

## Informal care providers for veterans with SCI: Who are they and how are they doing?

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**Abstract**—Veterans with spinal cord injury (SCI) who received care at the Houston Department of Veterans Affairs Medical Center were interviewed about their use of formal and informal assistance to meet their daily physical needs. Informal caregivers were found to play an important role in the daily care of veterans with SCI, with 37% receiving some informal, unpaid assistance with personal care. Primary informal caregivers were mostly women, had a mean age of 53, and provided an average of almost 12 hours of care a day. Nearly one-third of participants rated their primary caregiver as being only in fair or poor health, and one-fourth thought their caregiver was unlikely to be able to provide the same level of care 5 years from now. Of particular concern, more than half reported that they did not have anyone else willing and able to provide assistance if their primary family caregiver became permanently unable to care for them.

**Key words:** caregivers, long-term care, spinal cord injuries.

### INTRODUCTION

Because of recent advances in medicine, people sustaining a severe spinal cord injury (SCI), who a decade or two ago would not have survived, not only are surviving the injury but also are living long lives [1,2]. Life expectancy, while remaining below normal, has been increasing [3]. In the United States, the average age of persons with SCI is approximately 40 years, with more than 40 percent

over age 45 and 35 percent over age 65 [2,4]. Data from a national registry of veterans with spinal cord dysfunction suggest that veterans with SCI are, on average, even older than the general population of persons with SCI [5].

With new medical advances, and the accompanied increased longevity, have come new questions and concerns about how persons with SCI age [1]. Over the past 15 years, investigators have begun studying the physical aging process of persons with SCI and have documented a wide array of physiological and health-related changes that persons with SCI experience with age [6–13]. Because of increasing problems with health and function caused by advancing age, increasing care needs can also be anticipated [1,14]. This translates into greater care demands on formal, as well as informal, care assistants.

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**Abbreviations:** df = degree of freedom, M = mean, SCI = spinal cord injury, SD = standard deviation, VA = Department of Veterans Affairs.

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Researchers recently have highlighted the important role that informal family caregivers play in the ongoing healthcare of persons with SCI [11,15]. Family members have assumed responsibility for a wide range of services and care tasks. Elliott and Shewchuk have argued that the health and well-being of caregivers affects the care they are able to provide persons with SCI and thus have stated, "From a policy standpoint, the well-being of caregivers of people with SCI should be of paramount importance" [15, p. 126]. The health of family caregivers not only will affect the health of persons with SCI but also their ability to stay at home in the community [1,16].

With the population of veterans with SCI aging, concern arises about the ability of family caregivers to provide the level of care needed. Little is known, however, about the nature of these informal care networks. Caregivers participating in a recent study on adjustment to SCI consisted of 39 percent parents, 35 percent spouses, 8 percent siblings, and 11 percent children [17]. Because the sample in this recent study was small and consisted only of persons with recent SCIs, their sample of caregivers may not represent the larger population of caregivers for persons with SCI. Nonetheless, the majority of caregivers in their study were either of the same generation as their care-recipients or were older. This would suggest that persons with SCI who are aging and facing increasing disability with age may have informal caregivers who are coping with the problems of aging as well.

A better understanding of the informal care networks of veterans with SCI is needed to anticipate the future care needs of veterans aging with SCI. Such information is critical for planning future care and identifying solutions that will allow veterans with SCI to live as independently as possible as long as possible. The aims of this study were to (1) determine the number of veterans with SCI who rely on informal family assistance to provide for their daily physical needs, (2) describe the characteristics of primary family caregivers, (3) assess veterans' perceptions of the stability of their informal care network in the future, and (4) explore possible correlates of self-reported care and of perceived network instability.

## METHODS

### Participants

Veterans with SCI who received care at the Houston Department of Veterans Affairs (VA) Medical Center were interviewed by telephone as part of a larger study on pain

following SCI. Before data was collected, the study was explained and oral consent was obtained. The appropriate Institutional Review Boards approved study procedures, and we collected all data in compliance with these boards' standards. An attempt was made to contact and interview all veterans with SCI who had received care in FY 1999 to 2001. The Houston VA Medical Center SCI Service serves not only residents of Texas but also veterans with SCI from Alabama, Arkansas, Florida, Louisiana, Mississippi, and Oklahoma. A total of 348 veterans (345 men, 3 women) completed interviews. Of the 161 who were not interviewed, 22 were deceased, 29 refused to participate, and 89 were unable to be located despite repeated attempts to contact them directly as well as through their identified next of kin. In addition, 21 were unable to participate for a number of reasons (8 had no assistance available to help them use the phone, 5 had dementia, 3 were unable to speak, 3 were ventilator dependent and unable to complete the lengthy phone interview, 1 was comatose, and 1 was out of the country).

