

**Caregivers in Crisis:
Caregiving in the Time of COVID-19**

October 2020



Rosalynn Carter

INSTITUTE
FOR CAREGIVING



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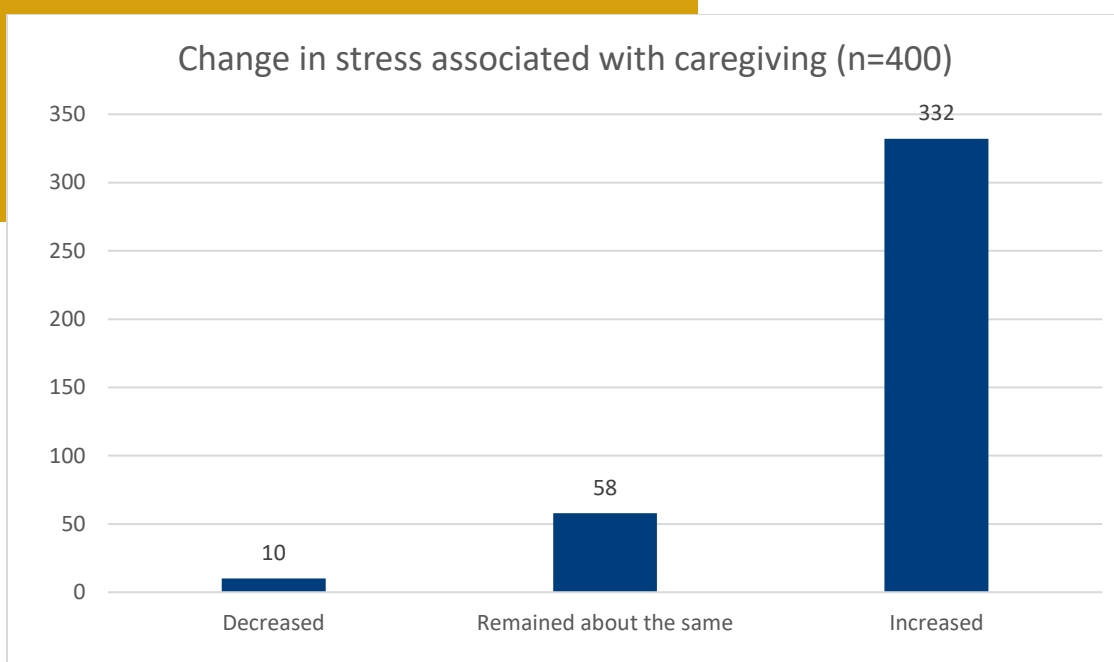


Introduction and Overview

The Rosalynn Carter Institute for Caregiving (RCI) undertook a study of caregiving in the time of COVID-19 with the support of the Bristol Myers Squibb Foundation. The impetus for this study was a steady stream of informal reports from the caregivers served by RCI regarding the increase in their stress. While other studies have explored the conditions faced by caregivers and the impacts of caregiving, the purpose of this study was to understand the direct experience of caregivers, particularly changes in and causes of stress, since the beginning of the COVID-19 pandemic to:

- 1 Amplify the lived experiences and voices of caregivers
- 2 Inform program activities to support caregivers for both RCI and its program partners; and
- 3 Build commitment to public and workplace policy to support caregivers

An online survey was distributed to caregivers through RCI's partner network. We define caregiver as a person who at any time in the last 12 months provided unpaid care to a relative or friend to help them take care of themselves (e.g. helping with personal needs or household chores, managing finances, arranging for outside services, or visiting regularly to see how they are doing). 422 respondents who self-identify as caregivers completed the survey between June 2 and August 1, 2020, responding to questions that consider changes in their lives since the pandemic created widespread stay-at-home orders, school closures, and social distancing. Most of those who completed the survey were primary caregivers, but a small number were secondary caregivers or others who have been caregivers in the past. The findings portray a segment of the population under pressure, fighting to keep themselves safe while protecting the most vulnerable among us.



- 83% of caregivers surveyed reported increased stress related to caregiving since the start of the COVID-19 pandemic
- 42% noted that the number of other caregivers available to help them has declined during the pandemic
- Isolation, increased burden resulting from additional caregiving/household responsibilities, and worry about getting infected or a family member becoming infected with COVID-19 were key sources of stress
- Financial concerns, instability, and resource insecurity were also a source of stress

“More responsibility in assisting family members with their needs of shopping, meal planning and preparation, running errands, doctor visits, keeping up with scheduled appointments, communicating with debtors regarding billing and insurance issues, etc.”

- Caregiver burden and stress is impacting caregivers’ overall wellness, leading to increases in depression and anxiety, and decreases in overall health and wellness

*“High stress, constant migraines that are debilitating.
My personal mental health is deteriorating.”*

“The stress has increased because self-care has become a thing of the past.”

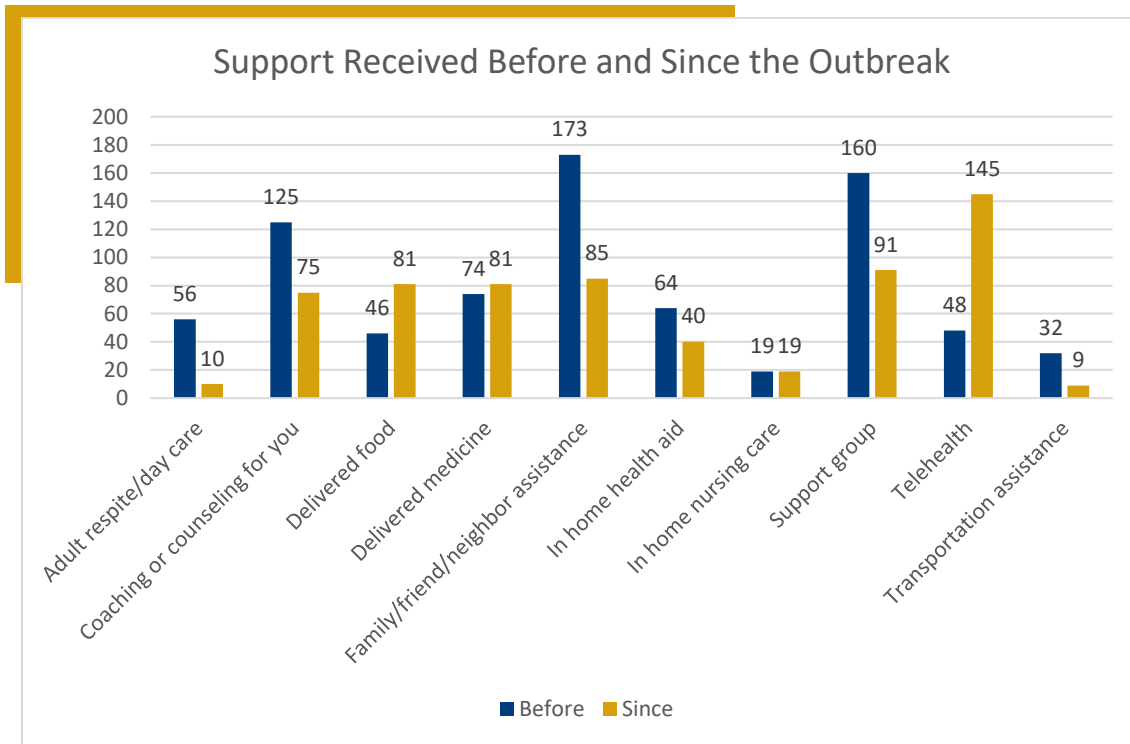
- Caregiver burden and stress (and the amount of time that caregivers and care recipients are forced to spend together) are taking their toll on relationships

“More stress leads to more anxiety for me and fighting. Higher stress also leads to more episodes of PTSD for my veteran.”

“There is less romance and connection. I feel more a caregiver and sometimes a parent to my husband than a spouse”



- While research shows the *need* for support is greater for caregivers during the pandemic, caregivers have actually *received* less support in their role since the onset of COVID-19. The table below shows support before and since the outbreak



Caregivers surveyed shared a statistically significant decline in support received from family and friends, adult respite/day care, coaching or counseling, support groups, and transportation. By contrast they reported a statistically significant increase in support received for delivery of food and telehealth.

Caregivers expressed a need for more support than they are getting, particularly naming the following:

- Respite and daycare
- Social interaction
- Peer support and self-care
- Financial assistance
- Clinical and in-home care services

There is no single solution that is sufficient in helping caregivers weather this storm. Research in the field has identified many of the challenges and stressors identified in this report but clearly there is a mental health crisis that has been exacerbated and amplified by the COVID-19 pandemic.



Creative integration of formal and informal support systems will be needed to provide much needed support to caregivers, and by extension, their care recipients and loved ones. The primary sources of stress identified by caregivers were the fear of getting infected or of placing a family member at risk. Caregivers also noted that access to remote services has been helpful since the beginning of the pandemic. Our recommendations for increasing virtual support in direct response to the added stress caused by the COVID-19 pandemic include:

- Increasing access to peer support through the continued development and promotion of remote caregiver support groups, support services that are inclusive of auxiliary/secondary caregivers, and programs that train and support peer specialist counselors for caregivers
- Creating online forums for community-building among caregivers to combat the isolation and empower caregivers to seek additional support and advocate for policy change (including increased financial assistance, expansion of insurance benefits, and expanded paid family leave)
- Building awareness, access, and availability of respite options for caregivers, including formal in-person respite services (if and when that becomes possible again) supplemented with virtual options

In addition, there are a number of caregiver challenges that have been amplified by the COVID-19 pandemic. The current crisis may offer an opportunity for advancing solutions to these perennial concerns. We recommend:

- Increasing access to formal, remote mental health services for caregivers, including increased access to individual, couples, marriage, and family counseling
- Broadening availability of caregiver psychoeducational programming, including caregiver workshops and coaching that can be accessed online, or via phone or text
- Strengthening support for basic needs, including food assistance, supplemental childcare and educational support, home health workers, and home cleaning services; while many of these services are available, they may remain inaccessible to many caregivers due to cost or other barriers



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Background

The outbreak of coronavirus disease 2019 (COVID-19) has limited access to activities and services as physical and social environments undergo drastic changes in response. This kind of public health event is largely unprecedented for most communities. With no tested vaccine available, some communities have been forced to rely heavily on containment strategies that depend upon personal engagement with strict healthcare and sanitary norms (Ebrahim, et al., 2020; Provenzi & Tronick, 2020; Tian et al., 2020). These strategies include sheltering in place, social distancing practices, the wearing of facemasks in public settings, and other sanitary practices. While people who are not already at high risk for severe illness can also experience emotional distress and anxiety during public health events and outbreaks such as this one (De Lucia et al., 2020), older adults and people with chronic illnesses, auto-immune diseases, and other underlying health conditions are at greater risk for severe illness and negative mental health outcomes (Centers for Disease Control and Prevention, 2020; Webb 2020).

For many, shelter-in-place orders and other safety restrictions and concerns have led to greater isolation and loneliness (De Lucia et al., 2020). This, along with other conditions created by the COVID-19 pandemic, continues to have a profound impact on older adults with disabilities (Hoffman et al., 2020), people living with amyotrophic lateral sclerosis (ALS)(De Lucia et al., 2020; De Marchi, et al., 2020), people living with cancer or cancer survivors (Chen et al., 2020; Indini et al., 2020; Ng et al., 2020), veterans and other people living with post-traumatic stress disorder (Venkateswaran & Hauser, 2020), people living with dementia and Alzheimer's disease (Brown, et al., Cuffaro et al., 2020; Tousi, 2020), and children with physical or developmental disabilities (Aishworiya & Kang, 2020; Cacioppo et al., 2020), among others. These populations traditionally rely heavily upon some degree of unpaid home care to supplement their ongoing care strategy. With increased safety restrictions being implemented on an already overburdened medical and palliative care workforce, unpaid home and family caregivers are being increasingly relied upon to provide complex care in the home (Kent et al., 2020).

Caregivers, a group comprised of individuals that already struggle to ask for help (Kent et al., 2020), are experiencing increased burden and stress for a number of reasons in addition to social isolation. These include changes to the delivery and scope of services they commonly utilize (De Marchi et al., 2020; Hado & Feinberg, 2020; Hoffman et al., 2020; Kent et al., 2020, Rossi et al., 2020), relationship and family stress (Prime et al., 2020; Provenzi & Tronic, 2020; Russell et al., 2020), and financial hardship. With this information as the backdrop, this study was designed to elevate the experiences and voices of caregivers to hear, in their own words, how the pandemic is impacting their experience of stress, their relationships with care recipients, and their ability to access support.

Methodology

Late last Spring, RCI developed the *Caregiving in the Time of COVID-19* survey to better understand the impact of the coronavirus pandemic on caregivers. RCI used a variety of distribution methods to capture a diverse and representative sample of caregivers. The menu-driven 43-question electronic survey was distributed via Microsoft Forms through RCI's program sites, coach network, email distribution list of over 5,000 recipients, social media, and network of partner organizations across the U.S.

Current RCI partnerships serve and support a variety of caregiver populations across the United States including military caregivers (e.g., RallyPoint and the Military and Veteran Caregiver Network), ALS caregivers (e.g., ALS Association Georgia Chapter), caregivers with young children in the home (e.g., Sesame Workshop), and dementia caregivers (e.g., RCI REACH, Dealing with Dementia). RCI also distributed the survey link to caregiver allied organizations to distribute amongst their networks; many



of these organizations focus on general caregiver support (e.g., Caregiver Action Network, Family Caregiver Alliance). See Appendix A for a list of the partners who were engaged in distributing the survey link.

