

Research In Focus: A Weekly Digest of New Research from the NIDILRR Community

Caregivers of People with Chronic Illness and Disability Reported Increased Health Care Roles During the Pandemic

A study funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

A chronic illness is a disease or condition that usually lasts over three months and may worsen over time. A disability is a physical or mental condition that may limit a person's mobility, senses, or activities. People with disabilities and chronic conditions may have support from a caregiver, often someone in their family or a close friend who may live with them, to help them meet their daily needs. Studies have shown that the ongoing COVID-19 pandemic has affected health access for many people, particularly those with chronic illnesses and disabilities. Pandemic safety measures resulted in the closure of health offices and the cancellation of services, and made it difficult for patients to receive necessary care. Therefore, during the pandemic, caregivers of people with chronic illness and disabilities may have seen their roles change and expand due to the pandemic restrictions.

In a recent NIDILRR funded study, researchers wanted to examine how the roles and activities of family caregivers caring for people with chronic illness and disability changed during the COVID-19 pandemic. Researchers wanted to know how caregivers' access to and use of health care for their care recipients with chronic illness and disability was affected during the pandemic.

Researchers at the [Center for Research, Training, and Dissemination of Family Support for People with Disabilities Across the Life Course](#) interviewed 610 caregivers between April and May 2020. These caregivers were registered in the University of Pittsburgh's University Center for Social and Urban Research (UCSUR) and self-identified as providing voluntary care to a family member, spouse/partner, or friend with a chronic illness or disability. The average age of caregivers was 59 years, 76% were women, and 56% of the caregivers lived with their care recipients.

During the interviews, caregivers were asked, "*Since the Covid-19 outbreak, how have you been helping your care recipient differently?*" For each of 10 items listed under this question, respondents could say whether they were helping more, less, or the same as prior to COVID-19. The ten items were: getting medical supplies, managing new medical problems or symptoms, helping care recipient attend phone or video medical appointments, contacting healthcare providers with questions, filling care recipient prescription medications, scheduling medical appointments, participating in care recipient's video medical appointments, helping care recipient complete medical tests, and participating in care recipient's in-person medical appointments.

When they looked at the results, the researchers found that, in general, caregivers had to take more active roles in supporting the health care of their care recipients during the pandemic than before. Specifically, the researchers found that:

- 59% of caregivers said they provided more help with one or more health care activities since the beginning of the pandemic.
- 30% of caregivers reported getting medical supplies during the pandemic more than before.
- 27% of caregivers said they did more managing of their care recipient's new medical problems or symptoms.
- 26% of caregivers reported providing more help to care recipients with attending virtual appointments.
- 21% of caregivers mentioned participating more in care recipient's phone appointments.
- 16% of caregivers said they directly participated more in care recipient's video appointments.
- 10% of caregivers said they attended more of their care recipient's in-person medical appointments; conversely, 11% of caregivers reported attending less of their care recipient's in-person medical appointments. This was the biggest decrease in caregiver roles since the pandemic.

According to the authors, the study's findings highlight the increased role of family caregivers in helping their care recipients stay engaged with health care during the pandemic. Caregivers, both those living with and apart from their care recipients, reported providing more assistance with tasks and being more involved with health care providers, including arranging and attending telehealth visits.

The authors noted that the caregivers in this study provided greater assistance and became more involved in the health care of their care recipients. During the pandemic, many appointments shifted to telehealth and, in many cases, caregivers reported that they were the ones arranging these appointments. Health care providers may want to identify those caregivers who are very involved in supporting their patients with chronic illnesses and disabilities and ensure that they have the information and resources they need to support their care recipient in adapting to changes in health care access. The authors suggested updating online patient portals, which store patients' health information, to serve as a platform where caregivers can make appointments, ask questions, and refill medications for their care recipient. Training and online support for caregivers on how to use the patient portals for their care recipient and how to make the most of telehealth visits may also be beneficial. The authors also suggested that health care providers should ask their patients if they had a caregiver and would like to share their health information and resources with them.

To Learn More:

The [Center for Research, Training, and Dissemination of Family Support for People with Disabilities Across the Life Course](#) conducts research and development to support people with disabilities, family caregivers, and health professionals. The center publishes research briefs, hosts [regularly scheduled webinars for family caregivers](#), and holds a [conference to share research](#).

The [National Center on Caregiving at the Family Caregiver Alliance](#) is a central source of information on caregiving and long-term care issues for policy makers, service providers, media, funders, and family caregivers throughout the country.

To Learn More About this Study:

Semere, W., Makaroun, L. K., Beach, S., Schillinger, D., & Rosland, A.-M. (2022, May 12). [Family Caregivers Navigating the Health Care System: Evolving Roles During the COVID-19 Pandemic](#). Families, Systems, & Health. Advance online publication. This article is available from the NARIC collection under Accession Number J89068.

Research In Focus is a publication of the National Rehabilitation Information Center (NARIC), a library and information center focusing on disability and rehabilitation research, with a special focus on the research funded by NIDILRR. NARIC provides information, referral, and document delivery on a wide range of disability and rehabilitation topics. To learn more about this study and the work of the greater NIDILRR grantee community, visit NARIC at www.naric.com or call 800/346-2742 to speak to an information specialist.

The contents of this publication were developed under a contract from the National Institute on Disability, Independent Living, and Rehabilitation Research (140D0421C0021). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this publication do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.