

Article

The Positive and Negatives of Caregiving for Older Adults During Coronavirus Disease 2019: Identifying Opportunities for Advancing Social, Health, and Economic Policies

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Decades of research have documented the increasing reliance of health systems and older adults on caregivers (“unpaid family members or friends”; [The National Academies of Sciences, Engineering, and Medicine, 2016](#); [Rosalyann Carter Institute for Caregivers, 2020](#)). Indeed, caregivers often assume responsibilities such as managing medical devices and medications, shopping for groceries, offering emotional support, and making decisions about care options. While assuming more responsibilities, caregivers often report a lack of support and resources ([Naylor & Keating, 2008](#); [Rouch et al., 2021](#)). As a result, caregivers may experience social, health, and economic consequences ([AARP & National Alliance for Caregiving, 2020](#)). These poor outcomes have led to a wide range of policies and recommendations to support caregivers.

Specific to the United States, the National Family Caregiver Support Program was established in 2000 as part of the reauthorization of the Older Americans Act ([Bangerter et al., 2019](#); [US Government Publishing Office, 2016](#)). The National Family Caregiver Support Program funds a range of supports that assist caregivers supporting dependent older adults. Most recently, the Recognize, Assist, Support, and Engage Family Caregivers Act was

mandated to improve federal programs ([Reyes et al., 2021](#); [US Government Publishing Office, 2018](#)). Here, the Department of Health and Human Services has identified a National Family Caregiving Strategy that emphasizes person- and family-centered care, assessment and service planning, information and training supports, and respite and financial security options. Globally, the International Alliance of Carer Organizations has increased recognition of caregiving as “one of the most important social and economic policy issues” and set a global strategy and action plan to “encourage the development of caregiver-friendly policies and ensure inclusion of caregivers’ experiences and voices in health and social policy planning” ([International Alliance of Carer Organizations, 2021](#), p. 2). These policies and recommendations illustrate the growing value of caregivers to health systems and older adults worldwide.

However, whether caregivers felt fully supported as a result of these and other advances in caregiving policies and recommendations during the COVID-19 pandemic is less documented and understood. This is problematic because many older adults have been forced to rely on caregivers for physical, social, emotional, and financial support due to lockdown measures, including stay-at-home orders, travel

bans, closures of support programs, and restrictions of social gatherings (FT Visual & Data Journalism Team, 2022; Haug et al., 2020). Therefore, this paper identifies opportunities for advancing social, health, and economic policies by synthesizing findings from a scoping review (Fields, 2021) on the positive and negative aspects of caregiving for older adults during the COVID-19 pandemic.

We conducted a comprehensive search that included peer-reviewed studies primarily focused on caregiving for older adults 65 years or older during the COVID-19 pandemic. Of the 40 studies we identified, 19 collected data during the lockdown period at the beginning of the COVID-19 pandemic; 9 studies were conducted during the summer of 2020, when restrictions were being lifted or decreased and businesses and social opportunities were once again open. The remaining studies were conducted between the reopening phase and the time when vaccines were widely available in the United States. These studies reported caregiver perceptions from around the world: 9 studies were with caregivers from North America, 23 from Europe, 4 in Asia, 1 in the Middle East, 1 in South America, 1 in Australia, and 1 from an unspecified location. We recognize that caregivers' experiences in different locations during the same time may have been drastically different based on virus impacts at various global areas, as well as local restrictions. Care recipients in 33 of the included studies had a diagnosis of some type of dementia or neurocognitive disorder, 3 included other diagnoses (end-stage renal disease, stroke, cardiovascular disease, arthritis), and 4 studies did not specify care recipient diagnoses. We also recognize that care recipient diagnoses can have an impact on caregiver experiences of burden and isolation, but we also recognize that some experiences are universally shared amongst caregivers regardless of care recipient diagnoses. For an in-depth summary of the included articles, please email the corresponding author. Below, we present our synthesized findings based on the positive and negative aspects of caregiving during the COVID-19 pandemic, as well as links to current policies and policy recommendations.

Positive Aspects of Caregiving

A small number of caregivers reported positive aspects of caregiving during the COVID-19 pandemic. The most reported positive aspect of caregiving during the pandemic involved the expansion of telehealth services. Caregivers reported increased communication and stronger relationships with health professionals through telehealth access. Many caregivers also reported a sense of connection and community during the pandemic. Some caregivers experienced strengthened bonds with care recipients and chose to view the pandemic as "quality time" they could share together. Caregivers described being able to increase connections with family and friends using technology and found additional levels of support through virtual support groups.