After collecting responses for several weeks, RCI realized respondents were not as representative of the caregiver population as intended. In order to address this challenge, RCI translated the survey and caregiver message into Spanish, so that it could be made available to Spanish-speaking caregivers. RCI used social media channels and e-newsletters, and notified all partnered and allied organizations of the survey's Spanish language option.

The result of these efforts was a convenience sampling of 422 caregivers who submitted responses to the survey between June 2 and August 1, 2020. Caregivers from 46 states responded to the survey with slightly over half of responses coming from Georgia, Texas, Florida, California, and New York. Some survey respondents submitted responses to fewer than 100% of the questions asked. A copy of the survey questions is attached as Appendix B.

Survey responses were downloaded from the survey platform to a Microsoft Excel (2007 version) spreadsheet. Quantitative results provided data used in charts and tables. Qualitative data was analyzed for key themes across responses. Two analysts independently reviewed the qualitative responses, met to compare results, and agreed upon key themes in the responses to each of the open-ended questions.

Findings

After collecting demographic data for the participating caregivers (summarized in Appendix C), we gathered data in three broad categories: 1) changes in the caregiver experience; 2) changes in the relationship between the caregiver and care recipient; and 3) changes in access to supportive services. In each of these three sections of the survey we began by asking multiple choice questions, typically offering a picklist and allowing caregivers to select all that apply. We then asked open-ended questions to hear from caregivers, in their own voice, what they have experienced.

The Caregiver Experience

Survey participants were asked how their stress level has changed since the outbreak of COVID-19. A preponderance of survey respondents (332 of 400, or 83%, of those who answered the question) indicated that their stress level had increased since the outbreak. Changes in reported stress levels were fairly consistent across household income and most age groups. Among those 60 or older 29 of 131, or 22%, said their stress level was “about the same.”

Female respondents were more likely to report that their lives were more stressful since the outbreak of COVID-19 (328 of 378 or 87%) than male respondents (26 of 35 or 74%).

For those who indicated that their stress had increased since the beginning of the COVID-19 outbreak, we asked about the source of the caregiver’s stress. The selected responses are shown in the table below.



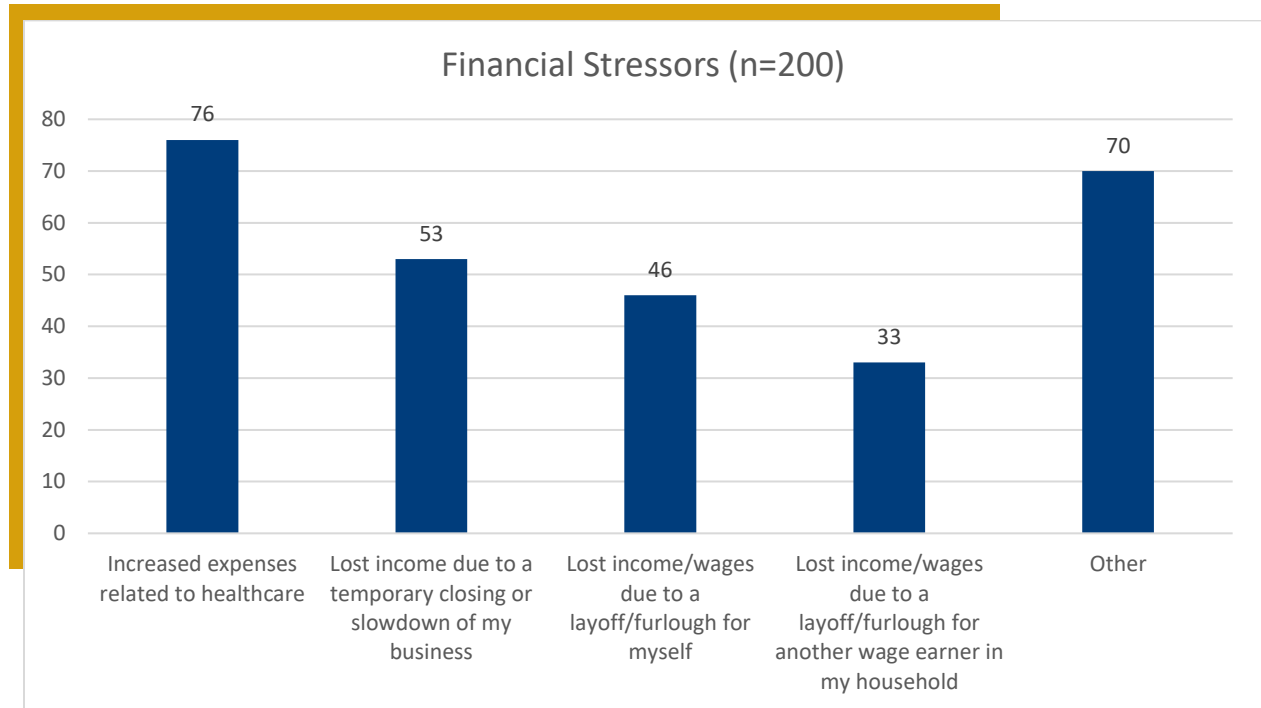
Source of stress	Count
Increased responsibility due to isolation or increased health risks	280
Worrying about you and a family member becoming infected with COVID-19	280
Delayed access to medical treatment for yourself and/or a family member	220
Employment or financial concerns/instability	177
Multiple caregiving responsibilities (e.g. caring for home-bound children)	142
Having to return to work outside your home	76
Loss of support for the person you are caring for (e.g. loss of a paid caregiver)	71
Caring for someone else who tested positive for COVID-19,has COVID-like symptoms	7
Other	49

Among the 49 respondents who provided “Other” sources of stress, responses included stress associated with isolation (12), caring for someone with a disability (6), a loved one’s declining health (6), mental health challenges (5), separation from a loved one (4), and the climate of social unrest (4).



Financial Stressors

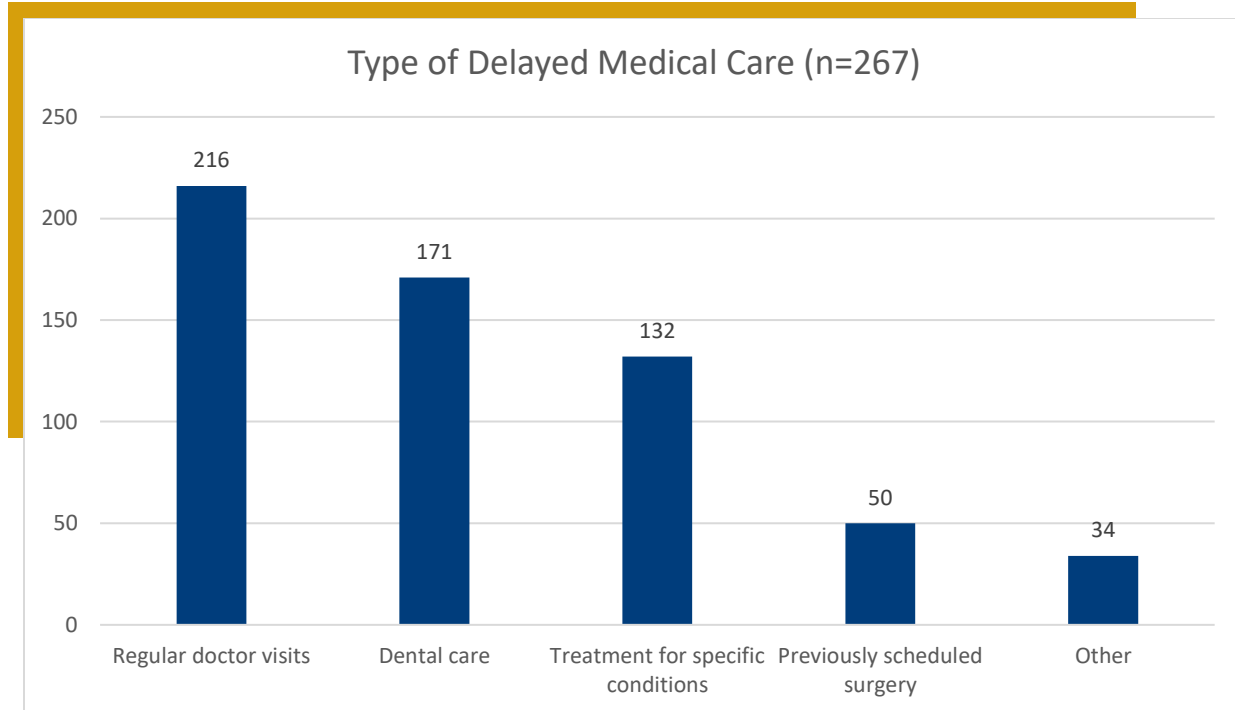
For those who indicated that the source of their stress was employment or financial concerns/instability, respondents were asked about sources of financial stress. The selected responses are shown in the table below.



Increased healthcare expenses were the most frequently noted financial stressor. Among the 70 respondents who provided “Other” financial stressors, responses included increased expenses unrelated to healthcare (23), fears about the future (e.g. job loss) (14), increased burden of providing for struggling family members (7), unemployment (6), and loss of or delay in getting government benefits (4).

Delayed Medical Care

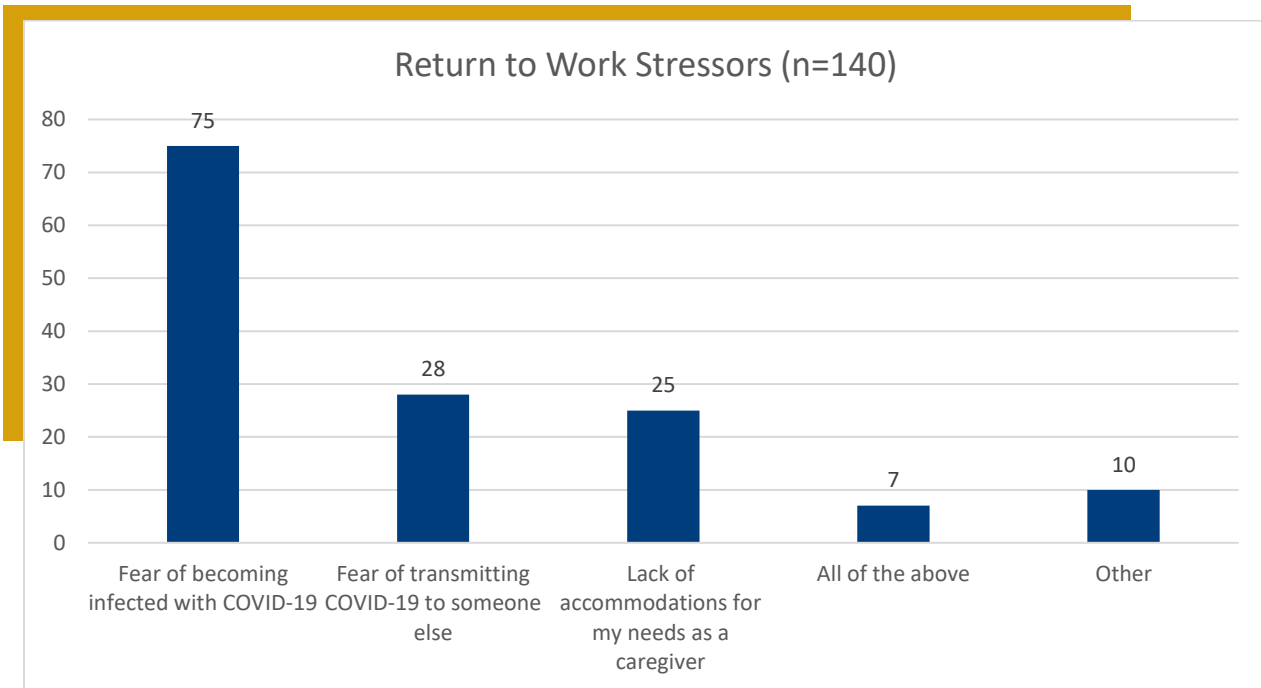
For those who indicated that delayed medical care was a source of stress, the most frequently mentioned types of delayed care were regular doctor visits (80% of the 270 caregivers who responded to this question); dental care (63%); and treatment for specific conditions (49%). Among the 34 respondents who selected “Other,” responses included access to mental health services (14), access to medications and laboratory services (6), access to vision services (6), and access to physical and occupational therapy (6).



In a related question, participants were asked if the person being cared for had been removed from a care facility due to safety concerns. A preponderance of respondents (97%) said “No.”

Return to Work Stressors

For those who indicated that returning to work was a source of stress, respondents were asked to indicate all sources of that stress. The selected responses are shown in the table below.



The most noted work-related stressor was the fear of becoming infected with COVID-19. Among the 10 respondents who selected “Other,” responses included concerns about workplace rules and expectations related to the pandemic.



More Stress, Less Support: Impact on the Caregiver Experience

While there are some positive aspects to caregiving, such as personal fulfillment and satisfaction (Xue et al., 2018; Yu et al., 2018), unpaid caregivers are also vulnerable to negative physical and mental health outcomes. There is evidence in the body of caregiving literature indicating that caregiver burden tends to increase with disease progression (Aarsland et al., 1999; Carter et al., 1998), and that increased perceived burden of care is directly related to the stress experienced by caregivers (Tuncay & Fertelli, 2019). Increased caregiver burden and stress have been shown to have an impact on caregivers' ability to care for their care recipient (Roepke et al., 2011). Increased caregiver stress is associated with negative mental health outcomes, including depression, anxiety, and PTSD (Carmassi et al., 2020; Schrag et al., 2004; Penning & Wu, 2015), as well as increased number of reported physical symptoms, declining personal health, and decreased physical functioning (Lu & Wykle, 2007). There is also a significant relationship between caregiver stress and self-care behaviors, suggesting a need for the development of early interventions designed to promote self-care behaviors in caregivers (Lu & Wykle, 2007).

