



## EXECUTIVE SUMMARY

*Maintaining Physical and Mental Well-Being  
of Older Adults and Their Caregivers During  
Public Health Emergencies*



# Introduction

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Coronavirus disease 2019 (COVID-19) is a public health emergency (PHE) that disproportionately impacts older adults and their unpaid caregivers. A 2020 study was completed on behalf of the National Foundation of the Centers for Disease Control and Prevention (CDC Foundation) with technical assistance from CDC to identify the needs and concerns of older adults (ages 50+) and unpaid caregivers in the U.S. during the COVID-19 pandemic. The findings are critical for understanding the resources and social supports they need for their health and well-being, and to help them better cope now, and during public health crises in the future.



## What's Known about COVID-19 and Older Adults and Caregivers

The risk for serious illness and death related to COVID-19 increases with age, with the highest risk among adults ages 85 and older.<sup>1,2</sup> Measures to prevent transmission of the virus, such as social distancing and stay-at-home orders, have had unfortunate side effects, including social isolation and limited access to basic necessities.<sup>3,4</sup>

Informal or unpaid caregivers of older adults have assumed increased responsibilities due to COVID-19. The number of unpaid caregivers has increased during the pandemic, with many providing care for the first time. Caregivers are family or friends who assist with an older adult's social or health needs, including but not limited to bathing and dressing, paying bills, shopping, and providing transportation. Caregivers often neglect their own health and well-being.

This study focused on understanding the needs of older adults and caregivers and the interventions available to support them, with a special focus on subpopulations disproportionately impacted by COVID-19, including racial and ethnic minorities, individuals with disabilities, rural populations, tribal populations, populations with limited English proficiency, and socioeconomically disadvantaged populations. The following report describes findings from the study.

# The Findings

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## Older Adults' Needs and Concerns during COVID-19



**I live alone...There have been two (COVID-19) cases in my apartment complex. I don't get out of my apartment except after 10 at night to get my mail or between 5 and 7 in the morning. Otherwise, I'm here. That's hard for me... I've had additional health issues that I haven't been able to handle because I don't want to go out there."**

*—Participant in a focus group with older adults with disabilities*

**Social isolation:** Older adults reported feeling more socially isolated and lonely due to the public health recommendations in place to combat spread of COVID-19. Nearly half (44 percent) of older adults reported feeling less socially connected, and more than one quarter (26 percent) of older adults said they were more lonely or sad since the start of COVID-19.

**Contracting and transmitting COVID-19:** About two thirds (67 percent) of older adults believed they were at high risk for developing serious illness from COVID-19. Those who said they were high risk due to their age and medical conditions were more likely to report feeling stressed or lonely. Older adults also reported anxiety about transmitting COVID-19 to loved ones.

**Access to and use of technology:** To reduce the spread of COVID-19, many activities became virtual. Nearly half of stakeholder organizations surveyed said that older adults need help with technology. Stakeholders also reported that lack of access to internet or technology created barriers to virtual engagement for some older adults. Older adults described challenges using technology to access health care services during COVID-19 and reported needing support from others to use technology.

**Obtaining household supplies and necessities:** Nearly half (49 percent) of older adults reported that, since the start of the pandemic, it was harder to get basic household supplies such as cleaning products (Figure 1). Almost one third of older adults were concerned about accessing necessities such as health care services and getting the food they wanted.

**Negative financial impacts:** Older adults reported that they or their household members experienced negative impacts due to the pandemic, such as reduced hours at work, unemployment, reduced wages or salary, lay-offs, overall financial difficulties, and loss of health insurance.