Sixty percent of the respondents were Caucasian, 35 percent were African American, 4 percent were Hispanic American, and 1 percent were "other." Participants' mean age was 54.8 years (SD [standard deviation] = 11.6, range = 22 to 83 years) with 15 percent of them over the age of 70. The sample consisted of persons with paraplegia (51%), low tetraplegia (35%), and high tetraplegia (14%). Participants' self-ratings of overall health varied widely, including excellent (9%), very good (24%), good (30%), fair (26%), and poor (12%).

### Informal Care Network Assessment

In addition to questions about their health, disability, and pain, veterans were asked about their informal care networks. Participants were first asked to report the number of hours in a typical 24-hour day that they have "someone with (them) to provide physical assistance for personal care activities such as eating, bathing, dressing, toileting, and mobility." Participants reported the number of hours of paid formal assistance as well as the number of hours of unpaid informal assistance. If they received informal, unpaid assistance with personal care activities, they were then asked if a primary person provided the majority of such care and how many hours in a typical day this individual provided care for them.

If they identified a primary caregiver, additional information on the age, gender, and health of this person was obtained. The SCI participant rated the health of the

primary caregiver as excellent, very good, good, fair, or poor, the same rating scale that participants used to rate their own health. In addition, participants were asked to rate how likely their primary care provider would be able to provide “the same amount of care for (them) 5 years from now as he/she is currently providing.” The possible responses to this item were very likely, somewhat likely, somewhat unlikely, and very unlikely. Finally, participants were asked that if their primary family caregiver became permanently unable to care for them, “would other family, friends, or neighbors be willing and able to provide the assistance that he/she now provides?”

## RESULTS

Thirty-eight percent of the respondents ( $n = 131$ ) reported receiving no paid or unpaid assistance with personal care activities. Approximately 25 percent ( $n = 87$ ) reported receiving paid assistance only, with an average of 8.2 hours ( $SD = 8.1$ ) of care provided in a typical day. Twenty-two percent ( $n = 75$ ) reported receiving unpaid assistance only, receiving an average of 12.9 hours ( $SD = 9.2$ ) of care in a typical day. Finally, 16 percent ( $n = 55$ ) reported receiving both unpaid and paid assistance, receiving on average 4.8 hours ( $SD = 4.5$ ) of paid care and 10.4 hours ( $SD = 8.7$ ) of unpaid care in a typical day. Although the type of care received (i.e., none, paid care only, unpaid care only, both) was unrelated to the avail-

able demographic variables, including age, education level, race, and self-rated health, type of care was related to level of injury ( $X^2 = 56.74$ ,  $df$  [degree of freedom] = 6,  $p < 0.001$ ) ( $X^2$  is the Pearson chi-square statistic and  $p$  is the probability value). Persons with paraplegia were most likely to have no assistance and least likely to have paid assistance. Persons with high tetraplegia were most likely to have both paid and unpaid assistance. (See the **Table** for a more detailed description of the number of hours of care received by level of injury.) Using hierarchical multiple regression analysis, we found that the number of hours of informal care received was significantly inversely related to the number of hours of paid care, after controlling for level of injury ( $\Delta R^2 = 0.04$ ,  $F = 14.2$ ,  $df = 1, 344$ ,  $p < 0.001$ ) ( $\Delta R^2$  is the change in the  $R^2$  and  $F$  is the  $F$ -ratio of the change in  $R^2$ ), suggesting that paid assistance may reduce the care demands on informal unpaid care providers. This finding also can be seen in the **Table** as reflected by the higher number of unpaid care hours received by those with unpaid assistance only relative to those receiving both paid and unpaid assistance, particularly for persons with low tetraplegia or paraplegia.