The COVID-19 pandemic has impacted daily routines of living for many people. Shelter-in-place orders and other conditions created by the pandemic have affected the way businesses and services operate as well. In hopes of understanding how these factors and conditions have affected caregivers, respondents were asked: **“What is the biggest change over the past 2-3 months for you personally related to your role as a caregiver?”** Pressure has mounted for caregivers – increased social isolation, concerns for wellbeing and safety, more people in the home, and loss of support and available caregiver resources are having a significant exacerbating effect on caregiver burden and stress. This has further affected caregivers' ability to not only care for their care recipients, but for themselves as well.



“Feeling alone, isolated, no help, not able to get out, not able to get respite care, loneliness and sometimes depression.”



Increased Social Isolation and Separation

Many caregiver survey respondents expressed that they are experiencing increased social isolation due to the conditions created by the COVID-19 pandemic. Social isolation is a substantial theme found in survey responses in a number of different categories. Stemming from concerns about health and safety, local shelter-in-place ordinances, and financial concerns, many caregivers find themselves affected by social isolation and its impact on their ability to access certain needed services and activities. As one caregiver expressed: “The isolation has been the biggest hurdle. Not being able to participate in activities that get me out of the house has made me frustrated and resentful.”

Some respondents expressed how social isolation has affected their own self-care and mental health in other ways: “Having fewer chances for entertainment, to get out of the house, run errands, go the bank... not so easy to take a break outside the home.”

Caregivers also noted the impact of social isolation on their care recipient's wellness, and how that affects their ability to effectively care for their care recipient: “Because of isolation, my wife's Alzheimer's condition deteriorated quickly and I was no longer able to care for her. She is now in a memory care facility.”

In some cases, pandemic conditions have led to caregivers being separated from their care recipients. Separation is due, for some, to the facility where their care recipient resides employing isolative protection measures to safeguard patients. One caregiver wrote:



I now have a father that got COVID-19, had a stroke and is currently going through rehab in a nursing home. Once he went into the hospital, we could not see him. Since going into rehab, we can see him through the window but that is still not the same as being able to hug my father.

Separation from one's care recipient can also be due to travel limitations in response to shelter-in-place regulations limiting travel or access to the recipient out of concern for safety. One caregiver noted: "Not being able to enter my mom's apartment to assist her due to COVID-19 restrictions."

Caregivers often rely on friends, family, and neighbors to provide additional assistance and respite. At a time when many caregivers need more of this kind of support due to changes in formal services, many have reduced access to community help. One respondent cited the challenge of "[not] being able to get respite from friends or family because of risk of Covid-19 infection."

Loss of Support Services

The conditions created due to the COVID-19 pandemic have greatly impacted the services, both formal and informal, that caregivers rely on. Access to care services, like medical care, mental health care, and respite care, has been greatly affected. Access to these services can be limited due to sudden changes in one's personal finances, the scaling back of the services offered by providers and organizations, or difficulties navigating the migration to telehealth services. Access to in-home care is also affected by concerns for paid caregiver safety, illness, and other factors that may impact professional caregiver availability. Regarding their access to medical care, one respondent wrote: "Lack of medical care and face-to-face visits for my veteran. Limited visits while inpatient at the [VA Medical Center]." Another caregiver noted "Decreased access to both respite care and hospice support."

Mental health care services have been similarly impacted, as one respondent commented: "Being home with my veteran who suffers from PTSD and having all his mental health appointments canceled and moved to telephone appointments."

Full House

A significant number of caregivers who responded to the survey are experiencing increased stress because of the number of people isolating together in their homes during the pandemic. This includes school-age children, adult children, spouses, and elderly parents. The additional burden created by having a full house manifests in increased caregiver stress driven by juggling responsibilities, including working from home and home-schooling family members. One caregiver noted: "Our entire routine was messed up and caused a lot of stress and chaos. Taking care of 5 small children and a teenager and the home and myself and my wounded warrior ... with no help. Goodness, I can't believe I'm not crazy."

Many caregivers find themselves working from home while juggling caregiving responsibilities. One reported: "Loss of a job has caused me to work from home and have to take care of three kids and my veteran. And an adult child. All on my shoulders."

Others mentioned that an immediate need to provide home schooling has resulted in added stress. As one caregiver commented: "Aside from normal responsibilities becoming a teacher for three in different grades overnight was stressful."

Decline in Caregiver Wellness

Many caregivers noted a change in their overall wellness due to the impact of COVID-19. The key wellness themes found throughout the survey responses related primarily to increased caregiver burden, often resulting in increased caregiver stress. Increased burden was found to be due to several factors across responses. In many cases, caregivers have become responsible for more care-related tasks due to a decrease in the scope and availability of previously utilized care services. One caregiver noted: "More responsibility in assisting family members with their needs of shopping, meal planning and



preparation, running errands, doctor visits, keeping up with scheduled appointments, communicating with debtors regarding billing and insurance issues, etc.”

In some cases, a decline in the health of their care recipient led to increased caregiver burden. One respondent wrote: “Mom developed more neurological issues due to COVID-19, which has been challenging. Once she was in the hospital, it took a toll on me as caregiver being the only visitor during duration of her stay. I appreciate that policy, but it was draining not to have support.”

For many, the increased caregiver burden impacted their wellness by increasing their stress level, as well as the stress level of their families. One caregiver responded: “It’s become more stressful for me to take my parents to doctor’s visits. Both have mobility issues and one has some dementia. Them not being able to get out of the house much makes it more stressful on all of us.”

Caregiver burden and stress is impacting caregivers’ overall wellness, including increases in depression, anxiety, and decreases in overall health and wellness. One caregiver noted: “High stress, constant migraines that are debilitating. My personal mental health is deteriorating.”

As burden and stress increases in caregivers, many are finding they now lack the ability to engage in self-care practices and coping strategies previously utilized before the pandemic. One respondent wrote:

The stress has increased because self-care has become a thing of the past. There is no time for that because my veteran has regressed so much in his progress due to the stay-at-home order and COVID-19 pandemic situation. He is having more PTSD symptoms and more suicidal ideation, which means he needs to be watched more.

Protection of Care Recipients and Loved Ones

Many caregivers expressed concerns about protecting their care recipients and other loved ones from becoming infected with COVID-19. This impacts their routines, what services they choose to utilize, the people they allow in their home, and their level of burden and stress. One caregiver offered this list of concerns about accessing in-home support: “Management of the caregivers coming into home, providing [personal protective equipment], and monitoring them to ensure they are practicing social distancing while not in our home.”

Some caregivers experienced increased burden as a result of having to educate their care recipient about safety restrictions due to COVID-19, which was complicated by the care recipient’s illness in some cases. One caregiver commented: “[I am] trying to keep my mother safe during COVID-19. She forgets or disregards the seriousness of the virus. She touches everything when out and wants to get close to people and talk to everyone.”

Resource Insecurity

Resource insecurity has affected many caregivers during the COVID-19 pandemic. This is important not only because there is a need to better understand caregiver service utilization and need, but the impact on increased caregiver burden is also significant. Many are experiencing financial instability as their household expenses have gone up. One caregiver noted: “Financially, we are now struggling as our household expenses have gone up and we are having to provide for our grown child’s family because they have no source of income at all due to the virus.”

Some caregivers are experiencing job insecurity due to the nature or conditions of their work changing. One respondent wrote: “I’m having to work extra due to other people not being able to work.” Some caregivers also lost their jobs or other sources of household income. One caregiver commented: “I lost my job. The savings we had had been used. The uncertainty is stressful.” The pandemic has also created resource insecurity for caregivers who are finding it difficult to access needed items, whether because of shortages, the safety restrictions involved with the procurement process, or financial strain. One



respondent wrote: “[I’m] unable to get products needed for proper care and hygiene: disinfectant, bleach, tissues, toilet tissue, incontinence pads, [etc].”

Other

A small number of caregivers also noted an improvement in burden and stress due to the pandemic. One caregiver wrote: “I am home a lot more. In some ways, things are less stressful because my schedule doesn't involve going to work. I am still caring for my husband but have more time to do things for him because I am not working.”

A small number of survey respondents noted that they were experiencing no changes. Some noted a general increase in worry, or unspecified changes in mood or mental health. One caregiver wrote: “Just worry about all the stuff that’s going on in the world.”

On the other end of the spectrum, a notable outlier was one response that indicated that they had become homeless during the pandemic. They noted: “We've ended up homeless and it's much more challenging being a caregiver when you're homeless. It brings a whole new set of challenges.” Other notable outliers included responses that indicated difficulty adapting to the migration of many services online due to a lack of access to technology. One caregiver commented:

Lack of access to sufficient internet. We have rural satellite internet with no video-conferencing capabilities. No Zoom, no telehealth, no online religious services, no at-home school classroom video conferencing, no possibility to find online work. We need broadband internet access for rural veterans.

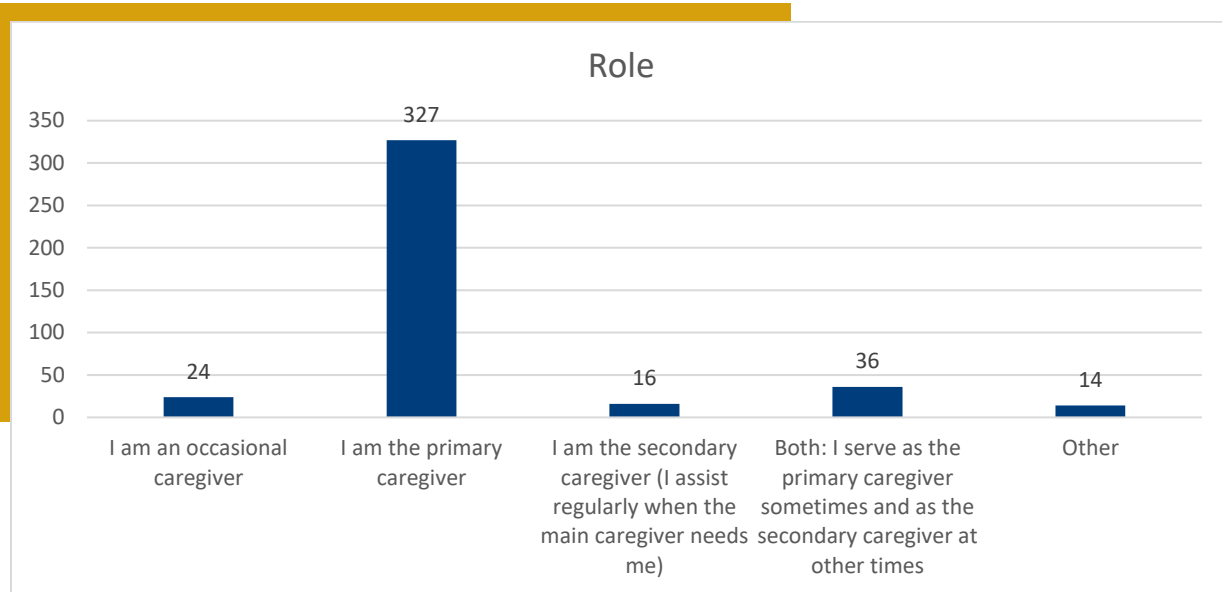
Relationship with the Care Recipient

Caregivers were asked to characterize their relationship with the care recipient and how that relationship has changed during the pandemic. The responses to these questions offer a glimpse at caring relationships under pressure.



Role Description

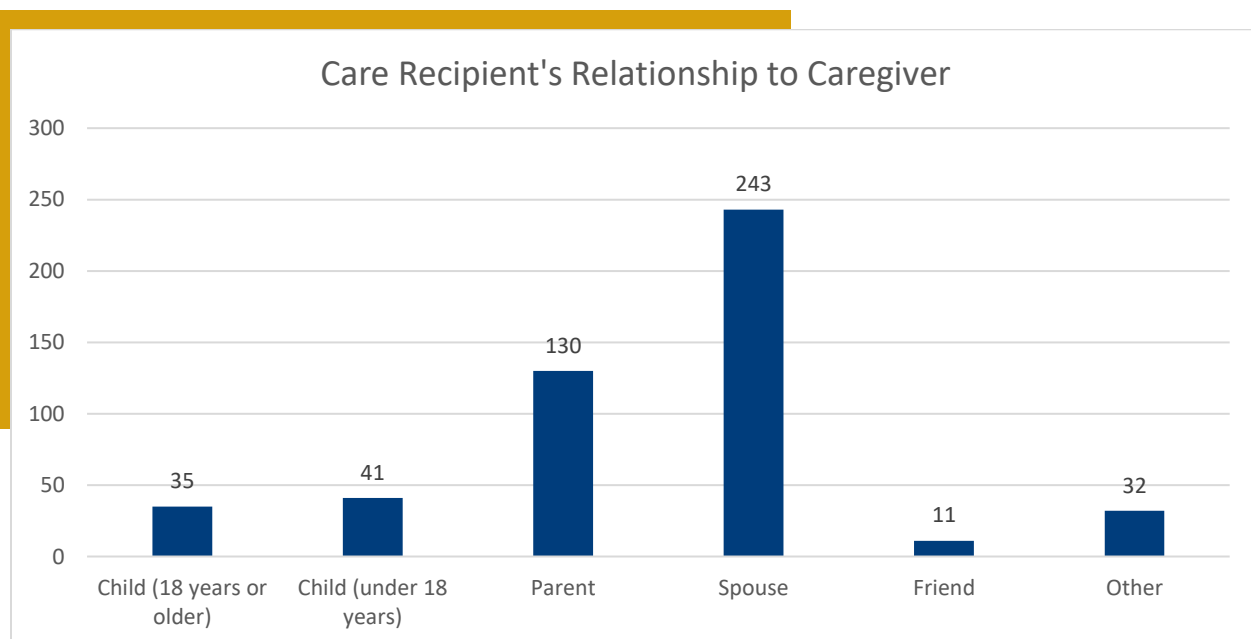
Caregivers described their role as occasional, primary, secondary, both primary and secondary, or other. Responses are shown in the table below.