## Types of Assistance Received by Older Adults during COVID-19

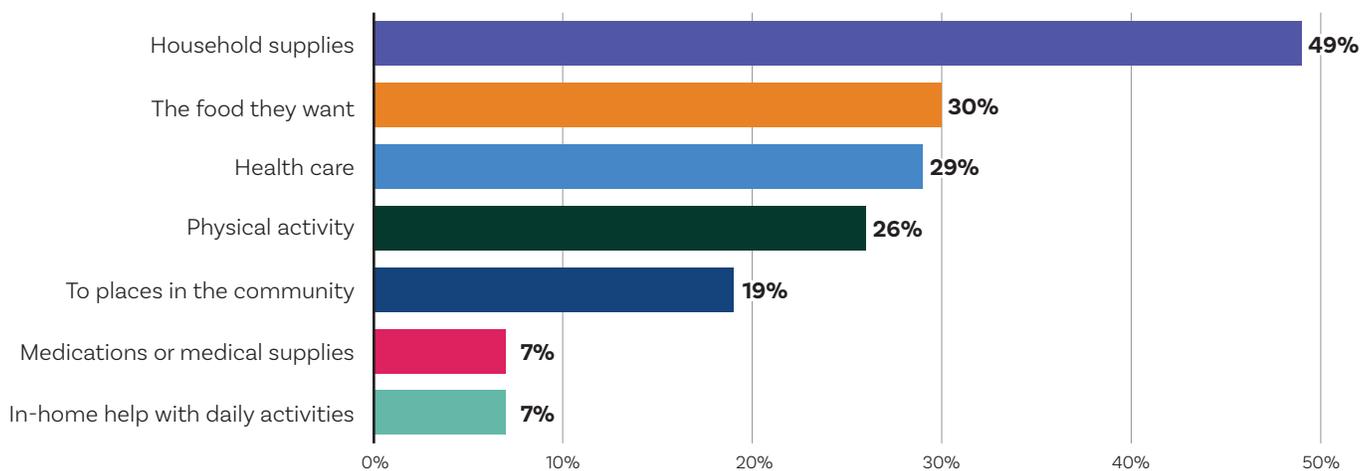
About half of older adults received assistance from family, friends, neighbors, or programs, most commonly check-ins, help with delivering groceries or basic supplies, and transportation. Older adults ages 75-84 were more likely to receive help from family, friends, or neighbors than those ages 50-74. Also more likely to receive help were older adults with disabilities (compared to those without disabilities), and Black and Hispanic older adults (compared to White older adults). Black and Hispanic older adults were more likely to receive assistance from health care providers or community programs than White older adults.

## Older Adults' Trusted Sources of Information during COVID-19

Nearly nine out of ten (89 percent) older adults reported getting information about COVID-19 from local and national news sources. Almost half (46 percent) relied on guidance from government officials or government websites, and four in ten (40 percent) reported using other webpages. Adults ages 50-64 were more likely than those ages 75-84 to rely on social media for information about COVID-19 (26 percent versus 16 percent). Older adults also relied on people they know, including health care providers, friends, and family members, for information about COVID-19.

**Figure 1.**

Since the Start of the Pandemic, Older Adults (Ages 50+) Report It Is Harder to Get...



Source: NORC AmeriSpeak Omnibus Survey of Older Adults in the U.S., October 2020.



**I find being a caregiver...a lot of times people want to focus on the person in need and a lot of attention goes to the person in need, but there's an insane amount of stress placed on the person who's the support. It's like you're invisible. You don't exist. You're a bookcase holding everything up... You're the tree. If someone's chopping at the roots, you need to take care of yourself first."**

*—Participant in a caregiver focus group*

## Caregivers' Needs and Concerns during COVID-19

**Their own physical and mental health:** Caregivers delayed doctor's appointments and routine health care and reported a decline in their social activity and interaction with others. Caregivers also described the negative impact of COVID-19 on their mental health, including increased fear, anxiety, frustration, and depression.

**Physical and mental health of the person in their care:** More than four in 10 (44 percent) caregivers of older adults were extremely or very concerned with the older adult they cared for becoming infected with COVID-19, compared to only 28 percent who were extremely or very concerned with the risk for themselves. Caregivers also worried about the mental health of the older adult in their care.

**Respite care:** With increased responsibilities during COVID-19, caregivers expressed the need for respite care to give them temporary relief. Caregivers described the challenges of balancing work and caregiver duties. These issues were amplified among caregivers of people with disabilities, cognitive impairment, or limited English proficiency.

**Financial insecurity:** Prior to COVID-19, in 2018, nearly 80 percent of caregivers were paying for caregiving expenses out-of-pocket, with one quarter reducing their retirement savings to pay for such expenses. During COVID-19, caregivers shared similar concerns and experienced financial insecurity due to a loss of employment or other economic consequences of the pandemic. Caregivers also faced challenges balancing work and caregiving responsibilities, which jeopardized their employment.

