

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

People Aging with Spinal Cord Injuries and Their Caregivers Share Experiences with Aging

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

A spinal cord injury (SCI) is damage anywhere along the spinal cord from an accident or other trauma. As a result of advances in medical care, rehabilitation, and assistive technology, more people with SCI are living longer. People with SCI may experience health-related challenges that may become worse or more complex as they get older. They may benefit from using a variety of services and supports to optimize their quality of life as they age. In a recent NIDILRR-funded study, researchers interviewed older adults with SCI and family members caring for older adults with SCI. The researchers wanted to find out what health-related changes the individuals with SCI experienced as they got older, what health services they used, and what supports they received and challenges they encountered in their lives.

Researchers at the [Regional Spinal Cord Injury Center of the Delaware Valley](#) interviewed 41 people with SCI and 8 family caregivers. The participants with SCI were at least 60 years old and had experienced their SCI for at least 5 years before the study. All of the participants with SCI had received care through the Center. During the interviews, the participants with SCI were asked about their health and how it had changed in the last 5 years. They were also asked about medical services and therapies that they used, and about their participation in major life activities. The caregivers were asked about the services or assistive tools that they used to perform their caregiving, and about their family member's health during the last 5 years.

The researchers found that the responses of the participants with SCI and the caregivers fell into four general themes during the interviews:

1. **Health literacy:** The participants and caregivers described having different levels of knowledge about their health and how to manage their changing health needs. For example, some of the participants were unsure about what medications they should be taking or whether they should keep using rehabilitation services like occupational therapy. Some of the participants also described themselves as “problem solvers” who were able to identify a health or mobility challenge and find solutions on their own, whereas others reported being overwhelmed or having difficulty solving problems related to their SCI.
2. **Health services:** The participants and caregivers described challenges with accessing health services. For example, some of the participants had difficulty getting insurance coverage for multiple services that they needed, so they had to choose between therapies, or between a therapy and medications. Some of the participants and caregivers also described having difficulty working with healthcare providers who had limited knowledge of SCI.

3. Health changes with aging: Many of the participants and caregivers described recent changes to their health that were related to getting older, but some participants were unsure about what changes were due to aging in general versus aging with SCI. The most common changes included more frequent falls, skin problems, and having less energy. Participants described how changes in their health and mobility adversely affected their ability to participate in social and work activities.
4. Environment: The participants and caregivers described having to make changes to their homes in order to make them accessible after their injury and to maintain accessibility as they aged. These changes and renovations were often costly. The participants and caregivers also described how the need for caregiving affected their personal relationships: Some participants expressed concerns about becoming a burden while some caregivers were concerned about being able to fill multiple roles of aide, therapist, and spouse.

The authors noted that policy reforms may reduce challenges encountered by older adults with SCI and their caregivers. For example, the authors noted that Medicare will currently pay for either in-home health services or outpatient therapies, but not both. Some of the participants in this study described having a need for both types of services to address different health issues. Policymakers may wish to consider more flexible, customizable health plans to address the individual needs of people aging with SCI. In addition, the authors noted that improving health literacy may help empower people aging with SCI to optimize their own health and give caregivers the information they need to provide adequate support and care. Rehabilitation providers may wish to provide ongoing health education services for individuals aging with SCI, and their caregivers, as they continue to experience changes in their health.

To Learn More

The Model Systems Knowledge Translation Center (MSKTC) offers a range of information resources about SCI, from factsheets and videos to summaries of scientific research. <http://www.msktc.org/sci>

The Spaulding New England SCI Center's website includes the New England SCI Toolkit, designed for people with SCI and their healthcare providers to collaborate for better health outcomes. It covers standards for care and includes referral to providers and support resources in the New England area and beyond <http://snerscic.org/resources/new-england-sci-toolkit-nescit/>

The Rehabilitation Research and Training Center on Healthy Aging with Physical Disabilities conducted long-term surveys with older adults living with SCI, multiple sclerosis, and other disabilities. The data gathered was used to create a substantial collection of articles and factsheets around how to manage age-related issues alongside a physical disability. <http://agerrtc.washington.edu/>

To Learn More About this Study

Kern, S.B. (2019) [Understanding the changing health care needs of individuals aging with spinal cord injury](#). Topics in Spinal Cord Injury Rehabilitation, 25(1), 62-73. This article is available from the NARIC collection under Accession Number J80539.

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.

NARIC operates under a contract from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living, Department of Health and Human Services, contract #GS-06F-0726Z.