78% of respondents reported being the primary caregiver. Among the 14 respondents who selected “Other,” roles included some former caregivers.

Relationship to Care Recipient

Caregivers also indicated their relationship to the care recipient. Responses are shown in the chart table below.

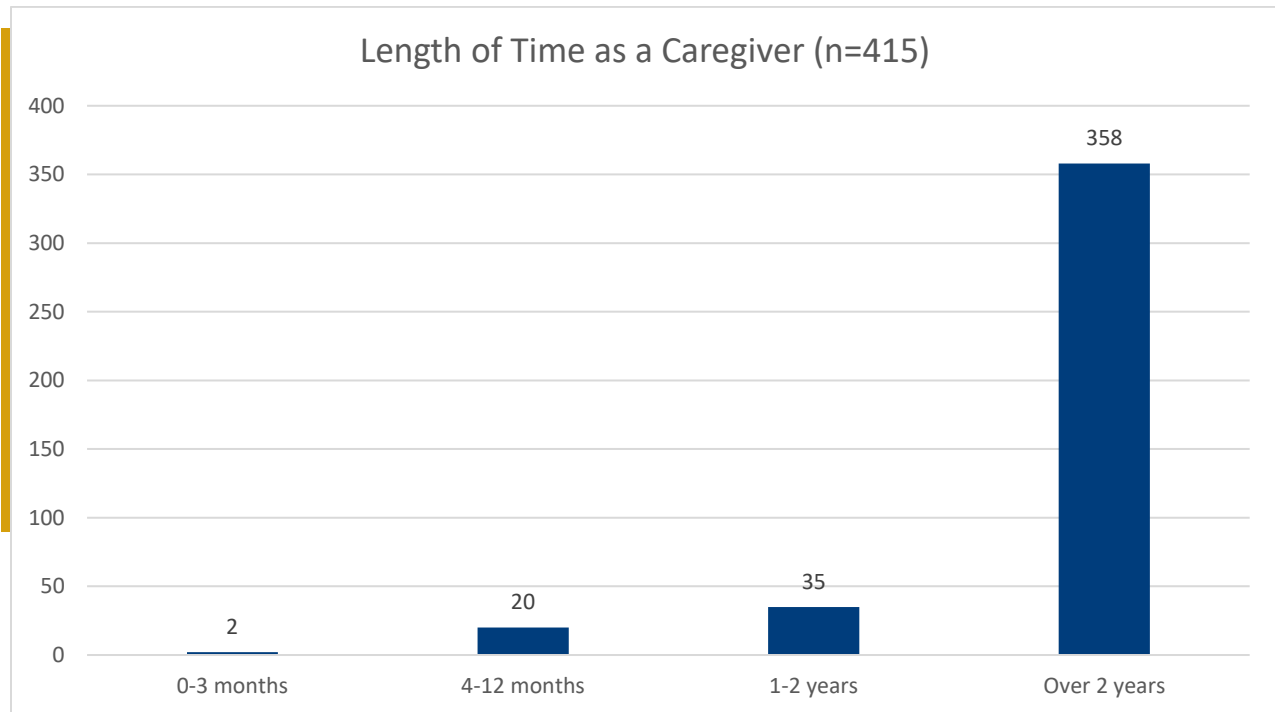




A little more than half (58%) of the respondents reported being the spouse of their care recipient, and 31% indicated they are the care recipient's parent. Among the 32 respondents who selected "Other," responses included grandparent (13), sibling (10), in-law (4), and other relative.

Length of Time as a Caregiver

Respondents shared how long they had been a caregiver. Their responses are shown in the chart below.



A significant majority (86%) of respondents have been providing care for over two years and almost 95% have been provide care for one or more years. This contrasts with the findings of the report Caregiving in the United States (AARP, 2020) which showed 56% of caregivers nationally having provided care for one or more years.

Living Situation and Transportation

Most respondents (79%) live with the person they are caring for, while the remaining 21% do not. When those who live apart from their care recipient were asked if transportation was an issue, just under a quarter (24.4%) indicated that it was.



Time with Care Recipient

Respondents indicated how their time with the care recipient had changed since the outbreak of COVID-19. Responses are shown in the table below.

	Increased	About the Same	Decreased
Frequency of contact	223 (55%)	128 (32%)	52 (13%)
Use of Internet for support	220 (57%)	140 (36%)	29 (7%)
Change in personal connect with care recipient	156 (39%)	162 (41%)	80 (20%)
Change in stress associated with caregiving	332 (83%)	58 (15%)	10 (3%)
Number of other caregivers available to help	20 (5%)	205 (53%)	161 (42%)

The responses reflect significant changes in the relationship between caregiver and care recipient since the onset of the pandemic, including:

- A majority (55%) reported an increase in the frequency of contact with the care recipient.
- An increase in the use of the Internet for support was reported by a majority (57%) of respondents.
- 41% of respondents indicated that their personal connection with the care recipient had remained about the same, while 39% said that connection had increased since the onset of the pandemic.
- A majority (83%) of respondents indicated that the stress associated with their role as a caregiver had increased since the onset of COVID-19.
- A little more than half (53%) of the respondents noted that the number of other caregivers available to help them had remained about the same, while 42% indicated there has been a decrease since the pandemic started.

More of those who reported a decrease in the frequency of contact with their care recipients also indicated a decrease in personal connection (64.7% v. 20.1% for all respondents and 12.4% for those with increased frequency of contact). Statistically significant changes for those who indicated an increase in the frequency of contact in comparison those who reported a decrease in are captured in the table below.

	Those reporting an increase in frequency of contact	Those reporting a decrease in frequency of contact
Increase in personal connection with care recipient	130 (60%)	9 (18%)
Increase in stress level associated with caregiving	204 (92%)	34 (51%)



Stuck Together, Torn Apart: Impact on the Caregiver-Care Recipient Relationship

The caregiver-care recipient relationship can look very different for different individuals. Much of the available literature on the subject focuses on relational dynamics in spousal and parental dyads, as many unpaid caregivers find themselves within the framework of such a relationship with their care recipient (Agree & Glaser, 2009). Some caregivers are providing care for a sibling or other relative, and some for other nonfamily members, as shown above. Within that context, it has been documented in the literature that caregiving burden directly affects relational satisfaction for caregivers (Tzitzika et al., 2020; Akkuş, 2011). It has also been suggested that caregiver burden is greater for caregivers that live with their care recipient, and that the type of relationship and perceived closeness has an impact on relational satisfaction (Litwin et al., 2014).

The reported increase in burden and stress for caregivers is notable in the way they suggest it has affected their relationships. Respondents were asked: **“What has been the biggest or most challenging change in your relationship with the person you are caring for?”** In addition to increases in burden and stress previously noted, caregivers reported that their closeness and ability to communicate well with care recipients has declined. Role confusion also persists as caregivers experience increased caregiver duties and the need to provide more constant care. Caregivers expressed challenges navigating relationship changes, including increased care recipient dependency or access to the care recipient, that may have been previously ameliorated by support or service utilization.

Impacts of Declining Caregiver Wellness

As many caregivers noted in their responses to the previous survey question, their mental health, physical health, and general wellbeing have been impacted by COVID-19. For some, this change in their personal wellness has affected their relationship with their care recipient. One caregiver noted: “My moods and mental health have changed my behavior in our relationship. I’m frequently frustrated, angry, overwhelmed and it’s added more stress to the relationship.”

Some noted the negative impact that the change in their ability to engage in self-care behaviors had on their relationship with their care recipient. One caregiver commented:

I now have absolutely no time at all for self-care. I am either working or playing with my daughter and have no time for anything else. As a result, I find that I am often more easily frustrated and less eager to engage.

Impacts of Declining Care Recipient Wellness

Many survey respondents noted how a change in their care recipient’s wellness affected their relationship. For some, this was due to a decline in the care recipient’s mental health. Responses that noted a change in care recipient mental health were typified by increases in isolative behavior, anxiety, and other behavioral changes. One caregiver wrote: “He has become very violent and the drinking is out of control. [He has] major mood swings and he is also creating damage in the home and cleaning is taking up most of the day.”

Pandemic conditions have also led to increases in behavioral issues for care recipients with certain conditions like Post Traumatic Stress Disorder and Dementia. Typical responses in this category were brief, and, while they were not explicit as to the effect of such changes on the caregiver-care recipient relationship, relational impact may be inferred. Examples of these types of statements include: “Heightened PTSD,” “Dementia-related behavioral problems,” and “My husband has Alzheimer’s and him not being on his routine has been very stressful.”



Changes in the physical health of the care recipient and its effect on the relationship with the caregiver were also documented. Many of these changes suggest a relationship between changes in the care recipient's physical and mental health, impact on the caregiver-care recipient relationship, and expression of relationship roles. One such response read: "Watching him deteriorate mentally from a cognitive disorder, suffer from chronic pain and depression. [I'm] turning into a caregiver that is losing her husband." Concerns for safety and wellness, on the part of both caregivers and care recipients, also affected relationships. One caregiver noted: "The extra stress of this pandemic has caused my husband to be on extreme high-alert, worried, and trying to prepare. He is afraid of one of us getting sick."

A significant number of respondents noted an increase in their care recipient's dependency on them for care. Some caregivers noted this was because of a lack of sufficient outside help. In some cases, this was due to availability, as one caregiver noted: "She has become far more dependent on me, as paid caregivers have not been available." In other cases, concerns for safety were cited. One caregiver wrote: "No assistance during this time (personal choice for health and safety reasons) so I am on-duty 24/7 without any breaks."

Breakdown in Communication and Intimacy

A number of respondents noted a general change in their connection with their care recipient, and many caregivers reported an increase in issues regarding communication and intimacy within their relationship. One respondent wrote: "Losing our communication; it feels very lonely without [it]. We were one of these couples that did almost everything together and felt good about it."

Some survey responses indicated an increase in tension and relationship stress. One caregiver provided insight into the complexity inherent in the connections between increased stress, caregiver/recipient wellness, and the impact on relationship dynamics: "More stress leads to more anxiety for me and fighting. Higher stress also leads to more episodes of PTSD for my veteran."

As many caregivers experience increased burden and greater care recipient dependency, there is an increase in role confusion noted by caregivers. Some caregivers expressed frustration with taking on the additional role of educating their care recipients about the dangers of transmission and risk of infection from COVID-19. One caregiver reported: "Fights, stress, and disagreements about how careful they should be with social distancing. Their news intake [...] is especially problematic in them understanding the gravity of the situation[...]."

Similarly, some caregivers reported a shift in the relational dynamic with a parent care recipient. One respondent wrote: "Parent-child role reversal of trying to get them to obey." Role confusion also occurred as some respondents noted how their increased care responsibilities affected their ability to step away from their role as caregiver. One caregiver wrote: "There is less romance and connection. I feel more a caregiver and sometimes a parent to my husband than a spouse."

A notable theme among survey responses commenting on intimacy and communication was the impact that stay-at-home orders and pandemic conditions has had on the amount of time caregivers are spending with their care recipients. These responses were typified by the use of phrases like "more time together," "no time alone," and "no breaks from each other." One caregiver wrote: "We are on top of each other all the time. There is very little to no opportunity to have some healthy time apart." Not having time apart was also seen as having a negative impact on caregivers' likelihood to engage in self-care practices. One caregiver mentioned: "Not being able to have time away or time for self-care."

Impact of Reduced Access to the Care Recipient

Isolation was found to be a significant theme among responses about changes in the relationship with the care recipient. The most significant of these factors was found in responses noting a change in the



caregiver's access to their care recipient. Access was reduced for some, while others have had no access to their care recipient at all. This could impact the quality of social interactions between the caregiver and care recipient. One respondent wrote: "Not having personal contact with them. Inability to kiss her, hold her hand, etc." Another caregiver noted: "Not having as much face to face time with her."

Caregivers expressed concerns for the wellbeing of their care recipient, and often found difficulty navigating ways to express concern and provide support. One caregiver mentioned:

Trying to keep my son's emotional fragility and severe depression from [rapidly declining], while attempting not to show any of my concern and fear. My son has also been distancing himself, as if preparing for the worst outcomes. [We] are geographically apart for now, and although he won't verbalize it, I know he is alone and scared, but trying to put on his "brave warrior" face, in an attempt not to additionally worry me.

Other

While most responses noted some change in their relationship to their care recipient, some noted no change. One recipient pointed out: "Caring for a parent with Alzheimer's is challenging all the time. There really haven't been any changes due to COVID-19."

A small number of participants, in light of the challenges they may be facing, noted that they have enjoyed the increased time spent together, or an increase in their capacity to care for their care recipient. One caregiver wrote:

I don't find it a challenge because I have enjoyed the extra time with my husband. I have been back in the workforce for the past 5 years so being at home on a full-time basis again has just been an adjustment.