Of the 130 participants who reported receiving informal unpaid care, 59 percent identified a spouse or partner as their primary caregiver; 17 percent, a parent; 9 percent, a sibling or spouse of a sibling; 8 percent, a child or spouse of a child; 2 percent, a friend; and 3 percent, some other person (e.g., grandparent, niece). Only 2 of the

**Table.**

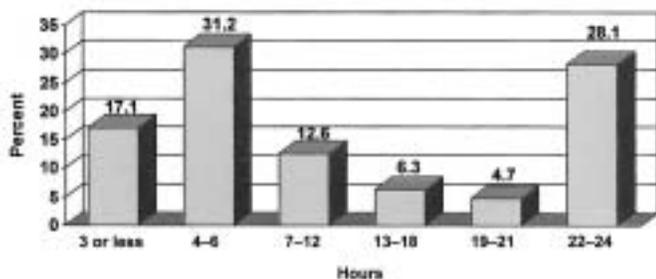
Type of care received and mean hours of care received by level of injury.

Care Received	High Tetraplegia	Low Tetraplegia	Paraplegia
No Care			
n (%)*	10 (20.8)	22 (18.3)	97 (54.5)
Paid Care Only			
n (%)	17 (35.4)	42 (35.0)	28 (15.7)
M (SD) No. of Hours	12.9 (10.3)	7.3 (7.1)	6.7 (7.1)
Unpaid Care Only			
n (%)	7 (14.6)	31 (25.8)	37 (20.8)
M (SD) No. of Hours	16.1 (8.0)	14.6 (9.3)	10.8 (8.9)
Both Paid and Unpaid Care			
n (%)	14 (29.2)	25 (20.8)	16 (9.0)
M (SD) No. of Paid Hours	3.4 (2.1)	5 (4.7)	5.4 (5.7)
M (SD) No. of Unpaid Hours	15.9 (8.3)	10.4 (9.0)	5.7 (5.5)

\*Column percentages

130 were unable to identify a single individual as their primary informal caregiver because they had several caregivers who provided equal amounts of care. The vast majority of primary informal caregivers were women (88%). The mean age of primary caregivers was 53.1 years ( $SD = 15.6$ , range = 15 to 85), a value just slightly lower than the mean age of the participants for whom they were caring (54.6 years,  $SD = 12.1$ , range = 22 to 81), and approximately 10 percent of the caregivers were over the age of 70.

Of the 11.9 hours of daily care reported to be provided, on average, by informal care networks, primary informal caregivers provided an average of 11.6 (97.5%) hours of that care ( $SD = 9.0$ , range = 1 to 24), suggesting that very little care was typically provided by other family members or friends. As can be seen in the **Figure**, 39 percent of primary informal caregivers provided all day care (13 or more hours a day). As expected, the number of hours of care provided by primary informal care providers increased significantly with the severity of the injury (high tetraplegia,  $M$  (mean) = 16.0,  $SD = 8.0$ ; low tetraplegia,  $M = 12.7$ ,  $SD = 9.3$ ; paraplegia,  $M = 8.8$ ,  $SD = 8.2$ ;  $F(2, 125) = 5.94$ ,  $p < 0.01$ ). The number of hours of care provided by the primary informal caregivers was unrelated to caregiver gender, participant or caregiver age, and participant race. Although there was a trend toward fewer hours of unpaid care provided to those with increasing levels of education, this relation did not achieve statistical significance ( $F[4, 123] = 2.02$ ,  $p < 0.10$ ). Finally, the number of hours of informal care was also unrelated to time since injury, self-rated health, and whether or not they experienced chronic pain. Looking only at those who experienced chronic pain of at least a 6-month duration ( $n = 260$ , 75% of the sample), average pain severity was significantly, although weakly, positively associated with hours of unpaid assistance ( $r = 0.13$ ,  $p < 0.05$ ) ( $r$  is the correlation coefficient).



**Figure.**  
Hours of care provided by primary caregivers.

While most of the participants rated their primary caregiver's health as being at least good (good, 26%; very good, 27%, excellent, 17%), nearly a third of the participants rated their caregiver's overall health as only fair (22%) or poor (8%). The number of hours of care provided by informal caregivers was unrelated to the caregiver's overall health,  $F(4, 122) = 0.81$ ,  $p = 0.52$ , suggesting that care demands do not necessarily lighten as a caregiver's health declines. In fact, the number of hours of care provided by caregivers rated as being in poor health ( $M = 12.1$ ,  $SD = 9.0$ ) was quite similar to the number of hours of care provided by caregivers rated as being in excellent health ( $M = 13.0$ ,  $SD = 9.3$ ).