Negative Aspects of Caregiving

Most of the studies reported negative aspects of caregiving during the COVID-19 pandemic. A major challenge experienced by caregivers was the disruption of in-home care and support services. Many caregivers reported cancellations of in-home services and postponements of routine medical care. These disruptions resulted in increased feelings of being overwhelmed and caregivers questioning their ability to provide adequate care to care recipients. Caregivers felt unprepared for specific caregiving responsibilities that are usually provided by trained staff (e.g., assisting with medications, mobility, toileting). They also reported being unprepared for providing care within the context of a pandemic (e.g., keeping loved ones from contracting the virus), as well as increased reliance on technology (e.g., telehealth, online care tools) to provide this care. Some caregivers experienced increased worry about care recipient health, including concern that they would inadvertently pass COVID-19 on to the care recipient and uncertainty about the future. Caregivers also reported increased anxiety, depression, loneliness, and isolation.

Key Priority Areas for Caregiving Policy

Available evidence suggests that the effects of caregiving for older adults during and immediately following the lockdown period of the COVID-19 pandemic were overwhelmingly negative across the globe. The urgency for caregivers to assume more responsibilities with little support magnified previous calls to consider caregiving as a public health system in crisis. While most of the studies represent perspectives and contexts outside of the United States, caregiving has been described as a universal experience (Elder and Long Term Care, Payers of Health, 2016). Indeed, former First Lady Rosalynn Carter shared, "there are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver" (Rosalynn Carter Institute for Caregivers, 2020, p. 4). To mitigate this universal experience, social, health, and economic policy solutions need to be amplified. Specific to the United States, policymakers should use the information from this paper to further stimulate policy surrounding technology-based service delivery, caregiver training and well-being, and caregiver-centered care.

Technology-Based Service Delivery

Although telehealth technologies and online care tools existed prior to the beginning of the COVID-19 pandemic, never have they been more widely used. Whether contact with the care recipient's health-care team was made by telephone or via videoconferencing, caregivers reported both positive and negative feelings associated with increased reliance on technology for care delivery. Caregivers appreciated the increased communication and information

available through virtual appointments and being able to attend these appointments without having to drive. Telehealth technologies are agreed to be not only safer than in-person appointments, but also much more convenient (Quinn et al., 2018). However, there are barriers to widespread adoption of telehealth and online care tools. First, caregivers have reported difficulty with the learning curve of virtual technologies; nearly two-thirds of caregivers agree that additional guidance and training to use telehealth and online care tools is needed (International Alliance of Carer Organizations, 2022). Second, particularly among caregivers of older people living with dementia, a major barrier to participating in telehealth was the lack of previous internet access in the home. Previous research has found that one-third of caregivers were spending more money on technology after the COVID-19 pandemic began (International Alliance of Carer Organizations, 2022).

Despite the increase in costs to caregivers, the widespread adoption of telehealth and online care tools may be a silver lining. Based on this scoping review, caregivers clearly preferred having virtual options for accessing their family member's or friend's health appointments. Though the barriers to widespread adoption may seem daunting, simple improvements to existing systems can improve the convenience of caregiving. Caregivers should be provided support and training on how to effectively access and use telehealth and online tools (Quinn et al., 2018). Second, particularly in underserved communities, caregivers should have access to high-speed internet and technology to access care remotely. There is already work underway, with funding from the American Rescue Plan Act, to increase access to technology through broadband infrastructure improvement projects (Read & Wert, 2021). While states have prioritized using the funding to increase access to broadband internet, the same momentum for support and training on how to access and use virtual technologies is less evident. Advocacy is needed to promote support and training, in addition to infrastructure, as viable ways to manage health and decrease disparities in internet access.

Caregiver Training and Well-Being

Before the pandemic, caregiving was associated with higher health risks. Unfortunately, this scoping review and other work (Cornish, 2021) has revealed that the struggle has only gotten worse since COVID-19. This exacerbation has exemplified the continued need to improve and expand effective policies that address caregiver training and well-being. Though the availability of caregiver programs varies by state, state Medicaid waivers, such as 1115 and 1915(c) waivers, can be used to support caregivers in multiple ways (Center for Health and Research Transformation, 2021). For example, states have the authority to expand definitions of who qualifies as an unpaid caregiver and increase coverage of respite care, as well as provide education and training opportunities, under Medicaid waivers. While some caregivers in the included articles found additional

levels of support through virtual support groups, many still reported increased anxiety, depression, loneliness, and isolation because of caregiving during the pandemic. Given these unfavorable outcomes, states should consider expanding their home- and community-based service options. This is especially important given that most states have long waiting lists for home- and community-based service (Ralls, 2021) and many caregivers lack access to adequate and sustainable respite options (Litzelman, 2019; Winslow, 2003). Federal programs should also consider expanding definitions and increasing resources. For example, the Family and Medical Leave Act is restrictive regarding who is eligible to receive up to 12 weeks of unpaid, job-protected leave. Because family size continues to decline as divorce and childlessness rates increase (AARP & National Alliance for Caregiving, 2020), older adults will be inclined to widen their caregiving relationships. This shift will require policymakers to advocate for more inclusive caregiving policies.