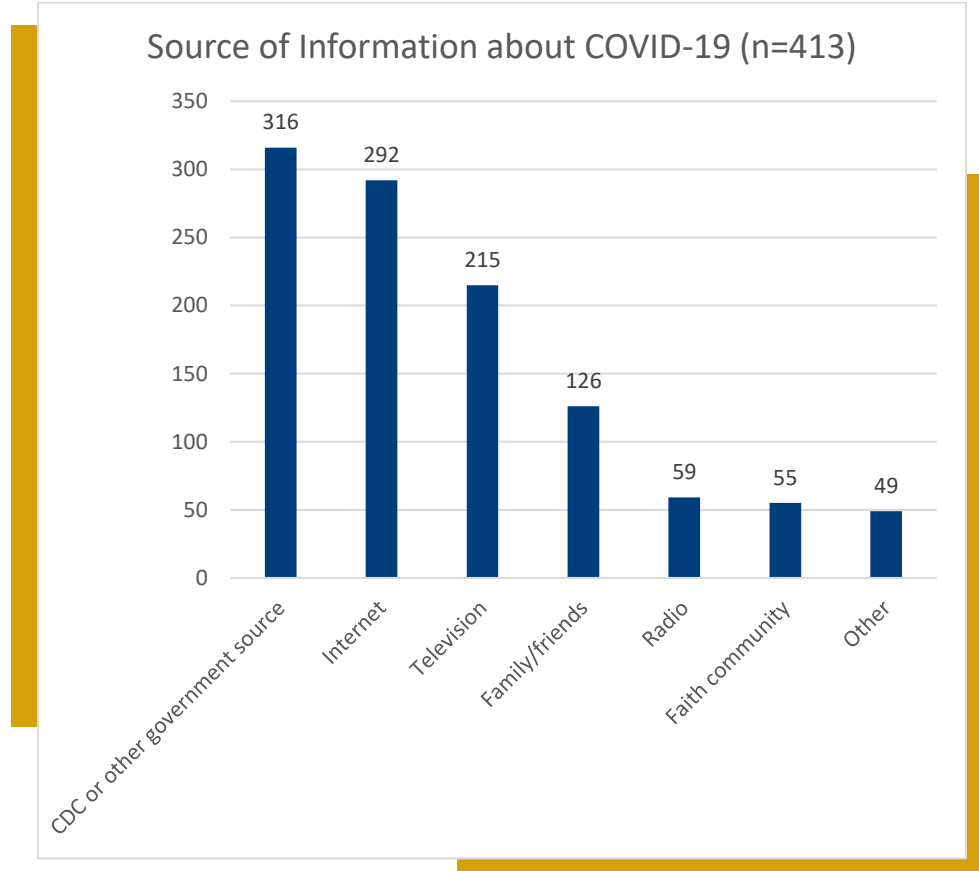


Getting Support

Caregivers were asked to reflect on access to support during the pandemic. The responses reveal important gaps in much needed support systems

Access to Information

Respondents were asked, “Where do you get information about COVID-19 and taking care of others?”



Respondents most often indicated that they get information about the coronavirus pandemic from the government, followed closely by the Internet, and television. Over a quarter of respondents said they receive information from family and friends. Among the 49 respondents who selected “Other,” responses included health care worker or health system (16), work sources (12), support groups (5), other media (4) among other miscellaneous sources.

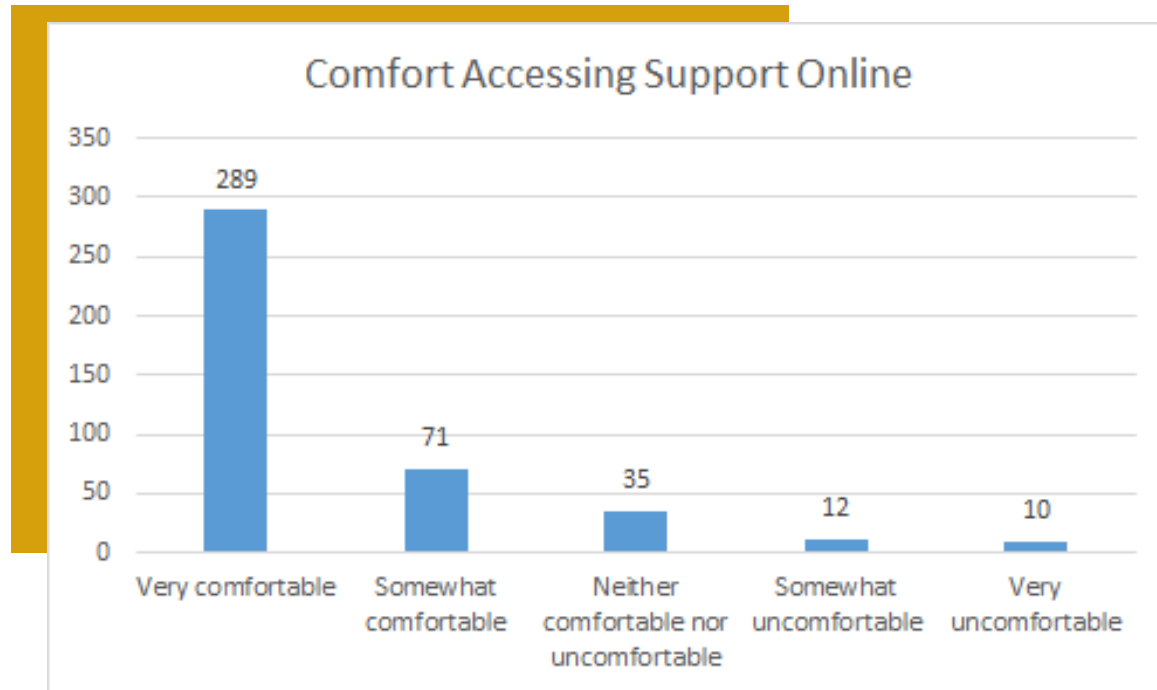
Those 60 and over indicated that they get information from the CDC or other government sources less frequently than did all respondents (71.0% to 76.5% respectively). They more frequently reported getting their information about COVID-19 from television (64.8% vs. 52.1% for all respondents).

We asked caregivers if they need information that they cannot get. Almost all respondents (94% of the 417 who answered this question) said they did not. Among the 27 caregivers (6%) who answered that there was information they need and cannot get, responses were primarily about getting truthful, consistent, and non-politicized information about the virus, particularly its prevalence and transmission. Other caregivers were interested in more information about financial assistance available for caregivers and anti-body testing.



Access to Support Online

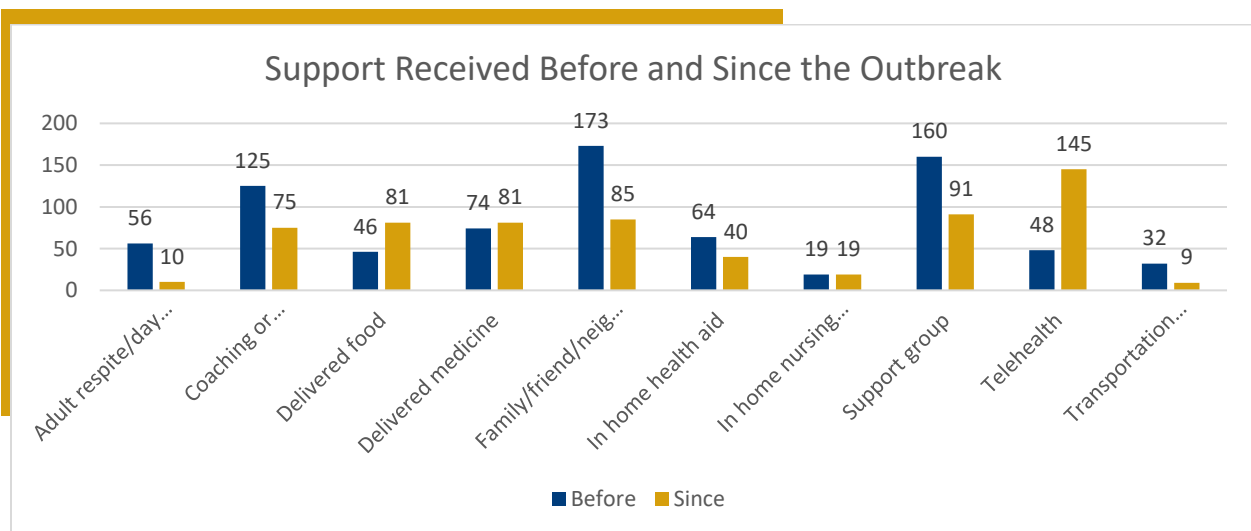
Respondents were asked to share their comfort with accessing support for themselves online.



Most (87%) respondents indicated that they are either very comfortable or somewhat comfortable accessing support online.

Supports Received

Caregivers were asked what support they had received before the pandemic and what support they have received since the outbreak of COVID-19. The results show a marked difference between support caregivers received before and during the pandemic.



Responding caregivers indicated a decline in support in most of the survey categories, from family and friends to adult respite and in-home health aids. An increase in support was indicated for delivery of food, delivery of medicine, and telehealth. Only in-home nursing care remained unchanged.



Among those 30 caregivers who shared “other” support received *before* the pandemic, responses included: care facility, school, employment support, hospice/palliative care, and online support. For those 15 caregivers who shared other support received *since* the outbreak of COVID-19, responses included online support and support from a faith community, along with a several complaints about the loss of services provided during the pandemic. One potentially positive finding is that fewer caregivers indicated that they received no support since the outbreak (39) than those who indicated they received no support before the outbreak (74).

Helpful Services

Many services that caregivers have traditionally relied upon, such as in-home care assistance, respite care, and support groups, have had to adjust the scale and delivery method of their operations. To gain a better understanding of the service utilization landscape among caregivers in the midst of the COVID-19 pandemic, respondents were asked: **“What is the most helpful service you have received since the COVID-19 outbreak?”** Remote care services, financial support, and access to a greater range of delivery services for food, medication, and necessary items, were among the most commonly listed services caregivers found helpful.

Support from Professionals and Peers

Many survey respondents reported receiving some form of supplemental support that they found helpful. This support comes in different forms, from professionals, peers, and other members of the community. Telehealth, telemental health, counseling, and caregiver training and coaching programs were listed among the received support services that some caregivers found to be the most helpful since the COVID-19 outbreak. Many caregivers also receive in-home care. One respondent noted:

Hospice sent people to our home to do all of the assessments, paperwork, [durable medical equipment] delivery, [as well as nurses and a] social worker. They gave me the best support and instant relief to all my issues about my mother’s care and the stage of her illness.

Many caregivers also mentioned support groups as being the most helpful service they received. Some caregivers specifically mentioned virtual peer support groups attended via teleconferencing platforms.

Caregivers also received additional support from their friends, family, and neighbors. Friends and family provided support by helping with food deliveries, secondary caregiver services when the primary caregiver was at work, and emotional support (often noted to be via telephone).

Resource Assistance

Many respondents reported receiving some form of resource assistance, the most common of these was food. While some specified receiving food assistance in the form of charitable donations, such as those from organizations like Meals on Wheels, many were not specific about the method or source and noted simply “food delivery” or “grocery delivery.” One caregiver mentioned: “Nonprofits delivering my food and volunteers that do my grocery shopping.” A significant theme in the responses, however, was the utilization of contactless pickup and delivery services of food, groceries, and medications.

Caregivers also noted receiving financial assistance. The most common form of financial assistance reported was a check received from the federal government as part of the Coronavirus Aid, Relief, and Economic Security (CARES) Act passed in March 2020. Some respondents received help in the form of temporary rent and housing assistance, and a few noted receiving gift cards to assist with food.

Remote Access and Technology

Participants mentioned receiving services and resources that have shifted to online delivery formats, if they were not already virtual. Email newsletters, online training and support, virtual support groups, and specific websites were mentioned in survey responses. Some respondents also noted that being able to



work remotely has been helpful. One caregiver noted: “Not having to be out of the home to work. Working remotely has made it easier for me to be here for him 24/7.” Some caregivers mentioned that they received phone calls to monitor their wellbeing. One caregiver mentioned: “Calls to check up on us.”

Other

A number of caregivers mentioned types of information that were helpful to them, including “Information about the virus,” “emails with information and activity ideas,” and “weekly updates from [the state government] as soon as [they have] information for us.” A significant number of respondents also noted that they received no support or services.

Most Needed Services

Caregivers were asked: “**What services have you not yet received but which would make a big difference in the quality of your life in the coming months?**” The findings indicated that some of the same services utilized by some caregivers were still needed by many others. While caregivers need services to supplement or replace services previously utilized, they also expressed need for services and assistance to help overcome new challenges brought on by caregiving during a pandemic. Respite assistance, financial assistance, food assistance, and access to more social activities were among the most common needs reported.

Respite and Daycare

Services that many caregivers indicated they have not yet received that would improve their quality of life include respite and daycare services. Many of these responses specified only “respite” or “respite care” without noting the level of formality of care. In some cases, caregivers were expressing a need for a break, whether in the form of relief by a family member, assistant caregiver, or otherwise. One caregiver wrote: “Respite of any type.”

Some caregivers specified a desire for the return of daycare and professional respite services. One caregiver mentioned: “The adult day respite care in a safe environment.”

In-Person Social Interaction

Given the impact of isolation on caregiver/recipient wellness, many survey responses highlighted a desire for quality in-person social interactions. These responses included wishes for the return of in-person medical and mental health services, other in-person social services like senior centers, and more opportunities for socialization for their care recipients. One caregiver wrote: “The ability to meet physically with friends, and the ability to participate in social and cultural activities again.”

Peer Support and Self-Care

Caregivers also mentioned the need for various forms of caregiver support services. The most prevalent of these was support groups. In some cases, responses simply stated “support groups,” but some respondents named specific services like Alcoholics Anonymous, as well as a desire for their existing support group to be available via remote access. One caregiver wrote: “To talk to other caregivers providing care during COVID-19.”

