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## Symptom Burden in Persons With Spinal Cord Injury

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### Abstract

**Objective**—To determine (1) the frequency, severity, and reported course of 7 symptoms in persons with spinal cord injury (SCI) and (2) the association between these symptoms and patient functioning.

**Design**—Postal survey.

**Setting**—Community.

**Intervention**—A survey that included measures of the frequency, severity, and recalled course of pain, fatigue, numbness, weakness, shortness of breath, vision loss, and memory loss, as well as a measure of community integration and psychologic functioning was mailed to a sample of persons with SCI. One hundred forty-seven usable surveys were returned (response rate, 43% of surveys mailed).

**Main Outcome Measures**—The frequency and average severity of each symptom was computed, and the frequencies of each type of reported course were noted. Analyses estimated the associations among the symptoms, and between symptom severity and measures of patient functioning.

**Results**—The most common symptoms were pain, weakness, fatigue, and numbness. All symptoms were reported to remain the same or to get worse more often than they were reported to improve once they began. Pain, weakness, fatigue, and memory loss were the symptoms most closely associated with patient functioning.

**Conclusions**—Patients with SCI must deal with a number of secondary complications in addition to any disability caused by the injury itself. Of 7 symptoms studied, pain, weakness, and fatigue appeared to be most common and most closely linked to patient social and mental health functioning. Research is needed to identify the causal relationships between perceived symptoms and quality of life in patients with SCI and to identify effective treatments for those symptoms shown to impact patient functioning.

### Keywords

Fatigue; Pain; Rehabilitation; Signs and symptoms; Spinal cord injuries

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Although secondary complications in persons with spinal cord injury (SCI), such as pressure ulcers,<sup>1,2</sup> bowel dysfunction,<sup>2,3</sup> bladder dysfunction,<sup>4</sup> urinary tract infections,<sup>5</sup> and obesity,<sup>6</sup> as well as a limited number of complications that are related to subjective experience, such as pain and fatigue, have received a great deal of attention in the research literature, the scope and impact of a number of other secondary complications associated with SCI have not yet been the focus of much empirical study.

As indicated above, of the symptoms reported by persons with SCI, pain and fatigue have received the greatest empirical attention. Research on pain, for example, indicates that about one third of patients with SCI report severe pain.<sup>7</sup> Research also indicates that pain can have a significant negative impact on the daily functioning of persons with SCI, including psychological functioning<sup>8–12</sup> and sleep.<sup>9,13</sup> Moreover, research indicates that once pain problems develop, they rarely if ever resolve over time and in fact, for shoulder pain, show a tendency to worsen over time.<sup>14</sup>

Fatigue also is common in patients with SCI.<sup>15</sup> Fatigue in persons with SCI has been typically discussed in terms of muscle fatigue and lack of endurance; that is, fatigue among persons with SCI has mostly been viewed as a physical construct<sup>16–18</sup> caused by weaker muscles that are more easily fatigable because of disuse (or overuse) and nerve damage.<sup>16,18,19</sup> Like pain, research indicates that fatigue may have serious adverse impacts in the daily lives of persons with SCI.<sup>15,20</sup> However, to our knowledge, no research has examined the extent to which fatigue improves or worsens over time in persons with SCI.

Prior research and our own clinical experience indicate that other symptoms, such as dyspnea (breathlessness), memory problems, vision problems, numbness, and perceived weakness, are reported by persons with SCI. Dyspnea has been reported in 24% and 6% of users and nonusers of motorized wheelchairs, respectively, in 1 sample of persons with SCI,<sup>21,22</sup> and presence of dyspnea has been associated with level of injury.<sup>23,24</sup>

Concerning potential memory problems, the Model Spinal Cord Injury Systems (MSCIS) reported that 28% of patients with acute SCI had at least a minor brain injury, with 12% reported to have cognitive or behavioral changes associated these injuries.<sup>25</sup> Kreutzer et al<sup>26</sup> performed neuropsychologic testing in 30 consecutive SCI patients with no obvious traumatic brain injury and found problems in visual learning, verbal learning, visual organization, and attention.<sup>27, 28</sup>

Sherman et al<sup>29</sup> reported a case of traumatic optic neuropathy documented by magnetic resonance imaging in a man with T4 paraplegia after a motorcycle crash who denied any loss of consciousness. Vaccaro et al<sup>30</sup> similarly reported a case of delayed cortical blindness in a patient with a C1 burst fracture (that resolved somewhat after cervical fusion). These case reports are consistent with our clinical experience that some patients with SCI report significant problems with their vision. However, to our knowledge, the frequency of vision problems and the potential impact of these problems on functioning have not yet been systematically examined in patients with SCI.

