Quality of Caregiving Among People with SCI and Its Impact

Martin B. Forchheimer, MPP
University Of Michigan Department of Physical Medicine & Rehabilitation

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Learning Objectives

- To provide background on the literature regarding the relationships that people with SCI have with their caregivers.
- To describe differences between people who do and do not receive caregiver services.
- To describe the Quality of Caregiving Measure and the relationship of scores to demographics, neurological status, and measures of health and well-being.
- To discuss the implications of findings for clinical care.
While some people with SCI live quite independently, most require some caregiver services, with many receiving 24 hour care.

Quality care can be essential to maintaining physical and mental health - inadequate care is associated with higher rates of pressure ulcers, urinary tract infections, and hospitalization. (Nosek MA, 1993)

Relationships with caregivers can have a big impact on physical and emotional adjustment. (Elliott TR, 1998)
The dynamics of relationships between people with SCI and their caregivers can vary depending upon numerous factors including (Galvin R 2004; Nosek et al 1993; Walker EA et al 2015):

- Whether caregivers are paid or unpaid;
- Whether a relationship existed prior to the onset of SCI;
- Severity of impairment;
- Race / Ethnicity;
- Other demographic factors;
- Specific duties and needs
Finding the relationship with a caregiver to be problematic is associated with increased distress (McPherson CJ et al, 2010).

This relationship can either facilitate or hamper community participation and employment outcomes. (Hagglund KJ et al, 2004), along with relationships with medical professionals.
Existing Measures

While a lot of research has been done on caregiving, there are few measures of caregiving from the perspective of people with disabilities. The few measures that exist include:

- The Personal Attendant Care Questionnaire; (Bushnik T. et al 2007)
- The Personal Assistance Satisfaction Index; (Nosek M. et al 1992);
- The Quality of Caregiving Measure (Warschausky S. et al 2005); and
- Self-Perceived Burden Scale; (Cousineau N. et al. 2003).
The findings reported on in this presentation come from two studies:

1) A large survey study conducted as part of the SCI Model Systems (SCIMS) from 2011-2016 that conducted interviews with 303 participants.

2) A study funded by the Department of Defense (DoD) that conducted in-depth interviews with 40 veterans and civilians.
Both of these studies used the Quality of Caregiving Measure (QCM).

The QCM has 3 sections, the 1\textsuperscript{st} addresses the amount of care received and the nature of the caregivers providing it.

The 2\textsuperscript{nd} section concerns one’s relationship with their primary caregiver.

The 3\textsuperscript{rd} section concerns relationships with caregivers in general.
In the SCIMS study of 303 participants, 55% received Caregiver Services. This rate was 89% among those with complete tetraplegia, significantly higher than among those with paraplegia (p<.0005).

They were less likely to be married (p<.05) or employed (p=.001). Interestingly, white non-Hispanics were the least likely to receive services (p<.01).

Overall life satisfaction did not differ as a function of receipt of services.
While there were no gender difference in receipt of services, among those receiving them, females received significantly more hours (p<.01).

Those receiving services reported having better relationships with their primary clinicians (p<.05).

They had higher Neurogenic Bowel Dysfunction score (p<.05) indicating more problems with bowel issues and tended to feel worse about their bladder health (p<.05) as measured by the SCI-QOL Bladder Complications Scale (p<.05).

Interestingly, hours of caregiving was not associated with number of bowel and bladder complications reported.
In the smaller DoD-funded study, 78% of participants received Caregiving.

As in the larger study, receipt was associated with severity of impairment ($p<.05$).

There was an association between receiving services and household income, those receiving services had higher incomes ($p<.05$).

Those receiving services had higher levels of anxiety ($p=.05$).

There were no differences between veterans and non-veterans in receipt of services.
In the larger, SCIMS study, there were no differences in scores on the QCM as a function of gender, age, time since injury, level of education, or impairment severity.

Married participants had significantly higher scores on the primary caregiver scale than either those who were single or previously married (p<.05).

Scores did not differ as a function of whether caregivers were paid or unpaid and there was not a significant relationship between scores and hours of care.
Scores on the Primary Caregiver and General Caregiving scales were both strongly associated with the quality of relationships with one’s primary clinician (p<.005).

Scores on the Primary Caregiver Scale were also associated with Quality of Life (QoL) (p=.05) and perceived ability to participate in social roles and activities (p=.005).
In the DoD-funded study, there were no difference in QCM scores as a function of demographic factors or impairment severity.

There were no differences between those with military and civilian backgrounds.

There were no differences as a function of hours of caregiving services received or the number of caregivers that participants had.
Scores on none of the study’s outcomes varied as a function of General Caregiving scores on the QCM. Scores on numerous outcomes differed as a function of Primary Caregiver scores:

- Overall QoL was higher for those with better relationships (p<.01)
- Perceived Physical and Mental Health were better (p<.05 and p<.0005)
- Levels of Anxiety and Depression were lower (p<.01)
- Subjects were less impacted by bladder complication (p<.05)
- Satisfaction with participation was higher (p<.01)
Implications for Clinical Care

A more comprehensive measure of the relationship of people with SCI and their caregivers is needed which covers the topics that are pertinent to all people with SCI receiving caregiving.

It must also address the specific issues that are relevant depending upon one’s relationship with their caregiver.

This could be valuable to people with SCI, clinicians who work with people with SCI, as well as to agencies that hire and supply caregivers.
A new measure needs to take into account several factors:

- The nature of the care needs of the person with SCI;
- Whether there are multiple caregivers;
- If they are paid;
- The nature of the relationship – is the caregiver a spouse, another family member, or someone with whom there was no relationship prior to caregiving.
Currently conducting a study, funded by the Craig H. Neilsen Foundation to create a new measure. Work has focused on reviewing measures developed on this and related topics. We have also conducted focus groups both with people receiving caregiving and other groups with people providing caregiving. We also plan to get input from various types of clinicians.


Nosek MA, Quan H, Potter C. Personal Assistance Satisfaction Index: An assessment tool for individuals with severe physical disabilities. Houston, TX: ILRU; 1992.