

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

Caring for a Family Member with Spinal Cord Injury Can Be Both Challenging and Rewarding

A spinal cord injury (SCI) is damage anywhere along the spinal cord, usually from an accident or other trauma. SCI can cause a loss of feeling and movement below the point of damage. As a result, people with SCI may need help with basic daily activities such as bladder and bowel care, dressing, and bathing, as well as more complex tasks like shopping and transportation. Often, a spouse or other close family member takes on most of this caregiving responsibility. Most past research has focused on the burdens and stresses of being a caregiver to a person with SCI. However, caregiving may also have positive, affirming aspects for the caregiver. A recent NIDILRR-funded study looked at both the negative and positive aspects of caring for a family member with SCI and how caregivers cope with the demands of caregiving.

In a field-initiated study on [Developing a Relevant Instrument to Assess Caregiver Distress and Benefit in Spinal Cord Injury](#), researchers conducted 16 focus groups in 4 states (Colorado, Alabama, California, and New Jersey) with a total of 73 caregivers. Each caregiver was a close family member to a person with SCI and spent an average of 8 hours each day helping their relative with personal care needs. Each focus group met once with the researchers to discuss their feelings about caregiving. The participants talked about both the negative and positive impacts of caregiving on their lives, and what gave them strength to cope with caregiving demands.

The researchers identified several themes that came up most often in the focus groups. Generally, the caregivers described caregiving as a mixed experience with both negative and positive aspects. Negative aspects of caregiving included:

- Physical and emotional strain and feelings of burnout. One caregiver said, “It’s the hardest work I’ve ever had to do.”
- Feeling unappreciated by family members, including the family member with SCI.
- Strains on family relationships. Some of the caregivers described a loss of spontaneity or no longer being able to enjoy favorite family activities after the injury.
- Feeling a sense of isolation, especially if other people didn’t understand the demands of caregiving.
- Feeling dissatisfied with hired personal care assistants or respite workers. Some of the caregivers were frustrated with hired assistants who were not well-trained, kept inconsistent schedules, or who were unwilling to take on more unpleasant tasks such as bowel care. As a result, people with SCI and their family caregivers may have felt reluctant to hire help even when the caregivers were feeling burned out.

- Negative impacts on their physical health, particularly due to fatigue and lack of sleep. Some of the caregivers described needing to stay awake and vigilant in case of emergencies like a ventilator failure.

However, the caregivers also described positive aspects of caregiving, including:

- Feeling useful, needed, or appreciated by their family member with SCI.
- Satisfaction in helping others.
- Watching their loved one improve and playing a role in that improvement.
- Stronger family bonds as a result of being depended upon by the family member with SCI.
- Improved self-awareness and opportunities for personal growth. One caregiver said, “I gain as much as I give.”
- Making important connections with new people such as SCI professionals and other families living with SCI.

Finally, the caregivers identified sources of strength that they drew upon to cope with caregiving demands. These included their religious faith, social support from others, taking time for themselves, and drawing on their own inner strength.

Caring for a family member with SCI can be difficult, physically and emotionally, but it can also be rewarding. The authors noted that a strong social support network may help relieve the sense of isolation often reported by caregivers of people with SCI. Supportive family members and friends could also help to share the burdens of caregiving. In addition, family caregivers may benefit from training in problem-solving and coping strategies that can help them identify their personal strengths and what they might gain from caregiving. For future research, researchers may want to further explore the stresses and benefits of caregiving in order to improve long-term quality of life for people with SCI and their families.

[To Learn More](#)

The Northwest Regional SCI System Center hosts [SCI Forum sessions](#), where people with SCI, families, and practitioners discuss important topics related to living with SCI. In two recent forums, [people with SCI](#) and [caregivers](#) shared their perspectives on the topic of caregiving and managing caregivers.

The Model Systems Knowledge Translation Center offers extensive information on SCI for individuals, caregivers, and practitioners: <http://www.msktc.org>

The Family Caregiver Association is the leading support and advocacy organization for those who provide care and support for a family member or friend.
<http://www.caregiver.org>

[To Learn More About this Study](#)

Charlifue, S. B., Botticello, A., Kolakowsky-Hayner, S.A., Richardson, J.S., and Tulsy, D.S. (2016) [Family caregivers of individuals with spinal cord injury: Exploring the](#)

[stresses and benefits](#). Spinal Cord, 54, 732-736. This article is available through the NARIC collection under Accession Number J74669.

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