT THE UNIVERSITY CENTER FOR SOCIAL AND URBAN RESEARCH

The University Center for Social and Urban Studies (UCSUR) at the University of Pittsburgh works collaboratively to conduct interdisciplinary research that improves communities and addresses social, economic, health and policy issues that are most relevant to society. UCSUR carries out this mission by providing research support infrastructure and training in the social and behavioral sciences to faculty throughout the University; collecting and disseminating regional and national policy-relevant data to support faculty research and community development; and conducting original research in a few focused areas, including urban impact analysis, survey methodology, and psychosocial aspects of aging.

Summary

A team of researchers from the National Rehabilitation Research and Training Center on Family Support and the University Center for Social and Urban Research at the University of Pittsburgh recently conducted a survey to identify the specific effects of the pandemic on families and family caregivers. The survey, which was conducted between April 15 and May 27, 2020, assessed the impacts of the pandemic on employment, financial well-being, social interactions, health behaviors, and physical and mental health. This report summarizes the results, specifically identifying differences in how the pandemic uniquely affected family caregivers compared to noncaregivers.

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.

The following are key highlights from the findings and implications for policy:

- Family caregivers reported more negative effects from the pandemic than noncaregivers. They were more likely to report taking precautions and worries about getting themselves or the care recipient sick. They were also more likely than noncaregivers to be experiencing social isolation, anxiety and depression, fatigue, sleep disturbance, financial hardship and food insecurity.
- Family caregivers report that the pandemic has increased their caregiving responsibilities, and that providing care is more emotionally, physically, and financially difficult. This was largely due to interrupted access to care [both for themselves and their care recipient(s)], and the resulting lifestyle adjustments have led to the reported increases in worries, fear, depression, and anxiety.
- Female caregivers, minority caregivers, caregivers with less education, caregivers with lower income, younger caregivers, caregivers who care for persons with mental health/behavioral issues, and caregivers who live with the care recipient tended to report greater negative impacts of the pandemic.
- During this public health crisis, family caregivers should receive increased support and assistance, and be specifically targeted in policy discussions and intervention/ program planning.

Overview and Methodology

The COVID-19 pandemic has caused major impacts on employment, financial well-being, social relationships, and physical and mental health. This research focuses on the impacts of the pandemic on family caregiving. The term "family caregiver" refers to anyone who provides unpaid care to a spouse, parent, child, other relative, partner or friend who has a chronic illness or disability. Note that family caregiver is defined broadly—it includes relatives of an individual needing care, as well as friends and neighbors.

Decades of research on family caregiving have shown that the role can have negative psychological, social, physical and financial impacts on caregivers. The continuing demands and complex combination of caregiving tasks can result in chronic stress, which in turn can have negative effects on caregiver health and the ability to provide quality care to their loved one. The COVID-19 pandemic has the potential to add to the complexity and intensity of caregiving, and this study was an attempt to collect data on impacts of the pandemic on both family caregivers and a comparison sample of those not providing care. We also examine impacts of COVID-19 on caregiving duties and responsibilities, and the ability to provide quality care.

An online survey was conducted between April 15 and May 8 with UCSUR research registry members. This registry contains approximately 10,000 community members recruited through UCSUR surveys and research studies who have agreed to be contacted for future research studies. Studies used to recruit registry members employed a combination of probability and nonprobability sampling designs. Email addresses are available for approximately 80% of the registry members. Those without emails tend to be older, African American and less educated.

An initial email was sent to 7,989 registry members on April 15, 2020, inviting them to participate in the survey, with follow-up emails to nonrespondents sent on April 21, April 27 and May 2. The survey closed on May 8. This resulted in 3,113 responses for a 39% response rate. Responses were obtained from 435 family caregivers and 2,678 noncaregivers.

A subset of the UCSUR registry had previously indicated that they were family caregivers. In order to maximize caregiver response, we followed up directly via telephone with those indicated as caregivers who did not respond to the initial web survey invitation. We attempted to call 185 of these individuals, beginning on April 20 and ending on May 5. Up to 6 attempts were made to each number on different days and different times of the day. This resulted in 112 completed phone surveys for a 60.5% response rate. An additional 54 family caregivers were interviewed, along with 58 noncaregivers.

In order to recruit additional caregivers and broaden the geographic reach of the survey, we provided a link to the survey to various local and national disability and caregiver organizations for distribution to their members. This link was first provided on April 22, 2020 and the survey was closed on May 27. This resulted in 327 completed surveys, including 130 family caregivers and 197 noncaregivers. Among the 130 family caregivers, approximately half were from the National Alliance on Mental Illness, with the remainder from other disability and cancer organizations.

Summary: Final Samples

	Total	UCSUR web	UCSUR Phone	Open link web
Family caregivers	**619**	435	54	130
Noncaregivers	**2,933**	2,678	58	197
Total	**3,552**	3,113	112	327

It is important to note that this is a nonprobability survey, as registry/panel/organization members are self-selected volunteers. Thus, statements about "margin of error" are not appropriate, as these apply only to probability sample designs. However, given the urgency of the COVID-19 pandemic and potential impacts on family caregivers, we feel comfortable presenting this information with this caveat in mind. The relatively large and sociodemographically diverse sample size also lends further credibility to the generalizability of our findings.

Survey Instrument

The survey instrument consisted of approximately 100 items focused on (1) COVID-19 diagnoses, testing and symptoms; (2) employment impacts; (3) concerns and behavioral responses to COVID-19; and (4) health and financial impacts. The health items assessed a variety of physical, mental and social domains. In addition, the section for current family caregivers assessed (1) COVID-19 diagnoses and testing for the care recipient and other household members; (2) impacts of COVID-19 on caregiving duties and the caregiver burden; and (3) use of technology to aid caregiving during the pandemic. Both structured and text-based qualitative data were collected, with open-ended follow-ups when caregivers reported a particular impact. We also obtained basic caregiving context and demographic information. The survey took about 20 minutes to complete on average.

Current family caregivers were determined using the following screening question:

> Are you currently providing unpaid care to a spouse, parent, child, other relative, partner, or friend to help them take care of themselves because of a chronic illness or disability? This may have included helping with personal needs, household chores, or medical/nursing tasks. It might also be managing a person's finances or arranging for outside services. This person does not need to live with you. [y/n]

We assessed caregiver status both prior to the COVID-19 pandemic and currently. Of the 619 current caregivers, 74 reported that they had begun caregiving in response to the pandemic, while 545 were continuing caregivers.

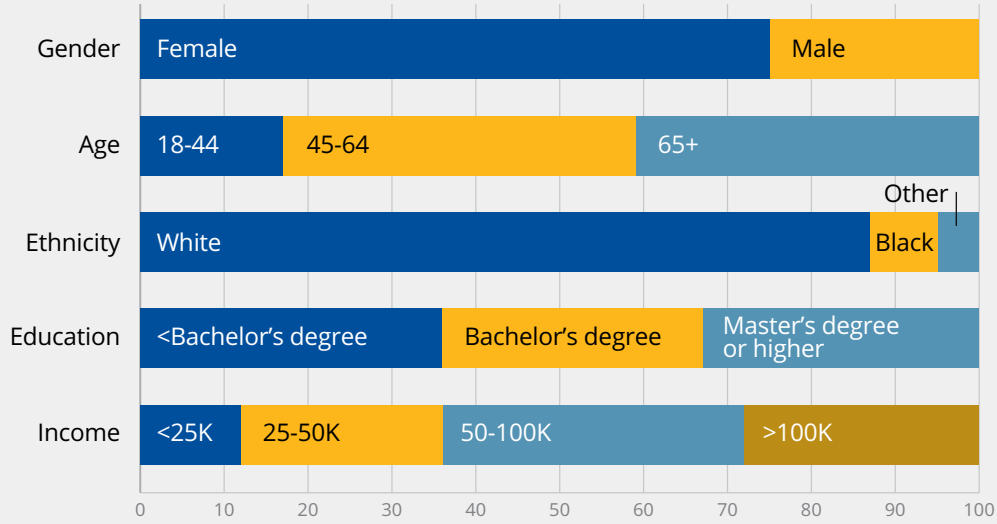
Summary Results

This report focuses primarily on the results for the 619 family caregivers. After providing basic descriptive information on family caregiver demographics and the caregiving situation, family caregivers are compared to noncaregivers in terms of COVID-19 diagnoses and testing, concerns and behavioral responses to COVID-19, and health and financial impacts of the pandemic. We also present the family caregiver-specific findings on COVID-19 impacts, using both quantitative structured and qualitative approaches. This report additionally identifies subgroups of family caregivers who are at higher risk for negative impacts of the pandemic.