One-fourth of participants reported that their primary informal caregiver was unlikely (somewhat unlikely, 12%; very unlikely, 13%) to be able to provide the same amount of care for them 5 years from now. Concerns about their caregiver's ability to care for them in 5 years were related to both the caregiver's overall health rating,  $X^2(12) = 30.72$ ,  $p < 0.01$ , and the participant's overall health rating,  $X^2(12) = 28.82$ ,  $p < 0.01$ . As one would expect, poorer overall health ratings predicted greater concern that the caregiver would be unable to provide the same level of care in 5 years. Concerns about their caregiver's ability to care for them in 5 years also increased with caregiver's age,  $F(3, 117) = 9.52$ ,  $p < 0.001$ , and participant's age,  $F(3, 123) = 3.77$ ,  $p < 0.05$ . Concerns about the caregiver's ability to provide care in 5 years were unrelated to level of injury, race, years of education, and caregiver gender.

Finally, more than half (54%) of the participants who identified a primary informal caregiver reported that they did not have anyone else willing and able to assist them if their primary family caregiver became permanently unable to care for them. Patterns in the data revealed that those without an alternate care provider were older ( $t = -2.32$ ,  $p < 0.05$ ), rated their own health as poorer,  $X^2(4) = 13.12$ ,  $p < 0.05$ , and were more likely to have a female rather than a male primary caregiver,  $X^2(1) = 7.96$ ,  $p < 0.01$ . Availability of an alternate caregiver was unrelated to level of injury, race, and years of education.

## DISCUSSION

Researchers have begun to study the physical health problems that persons aging with SCI might anticipate. What has often been overlooked in research on persons aging with SCI is the critical issue of who will be available to care for them as they age. Our data from a sample of

veterans with SCI highlight that this issue may not be a concern for the distant future; rather, it appears to be a very real concern facing some veterans with SCI now and in the relatively near future. Our data confirm that informal family caregivers play an important role in the care of veterans with SCI. Possibly, our data actually underestimate the informal care provided to veterans with SCI because some of the participants who were unable to participate in our study may have required greater than average levels of care because of dementia, aphasia, and use of a ventilator. We were unfortunately unable to evaluate care based on physical or cognitive limitations and comorbid health conditions because this information was not collected, except as a stated reason for nonparticipation.

The vast majority of informal care is provided by a single primary care provider, and these informal care providers are aging along with the veterans with SCI. Although other family members did not appear to lighten the care load of primary informal care providers, having paid care assistance did. Of concern is that nearly one-third of participants who rely on some informal care reported that their primary informal care provider was only in fair or poor health, and one-fourth of them were uncertain of their primary care provider's ability to continue to care for them in the relatively near future. Future care appears to be most jeopardized among those who are older and in poorer health and among those who have primary caregivers who are older and in poorer health. A significant concern is that more than half the participants who rely on a primary caregiver indicated that they did not have an alternate care provider available if their primary caregiver were no longer able to care for them.

While these data seem to foreshadow a potential crisis in care that many persons with SCI may face in the future, the data have several notable limitations. First, the data are limited to veterans with SCI, a predominantly male population, and therefore may not be generalizable to women or to nonveterans with SCI. The data were collected on veterans receiving care at only one VA Medical Center and therefore may not represent all veterans nationwide. Even more importantly, because the data reported here were extracted from a larger study focusing on other issues, only limited data provided by the veterans with SCI were available and no data from the informal care providers were available for analysis. While these data provide a small window into the informal care provided to veterans with SCI, we were limited to global estimates of the number of hours of care provided and

were unable to differentiate time spent in active care tasks from time spent being available to provide care.

We need to know more about the informal care networks of veterans with SCI to better anticipate the future needs of veterans with SCI. In addition to obtaining more detailed information about the informal care provided, identifying specific tasks or activities that primary informal care providers are having increasing difficulty performing would be helpful. Such information could help healthcare planners better anticipate future care needs, develop programs to address those needs, and possibly help veterans remain living in the community longer.