A desire for self-care support was also expressed. Some responses consisted only of the phrase “self-care.” In other cases, respondents noted the importance of services they had previously utilized as part of their self-care strategy, such as gyms and yoga classes. One respondent wrote: “I would love to do an online yoga or meditation class to help reduce stress.”



Financial Assistance

Many caregivers reported needing financial assistance, specifically in the form of a caregiver stipend from the Veterans Benefits Administration or a second stimulus check from the federal government. One caregiver wrote:

[I'd like] my job back or the federal stimulus package. Since I am a college student, my parents have to claim me as a dependent for student loan reasons despite me talking care of most of my own bills from my wages. Because I was claimed, and I was over 17, I did not qualify for any type of federal relief.

Responses in this category also included requests for gift cards for food and gas, unemployment pay, and utility bill assistance.

Food

Much in the way caregivers reported utilizing a wide range of food-related services, respondents also expressed a need for them. “Grocery delivery,” “Help with food,” and “Delivered food” typified the responses in this category. One caregiver noted how food assistance would alleviate them of some of their burden as a caregiver: “Delivered food would be nice since I solely cook all meals and clean afterwards.”

Clinical and In-Home Care Services

While some caregivers specifically mentioned a return to in-person medical and mental healthcare services, some caregivers noted that they would like more consistent access to medical and mental healthcare in general. One respondent commented: “More consistent medical care for all of his health issues, and a care advisor on how to navigate his medical health with living his life.

Regarding mental health care, many caregivers requested counseling services in addition to caregiver support like coaching. One caregiver wrote: “I am completely exhausted. I need help for myself so I can continue to be here for him. Seeing a therapist or counselor.”

Caregivers also requested additional professional in-home help for assistance with physical therapy, respite care, cleaning, and other care tasks. One caregiver wrote: “Finding [someone on] weekends or evenings who can handle a feeding tube for respite.”

Other

As part of other multifaceted responses, caregivers expressed the need for additional support from family and friends. Usually, this was in the context of the need for informal respite care, but one caregiver wrote: “Family provides no emotional support and never will.”

Technology was also a subordinate theme found across different categories in the responses to this survey item. Respondents reported either a desire to return to in-person services, difficulty navigating remote services, or a lack of appropriate access to internet to engage with such services. Regarding remote services they would like to see, one caregiver wrote: “A way for my parent to access religious content independently from home.”

Some caregivers expressed a need for clear information regarding COVID-19. Frustration regarding the lack of clarity of information received was expressed, as well as the desire for a way of receiving information without taking in information that would be potentially triggering for their care recipient. As one caregiver put it: “Information without putting the news on. It's a trigger for my husband.”



Conclusions

The COVID-19 pandemic continues to have significant impact on the wellbeing of family caregivers, who continue to provide care to some of our most vulnerable populations, at great personal risk. Increased isolation, the evisceration of vital support services, and increased overall burden has contributed to continued physical, mental, and emotional decline among caregivers. With no immediate end to the pandemic in sight, it is likely this decline will continue, precipitating a mental health crisis for caregivers.

As caregiver wellbeing has declined, there has also been increased relationship stress for caregivers. This is exemplified by the increased strain in the caregiver-care recipient relationship, as well as the relationships between caregivers and their support network of family and friends. The increase in the number of dependent people in the home, as well as increased care recipient dependency, correlates with an increase in caregiver stress, which, ultimately, effects caregivers' ability to provide effective care. At a time when additional support from family members and auxiliary caregivers is at a critical new low, family resiliency and support, which remains largely unstudied in the context of the current pandemic (Prime et al., 2020), will continue to be a significant concern for caregivers.

The findings of this study suggest that while the burden on caregivers continues to increase, service availability to caregivers has become complex and, in many cases, continues to decrease. The lack of consistency in resource availability to caregivers is also evident in the above findings. Services, such as caregiver support groups, are being utilized by some and still needed by many. The same is also true when looking at other forms of assistance, such as financial support and food assistance.

Limitations

The convenience sampling of caregivers within RCI's current network created a bias in the data favoring individuals who are already connected to services. Older white women were the largest group of participants in the survey, comprising 18% of all respondents and creating perspective bias related to age, gender, and ethnicity. The survey, offered in English and Spanish, excluded monolingual persons who speak other languages. And, the collection of only one Spanish-language response suggests that the channels of distribution were insufficient to reach larger numbers of monolingual Spanish speakers. RCI is committed to being a more inclusive organization and, as such, will stive to reach diverse communities with its communications, outreach, programs, and partnerships. The organization's commitment to greater diversity and inclusion should result in a more diverse sample for future surveys.

This survey was, because of the data collection format, also limited to people with some existing Internet access. Finally, the survey took an average of just over 26 minutes for participants to complete, potentially excluding caregivers who are simply too busy or overwhelmed to spare the time to respond. Taken together, these limitations – favoring English speakers with Internet access, awareness of services, and time to respond -- suggest that the stress for those caregivers who were not reached by this survey may in fact be far greater than what is reflected in this report.



Recommendations

There is no single solution that is sufficient in helping caregivers weather this storm. Creative integration of formal and informal support systems will be needed to provide much needed support to caregivers, and by extension, their care recipients and loved ones. The COVID-19 pandemic has brought to light new challenges to supporting caregivers who are deeply concerned about the risk of becoming infected or placing a loved one at risk. Based on the significance of these concerns, as well as the responses from caregivers noting how vital access to remote services has been since the start of the pandemic, we recommend the following:

- Increased access to peer support. In light of the increased social isolation being experienced by caregivers, this is needed now more than ever. Access to peer support could be increased through the continued development and promotion of remote caregiver support groups, support services that are inclusive of auxiliary caregivers, and programs that train and support peer specialist counselors for caregivers. Such training may include interpersonal communication strategies, healthcare and telehealth navigation, critical incident stress management, as well as other self-care techniques and strategies. Increased formalization of peer support services, along with further participatory research alongside caregivers, care recipients, and relevant stakeholders, is recommended.
- Creating more comprehensive virtual community-building resources for caregivers to combat isolation and perceived loneliness. This would potentially further empower caregivers to seek help and additional support, and would aid in the organization of community-based caregiver advocacy groups. Such advocacy groups could function remotely and work together with community-based organizations and other relevant stakeholders to create change in policy that would support many of the needed services documented in this study. Policy change could include increased financial assistance for caregivers (e.g. caregiver stipends, federal aid), expansion of insurance benefits to cover needed supplemental support services (e.g., in-home health help, respite care, increased palliative services), more paid family leave for caregivers, and other policy areas identified by participating stakeholders.
- Increased awareness, access, and availability to respite options. Additionally, formal in-person respite services could be supplemented with virtual options. Practical support should be increased, including food assistance, supplemental childcare and educational support, home health workers, and home cleaning services. Further research should also be conducted on the efficacy of remote service delivery, as well as access to the necessary technology to utilize available remote services. Research of this kind should be mindful of methodology, as remotely conducted research may miss potential participants in rural settings, or those without internet access.

In addition to the obstacles brought about by the COVID-19 pandemic, some previously extant challenges for caregivers have been exacerbated. The current crisis provides an opportunity to revisit these perennial concerns for caregivers and work to close the gaps in much needed support services. We recommend:

- Increased access to a broad range of remote, formal mental health services. This includes increased access to individual, couples, marriage, and family counseling.



- Wider availability of a broad range of caregiver psychoeducational programming. This should include caregiver workshops and coaching with a variety of access options, including phone or text, and online. This type of service would be most effective when provided in the early stages of the caregiving journey to aid in the formation of caregiving teams and support structures, which would be empowering for caregivers seeking assistance.
- Strengthening support for basic needs, including food assistance, supplemental childcare and educational support, home health workers, and home cleaning services; while many of these services are available, they may remain inaccessible to many caregivers due to cost or other barriers.



References

- AARP. (2020). *Caregiving in the U.S. 2020*. AARP & the National Alliance for Caregiving. <https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>
- Aarsland, D., Larsen, J. P., Karlsen, K., Lim, N. G., & Tandberg, E. (1999). Mental Symptoms in Parkinson's Disease are Important Contributors to Caregiver Distress. *INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY*, *10*, 866.
- Agree, E.M, & Glaser, K (2009). Demography of Informal Caregiving. In P. Uhlenberg (Ed.), *International handbook of population aging* (pp. 647-667). Springer.
- Aishworiya, R., & Kang, Y. Q. (2020). Including Children with Developmental Disabilities in the Equation During this COVID-19 Pandemic. *Journal of Autism and Developmental Disorders*. <https://doi-org.proxy-remote.galib.uga.edu/10.1007/s10803-020-04670-6>
- Akkuş, Y. (2011). Multiple sclerosis patient caregivers: The relationship between their psychological and social needs and burden levels. *Disability and Rehabilitation: An International, Multidisciplinary Journal*, *33*(4), 326–333. <https://doi-org.proxy-remote.galib.uga.edu/10.3109/09638288.2010.490866>
- Brown, E. E., Kumar, S., Rajji, T. K., Pollock, B. G., & Mulsant, B. H. (2020). Anticipating and Mitigating the Impact of the COVID-19 Pandemic on Alzheimer's Disease and Related Dementias. *The American Journal of Geriatric Psychiatry*, *28*(7), 712–721. <https://doi-org.proxy-remote.galib.uga.edu/10.1016/j.jagp.2020.04.010>
- Cacioppo, M., Bouvier, S., Bailly, R., Houx, L., Lempereur, M., Mensah-Gourmel, J., Kandalaft, C., Varenque, R., Chatelin, A., Vagnoni, J., Vuillerot, C., Gautheron, V., Dinomais, M., Dheilly, E., Brochard, S., & Pons, C. (2020). Emerging health challenges for children with physical disabilities and their parents during the COVID-19 pandemic: The ECHO French survey. *Annals of Physical and Rehabilitation Medicine*. <https://doi-org.proxy-remote.galib.uga.edu/10.1016/j.rehab.2020.08.001>
- Claudia Carmassi, Claudia Foghi, Valerio Dell'Oste, Carlo Antonio Bertelloni, Andrea Fiorillo, & Liliana Dell'Osso. (2020). Risk and Protective Factors for PTSD in Caregivers of Adult Patients with Severe Medical Illnesses: A Systematic Review. *International Journal of Environmental Research and Public Health*, *17*(5888), 5888. <https://doi-org.proxy-remote.galib.uga.edu/10.3390/ijerph17165888>
- Carter, J. H., Stewart, B. J., Archbold, P. G., Inoue, I., Jaglin, J., Lannon, M., Rost-Ruffner, E., Tennis, M., McDermott, M. P., & Amyot, D. (1998). Living With a Person Who Has Parkinson's Disease: The Spouse's Perspective by Stage of Disease. *MOVEMENT DISORDERS -NEW YORK-*, *1*, 20.
- Centers for Disease Control and Prevention. (2020, August 14). People with Certain Medical Conditions. https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fneed-extra-precautions%2Fgroups-at-higher-risk.html
- Chan, W.-L., Ho, P., & Yuen, K.-K. (2020). Impacts of social distancing on cancer care during COVID-19 pandemic: Hong Kong experience. *Palliative & Supportive Care*, 1–8. <https://doi-org.proxy-remote.galib.uga.edu/10.1017/S1478951520000541>



- Cuffaro, L., Di Lorenzo, F., Bonavita, S., Tedeschi, G., Leocani, L., & Lavorgna, L. (2020). Dementia care and COVID-19 pandemic: a necessary digital revolution. *Neurological Sciences: Official Journal of the Italian Neurological Society and of the Italian Society of Clinical Neurophysiology*, 41(8), 1977–1979. <https://doi-org.proxy-remote.galib.uga.edu/10.1007/s10072-020-04512-4>
- De Lucia, N., Ausiello, F. P., Spisto, M., Manganelli, F., Salvatore, E., & Dubbioso, R. (2020). The emotional impact of COVID-19 outbreak in amyotrophic lateral sclerosis patients: Evaluation of depression, anxiety and interoceptive awareness. *NEUROLOGICAL SCIENCES*. <https://doi-org.proxy-remote.galib.uga.edu/10.1007/s10072-020-04592-2>
- De Marchi, F., Cantello, R., Ambrosini, S., & Mazzini, L. (2020). Telemedicine and technological devices for amyotrophic lateral sclerosis in the era of COVID-19. *Neurological Sciences: Official Journal of the Italian Neurological Society and of the Italian Society of Clinical Neurophysiology*, 41(6), 1365–1367. <https://doi-org.proxy-remote.galib.uga.edu/10.1007/s10072-020-04457-8>
- Ebrahim, S. H., Ahmed, Q. A., Gozzer, E., Schlagenhaut, P., & Memish, Z. A. (2020). Covid-19 and community mitigation strategies in a pandemic. *BMJ (Clinical Research Ed.)*, 368, m1066. <https://doi-org.proxy-remote.galib.uga.edu/10.1136/bmj.m1066>
- Hado, E., & Friss Feinberg, L. (2020). Amid the COVID-19 Pandemic, Meaningful Communication between Family Caregivers and Residents of Long-Term Care Facilities is Imperative. *JOURNAL OF AGING & SOCIAL POLICY*. <https://doi-org.proxy-remote.galib.uga.edu/10.1080/08959420.2020.1765684>
- Hoffman, G. J., Webster, N. J., & Bynum, J. P. W. (2020). A Framework for Aging-Friendly Services and Supports in the Age of COVID-19. *Journal of Aging & Social Policy*, 32(4–5), 450–459. <https://doi-org.proxy-remote.galib.uga.edu/10.1080/08959420.2020.1771239>
- Indini, A., Rijavec, E., Ghidini, M., Cattaneo, M., & Grossi, F. (2020). Developing a risk assessment score for patients with cancer during the Coronavirus Disease 2019 pandemic. *European Journal of Cancer*, 135, 47–50. <https://doi-org.proxy-remote.galib.uga.edu/10.1016/j.ejca.2020.05.017>
- Litwin, H., Stoeckel, K. J., & Roll, A. (2014). Relationship status and depressive symptoms among older co-resident caregivers. *Aging & Mental Health*, 2, 225.
- Lu, Y.-F. Y., & Wykle, M. (2007). Relationships Between Caregiver Stress and Self-Care Behaviors in Response to Symptoms. *CLINICAL NURSING RESEARCH*, 1, 29.
- Kent, E. E., Ornstein, K. A., & Dionne-Odom, J. N. (2020). The Family Caregiving Crisis Meets an Actual Pandemic. *JOURNAL OF PAIN AND SYMPTOM MANAGEMENT*, 60(1), E66–E69. <https://doi-org.proxy-remote.galib.uga.edu/10.1016/j.jpainsymman.2020.04.006>
- Ng, D. W. L., Chan, F. H. F., Barry, T. J., Lam, C., Chong, C. Y., Kok, H. C. S., Liao, Q., Fielding, R., & Lam, W. W. T. (n.d.). Psychological distress during the 2019 Coronavirus Disease (COVID-19) pandemic among cancer survivors and healthy controls. *PSYCHO-ONCOLOGY*. <https://doi-org.proxy-remote.galib.uga.edu/10.1002/pon.5437>
- Penning, M. J., & Wu, Z. (2016). Caregiver stress and mental health: Impact of caregiving relationship and gender. *The Gerontologist*, 56(6), 1102–1113. <https://doi-org.proxy-remote.galib.uga.edu/10.1093/geront/gnv038>



