

ORIGINAL ARTICLE

# Family caregivers of individuals with spinal cord injury: exploring the stresses and benefits

SB Charlifue<sup>1</sup>, A Botticello<sup>2</sup>, SA Kolakowsky-Hayner<sup>3</sup>, JS Richards<sup>4</sup> and DS Tulsky<sup>2</sup>

**Study design:** Cross-sectional, focus group.

**Objectives:** To explore positive and negative issues reported by family caregivers of people with spinal cord injury (SCI) to develop a relevant and valid tool to assess caregiver distress and benefit for this unique population.

**Methods:** Seventy-three family caregivers of people with SCI participated in 16 focus groups. We audio-recorded all focus group discussions and transcribed the recordings verbatim. Qualitative analysis of the transcripts was performed to identify major themes and subthemes relating to family caregiving activities.

**Results:** Positive themes were disproportionately limited in comparison with negative themes. Positives included changes in self-awareness, enhanced family cohesiveness and feeling appreciated. Negative themes included physical and emotional strain, dissatisfaction with hired carers and strain on family relationships. Health-related themes included fatigue and lack of sleep. Caregivers identified sources of strength that helped them manage stresses including faith and support from friends and co-workers.

**Conclusion:** The numerous themes help lay the groundwork to develop a valid and reliable assessment tool to assist health-care providers in treatment planning and the provision of long-term assistance to people with SCI by enhancing areas of strengths and addressing factors that contribute to burden and distress for family caregivers.

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## INTRODUCTION

Serious physical trauma or illness, while devastating to the individual incurring such an event, can also have a far-reaching impact on family members. This is particularly true when the trauma such as a spinal cord injury (SCI) results in limitations that necessitate physical assistance from others. The help required may range from assistance with basic daily activities such as bowel and bladder management and dressing to instrumental activities of daily living, including managing household finances, shopping or transportation. One individual in a family frequently assumes most or all of the responsibilities of caring for a person with a disability,<sup>1</sup> and this responsibility may have several physical and emotional consequences. For instance, the challenges that accompany a family caregiving role may result in a caregiver's inability to balance responsibilities at home and in the workplace. In addition, there is a tendency for caregivers to neglect their own health,<sup>2</sup> which may lead to the person with SCI being unable to have the necessary care and support they require to function as independently as possible and participate in society because of the diminished capacity of their family support system.

As interest and awareness of family caregiver needs increase, investigators have started looking at the broad array of factors related to caregiver distress and caregiver life satisfaction. This is particularly important because of the fact that a growing number of people provide intensive, long-term care for their family members,<sup>3</sup> as is true for many caregivers of those with SCI. In addition to the numerous studies of caregiver distress, several researchers have focused on the

potentially beneficial aspects of caregiving. Schulz *et al.*<sup>4</sup> reported that the negative effects of caregiving may be counteracted in part by benefits and found that although caregivers reported a great deal of distress associated with caregiving, they also reported a number of beneficial effects. Almost 75% reported that caregiving made them feel useful. Caregiving may also improve relationships between caregivers and care recipients and provide company for caregivers. However, changes in the nature of close and loving relationships may put the family dynamics at risk when one partner is required to assume greater responsibilities in the caregiving role.

Several studies have identified a number of predictors and outcomes related to physical and psychological caregiver distress, but few have investigated the more qualitative aspects of caregiving. A qualitative research approach can generate more exploratory (as opposed to confirmatory) information. Most quantitative measures of caregiver issues focus on factors that are prevalently negative—stress, depression and perceived burden. Few studies have attempted to identify the positive side of caregiving, and even fewer have incorporated qualitative methodology to explore the experience of caregiving. In addition, the little that is known about SCI-specific issues has generally been extrapolated from studies of other populations, which may be informative but may miss essential information about this unique group of individuals. A qualitative approach, therefore, is the first logical step to help better define family caregiving issues in SCI.

Although there are clearly numerous issues related to caregiving, the majority of instruments used to measure the specific areas of 'burden'

<sup>1</sup>Research Department, Craig Hospital, Englewood, CO, USA; <sup>2</sup>Kessler Foundation, West Orange, NJ, USA; <sup>3</sup>Santa Clara Valley Medical Center, San Jose, CA, USA and <sup>4</sup>University of Alabama at Birmingham, Birmingham, AL, USA

Correspondence: Dr SB Charlifue, Research Department, Craig Hospital, 3425 South Clarkson Street, Englewood, CO 80113, USA.