I. WHO ARE THE FAMILY CAREGIVERS?

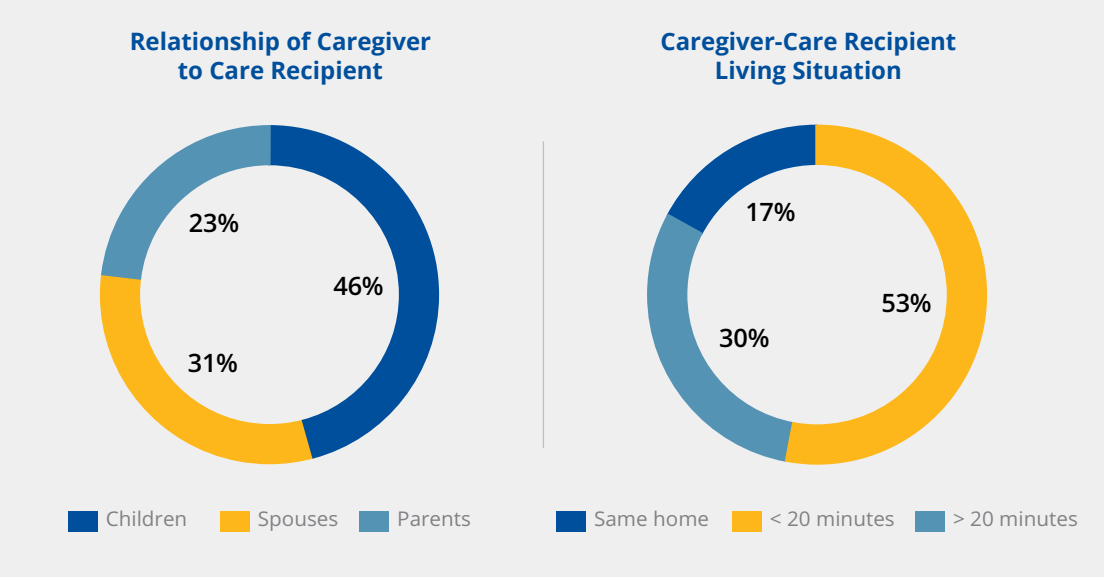
The family caregivers who competed the survey look similar in many ways to typical caregiver samples. Key caregiver demographics are shown below.

Caregiver Sociodemographics



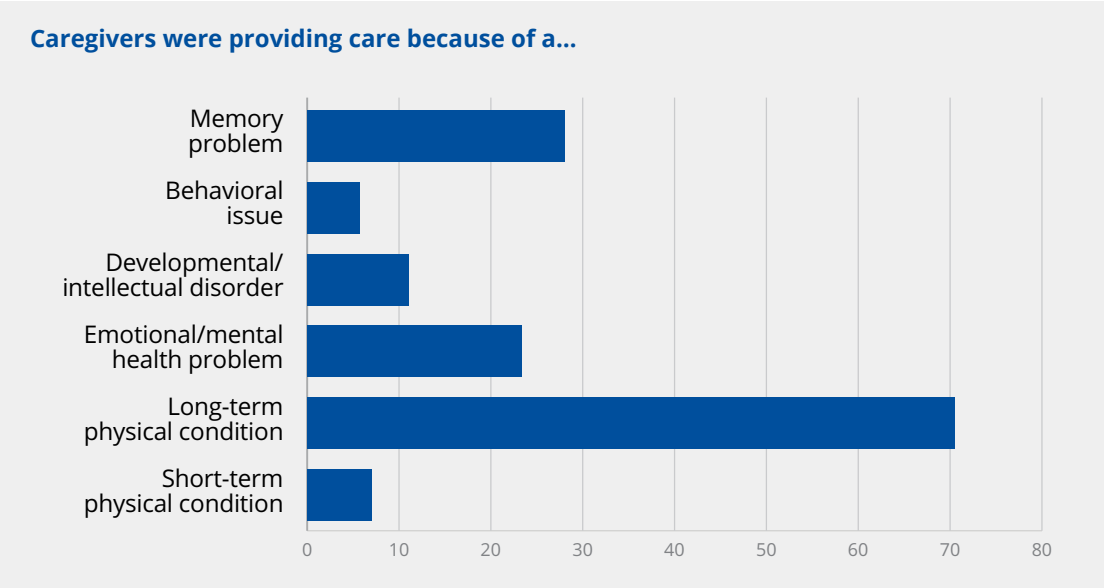
Compared to noncaregivers, the caregivers were more likely to be age 45-64 than noncaregivers (43.3% vs 33.2%) and less likely to be age 75 or older (10.5% vs. 15.2%); or age 18-29 (3.6% vs. 7.8%). However, overall mean age did not differ (59.2 vs. 58.4) for caregivers versus noncaregivers. In addition, caregivers were more likely to be female (75.6% vs. 68.2%) and married (69.0% vs. 57.1%). There were no differences between the groups on race, education, income or employment.

The caregiving situation or context can be seen in the figure below.



The vast majority of family caregivers (93%) provided help with household tasks like shopping, managing finances, arranging for outside services or providing transportation. 35% provided help with personal care tasks such as bathing, dressing, grooming, eating, moving from bed to chair, or going to the toilet. 45% provided help with medical or nursing tasks such as managing medications, changing dressing on wounds or monitoring equipment like oxygen tanks.

Care recipients tended to have a wide variety of physical conditions (cancer, heart disease, stroke, renal failure, pulmonary/respiratory), cognitive disabilities, mental health conditions and injuries/accidents, as seen below.



These data are typical of previous caregiver samples.

II. DO FAMILY CAREGIVERS REPORT DIFFERENT COVID-19 IMPACTS THAN NONCAREGIVERS?

We found consistently more negative impacts of the COVID-19 pandemic on family caregivers compared to the noncaregiver sample. These differences cut across many survey domains and are summarized here. It is important to note that these are simple bivariate comparisons between family caregivers and noncaregivers, and they do not adjust for sociodemographic variables or other covariates which may differ between groups. However, given the few sociodemographic differences between the two groups reported above and the consistency of the findings, we are confident that many of these effects will remain once more complex statistical methods are employed. We do plan more detailed and complex future analyses, but providing the unadjusted comparisons is a crucial first step.

Key differences are summarized by survey domain. All reported differences were statistically significant at $p < .01$ level unless otherwise noted. See Appendix B, which shows complete distributions of responses for all survey questions separately for caregivers and noncaregivers, along with indicators for statistical significance. There were many indicators for which no differences were found between the two groups, and the focus of this section is to highlight significant differences by showing data for only extreme response categories.

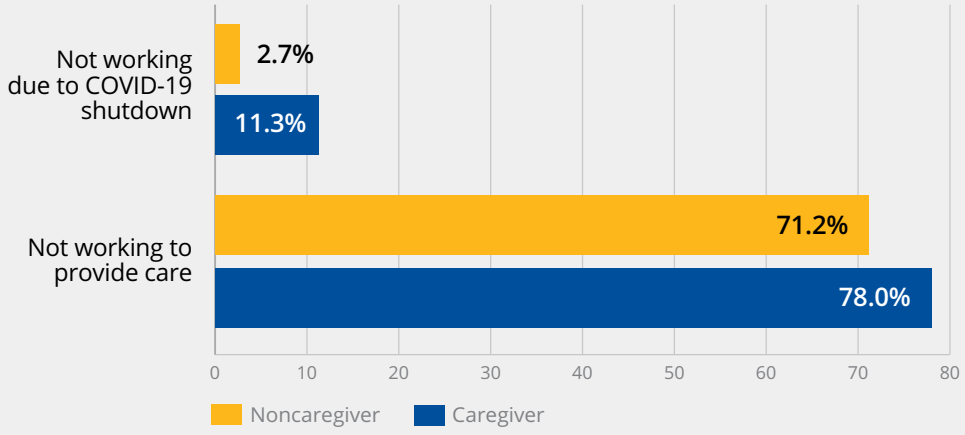
COVID-19 DIAGNOSES AND TESTING

COVID-19 diagnoses were extremely low, both among caregivers, care recipients, and other household members: There were 1, 2, and 21 diagnoses, respectively. These numbers are consistent with the extremely low overall prevalence rates in Pennsylvania and the United States at the time of the survey. However, more family caregivers had been tested for COVID-19—2.9% of caregivers vs. 1.5% of noncaregivers—or had attempted to get tested—4.8% of caregivers vs. 2.6% of noncaregivers. Even being in a household with a caregiver increased testing rates from 1.4% to 3.7%.