To further assist the growing number of caregivers providing care in the United States, tax breaks, as well as a national paid family leave and medical leave program, are desperately needed. Caregivers can “claim a portion of up to \$8,000 in caregiving costs for one person and up to \$16,000 for two or more” via the Child and Dependent Care Credit (AARP, 2022, p. 1). However, only caregivers that live (for at least 6 months) with a dependent older adult receiving support from a home health worker or day program can claim the tax credit. On top of that, the United States is one of the last few countries that has yet to mandate paid and medical leave (Miller, 2021). Considering the negative aspects of caregiving during the pandemic that were illustrated through the scoping review, reforms for tax credits and paid leave options under the Family and Medical Leave Act and other state programs would further support caregivers in providing time to determine care needs, participate in education and training, and adequately plan for sustainable care. These reforms are essential in meeting the ongoing demands of caregivers and supporting their overall well-being.

Caregiver-Centered Care

While many system and organizational policies and recommendations have championed the concept of person- and family-centered care (Institute for Patient and Family-Centered Care, n.d.; Marshall, 2021; The National Academies of Sciences, Engineering, and Medicine, 2016), findings from this scoping review illustrate the need to draw more attention to the caregiver. Indeed, very few studies found an increased sense of partnership or improved relations among health-care professionals, older adults, and caregivers. The lack of person- and family-centered care may be associated with the poor health outcomes that so many caregivers reported experiencing during COVID-19. To better identify, assess, and train caregivers, health-care system administrators should consider developing and

implementing culturally tailored, caregiver-centered care policies. Caregiver-centered care is “person-centered care for family caregivers. This approach respects and meaningfully involves the care receiver’s family caregiver in the planning and delivery of supportive services” (Parmar, n.d., p. 1). It also acknowledges and addresses caregiver needs, values, preferences, and cultural contexts and seeks to integrate family caregivers as active partners in care.

Before a caregiver-centered care approach can be thoroughly executed, changes in the way systems and organizations use and share access to patient information via portals (e.g., electronic medical records [EMRs]) are needed (Latulipe et al., 2020). Indeed, many systems and organizations believe that EMRs are not worth the cost of implementing, yet, at the same time, they choose to hire and pay for specific positions (e.g., medical scribes) that maintain the biomedical model and serve to maximize profits. By using EMRs, systems and organizations could help reduce medical errors that care receivers and caregivers too frequently experience and improve care coordination and communication through standardized forms (O’Neill Hayes, 2015). Additionally, DesRoches et al. (2020) suggested several transformations for sharing patient information: namely, EMR vendors should simplify procedures for granting proxy access, health-care systems should provide older adults and caregivers with training on how to use patient portals, and Congress should modernize the Health Insurance Portability and Accountability Act to grant caregivers a special status under the Privacy Rule. To further align with a caregiver-centered care approach, vendors should also consider the caregiver needs, values, preferences, and cultural contexts when designing and revising EMR portals. Until these changes are realized, caregivers will continue to bear the brunt of the disruptions caused by the pandemic, seeing that “providers cannot be confident about whom they are communicating with, care partners [i.e., caregivers] may become privy to information a patient may not want to share, and health care organizations may be violating their patients’ right to privacy” (DesRoches et al., 2020, p. 850).

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Supporting caregivers through advances in social, health, and economic policies around technology-based service delivery, caregiver training and well-being, and caregiver-centered care will likely relieve this public health crisis.

Conclusion

Organizations and health systems across the globe have strong incentives—rising negative aspects of caregiving—to support caregivers of older adults. There is clear evidence that caregivers did not feel fully supported by existing policies and recommendations during and immediately following the lockdown period of the COVID-19 pandemic. Supporting caregivers through advances in social, health, and economic policies around technology-based service delivery, caregiver training and well-being, and caregiver-centered care will likely relieve this public health crisis.

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Conflict of Interest

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