E-mail: susie@craighospital.org

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(as reviewed by Visser-Meily *et al.*<sup>5</sup>) have been designed for use with caregivers of individuals who have cognitive impairments. The Family Caregiver Alliance produced a compendium of caregiver assessment instruments,<sup>6</sup> several of which are designed to assess a single dimension of caregiving, such as burden or satisfaction, whereas others are multidimensional. However, no single instrument exists to capture the overwhelmingly physical aspects of providing assistance to someone with SCI, including the very personal care of bowel and bladder management, or the long-term nature of SCI caregiving and the related family stressors that may exist. The goal of the present study was to explicate the specific issues related to caregiving in SCI. Using this information, the next step is to develop a relevant instrument to assess distress and/or benefit in family caregivers of those with SCI with the goal of improving the support system for people with SCI and their family caregivers, and thereby improving long-term outcomes for individuals with SCI.

## MATERIALS AND METHODS

### Recruitment and participants

Caregiver participants were recruited at four SCI rehabilitation facilities across the US (Craig Hospital, Englewood, CO, USA; the University of Alabama at Birmingham, AL, USA; Santa Clara Valley Medical Center in San Jose, CA, USA; and Kessler Institute for Rehabilitation in West Orange, NJ, USA). Mailers were sent to individuals with SCI at each site requesting that they identify a family member who provides assistance to them and inviting that family member to participate in a focus group to discuss caregiver issues. Focus group eligibility required that the family caregivers were related in some way to the individuals with SCI and that the family member with SCI was at least 1 year post injury and was living in the community. There were no specific exclusion criteria. Institutional Review Boards at each site reviewed and approved this research. Participants were given a stipend of \$60.00 USD to help cover their travel expenses and time.

### Data collection and analysis

Focus group methodology was used to identify the issues important to family caregivers of individuals with SCI. All focus groups were led by the study's principal investigator who traveled to each of the local sites to ensure consistency in content. A semi-structured interview format was used for the focus groups to ensure that key topics were addressed. After obtaining informed consent from the participants, they were instructed that the groups were being audiotaped to ensure that all of their concerns were heard and could be accurately and completely transcribed. Each focus group lasted between 90 and 120 min. Participants were asked to discuss their perceptions of both the positive and negative aspects of caregiving, from what or whom they draw their strength, how caregiving has affected their own health, and what changes they have experienced in their lives because of caregiving. In addition to discussing issues related to caregiving, participants were asked to complete a brief demographic questionnaire to gather data regarding their age, gender, relationship to the family member with SCI, how many years they had been providing assistance to their family member and how many hours per day such assistance was provided.

**Table 1** Participant demographics

	Caregiver
Gender	85% female
Age (mean)	52.5
Race	61% Caucasian
Relationship	54% spouse/partner 37% parent 9% other relative
Years being a caregiver (mean)	8.23
Hours per day caregiving (mean)	8.0

All audiotapes were transcribed verbatim by the principal investigator. NVivo 8<sup>7</sup> software was used to conduct the systematic qualitative analysis of the focus group transcripts. Each transcript was reviewed by the principal investigator and two researchers from the Research Department at Craig Hospital. Using constant comparative analysis, the three researchers independently examined each transcript, and broad and more detailed concepts were identified using open and axial coding as described by Strauss and Corbin.<sup>8</sup> The three analysts met to review the themes identified, and when coding differences were identified these were discussed to reach consensus on an appropriate code, which resulted in the final codebook scheme.

## RESULTS

Sixteen focus groups were convened, which included 73 family caregivers recruited through the collaborating SCI centers. Characteristics of the participants are shown in Table 1. Family members with SCI were primarily males (70%) with tetraplegia (60%) and an average age of 44.8 years.

The more frequently cited themes and subthemes are summarized in Table 2, and examples of the themes are illustrated in the following comments.

### Positive and negative themes

Themes related to the positive aspects were disproportionately limited in comparison with negative themes. Positive themes included changes in self-awareness, enhanced family cohesiveness, an increased sense of compassion and feeling appreciated by their family members with SCI. These themes were expressed in statements such as that from a son providing assistance to his mother:

*'I find it very rewarding. I feel like, in a way, I gain as much as I give.'*

In contrast to the positive themes, there were numerous negative themes identified by the participants, focusing on frustration that others did not understand the demands of caregiving, a lack of appreciation from all family members (including the person with SCI), the general physical and emotional strain that caregiving causes, dissatisfaction with hired carers and strains on family relationships. Family difficulties were reflected in statements such as that from a wife of a man with SCI:

*'My children always ask questions like 'you and daddy promised that we would go to the park'...or things like that. They get sad when we don't do the things we normally do...'*

Both the emotional and physical strains of caregiving were described in statements such as the following:

*'It's the hardest work I ever had to do.'*

*'It burns you out. It can take a toll on you.'*

One of the most prominent themes was a sense that the caregiver lost her/his identity as described by two spouses:

*'I think the way I see it is that my life is over.'*

*'Your time is not your own.'*

### Health issues and sources of strength

The participants identified numerous health issues resulting from performing caregiving activities. Fatigue and lack of sleep were common problems:

*'I feel like I'm tired and I don't get enough sleep sometimes...and I just feel drained.'*

*'...the physical—it's so long term...for us, this is the rest of our lives.'*

**Table 2 Themes identified by family caregiver focus groups**

Major theme	Subthemes
Positive aspects of caregiving	Watching loved one improve, gains, successes; opportunities to travel; satisfaction from helping others; personal growth, more empathy, patience; learning about SCI; improved family relationships; having good support from others—family and friends; finding inner strength; feeling appreciated
Negative aspects of caregiving	Anger or resentment toward family member with SCI with no outlet for anger; difficulty or unpleasantness of bowel and bladder care; burnout; change in job, opportunities, status; changed relationship; emotional strain; desire to escape situation, feeling trapped; fear of not knowing what to do in medical situations; fear for the future; financial issues; irritation or frustration toward loved one with SCI; guilt; difficulty asking for help; difficulty of the work; feeling helpless; difficulties with hired caregivers; hopelessness; insurance companies, doctors or hospitals that do not help; loss of intimacy; isolation; lack of appreciation or respect from family member with SCI; lack of privacy; lack of support groups or other resources; lack of respite care; loss of self; stress of multiple roles; negative impact on other family members; lack of support from family, friends; lack of recreational opportunities; lack of spontaneity and needing to plan ahead; lack of time for self; constant responsibility and vigilance; stress and anxiety; increased family difficulties; fear of being sick or injured and unable to provide help
Health issues	Aging of caregiver; musculoskeletal pain; depression; emotional and physical fatigue; having your own disability and health issues; risk of injury; sleep disturbance
Life changes	Changes in relationships; having to put education on hold; having to give up or change job; need to move or modify residence' adapting to a 'new normal'
Sources of strength	Faith; family; friends; having hope; having ideas and projects; inner strength; laughter, having a sense of humor; love; having a sense of obligation; having outside support from employment/job

Abbreviation: SCI, spinal cord injury.

To get a sense of the factors that help family caregivers manage stresses, they were asked to describe their sources of strength. Faith was an extremely prominent theme, and many participants mentioned that God or their faith and faith communities helped them:

*'You have to pray—it would be like a ship without a sail.'*

Others drew strength and support from their friends and co-workers, whereas others felt the strength came from within themselves:

*'...You got the strength—you just got to find the strength in you. It's in you already.'*

*'I draw on my motivation, just from a sense of duty to my mother.'*

### Life changes

The participants noted that numerous changes occurred following the SCI, such as their ability to work outside the home or to travel. Negative changes included a lack of spontaneity and limitations in socialization opportunities. Two wives noted the following:

*'We can't go to a lot of our friends' houses anymore because they live in apartments and he can't get through the door.'*

*'We used to be very active and take a lot of little road trips or vacation with my parents and we haven't done a single thing since the injury 5 years ago. We're homebound.'*

Positive changes were reflected in statements such as follows:

*'...I feel like because of (my husband's) injury, there have been a lot of people brought into our lives that have really blessed our lives—people we never would have known and I appreciate that.'*

### Coping strategies

Family caregivers described some of the strategies they used to help them cope with the caregiving role including finding time for themselves and taking opportunities to explore personal growth:

*'... you still have to have 'me' time—something that you personally want to do to help you relax—something that's good for you, even if it's just going to the beauty parlor or get your nails or toes done.'*

*'There's no going back, there's only going forward, so how do we turn this into something that has value not only for us but for something productive in the world? ...we both draw a lot of strength from thinking that way and working on projects and things that will not only enhance and develop our lives together, but also that has some value and productivity in the world.'*

Overall, nearly all of the participating family caregivers endorsed both positive and negative issues involved in living with and providing assistance to a loved one with SCI. Although the negative aspects of caregiving tended to predominate each of the focus group discussions, the participants did feel that being a caregiver provided opportunities for learning and personal growth.

### DISCUSSION

Providing care and support to a family member with SCI encompasses far more than assisting with personal care and daily living activities and can result in both negative and positive changes to the caregiver. Risk factors for caregiver burden include female gender, low educational attainment, living with the care recipient, depression, social isolation, financial stress, a greater number of hours spent caregiving and lack of choice in being a caregiver.<sup>9</sup> Several of these risk factors potentially relate to family caregiving in SCI and were evident in the current study in that the majority of the study participants were female, living with the family member with SCI and spent an average of 8 h per day in caregiving activities.