- Prime, H., Wade, M., & Browne, D. T. (2020). Risk and resilience in family well-being during the COVID-19 pandemic. *American Psychologist*, 75(5), 631–643. <https://doi-org.proxy-remote.galib.uga.edu/10.1037/amp0000660>
- Provenzi, L., & Tronick, E. (2020). The power of disconnection during the COVID-19 emergency: From isolation to reparation. *Psychological Trauma: Theory, Research, Practice, and Policy*, 12(S1), S252–S254. <https://doi-org.proxy-remote.galib.uga.edu/10.1037/tra0000619>
- Roepke, S. K., Mausbach, B. T., Patterson, T. L., von Kanel, R., Ancoli-Israel, S., Harmell, A. L., Dimsdale, J. E., Aschbacher, K., Mills, P. J., & Ziegler, M. G. (2011). Effects of Alzheimer caregiving on allostatic load. *JOURNAL OF HEALTH PSYCHOLOGY*, 1, 58.
- Rossi, R., Socci, V., Talevi, D., Mensi, S., Niolu, C., Pacitti, F., Di Marco, A., Rossi, A., Siracusano, A., & Di Lorenzo, G. (2020). COVID-19 pandemic and lockdown measures impact on mental health among the general population in Italy. *Frontiers in Psychiatry*, 11. <https://doi-org.proxy-remote.galib.uga.edu/10.3389/fpsyt.2020.00790>
- Russell, B. S., Hutchison, M., Tambling, R., Tomkunas, A. J., & Horton, A. L. (2020). Initial Challenges of Caregiving During COVID-19: Caregiver Burden, Mental Health, and the Parent-Child Relationship. *Child Psychiatry and Human Development*. <https://doi-org.proxy-remote.galib.uga.edu/10.1007/s10578-020-01037-x>
- Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshahi, M. (2006). Caregiver-burden in Parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. *Parkinsonism and Related Disorders*, 12(1), 35–41. <https://doi-org.proxy-remote.galib.uga.edu/10.1016/j.parkreldis.2005.06.011>
- Tian, T., Luo, W., Jiang, Y., Chen, M., Wen, C., Pan, W., & Wang, X. (2020). *The effects of stringent interventions for coronavirus pandemic*. arXiv: <https://arxiv.org/abs/2006.00523>
- Tousi, B. (2020). Dementia Care in the Time of COVID-19 Pandemic. *JOURNAL OF ALZHEIMERS DISEASE*, 76(2), 475–479. <https://doi-org.proxy-remote.galib.uga.edu/10.3233/JAD-200461>
- Tuncay, F. O., & Fertelli, T. K. (2019). Effects of the caregiver burden perceived by caregivers of patients with neurological disorders on caregiver wellbeing and caregiver stress. *PERSPECTIVES IN PSYCHIATRIC CARE*, 55(4), 697–702. <https://doi-org.proxy-remote.galib.uga.edu/10.1111/ppc.12405>
- Venkateswaran, K. D., & Hauser, C. T. (2020). Living with PTSD amid a global pandemic. *Psychological Trauma: Theory, Research, Practice, and Policy*, 12(S1), S71–S72. <https://doi-org.proxy-remote.galib.uga.edu/10.1037/tra0000857>
- Webb, L. (2020, June 23). The mental health risk of being 'vulnerable' during COVID-19 pandemic. Medical Xpress. <https://medicalxpress.com/news/2020-06-mental-health-vulnerable-covid-pandemic.html>
- Xue, H., Zhai, J., He, R., Zhou, L., Liang, R., & Yu, H. (2018). Moderating role of positive aspects of caregiving in the relationship between depression in persons with Alzheimer's disease and caregiver burden. *Psychiatry Research*, 261, 400–405. <https://doi-org.proxy-remote.galib.uga.edu/10.1016/j.psychres.2017.12.088>



Yu, D. S. F., Cheng, S.-T., & Wang, J. (2018). Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *International Journal of Nursing Studies*, 79, 1–26.
<https://doi-org.proxy-remote.galib.uga.edu/10.1016/j.ijnurstu.2017.10.008>



Appendix A: Partner Organizations Provided a Survey Link for Distribution

Caregivers on the Homefront

Sesame Workshop

RallyPoint

ALS Association Georgia Chapter

Veterans Administration

Southern Caregiver Resource Center

Riverside Center for Excellence and Lifelong Aging

Hilarity For Charity

CaringBridge

REACH Sites, DWD Sites

CARENETs

Military and Veteran caregiver Network

National Alliance on Caregiving

Family Caregiver Alliance

Elizabeth Dole Foundation

Caregiver Action Network

American Association of Retired Persons

ARCH National Respite Network and Resource Center

CaringAcross Generations

American Association of Caregiving Youth

LatinosAgainstAlzheimers

RCI Social Media

Bristol Myers Squibb

Bob Woodruff Foundation

Ralph C. Wilson Jr. Foundation



Appendix B: Caregiving in the Time of Covid-19 Survey

Greetings caregiver!

You may have never considered yourself a “caregiver.” But, you are a caregiver if at any time in the last 12 months you have provided unpaid care to a relative or friend to help them take care of themselves (e.g. helping with personal needs or household chores, managing finances, arranging for outside services, or visiting regularly to see how they are doing). You are a caregiver. And you are important to us.

Here at the Rosalynn Carter Institute for Caregiving we know your time is precious and we appreciate you spending part of that time to share your thoughts with us. The purpose of this survey is to learn from your recent experience (and the experiences of others) so that we can become better advocates for caregivers and improve our programs. This survey should take only 15-20 minutes to complete. It is completely confidential. We will not share your individual responses or anything that would identify you with anyone. At the end of the survey, you’ll be given an opportunity to share your name and mailing address with us ONLY if you want to receive a special thank you gift from us (entirely optional) or if you’d like to see a summary of what other caregivers are saying in response to this survey. In any event, upon completion of the survey you’ll be directed to information about caregiving during the COVID-19 pandemic.

Tell us about yourself

1. Your age
 - Under 30
 - 30-39
 - 40-49
 - 50-59
 - 60 or older
 - Rather not say
2. Your gender
 - Male
 - Female
 - Not listed: _____
 - Rather not say
3. Your ethnicity
 - White
 - Black/African American
 - Hispanic/Latin
 - American Indian or Alaska Native
 - Asian American
 - Native Hawaiian/Other Pacific Islander
 - Multiracial
 - Other (please specify):
 - Rather not say
4. Zip code: _____
5. Your household income?
 - Under \$30,000/year



- \$30,001 - \$60,000/year
 - \$60,001 - \$90,000/year
 - Over \$90,000/year
 - Rather not say
6. Are you employed?
- Yes, I'm working full time away from home
 - Yes, I'm working part time away from home
 - Yes, I'm working remotely (in my home) full time
 - Yes, I'm working remotely (in my home) part time
 - No, I've been laid off and I'm collecting unemployment benefits
 - No, I'm unemployed and don't have access to unemployment benefits
 - Other (please specify): _____
7. How many people live in your household?
- Children (under 18 years): ____
 - Adults (18 years or older): ____
8. How many children and adults are you caring for?
- Children (under 18 years): ____
 - Adults (18 years or older): ____
9. Are you covered by health insurance?
- Medicare
 - Medicaid
 - Insurance through work
 - Obama-care/exchange
 - Other military/government coverage
 - Other coverage not listed above
 - No/not insured
10. Have you tested positive for COVID 19?
- Yes
 - No
11. Has anyone else in your household tested positive for COVID 19?
- Yes
 - No
12. Have you experienced COVID-like symptoms (whether you've been tested or not)?
- Yes
 - No
13. Has anyone in your household experienced COVID-like symptoms (whether you've been tested or not)?
- Yes
 - No
14. How has your stress level changed since the outbreak of COVID 19?
- More stressful
 - Less stressful
 - About the same
15. If you indicated that your situation is "more stressful," what has been the source of your stress?
(select all that apply)



- Loss of support for the person you are caring for (e.g. paid caregiver or in-home health worker)
 - Increase responsibility due to isolation or increased health risks
 - Multiple caregiving responsibilities (e.g. caring for home-bound children)
 - Increase in job responsibilities (e.g. essential worker)
 - Employment and/or Financial concerns/instability
 - Delayed access to medical treatment for yourself and/or a family member
 - Testing positive for COVID-19 or having COVID-like symptoms
 - Caring for someone else who has tested positive for COVID-19 or who has COVID-like symptoms
 - Worrying about you or a family member becoming infected with COVID-19
 - Other (please specify): _____
16. If you indicated that “financial concerns/instability” were a source of stress, how has your situations changed?
- Lost income/wages due to a layoff/furlough for myself
 - Lost income/wages due to a layoff/furlough for another wage earner in my household
 - Lost income due to a temporary closing or slowdown of my business
 - Increased expenses related to healthcare
 - Other (please specify): _____
17. If you indicated that delayed medical care for yourself or a family member has been a source of stress, what type of care have you (or your family member) postponed/delayed:
- Dental care
 - Regular doctor visits
 - Treatment for specific conditions (e.g. diabetes or cancer treatments)
 - Previously scheduled surgery
 - Other (please specify): _____
18. What is the biggest change over the past 2 months for you PERSONALLY related to your role as a caregiver? (open ended)

Tell us about your relationship with the person you are caring for

1. Which of the following best describes your relationship?
 - I am the primary caregiver
 - I am the secondary caregiver/I assist regularly when the main caregiver needs me
 - I serve as the primary caregiver sometimes and as a secondary caregiver at other times
 - I am an occasional caregiver
 - Other (please specify: _____)
2. How are you and the person you care for related?
 - grandparent
 - parent
 - child (under 18 years old)
 - child (18 years or older)
 - spouse
 - partner



- friend
 - other (please specify: _____)
3. How long have you been a caregiver?
- 0-3 months
 - 4-12 months
 - 1-2 years
 - Over 2 years
4. Do you live with the person(s) you are caring for?
- Yes
 - No
5. If you do not live with the person you are caring for, has transportation been an issue for you?
- Yes
 - No
6. Are you (or have you been) providing care for someone who has COVID 19?
- Yes
 - No
7. How has your time with the person you care for *changed* since the outbreak of COVID 19
- a. Frequency
 - More frequent visits
 - less frequent visits
 - about the same frequency of contact
 - b. Use of the Internet for caregiving/support
 - More online connection time (e.g. Facetime, Skype, Zoom) with the person you are caring for
 - less online connection time
 - about the same
 - c. Personal connection with the person you are caring for
 - Feeling more connected
 - feeling less connected
 - about the same
 - d. Stress associated with your caregiving role
 - More stressful
 - less stressful
 - about the same
 - e. Number of other caregivers available to help
 - More caregivers helping now
 - Fewer caregivers helping now
 - About the same
8. Has the person you are caring for been removed from a care facility due to safety concerns?
- Yes
 - No
9. What has been the biggest or most challenging change IN YOUR RELATIONSHIP with the person you are caring for? (open ended)



Tell us about how you are getting support for you and the person you are caring for

1. Where do you get information about COVID-19 and taking care of others?
 - CDC or other government source
 - Internet
 - Television
 - Radio
 - Family/friends
 - Faith community
 - Other (please specify): _____
2. Is there information about COVID-19 that you need but can't get?
 - Yes
 - No
3. If you answered yes, what additional information do you need? (open-ended)
 -
4. Do you have access to the Internet?
 - Yes
 - No
5. If you answered yes, how comfortable are you in accessing support for yourself online?
 - Very comfortable
 - Somewhat comfortable
 - Not very comfortable
 - Not comfortable at all
6. Before COVID, I received the following support for my caregiving responsibilities:
 - Adult respite/day care
 - Coaching or counseling for you
 - Delivered food
 - Delivered medicine
 - Family/friend/neighbor assistance
 - In home nursing care
 - In home health aid
 - Support group
 - Telehealth (seeing a doctor or other health care professional online)
 - Transportation assistance
 - Other (please specify: _____)
7. Since the COVID 19 outbreak I have received:
 - Adult respite/day care
 - Coaching or counseling for you
 - Delivered food
 - Delivered medicine
 - Family/friend/neighbor assistance
 - In home nursing care
 - In home health aid



- Support group
- Telehealth (seeing a doctor or other health care professional online)
- Transportation assistance
- Other (please specify: _____)

8. What is the most helpful service(s) you have received since the COVID 19 outbreak:
_____ (open-ended)

9. What service(s) have you not yet received but which would make a big difference in the quality of your life in the coming months? _____ (open-ended)

10. Is there anything else you would like to share? _____(open-ended)

11. Please provide us with your contact information ONLY IF you would like to receive a free copy of either a summary of the results of our survey or our special guide for caregivers, *Dealing with Dementia*.