EMPLOYMENT IMPACTS

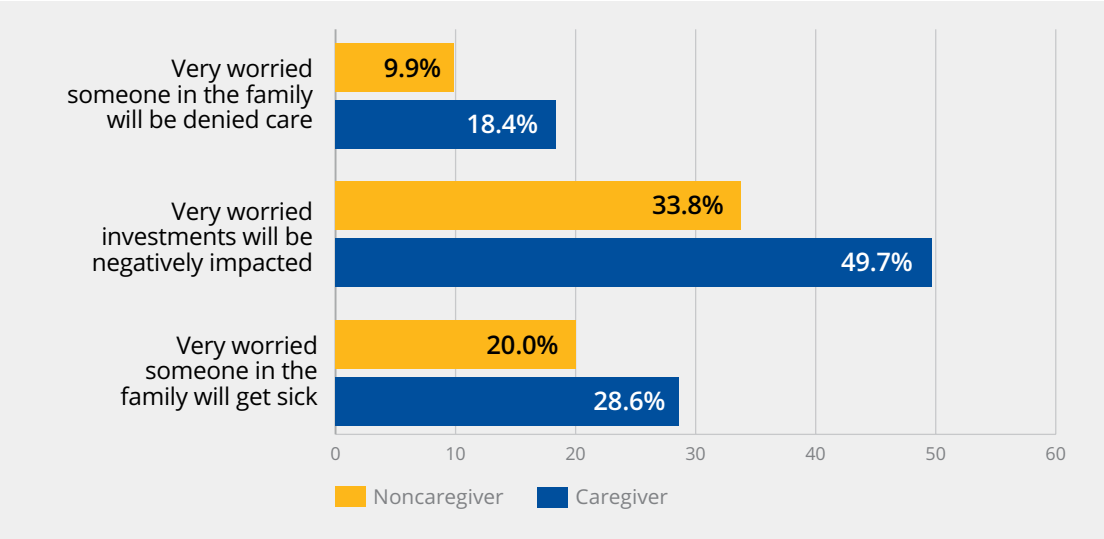
Among those who were no longer working after the pandemic, noncaregivers were more likely to say it was due to COVID-related shutdowns, while caregivers were more likely to no longer be working due to having to provide care for their family.

Employment Impacts

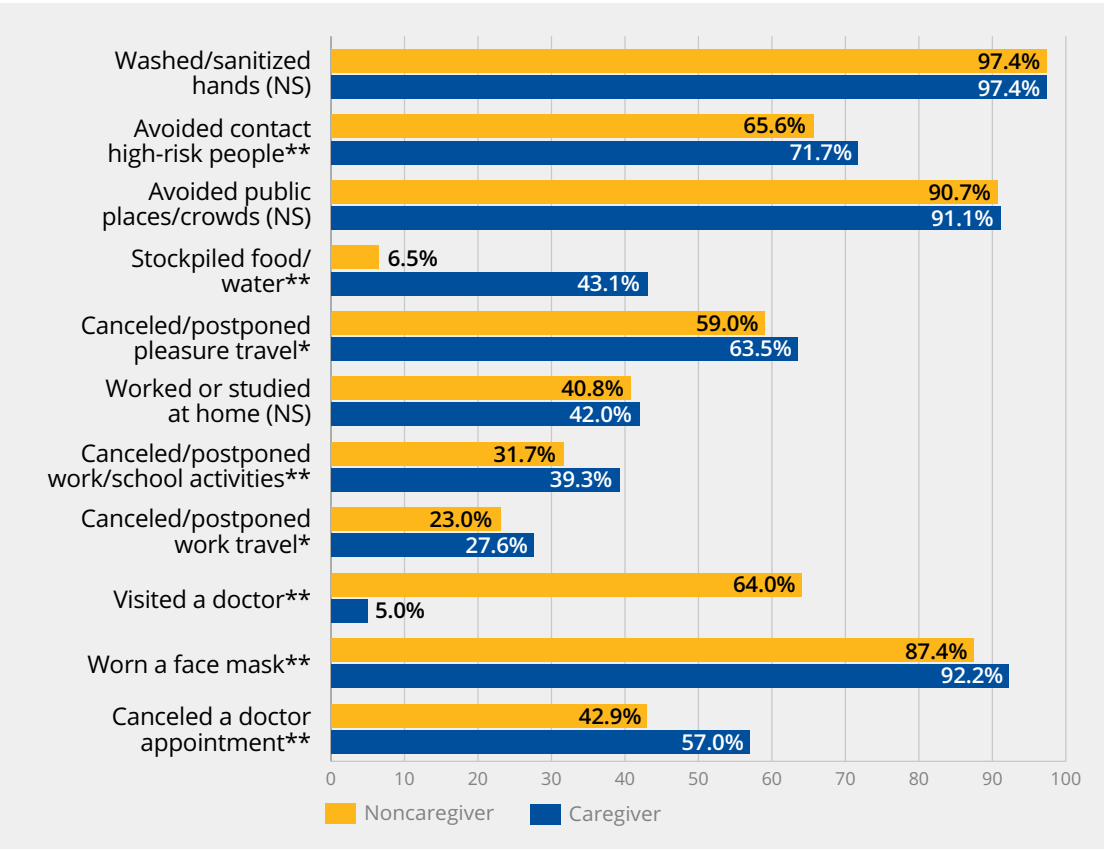


COVID-19 CONCERNS AND BEHAVIORAL RESPONSES

Family caregivers reported more COVID-related concerns and worries. The following differences were observed:



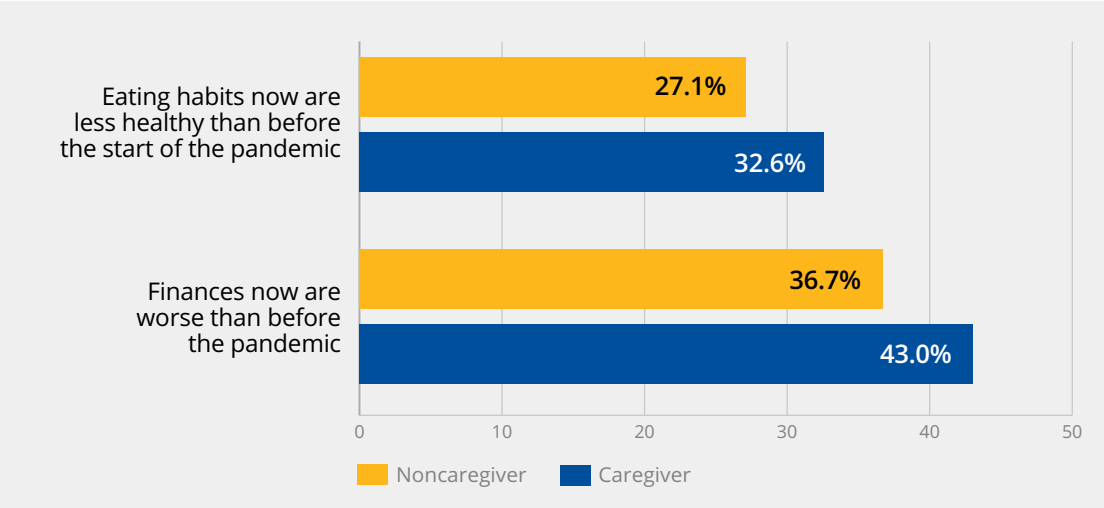
Family caregivers were also making more behavioral adjustments due to COVID than their noncaregiver counterparts. Behavioral responses by caregiver status were as follows:



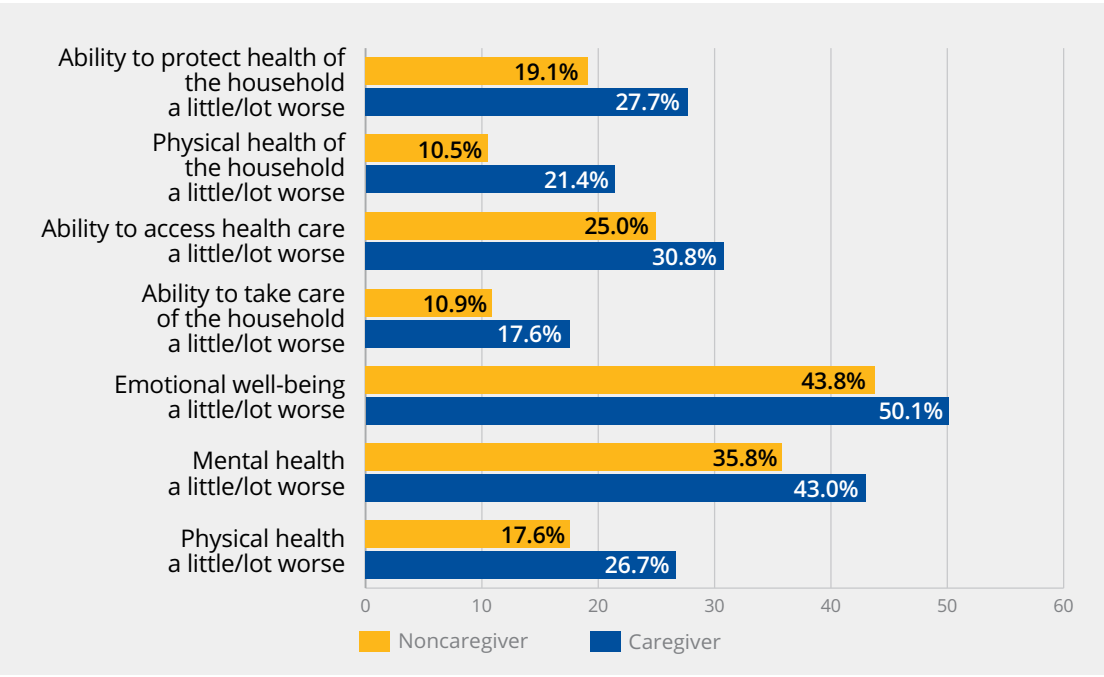
* p < .05; ** p < .01

PERCEIVED COVID-19 IMPACTS ON HEALTH AND FUNCTION

Family caregivers were more likely to perceive recent negative changes and impacts on health and function than noncaregivers. The following differences were observed:

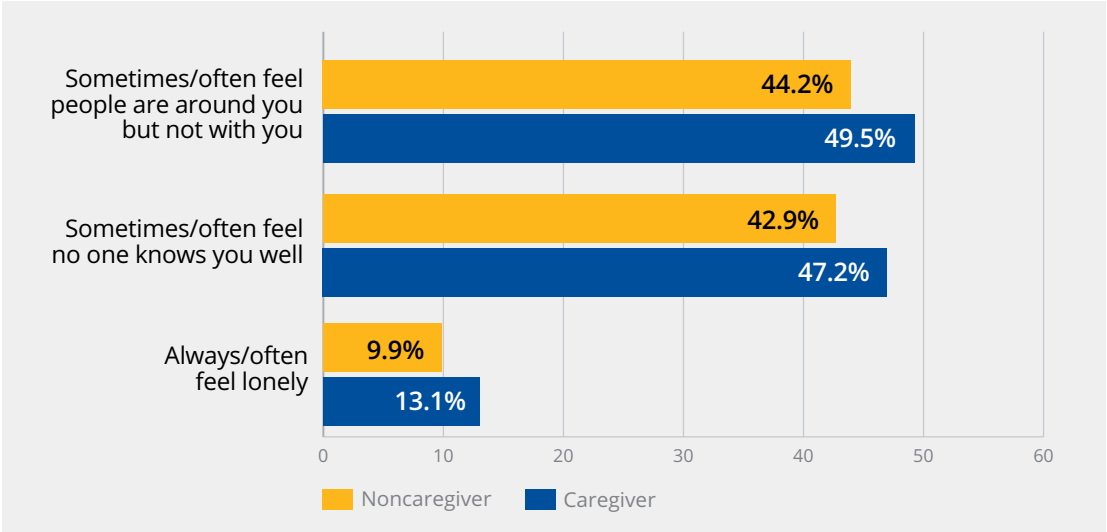


When asked about more recent changes (within the previous week), participants responded as follows.



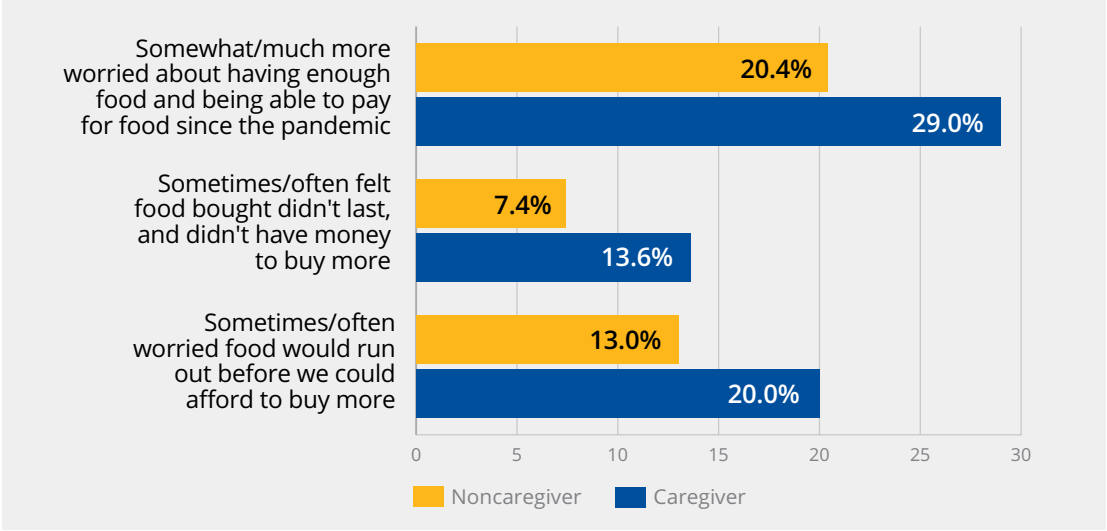
SOCIAL ISOLATION

While the effects were not as large, family caregivers also reported being more socially isolated than noncaregivers. Note that these are current perceptions and thus cannot be clearly attributed to the COVID-19 pandemic. The following differences ($p < .05$) were observed:



FINANCIAL IMPACTS AND CONCERNS; FOOD SECURITY

Family caregivers were much more likely to report financial impacts and worries due to the pandemic than their noncaregiver counterparts. This is the domain in which the most consistent differences were found. Note that the first two questions were framed as "in the last six months" to be consistent with other surveys, and thus these differences cannot unequivocally be attributed to the COVID-19 pandemic. However, the third item does indicate more food insecurity among caregivers since the outbreak. The following (all $p < .01$) were observed:

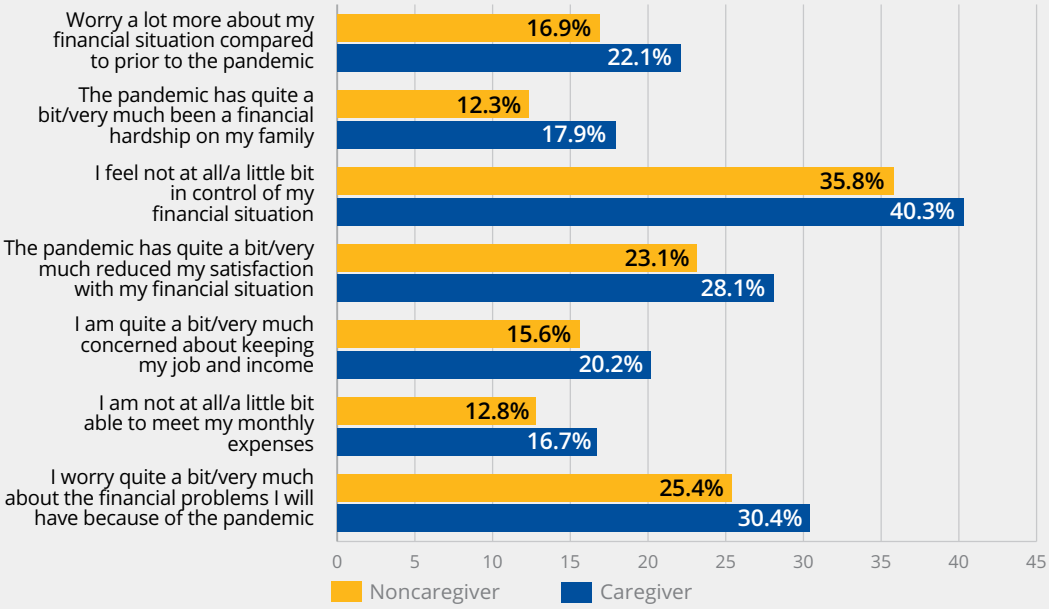


Financial problems and concerns [in the past 7 days; except for last item]

This was measured using an adapted version of the *Comprehensive Score for Financial Toxicity (COST)* scale. Higher scores on the scale mean a more positive financial situation.