Studies suggest that higher levels of perceived social support are related to less distress<sup>10</sup> and better psychological adjustment in partners of people with SCI.<sup>11</sup> Social support is one of the many factors that mitigate caregiver burden in SCI.<sup>12</sup> Participants in the focus groups did identify social support as helpful, and the absence of such support was noted to be associated with greater frustration, anger and greater feelings of burden. Additional social support can afford the family caregiver greater flexibility, as noted in another qualitative study examining the impact of caregiving on employment with nine family caregivers of people with SCI.<sup>13</sup> Participants in that study described the importance of flexibility in helping them manage home and work responsibilities, and the difficulties associated with balancing

responsibilities and their own needs. Additional support in the form of utilizing hired caregivers may be an option for some; however, individuals participating in our focus groups noted high levels of dissatisfaction with hired agency services, citing a lack of training, inconsistency in schedules and inability or unwillingness for hired carers to assume many responsibilities, in particular bowel care. The costs of respite or agency care also can be a limiting factor. In many cases, the family caregivers simply stopped using outside agencies even for short breaks because the frustrations outweighed the benefits. For example, in a study of 273 family caregivers in the Netherlands, 187 did not use respite care for a variety of reasons, citing care recipient refusal (38%), caregiver preference to perform caregiving him/herself (28%), the caregiver not desiring respite (31%) and the caregiver opinion that she/he knew best what the care recipient needed (22%).<sup>14</sup>

For those caregivers of family members with SCI who still need to maintain employment in addition to their caregiving responsibilities, the physical, emotional and financial burden can be quite significant. Analysis of data from the National Spinal Cord Injury Statistical Center in the United States indicates that those individuals with SCI using assistance receive an average of 7 h per day of help (combining both paid and unpaid care), 7 days a week. A study of 13 542 military veterans with spinal cord dysfunction showed a clear positive relationship between greater self-reported disability and increased need for personal assistance (measured by caregiver hours).<sup>15</sup> In addition to the visible, quantifiable amount of time spent in active caregiving, it has been suggested that there is additional 'on-call' time, which may involve long periods of passive vigilance.<sup>16</sup> With SCI, this time may be spent waiting for a suppository to work so a bowel program can be completed, being available in case a ventilator alarm is activated or simply being available to pick up dropped objects, empty a leg bag or perform other tasks needed by a family member with SCI. For the family caregivers, the degree of this quantifiable and on-call time can have a significant impact on the ability for the caregiver to maintain employment or schooling and engage in other social, leisure or productive activities.

Nonetheless, the focus group participants cited many positives related to caregiving. Positive themes of improved family cohesiveness, increased compassion for others, having previously unrecognized opportunities to learn and develop skills and a feeling of being appreciated were noted. The increased family bond was also noted in a qualitative study of caregiving in SCI by Dickson *et al*.<sup>17</sup> Similar positive aspects of caregiving have been found in studies with other disability groups such as muscular dystrophy<sup>18</sup> and stroke.<sup>4</sup>

A greater effort is needed to assist family members of people with SCI develop the skills needed to undertake caregiving, and, to date, relatively few intervention programs have been developed. In one study of problem-solving training with 60 caregivers of family members with SCI undergoing initial rehabilitation, half of the participants were assigned to intensive individualized training sessions focused on the problem-solving process, and the control group received the 'usual care' that involved access to and information from staff concerning SCI management. Those in the intervention group demonstrated decreased dysfunctional problem-solving styles, and there was some beneficial effect on their social and physical functioning compared with the control participants.<sup>19</sup>

### Limitations

This study helps provide insight into the experiences and concerns of family caregivers to individuals with SCI. However, it should be noted that convenience sampling was used to recruit family caregivers. As such, those individuals who did not feel that they had salient issues to

discuss may not have participated in the groups. Alternatively, those with significant concerns may have elected not to participate, as they would not be comfortable discussing their family issues in a group setting.

### CONCLUSION

Family members who provide assistance to a loved one with SCI are likely to experience varying degrees of physical and emotional strain and may feel unsupported by friends and family. At the same time, they may also experience personal growth and identify strengths that had not been previously identified. In order to better identify the numerous positive and negative aspects of family caregiving in SCI, a relevant assessment tool would be beneficial. The findings from the current study are being used to develop a valid and reliable tool that can assist health-care providers in treatment planning and the provision of long-term assistance to people with SCI by enhancing areas of strengths and addressing factors that contribute to burden and distress for family caregivers. In addition, this tool can be used to determine whether interventions designed to modify caregiver skills such as improving self-efficacy are effective.

### DATA ARCHIVING

There were no data to deposit.

### CONFLICT OF INTEREST

The authors declare no conflict of interest.

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