We also need to know more about the health and well-being of informal care providers. Future research should interview and assess informal care providers themselves to assess more accurately these issues. Elliott and colleagues reported that family caregiver characteristics were associated with recently injured patients' psychological adjustment at discharge and with actual health outcomes (i.e., pressure ulcer occurrence) 1 year later [17]. These researchers have encouraged early identification and early intervention with caregivers who use ineffective problem-solving and coping strategies. Identifying and intervening with long-term family caregivers who are beginning to struggle to provide adequate care for their family members may similarly provide important health benefits.

## CONCLUSIONS

Informal or family caregivers play an important role in the daily healthcare of veterans with SCI. As the population of veterans with SCI is aging and facing increasing disability with age, many of their caregivers are coping with the problems of aging as well. The data presented here shed but a little light on a problem that many veterans with SCI may face in the near future. Additional research on the informal care networks of veterans with SCI is needed urgently to prepare for this potential crisis in care.

Anticipating future needs and preparing for them may reduce healthcare costs as well as improve the quality of life of veterans with SCI. Healthcare costs resulting from the increasing inadequacy of informal caregiving networks could be enormous. A breakdown in the informal caregiving network may result in increased secondary conditions and increased hospitalizations and nursing

home placement of persons with SCI. To prepare itself to provide effective care to veterans aging with SCI in the future, the VA needs to examine more closely the informal care networks to anticipate the rapidly changing care needs of this population.

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## REFERENCES

- Eisenberg MG, Saltz CC. Quality of life among aging spinal cord injured persons: long term rehabilitation outcomes. *Paraplegia* 1991;29(8):514–20.
- Lasfargues JE, Custis D, Morrone F, Carswell J, Nguyen T. A model for estimating spinal cord injury prevalence in the United States. *Paraplegia* 1995;33(2):62–68.
- DeVivo MJ, Stover SL. Long-term survival and causes of death. In: Stover SL, DeLisa JA, Whiteneck GG, editors. *Spinal cord injury: Clinical outcomes from the model systems*. Gaithersburg (MD): Aspen; 1995. p. 289–316.
- Kemp BJ, Krause JS. Depression and life satisfaction among people ageing with post-polio and spinal cord injury. *Disabil Rehabil* 1999;21(5–6):241–49.
- Samsa GP, Hoenig H, Branch LG. Relationship between self-reported disability and caregiver hours. *Am J Phys Med Rehabil* 2001;80(9):674–84.
- Ernst JL, Thomas LM, Hahnstadt WA, Piskule AA. The self-identified long-term care needs of persons with SCI. *Spinal Cord Inj Psychosoc Process* 1998;10(4):127–32.
- McGlinchey-Berroth R, Morrow L, Ahlquist M, Sarkarati M, Minaker KL. Late-life spinal cord injury and aging with a long term injury: characteristics of two emerging populations. *J Spinal Cord Med* 1995;18(3):183–93.
- Lal S. Premature degenerative shoulder changes in spinal cord injury patients. *Spinal Cord* 1998;36(3):186–89.
- Lovasik D. The older patient with a spinal cord injury. *Crit Care Nurs Q* 1999;22(2):20–30.
- Bauman WA, Spungen AM. Disorders of carbohydrate and lipid metabolism in veterans with paraplegia or quadriplegia: a model of premature aging. *Metabolism* 1994;43(6):749–56.
- Menter RR. Spinal cord injury and aging: exploring the unknown. 1993 Heiner Sell Lecture of the American Spinal Injury Association. *J Am Paraplegia Soc* 1993;16(4):179–89.
- Teasell R, Allatt D. Managing the growing number of spinal cord-injured elderly. *Geriatrics* 1991;46(6):78, 83–5,89.
- Charlifue SW, Weitzenkamp DA, Whiteneck GG. Longitudinal outcomes in spinal cord injury: Aging, secondary conditions, and well-being. *Arch Phys Med Rehabil* 1999;80(11):1429–34.
- McColl MA, Stirling P, Walker J, Corey P, Wilkins R. Expectations of independence and life satisfaction among ageing spinal cord injured adults. *Disabil Rehabil* 1999;21(5–6):231–40.
- Elliott TR, Shewchuk RM. Recognizing the family caregiver: Integral and formal members of the rehabilitation process. *J Voc Rehabil* 1998;10:123–32.
- Trieschmann RB. *Aging with a disability*. New York: Demos; 1987.
- Elliott TR, Shewchuk RM, Richards JS. Caregiver social problem-solving abilities and family member adjustment to recent-onset physical disability. *Rehabil Psychol* 1999;44(1):104–23.

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