The subjective sensation of numbness can also be reported by persons with SCI, particularly at or below the level of injury, because of nerve damage or dysfunction. In a previous survey study of 84 community residents with SCI and chronic pain, 44 (52%) reported numb sensations, and 15 of these (18% of the sample) reported that the numb sensations were severe.<sup>31</sup> As with most other symptoms that could be experienced by patients with SCI, the association between numb sensations and patient functioning has not been adequately studied.

Finally, perceived weakness has also been reported to be a common problem in patients with SCI.<sup>32–34</sup> However, to our knowledge, its frequency and association with patient functioning

relative to other symptoms, such as pain and fatigue, have not yet been examined in samples of patients with SCI.

Although a great deal of research has studied a number of secondary medical conditions in persons with SCI, such as pressure ulcers and bladder and bowel dysfunction, less research has studied the many other symptoms often reported by patients with SCI. There is especially a lack of empirical information about the frequency and severity of symptoms such as dyspnea, memory problems, visual problems, numbness, and perceived weakness in persons with SCI. Moreover, the associations between these symptoms and measures of patient functioning have not yet been systematically examined. In addition, although some information about the course of pain in persons with SCI is available,<sup>19</sup> very little, if any, information is available concerning the course of other symptoms when they occur, either in the long (ie, since onset) or short (ie, over the past 6mo) term. Therefore, we do not know if fatigue, memory loss, vision loss, numbness, and shortness of breath tend to improve, stay the same, or get worse when and if they develop in persons with SCI. If research shows that these symptoms improve after they develop, then clinicians can use this knowledge to inform patients that any problems with symptoms such as weakness or fatigue may be expected to resolve on their own. On the other hand, if research shows that these symptoms do not resolve on their own or even get worse over time, then this knowledge can be used by clinicians as an indication for effectively treating such symptoms as soon as possible when they are reported. Knowledge about the natural course of symptoms is also helpful for clinical researchers; any symptoms that are shown to be consistently associated with poor quality of life (QOL) and that either do not resolve or get worse over time should be targeted for treatment development, especially when and if there is a lack of effective treatments for these symptoms.

The primary purpose of this study was to increase our knowledge about the nature and impact of a number of symptoms commonly reported by persons with SCI. Specifically, we sought (1) to determine the relative frequency and severity of pain, fatigue, numbness, weakness, shortness of breath, vision loss, and memory loss, in a sample of persons with SCI; (2) to examine the extent to which these symptoms are reported to have a tendency to improve or resolve, get worse, or stay the same over time; and (3) to estimate the associations among the symptoms and the associations between the severity of these symptoms and both community integration and psychologic functioning in a sample of persons with SCI.

Based on previous research, we developed a number of hypotheses regarding the analyses about which we are reporting. First, we anticipated that the frequency of pain would be around 80% in this sample, based on the findings from a previous study that used a similar sample.<sup>35</sup> We were also interested in exploring the frequency of other symptoms reported by the sample. We did not make any hypotheses concerning their specific frequency, because the frequency of occurrence of these symptoms had not been reported by previous researchers. In addition, we predicted that most respondents would report that their pain either remained stable or got worse over time, given that pain in persons with SCI is relatively refractory.<sup>14</sup> Again, however, because of the lack of previous research on the natural course of other symptoms, we did not make any hypotheses concerning the reported course of weakness, fatigue, numbness, memory loss, vision loss, or dyspnea. Finally, because each symptom plays an important role in patient functioning, we predicted that the severity of each symptom would show independent (ie, when controlling for the other symptoms) associations with patient functioning.

## METHODS

### Subject Characteristics

Participants for the current study completed a survey study that focused on pain in persons with SCI.<sup>14</sup> As described in our previous report of this sample,<sup>14</sup> questionnaires were mailed

to 339 persons with SCI in waves from September 5, 2002, to June 25, 2004, and surveys were returned from September 12, 2002, to August 13, 2004. A primary source of subjects for this study was the University of Washington MSCIS database, and therefore most surveys (320 [78%]) were sent to persons in Washington State. Other sources of data subjects included persons who learned about the study via word of mouth from study participants or from contact with one of the study investigators in their clinical practices. Each questionnaire was accompanied by a consent form and a cover letter inviting the potential study participants to participate in the study. Subjects were paid \$25 for completing and returning the consent forms and survey. The study procedures were approved by the University of Washington Human Subjects Review Committee.