The overall mean COST score (range 0 to 44) was 25.8 for caregivers, and 27.9 for noncaregivers ($p<0.01$).

The following individual COST items differed significantly:



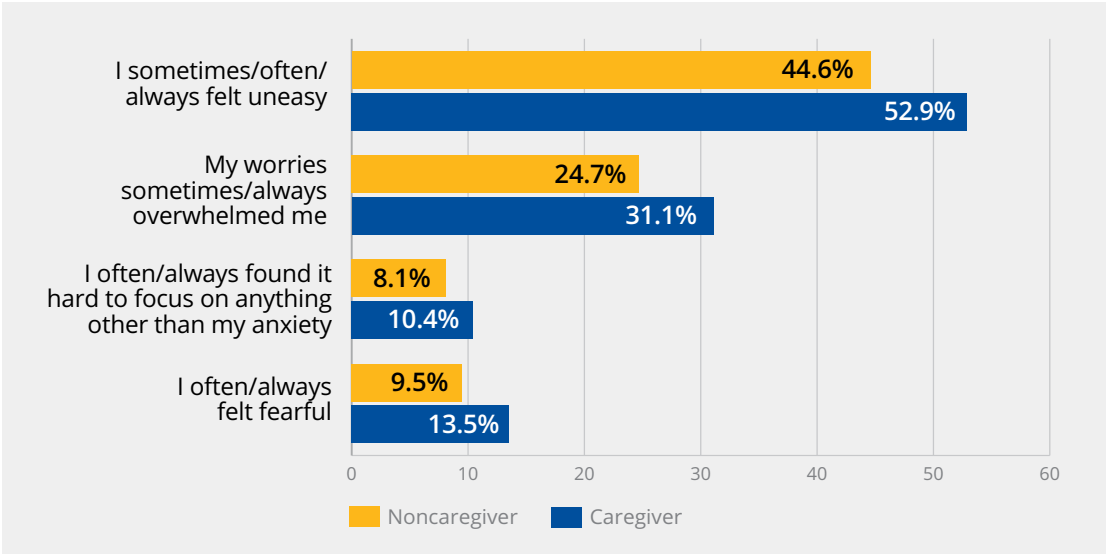
MENTAL HEALTH: ANXIETY AND DEPRESSION

These were measured using subscales for the Patient-Reported Outcomes Measurement Information (PROMIS)-29. We present raw scores for each domain (range 4-20) followed by individual items. Family caregivers reported more current anxiety and depression ($p < 0.05$) symptoms than noncaregivers. These effects may not be directly attributed to COVID-19 and may have existed prior to the pandemic. However, it should be noted that on average, both caregivers and noncaregivers scored higher than the population norms for anxiety and depression established prior to the pandemic. The following were observed:

Anxiety [in the past 7 days]

The overall mean PROMIS anxiety score was 9.1 for caregivers and 8.3 for noncaregivers ($p < 0.05$).

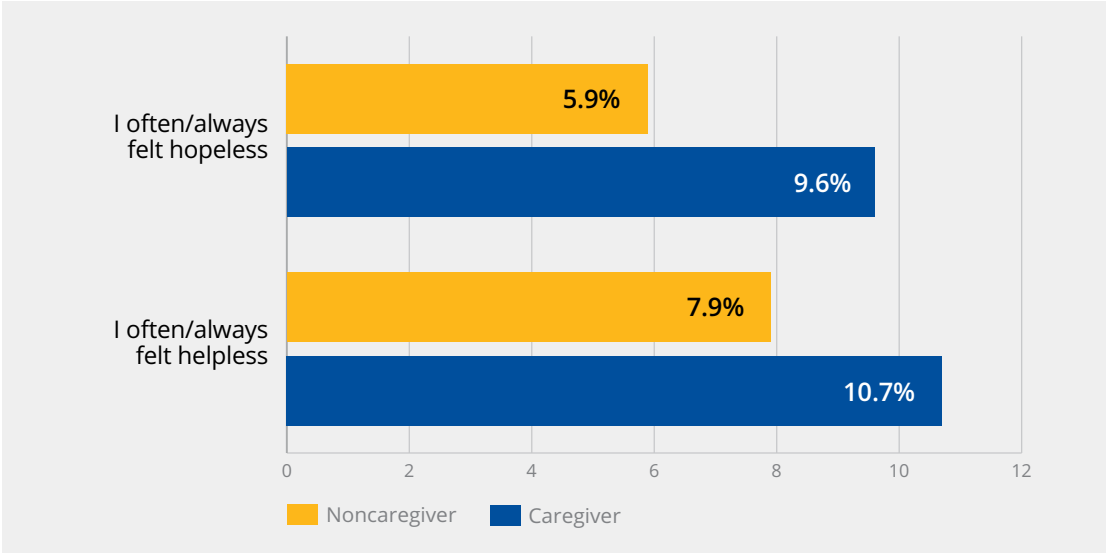
The following individual PROMIS anxiety items differed significantly:



Depression [in the past 7 days]

The overall mean PROMIS depression score was 7.5 for caregivers and 7.1 for noncaregivers ($p < 0.01$).

The following individual PROMIS depression items differed significantly:



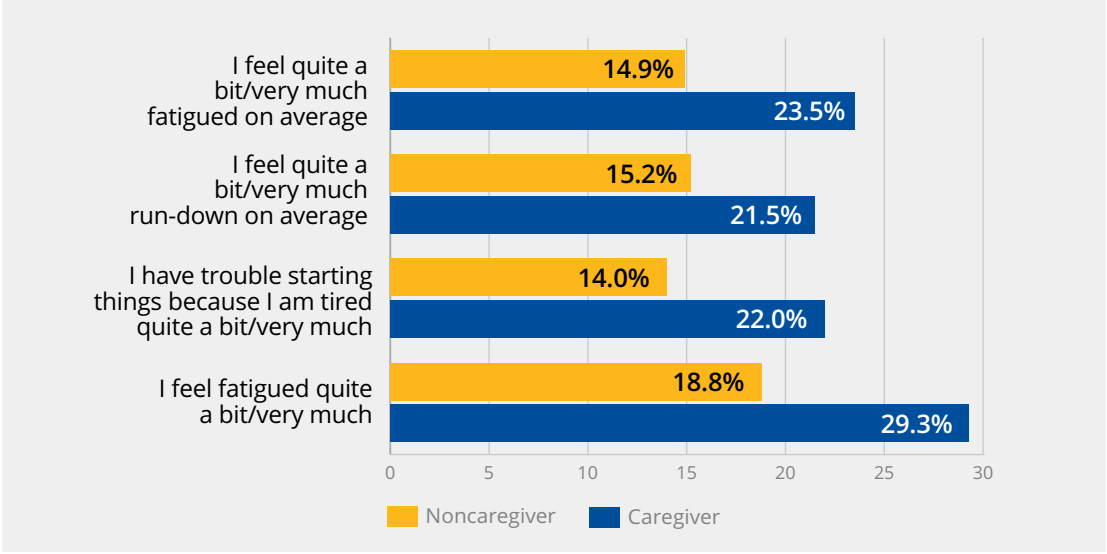
PHYSICAL SYMPTOMS: FATIGUE, SLEEP DISTURBANCE, PAIN INTERFERENCE

These were also measured using subscales for the Patient-Reported Outcomes Measurement Information (PROMIS)-29. Again, we present raw scores for each domain (range 4-20) followed by individual items. Family caregivers reported more current physical symptoms than non-caregivers. As with mental health, these effects may not be directly attributed to COVID-19 and may have existed prior to the pandemic. However, on average, caregivers scored higher than pre-pandemic population norms for all three physical symptoms, while noncaregivers scored higher than population norms for pain interference only. The following were observed:

Fatigue [during the past 7 days]

The overall mean PROMIS fatigue score was 10.2 for caregivers and 9.0 for noncaregivers ($p < 0.01$).