- Send me the survey results summary
- Send me the Dealing with Dementia guide

Name: _____

Mailing Address: _____ City: _____ State: ____ Zip: _____

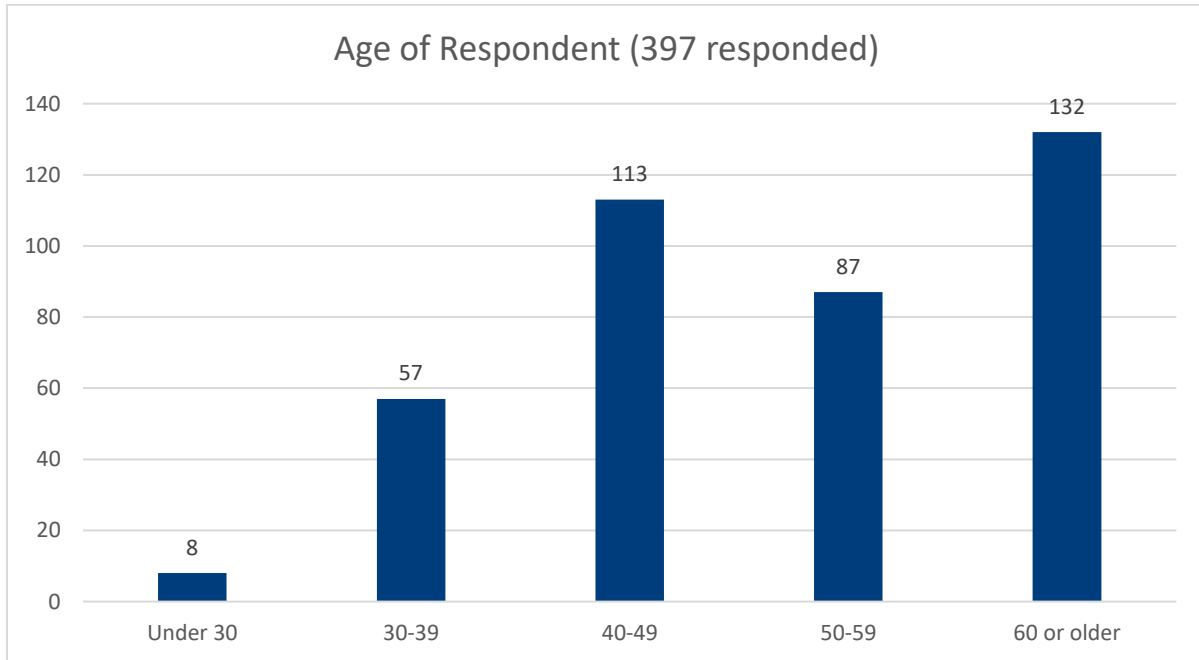
Thank you for taking the time to share your thoughts with us. Click the button below to submit your responses.

[INSERT HYPERLINK HERE TO CLOSE SURVEY AND CONNECT TO COVID-19 PAGE ON THE RCI WEBSITE]

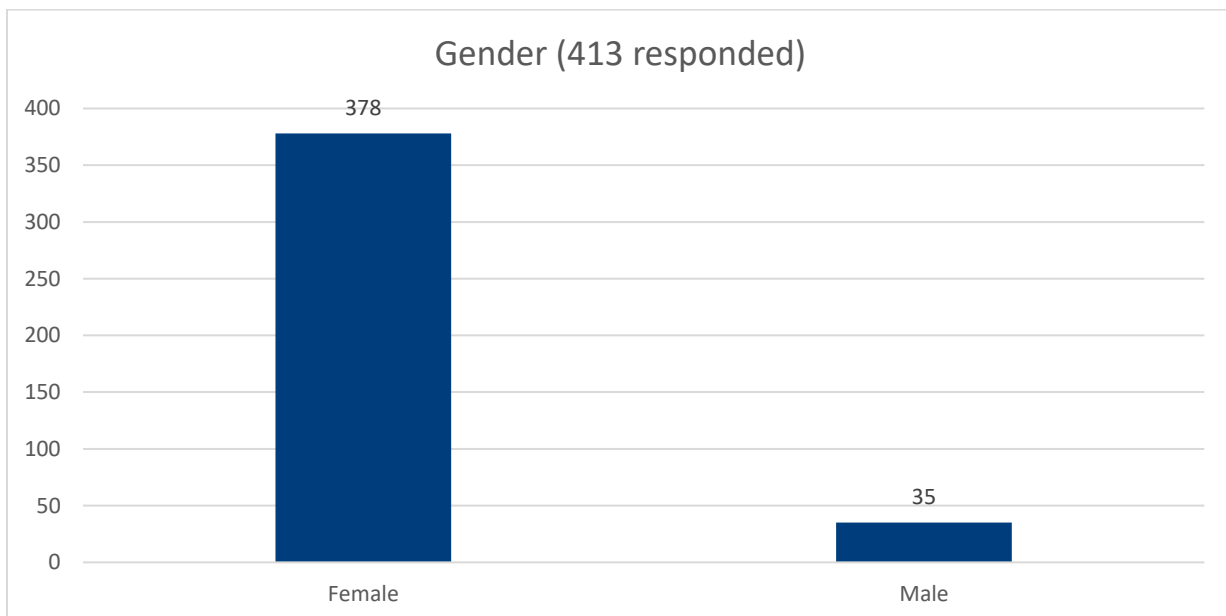


Appendix C: Demographic Profile of the Respondents

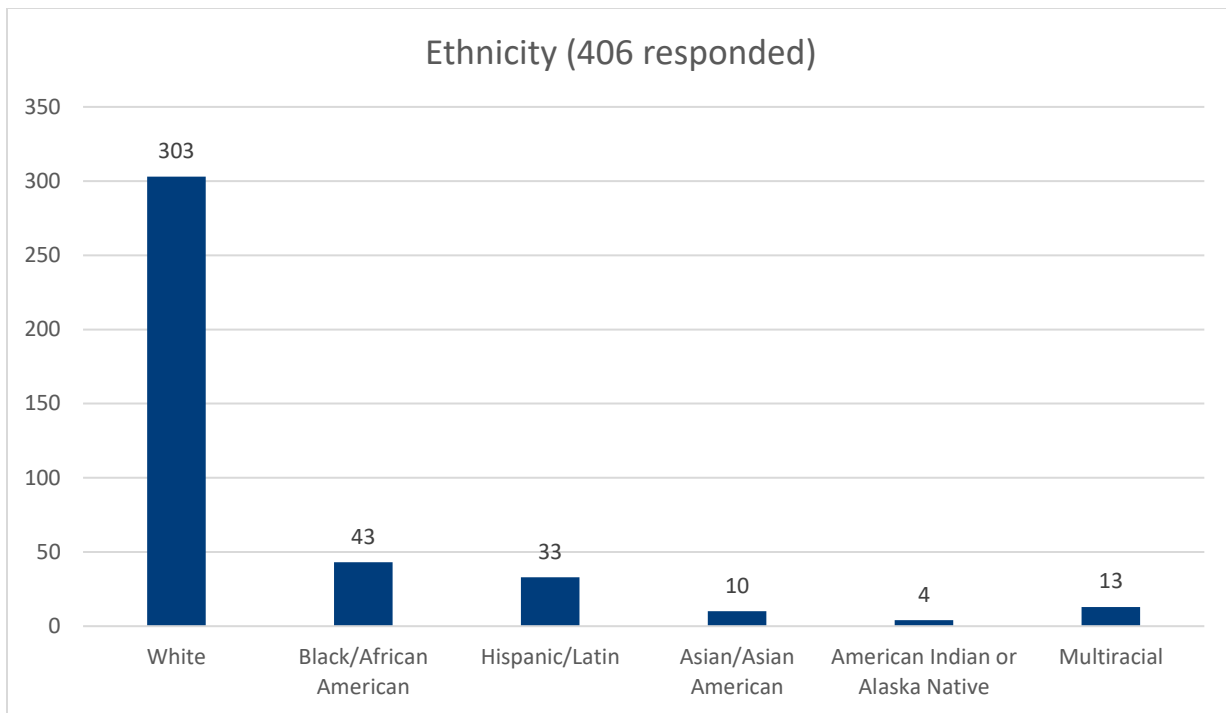
The first section of the survey asked a series of demographic questions. Responses to these questions are summarized below:



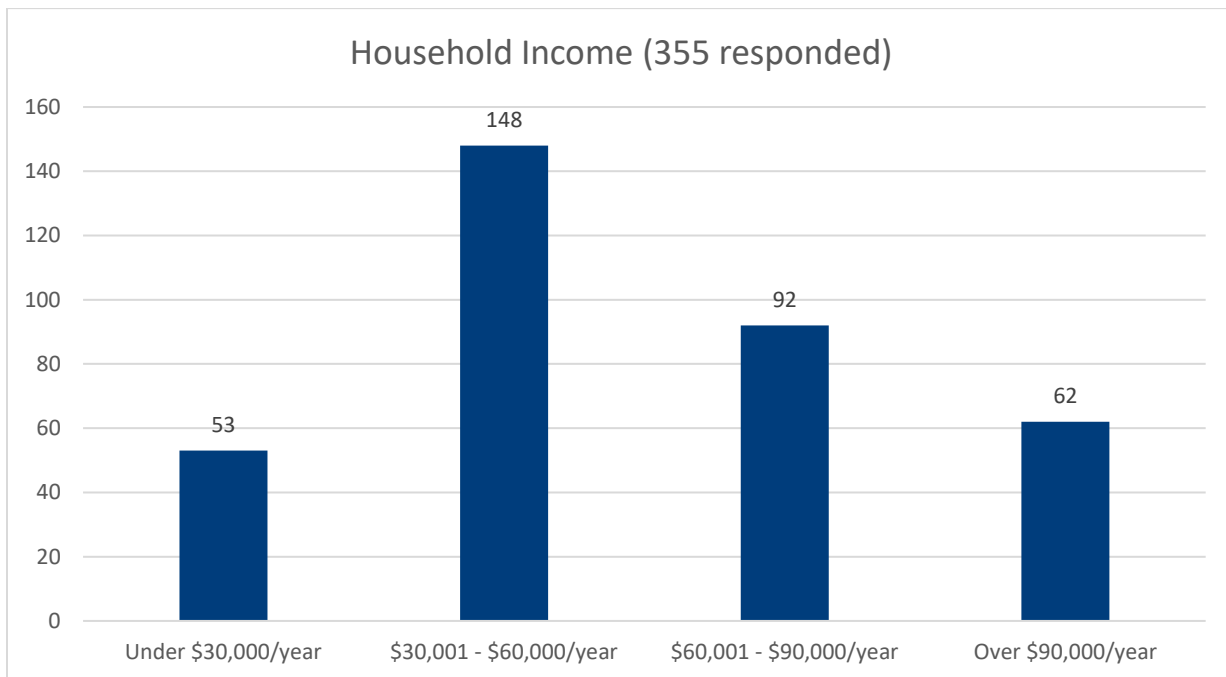
As shown above, the age distribution of survey respondents was bimodal with a majority of those providing their age being between 40 and 49 years old or 60 or older.



Over 90% of the survey respondents were female.



75% of survey respondents who shared their ethnicity were white.



Over 40% of survey respondents who shared their household income, reported income between \$30,001 and \$60,000.

Households of the Respondents



Children Under 18 in the Household. Sixty percent of 415 respondents reported having no children under the age of 18 in their households. The distribution of responses for those who indicated they have children under 18 living in their homes was:

Number of children under 18	Number of responses
1	70
2	50
3	27
4	11
5	2
6	1
7	1
9	1

Adults (18 years of older) in the Household. Fifty-six percent of 385 respondents reported having two adults living in their households. The distribution of responses for those who responded to this question was:

Number of adults (18 years or older)	Number of responses
1	56
2	216
3	84
4	13
5	9
6	3
7	1
10	1
20	1
32	1

Number of Adults Cared For. Over 75% of the 364 respondents who are currently providing care reported caring for one person. The distribution of responses from those who responded to this question was:

Number of adults (18 or older) Cared for	Number of responses
1	279
2	67
3	11
4	5
5	1
6	1
7	1



Tested positive for COVID-19 or Experienced COVID-like symptoms. Only three of 421 respondents reported testing positive for COVID-19. Sixty-six of 418 respondents (16%) said they had experienced COVID-like symptoms.

Twelve of 418 respondents indicated that someone in their household had tested positive for COVID-19. Sixty-two of 417 respondents (15%) reported that someone in their household had experienced symptoms of COVID-19.

When asked if the caregiver was (or had been) providing care for someone who has COVID-19, only 6 (1.4%) said “Yes”.