## Measures

The survey assessed demographic information (age, education level, employment status, race and ethnicity, marital status) and descriptive information about the SCI (time since SCI, SCI level). Survey respondents were also asked about the presence, severity (on 0 [none] to 10 [very severe] numeric scales), and course over the long and short terms (whether each symptom had become worse, become better, or stayed the same since its onset; whether it had become worse, become better, or stayed the same in the past 6 months) of 7 symptoms that they might be experiencing: pain, weakness, fatigue, numbness, memory loss, vision loss, and shortness of breath. These symptoms were selected based on (1) our clinical experience that at least some persons with SCI report experiencing these and (2) previous research that indicates that these are indeed reported by patients with SCI.

All participants were asked to complete a measure of community integration and psychologic functioning. The 13-item Community Integration Questionnaire (CIQ)<sup>36</sup> was used to assess community integration. The 3 integration domains of the CIQ include activities in the home (eg, meal preparation, housework), social activities (eg, leisure activities with others), and productive activity (eg, employment status). Evidence supports the reliability,<sup>37</sup> discriminant validity,<sup>36</sup> and construct validity<sup>36</sup> of the CIQ scales.

We used the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) mental health scale<sup>38</sup> to assess psychologic functioning. This measure has shown reliability and validity.<sup>38</sup> The mental health scale is scored so that it has a possible range of 0 to 100, with higher scores indicating better mental health.

## Analyses

The response rate to the survey and basic demographic and descriptive information about the respondents were examined first to describe the sample. Next, the frequency (rates of respondents who provided a response of “1” or more when rating the severity of each symptom) of each symptom and the average severity (both for all participants who rated the symptom on the 0–10 scale and also only among those who endorsed the symptom—ie, rated the severity as being at least “1”) were computed for each of the 7 symptoms for descriptive purposes. The frequencies of each course type (worse, the same, better) associated with each symptom since onset and during the past 6 months were also computed to determine the extent to which each symptom is perceived to change over time.

Pearson correlation coefficients were computed between the severity ratings of each symptom to determine the extent of overlap among these ratings. A very high level of overlap (eg, correlation coefficients of .50 or higher among the ratings) would suggest a possible factor that might be contributing to symptom reporting, such as depression or somatization, whereas lower coefficients would suggest that there are unique factors that contribute to the experience and reporting of each symptom. Correlations were also computed between the symptom severity

ratings and the criterion measures (3 subscales of the CIQ, SF-36 mental health scale) to estimate the associations between symptom severity and patient functioning. The association between symptom severity and patient functioning was initially examined by computing correlation coefficients between each severity rating and the measures of each functioning domain. To control for the increased risk of type I error rates associated with multiple tests, a Bonferroni adjustment was used (.05/28 tests = .0018) for determining whether an association was statistically significant.

Finally, 4 regression analyses were performed with the 4 measures of functioning as the criterion variables and the 7 symptom severity ratings as predictors entered as a block (ie, at the same time) to determine the extent to which each of the symptoms contributes independently to the prediction of the 3 community integration domains and psychologic functioning. Age, sex, and duration of SCI were controlled for in these analyses, because symptoms are likely to increase in frequency with age in the general population; both age and sex have been found to be associated with both community integration and mental health in SCI samples,<sup>39,40</sup> and the duration of SCI could be related to both the development of symptoms (eg, shoulder pain<sup>14</sup>) and the criterion variables.

## RESULTS

### Response Rate and Participant Characteristics

Of 339 surveys mailed, 27 were returned because the potential participant was no longer at the address on record, 2 were returned with information indicating that the subjects were deceased, 1 was returned with a note indicating that the patient was hospitalized and could not participate, and 2 potential participants wrote to say that they declined participation. Of the 309 possible surveys that might have been completed and returned (ie, excluding the 27 incorrect addresses, 2 deceased persons, and 1 unavailable person), we received 147 surveys with complete data (representing 48% of surveys that could have been returned and 43% of surveys mailed).