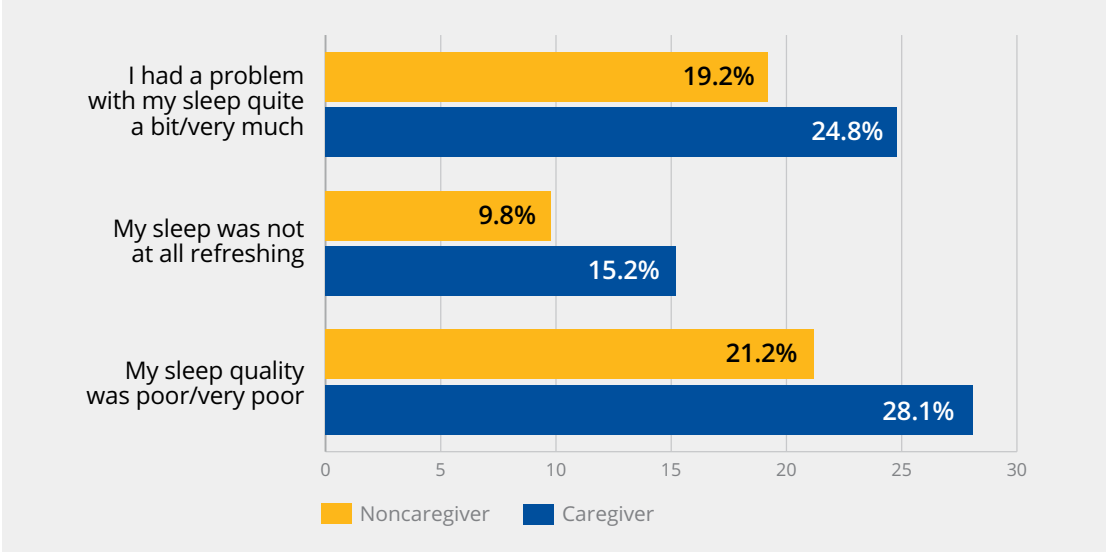
The following individual PROMIS fatigue items differed significantly:



Sleep Disturbance [in the past 7 days]

The overall mean PROMIS sleep disturbance score was 11.1 for caregivers and 10.4 for noncaregivers ($p < 0.01$).

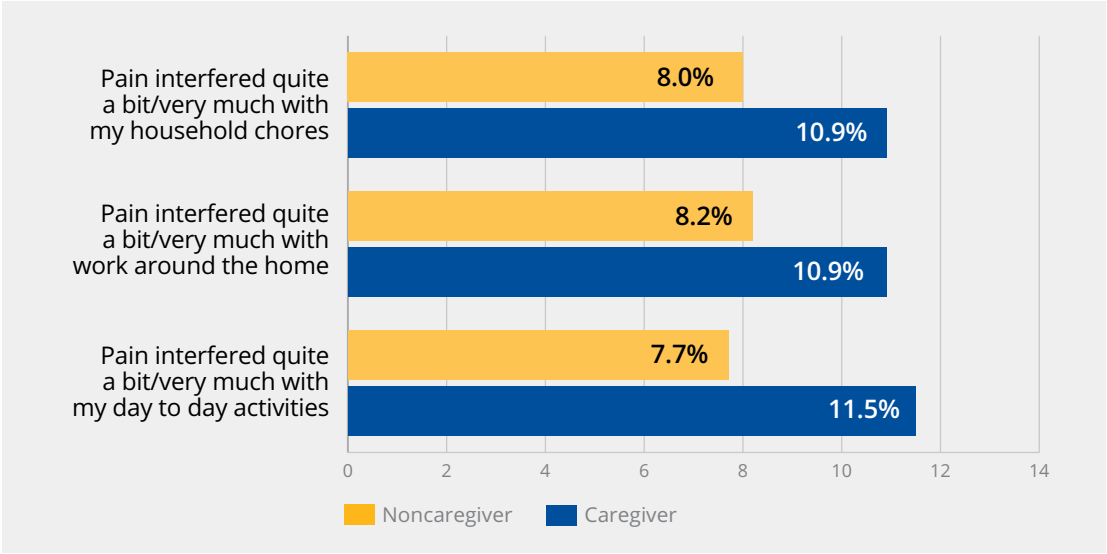
The following individual PROMIS sleep disturbance items differed significantly:



Pain Interference [in the past 7 days]

The overall mean PROMIS pain interference score was 7.3 for caregivers and 6.7 for noncaregivers ($p < 0.01$).

The following individual PROMIS pain interference items differed significantly:



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

The remainder of the report shifts focus to the 619 family caregivers. We report descriptive data on details of how the COVID-19 pandemic has affected caregivers, both in terms of caregiving responsibilities and the associated difficulties and burdens. If the caregiver noted a specific impact or change, they were asked to provide more details in open text fields. The previous section showed consistently more negative impacts for family caregivers compared to noncaregivers. This section provides more focused data on exactly how and why this may be the case. In order to provide a more vivid portrait, we supplement quantitative findings with text-based narrative themes and illustrative quotes.

CAREGIVING DUTIES AND RESPONSIBILITIES

- **23%** of family caregivers said the COVID-19 pandemic has required changes in caregiving arrangements, or in who is providing care. The following are major themes and representative quotes from the follow-up text responses.

  Social distancing/quarantining/isolation

  "They can't go out and it's not safe for others to come in. I take care of all their needs from food to medication."

  "I possibly have the virus, but tests are not available, so we had to find someone else to help until I can determine."

  Family/friends/neighbors have stepped in to help

  "I took my mother to live with my cousin as COVID worsened. He lives in a very rural area and has limited interactions with others."

  Access to health care/care services changed

  "Staff from the outside care/service provider is no longer available."

  "His psychological appointments have been cancelled for foreseeable future."

- **63%** reported that the pandemic has increased caregiving efforts or duties:

  Access to health care/care services changed

  "This has greatly complicated our ability to get my mother the care she needs. She should be seen personally by a doctor, not a phone call or video. She got pneumonia and had she been examined earlier, she probably could have avoided a seven-day hospital visit. Now, we can't get her seen by a cardiologist, either. This increased our duties because we've had to make extra phone calls to facilitate her care instead of just making an appointment and showing up."

  "Because my son's day program was discontinued, my husband and I must cover the time from 8 to 3 each weekday if there is no aide available."

  Needs of care recipient increased

  "I'm providing a higher degree of emotional support (i.e., frequent phone calls, visiting almost daily, ordering food for her), providing more assistance with household chores (she has cancelled the woman that cleans for her), and I've increased shopping online and grocery shopping for her."

"Her sons are unable to help even a little bit, so it all falls on me. They used to take her shopping and visit occasionally, but don't now because of the virus. This stresses her out, so her dementia gets worse, making it even harder for me."

Social distancing/quarantining/isolation

"Because her brother-in-law and I have not been visiting her, she calls me constantly wanting to know what I am doing. This social distancing has affected her greatly."

Vigilance/precautions against Coronavirus

"I have to thoroughly sanitize everything coming into our home as well as myself, since my husband has a severely compromised immune system, is at high risk for every virus, and gets and stays sicker than everyone else. Even small cuts take 60 or more days to close with proper daily wound care."

Mental health issues

"I provide more one-on-one care. I do the schooling and more intense therapy with her mental health issues. We are always busy to avoid melt down and keeping sugars down."

CAREGIVER BURDEN AND DIFFICULTIES

- **22%** of family caregivers reported that COVID-19 has made providing care more physically difficult:

"Yes, because I suffer from physical health problems, so having to do more for the kids can be hard. Especially when I'm having bad pain days. And because my specialist doctors' offices are closed, I can't get my medical treatments that help manage the pain. I'm in more pain than usual."