## Types of Assistance Offered to Caregivers during COVID-19

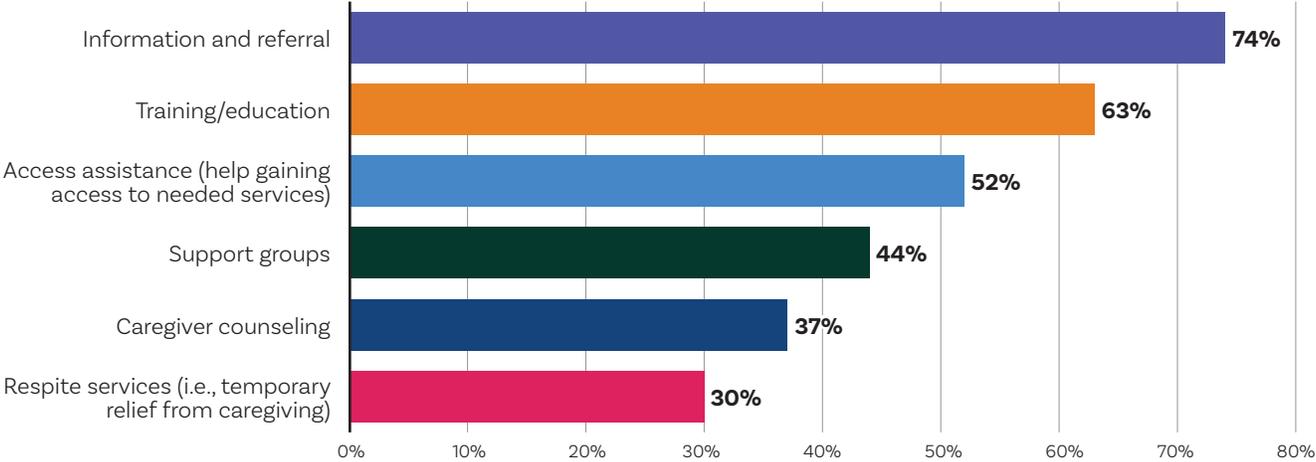
The most common types of assistance that organizations serving caregivers provided during the COVID-19 pandemic were information and referral services (74 percent), followed by education and training assistance (63 percent), and help with gaining access to needed services (52 percent). Caregivers' informational needs reflected gaps in the knowledge and training necessary to perform their caregiving responsibilities, particularly among caregivers of older adults with memory loss or cognitive decline. Most unpaid caregivers said they learned how to provide care on the job and felt undertrained.



## Caregivers' Trusted Sources of Information during COVID-19

Similar to older adults, unpaid caregivers relied on the internet as a key source of information during COVID-19. They searched Google, WebMD, and hospital websites to get information about COVID-19. Caregivers also used social media to share resources and connect with other people who had similar experiences, as well as online communities that provided a forum for support and sharing advice with other caregivers. They also relied on information from friends or family and national organizations. Caregivers also consulted health care providers for information during COVID-19, including providers serving the person they cared for.

**Figure 2.** Types of Interventions or Services Offered by Organizations Serving Caregivers during COVID-19



Source: CDC Foundation Stakeholder Organization Survey, October 2020.

# Public Health Interventions to Support Older Adults and Caregivers

The environmental scan identified over 300 public health interventions available to serve older adults and caregivers during PHEs such as COVID-19. The most common interventions and strategies were programs and resources focused on:

- ▶ Providing education using materials, campaigns, or media
- ▶ Direct services, such as support groups, counseling, and social services
- ▶ Health care, including telehealth
- ▶ Policy and system change at the local, state, and national level

Most interventions developed in response to the pandemic were educational resources available online. These included blogs, toolkits, checklists, infographics, tip sheets, publications, and contact information for organizations that can help. National, state, and local agencies, organizations, and advocates dedicated to promoting the health and well-being of older adults and caregivers developed the majority of interventions. The target audiences for interventions were broad and diverse, including older adults, caregivers, community-based organizations, health care providers, and others. Most interventions were targeted directly at older adults or caregivers and, to a lesser extent, advocates and direct service providers.

Telehealth and other digital health technology use has increased during the COVID-19 pandemic, and many interventions have adjusted components of their interventions to be virtual. These formats were particularly promising for reaching older adults and caregivers in rural areas. However, few interventions targeted older adult subpopulations, such as racial and ethnic groups and individuals with disabilities, despite findings that suggest subpopulations faced unique challenges during the PHE and may benefit from targeted interventions. Most interventions that focused on specific subpopulations were developed to support caregiving and management of chronic conditions, and to a lesser extent, for addressing topics such as social isolation. The scan did not reveal interventions to address the deferral of medical care and elder abuse among specific subpopulations of older adults, suggesting needs in these areas.