The mean age  $\pm$  standard deviation (SD) of the study subjects was 48.8 $\pm$ 13.0 years (range, 21–88y). As previously reported,<sup>14</sup> there was a wide degree of variability in the number of years since SCI (mean, 16.6 $\pm$ 10.4y; range, 3.2–57.4y). The most frequent single cause of SCI was a motor vehicle collision (40.8%). Other causes included a fall (17.0%), a sports injury (7.5%), diving (7.5%), a gunshot wound (2.7%), or one of a variety of other causes (24.5%). The levels of injury reported by participants were C1-4 (15.6%), C5-8 (34.7%), T1-5 (10.2%), T6-12 (32.0%), and L1-S4/5 (7.5%). Thirty-nine percent of respondents reported that they had a complete injury, 50% reported that the injury was incomplete, and 11% reported that they did not know if their injury was complete or incomplete.

The majority (74.8%) of respondents were men, consistent with the higher frequency of males in the SCI population. Most (89.2%) of the survey respondents reported their ethnicity as white, with the remainder reporting their ethnicity as Native American (6.1%), Hispanic (3.4%), Asian or Pacific Islander (3.4%), or black (1.4%). The respondents reported having attended vocational or technical school (7.5%), having had some college (29.9%), being college graduates (27.9%), or having attended graduate school (19.0%). Relatively few (8.8%) had only a high school education or General Educational Development certificate, and only 6.8% reported that they did not graduate from high school.

Respondents to this survey were compared with nonrespondents on all demographic variables. The only significant difference to emerge was for education level; respondents to the current survey reported a higher frequency of having completed college or attended graduate school (46.9%) than persons who responded to the previous survey but not the current one (33.9%) ( $\chi^2_1$  test=5.96,  $P<.05$ ).



## Frequency and Course of 7 Symptoms

The most common symptoms reported by the survey respondents were pain (84%), fatigue (67%), numbness (66%), and weakness (64%) (table 1). Shortness of breath (34%), vision loss (27%), and memory loss (27%) were reported less frequently. The most severe symptoms were pain (with 35% reporting pain levels of  $\geq 7$  on the 0–10 scale; sample mean severity rating,  $4.71 \pm 3.14$ ) and numbness (38% reporting numbness levels of  $\geq 7$  on the 0–10 scale; mean severity rating,  $4.41 \pm 3.91$ ). Weakness and fatigue were also reported as severe by a substantial subset of participants (both 18%; mean severity ratings,  $3.21 \pm 3.08$  and  $3.23 \pm 2.89$ , respectively). Shortness of breath, memory loss, and vision loss were reported as less severe, on average.

All 7 of the symptoms were more often reported as staying the same (range, 24%–60%) or getting worse (range, 21%–69%) rather than getting better (range, 3%–35%) since the onset of the symptom. During the past 6 months, symptoms tended most often to be perceived as staying about the same (range, 53%–82%). When change did occur during the past 6 months, the symptoms were more likely to get worse (range, 14%–39%) than to improve (range, 0%–13%). In short, according to the respondents' recollections, little change seems to occur in symptom severity once symptoms begin, but when change does occur, symptoms are more likely to get worse than to get better.

## Associations Among the Symptom Severity Ratings

Strong correlations were found between fatigue and weakness ( $r=.63$ ), fatigue and shortness of breath ( $r=.52$ ), and shortness of breath and weakness ( $r=.52$ ). All but 3 of the other associations between the symptom ratings were in the moderate range ( $r$  range, .20–.49), with the exceptions of the associations between memory loss and imbalance ( $r=.13$ ), memory loss and numbness ( $r=.13$ ), and memory loss and shortness of breath ( $r=.16$ ). Overall, there was relatively little overlap among the symptom ratings, with the strongest association only indicating about 40% of variance shared between ratings of fatigue and weakness.

## Associations Between Symptom Severity and Patient Functioning

The zero-order correlation coefficients between the symptom severity ratings and the 4 criterion measures of functioning used in this study are presented in table 2. These analyses indicate that the symptoms reported by this sample were more closely linked to psychologic functioning and social integration than they were to home competency or productive activity. In addition, the symptoms that were most closely associated with these domains of functioning were pain, weakness, fatigue, and memory loss. All statistically significant correlations were negative, indicating that the greater the symptom intensity, the lower psychologic functioning and social integration. Numbness, vision loss, and shortness of breath were only weakly and nonsignificantly associated with the measures of functioning.