"24-hour care and support are now required, putting new physical demands on me."

- **56%** of family caregivers reported that COVID-19 has made providing care more emotionally difficult:

Lifestyle adjustments/loss of care resources

"He gets angry at me for reminding him of the restrictions on our lives."

"The breaks we had with caregivers made us better caregivers."

"He has become much more needy of family support because his support networks (AA, NA) have not been available except virtually, which is not working well for him."

Care recipient cognitive deficits

"It's hard to talk with someone who doesn't remember what I said to him an hour ago."

Fear of care recipient catching Coronavirus

"I worry that I'm potentially exposing her, since I am the one who has to go shopping. I do what I can, only shopping every 10 days and wearing gloves and masks when out and showering as soon as I get home. But if she ends up getting it, it's going to be because of me."

Fear of caregiver catching Coronavirus

"If she would get sick, how would I remain healthy?"

Lack of privacy due to Coronavirus

"Because of his emotional and behavioral challenges, the isolation is affecting both of us more, psychologically. There's times where both of us feel like we're bouncing off walls here."

Mental health issues/depression

"It's long days with no outlet for stress relief via getting outside or talking to other people. Very lonely."

"She is very nervous and emotional. I'm having a hard time dealing with my own anxiety, but I need to be there for her."

"I am not taking enough time for myself, and that impacts my overall mood & sense of helplessness."

"There isn't a day that I don't drive to work crying. My drive in and my drive home are the only two times I will allow myself to be emotional."

"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."

- **20%** of family caregivers reported that COVID-19 has made providing care more financially difficult:

Use of personal funds

"I am lucky enough to be receiving unemployment, but because we expect to need to isolate at home until there's a widespread vaccine, I have no idea what I will do for work once unemployment runs out."

"I continue to pay for everything, and my retirement funds have been drastically reduced due to the sudden recession."

Increased expenses

"It is much more expensive to have to order groceries -- basically everything and we pay higher prices and high shipping charges."

"It costs me money to drive there, and I lose work hours to help her."

"We are spending more on cleaning supplies and ordering take-out food as I am exhausted."

Loss of income/reduced income

"I am not working now, so there is no income."

"I had to switch jobs, because we closed down, and had to find a different job which pays less."

- **37%** report that the pandemic has interfered with doctors' appointments or treatments for care recipient:

Cancellations, postponements and reduced services

"He has had to discontinue medications and seeing a doctor for adult ADHD since they refuse to do telehealth, and no new doctors will accept him as a patient since he takes opioids. It is seriously worse than being a leper."

"He is afraid to go to the doctor's office for fear of being exposed to the virus. So, he has cancelled cancer treatment."

"I tried to change one of (my son's) appointments with a dermatologist to a telemedicine appointment, but he refused, and it was cancelled. His illness makes it hard to predict how he will react to changes in plans. I have to be very flexible."

"Yes, my mother was scheduled for a back-injection procedure in late March to help with pain and mobility and it was cancelled, which has contributed to her physical decline."

Alternate methods: Video or phone chats with doctor

"We (went to) video appointments for most of the doctors. It's hard to teach a 65 year-old who is not comfortable with technology."

"With the availability of teleconferencing, we have cancelled in-person appointments and elected to go with these, but they are not as in depth as in- person."

"All mental health has been moved to telehealth, and group therapy was suspended. Something that helped his mental health was being around other veterans. Now it is non-existent."

"My ill daughter will not do teleconference therapist appointments, which makes tension and confrontation at home unbearable."

- **21%** of family caregivers reported that the pandemic was interfering with their OWN health care:

Access to health care services

"I know I'm not taking care of myself; I know I need to go to the doctor, see a dentist, but I can't do that right now."

"I was afraid do go out to the doctor for the joint injections to help with arthritis pain for fear of bring home the virus to my husband and sister. Also, myself as I am the only caregiver—we have no other family to help."

"I can't see my counselor anymore. I can't do telehealth, although it was offered, because I don't have the privacy in my house to do it that way."

"I can't go to my appointments without having to take her, so I just cancel them."

Increased mental health issues

"My anxiety is through the roof. I take legal cannabis for anxiety (vaped) and have discontinued is because I don't want anything in my lungs. Dispensaries are not offering curb side pickup and I won't go inside."

"Concerns about him weigh heavily on me. I have fibromyalgia, and the stress is bad for me."

"No exercise, weight gain, anxiety."

- **17%** reported that the COVID-19 pandemic has led to family disagreements or conflict over caring for care recipient:

Lifestyle adjustments

"It is sometimes difficult scheduling personal care needs/requirements during the day as both caregivers and both. (There are 2 individuals who need care—both have the same diagnosis of SMA.) Care recipients are working from home and there are timing conflicts."

"The constant daily confrontations with our mentally ill daughter is taking a toll on all of our physical and mental health."

Mental health issues

"Tensions are greater between my husband and I due to care recipient's attitudes/ behaviors."

"There is lots of unpleasant tension between me and my mom, who is very intelligent but struggles so much with controlling her emotions and has been so out of control lately, so she knows things are going wrong, but continues to blame my brother and I without trying to change her own behavior or take suggestions. My brother is only 12 (also autistic) and is very hurt by the things she says, and very confused about why she acts so irrationally."

Vigilance/precautions against Coronavirus

"My parent refuses to not see friends, won't wear a mask when in public places. Won't listen to me about these things."

"My parents were very reluctant to let me take on extra responsibilities. They also still regularly make trips outside for things that are not needed."

- **43%** reported that the pandemic led to increased worry, fear, depression, sleep problems or other declines in care recipient's mental health:

Cognitive issues

"My mom doesn't understand why I don't go over every day. I explain, she understands, then she forgets again."

"There is increased delusional thinking. More argumentative."

Lifestyle adjustments

"Our son does not understand why he can't go to work, why he can't visit others and why they can't visit us. His world, like that of many others, has been turned topsy-turvy. He is sleeping fine because he's a great sleeper, but he misses the normal activities of his daily life."

Mental health/depression

"The little socialization he got before the pandemic is now gone, so he's a bit more depressed."

"She has become sad and somewhat fearful, wondering 'why no one likes her anymore'."

"She is too afraid to leave her house. All the things she was doing to improve her mental health—working, walking, planning meals and shopping for her family—have all stopped."

"She has declined immensely because she is acutely aware that due to her chronic health conditions, she is much more likely to die, but also to be straight-up refused ICU care at all, which has happened here at hospitals in our country. Her sleep schedule is all off, she's tired all the time, has daily panic attacks and meltdowns, and needs a lot more mental health support than I'm able to provide or what her therapist can provide in one hour per week over the phone."

Sleep problems

"Not sleeping at all—up for days at a time, then crashes for a few days. Spending much more time in the basement in his room—worried about depression."

"Yes, sleep cycles are all over the place, crashing into naps, lethargy, tiredness of the abnormal routines. Weight gain."

- **More detail on <u>how caregiving routines have changed</u> since the pandemic are summarized with a structured question series on specific tasks and if help has increased, decreased or remained the same since the outbreak. The majority of the responses were either "helping the same amount," or "not applicable (don't provide help)." Here, we present data on increased help.**

- *Since the COVID-19 outbreak, how have you been helping your care recipient differently?*
  - Help my care recipient get other supplies they need to care for their health conditions (30.2% helping more)
  - Help my care recipient figure out what to do about new medical problems or symptoms (27.5%)
  - Help my care recipient attend their health care appointment over a phone or video chat. (25.6%)
  - Participate in my care recipient's health care appointments by phone (21.3%)
  - Help my care recipient contact their health care provider with questions (21.1%)
  - Help my care recipient get prescription medications filled (20.4%)
  - Help my care recipient get medical appointments scheduled (18.9%)
  - Participate in my care recipient's health care appointments by videochat (Skype, FaceTime, etc.) (16.2%)

CAREGIVER TECHNOLOGY USE

Family caregivers reported using a variety of technologies for a range of tasks to assist with caregiving. Note that use of technology for communication with the care recipient is less relevant for those who co-reside with him/her.