The evidence base for COVID-19 interventions for older adults and unpaid caregivers is emerging. Nearly all newly launched efforts and adaptations to existing interventions were evidence-informed or emerging in nature. Because of the recent and ongoing nature of the COVID-19 pandemic in the United States, the majority of interventions have yet to be fully evaluated.



Deconditioning



Social Isolation



Deferral of Medical Care



Management of Chronic Conditions



Elder Abuse and Neglect



Unpaid Caregivers



## Conclusion

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The COVID-19 pandemic is an unprecedented PHE that has severely impacted older adults and unpaid caregivers in the United States. This study offers important insights about the pandemic's effect on these populations. Specifically, it describes the major needs and concerns of older adults and caregivers during PHEs such as COVID-19, and the range of public health strategies and interventions available to support their physical and mental well-being.

It is clear that while there are many interventions, strategies, and resources available to support older adults and caregivers, many people are unaware of these resources. There is an urgent need to raise awareness about existing support. The public health interventions and strategies that have been developed in response to the COVID-19 pandemic rely heavily on internet use and broadband access, but access to these resources may be limited due to technology barriers. Interventions to address technology access, cost, and literacy are needed. Additionally, interventions tailored to address the specific needs and concerns of older adult subpopulations are needed. For caregivers, respite care is vital, and with the increase of unpaid caregivers, it will be important to increase this support.

# Methods

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**Research activities occurred in October 2020 and took place in both English and Spanish. A description of the methods for each activity follows.**

## AmeriSpeak Omnibus survey

A nationally representative online survey was fielded to learn about older adults' needs and concerns during COVID-19. The survey was administered in English and fielded in two waves to 1,030 total respondents in October 2020 (response rate: 32.6 percent; margin of error: 4.09 percentage points).

## Focus groups

Four online focus groups were conducted with a total of 21 older adults (three groups in English, one in Spanish) and four with a total of 22 unpaid caregivers (three groups in English, one in Spanish) about their needs and concerns during COVID-19.

## Social data listening

Observational data from publicly posted content on social media sites including Twitter, Reddit, Facebook, Instagram, and YouTube was analyzed to understand how older adults, caregivers, and the stakeholder organizations that serve them described needs and concerns during COVID-19.

## Secondary analysis of caregiver surveys

Secondary data analysis of U.S. caregiver surveys was conducted to study the needs, concerns, and support systems of unpaid caregivers of older adults before and during COVID-19.

## Stakeholder organization survey and interviews

A survey and interviews with national, state, and local stakeholder organizations were conducted to study the needs and concerns of older adults and caregivers through the lens of organizations that serve them. The survey was sent to 101 organizations between October 8 and 26, 2020 (response rate: 37 percent). Virtual interviews were conducted with 27 organizations.

## Environmental scan

A targeted search was conducted to identify interventions, policies, programs, and strategies to support the physical and mental well-being of community-dwelling older adults and unpaid caregivers during PHEs. Areas of focus included 1) deconditioning (decrease of physiological adaptation to normal conditions); 2) social isolation; 3) deferral of medical care; 4) management of chronic conditions; and 5) elder abuse and neglect. The search included peer-reviewed and grey literature from 2017 through the present.

## About the Team

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**NORC at the University of Chicago** is an objective, nonpartisan research institution that delivers reliable data and rigorous analysis to guide critical programmatic, business, and policy decisions. NORC's health communication group includes experts in digital strategy and outreach, social media data analysis, and audience research and evaluation.

**Burness** is a mission-driven organization with the ability, along with its partners, to influence social change. Veteran communications, media, and policy experts work with digital strategists, designers, writers, and producers to create and execute communication strategies that move issues and elevate organizations.

**TMNcorp** is a minority- and woman-owned full-service communications and marketing company that combines a broad range of media, research, and strategic management expertise not ordinarily found in a single firm. TMN's strength lies in personal and professional diversity, commitment, and desire to make a difference.

*This report is part of a CDC Foundation project, utilizing donor funds from the flexible COVID-19 Response Fund.*

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