- *What technology do you use to connect with the person you care for? (check all that apply)*

Phone call	55.9	Email	14.1
Text messaging	27.4	Social media (e.g. Facebook)	7.8
Video call	14.4	None of the above	39.8

(If one or more technologies used to connect with care recipient)

- *Do you use communication technologies (phone, text, video, email, social media) for (check all the apply):*

Checking in and keeping in touch	85.9
Daily self-care routine	22.8
Monitoring health	43.8
Coordinating care	37.8
Ordering food, medical supply, or other household supply	53.6
Medical e-visit	17.0

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

This section summarizes subgroups of family caregivers who report significantly higher levels of negative impacts of the COVID-19 pandemic. These caregivers should be targets for interventions and other forms of attention and assistance. Note that these subgroups are presented individually (e.g., females, less educated, etc.) Of course, caregivers have multiple characteristics, and those falling into more than one of the following groups should receive special attention. This report provides brief narrative summaries for each group. Complete data for all survey questions by each caregiver subgroup breakdown is available on the project website. Lastly, we should note that the high-risk groups found in this survey are similar to those reported in more general family caregiver surveys. Exceptions include younger caregivers, those caring for younger care recipients, and those caring for care recipients with emotional or behavioral issues.

Female caregivers

More likely to report:

- caregiving as more emotionally difficult since pandemic
- worse mental health of care recipient
- their own emotional well-being as worse
- negative financial impacts
- anxiety
- fatigue

Younger (ages 18-44) caregivers

More likely to report:

- worries about not being able to afford COVID-19 testing
- caregiving as more emotionally difficult since pandemic
- school closures as making caregiving more difficult
- less healthy eating habits
- increased alcohol use
- their own emotional well-being as worse
- more social isolation
- more food insecurity
- negative financial impacts
- anxiety
- depression
- fatigue
- poor sleep quality
- pain interfering with usual activities

Minority caregivers

More likely to report:

- worse physical and mental health of care recipient
- more food insecurity
- negative financial impacts

Less-educated caregivers

More likely to report:

- worries about not being able to afford COVID-19 testing
- their own physical health as worse
- less ability to protect the health of household members
- more food insecurity
- negative financial impacts
- depression
- pain interfering with usual activities

Low-income caregivers

More likely to report:

- working at normal location rather than home
- worries about being forced to quit their job to stay healthy
- worries about not being able to afford COVID-19 testing
- worries about being denied care because of a pre-existing condition
- caregiving as more financially difficult since pandemic
- the pandemic has interfered with their own health
- their own emotional well-being as worse
- more social isolation
- more food insecurity
- negative financial impacts
- anxiety
- depression
- fatigue
- poor sleep quality
- pain interfering with usual activities

Caregivers for those with emotional/behavioral issues

More likely to report:

- worse mental health of care recipient
- less healthy eating habits
- their own physical and mental health as worse
- negative financial impacts
- anxiety
- depression
- fatigue
- poor sleep quality

Caregivers of younger care recipients

More likely to report:

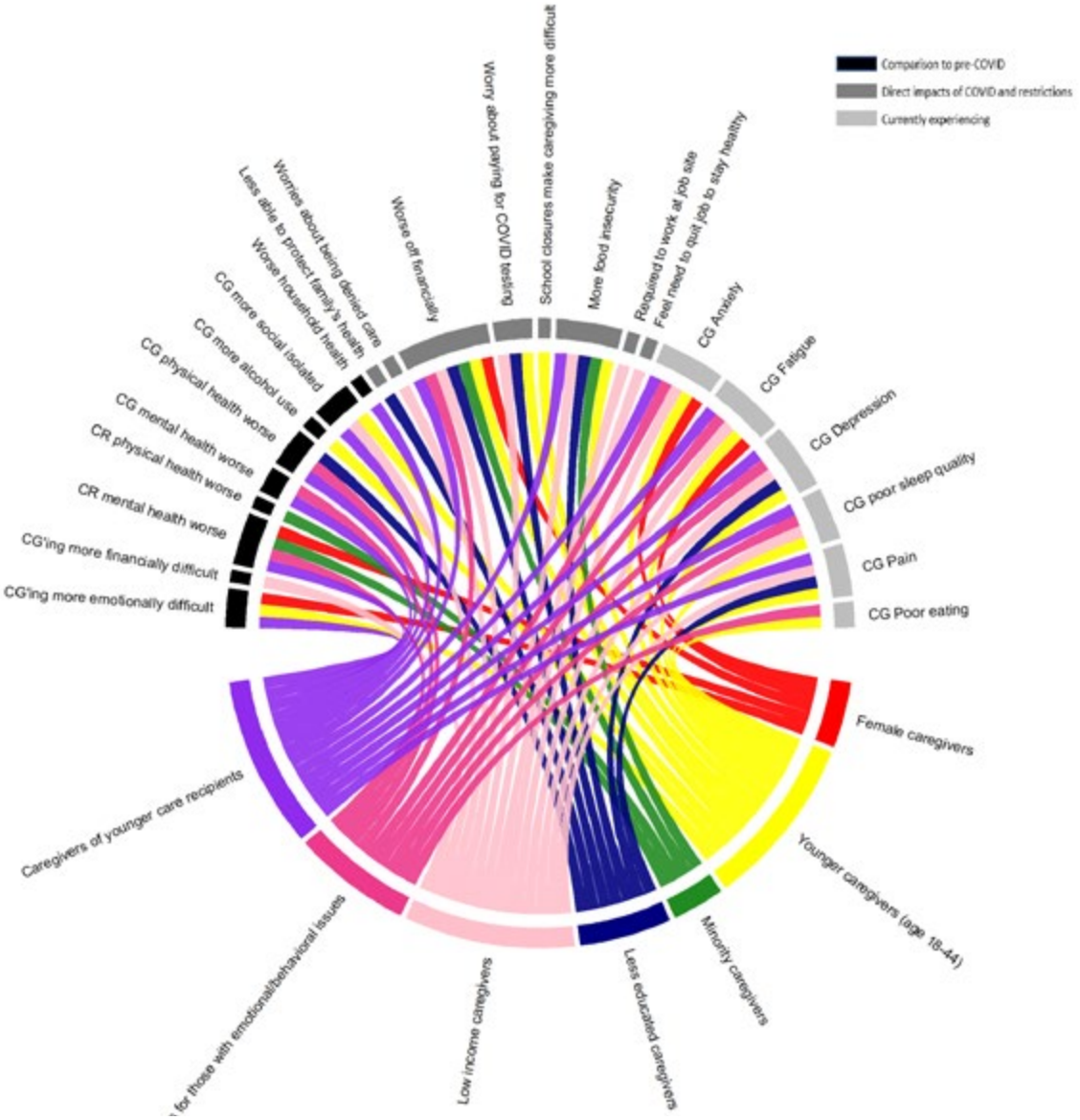
- caregiving as more financially difficult since pandemic
- worse mental health of care recipients
- their own physical and mental health as worse
- worse physical health of other household members
- more social isolation
- more food insecurity
- negative financial impacts
- anxiety
- depression
- fatigue
- poor sleep quality
- pain interfering with usual activities

Caregivers who co-reside with the care recipients

More likely to report:

- less health exercise habits
- their own physical and mental health as worse
- worse physical health of other household members
- more social isolation
- fatigue
- pain interfering with usual activities

In the chord diagram, follow the colored bands from each type of caregiver listed in the bottom half of the figure, to see the challenges they were most at risk to experience in the upper half of the figure.



V. CONCLUSIONS AND IMPLICATIONS

This study highlights the negative impacts of the COVID-19 pandemic on family caregivers. 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 in this study reported consistently more negative impacts of COVID-19 compared to those not providing care. These differences cut across many survey domains and were particularly striking in terms of financial strains and mental health impacts. We also found increases in caregiving duties and responsibilities, and that the pandemic has added to the perceived burdens and difficulties associated with care provision. Certain subgroups of family caregivers were at higher risk for negative impacts, including females, minorities, less educated, low income, and those who live with the care recipient. While these findings mirror the broader caregiving risk literature, we also found that younger caregivers, those caring for younger recipients, and those providing care for emotional/behavioral problems were also at increased risk. These findings are novel, and combined with the other effects reported here, suggest appropriate targets for interventions and policy discussions. While it might be assumed that COVID-19 would make caregiving even more difficult, this study provides empirical evidence that this in fact the case. Family caregivers should receive increased support and assistance during this serious public health crisis.

For additional information about the study: caregiving.pitt.edu.

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