Consistent with the correlation analyses reported earlier, the regression analyses indicated that symptom ratings did not contribute significantly to the prediction of the CIQ home competency scale or the CIQ productive activity. On the other hand, as a group, and controlling for age, sex, and SCI duration, the 7 symptoms were significantly associated with both the CIQ social integration and SF-36 mental health scales (table 3). As a group, the symptoms explained 23% of the variance of the CIQ social integration scale over and above statistically significant contributions of age, sex, and duration of SCI. Pain, weakness, memory loss, and vision loss all made independent and statistically significant contributions to the prediction of social integration in the multivariate analyses; fatigue showed a nonsignificant ( $P=.052$ ) trend for making an independent contribution to the prediction of social integration.

The regression analysis predicting the SF-36 mental health scale indicated that the symptoms explained 25% of the variance in this criterion measure over and above the contributions of age, sex, and duration of SCI. In this analysis, pain and memory loss made independent and statistically significant contributions, whereas the contributions of fatigue ( $\beta=-.19, P<.10$ ) and vision loss ( $\beta=.17, P<.10$ ) did not reach statistical significance (see table 3). In summary, the regression analyses indicated that when controlling for age, sex, duration of SCI, and each of the other symptoms, pain and memory loss made significant and independent contributions to the prediction of both social integration and psychologic functioning. Furthermore, weakness and vision loss made significant and independent contributions to the prediction of social integration, and fatigue showed a nonsignificant trend toward making an independent contribution to the prediction of both social integration and psychologic functioning.

## DISCUSSION

This study provides new information concerning the frequency and severity of a number of symptoms and their association with functioning in persons with SCI. As predicted—and consistent with previous research—pain was very common (84%) and was reported to be more likely to stay the same or to get worse than to resolve or improve both since the onset of the symptom and within the past 6 months. We also found that each of the other 6 symptoms assessed were endorsed by at least some of the respondents. Of these, the most common were weakness, fatigue, and numbness (endorsed by about two thirds of the sample); memory loss, vision loss, and dyspnea were endorsed by about one third of the sample. Like pain, once these other symptoms develop, they are reported to be more likely to stay the same or get worse than to resolve or get better. These findings have significant implications for the assessment and treatment of symptoms in persons with SCI.

Vision loss, in particular, is rarely reported as a direct consequence of SCI and yet, of the 27% of respondents who endorsed this symptom, 69% reported that it has become worse since onset, and 39% reported worsening vision over a relatively short time period, 6 months. The rate of vision difficulties in our sample is particularly notable given the low prevalence of vision problems reported in epidemiologic studies (usually <3%).<sup>41–43</sup> Further study is needed to determine the extent to which the high rate of perceived vision problems in our sample is the result of medical conditions associated with aging (eg, presbyopia, cataracts, glaucoma) or associated medical conditions (eg, diabetes mellitus) or if there are additional conditions found in SCI, such as autonomic dysreflexia or postural hypotension, that could potentially be impairing vision in this population.

The frequency, severity, and refractory nature of pain reported by participants in this study provide additional support for the growing body of research indicating that pain is a serious problem among many persons with SCI.<sup>7,14</sup> These findings support the need to develop more effective treatments for pain in persons with SCI. On a positive note, a review of the literature suggests that researchers may be now responding to this need. For example, recent pilot studies have reported on the potential efficacy of a number of innovative treatments, including electric oscillating field stimulation,<sup>44</sup> magnet therapy,<sup>45</sup> cognitive behavioral therapy,<sup>46</sup> transcranial electric stimulation,<sup>47</sup> exercise,<sup>48</sup> hypnotic analgesia,<sup>49</sup> and a number of medications such as gabapentin,<sup>50,51</sup> lamotrigine,<sup>52</sup> and amitriptyline.<sup>53</sup> Much of this preliminary work is promising, although none of these treatments appears to produce a marked decrease in pain in all study participants. Our findings support the importance of this work to develop effective treatments for SCI-related pain or at least examine ways of combining existing treatments that have moderate efficacy, on average, into regimens and treatment protocols that could have a significant clinical impact on pain and suffering.

Although not as frequent or severe as pain in this sample, fatigue was also very common, was significantly linked to measures of patient dysfunction, and was reported to be very refractory among those who reported it. This finding underscores the potential negative impact that fatigue may have on the lives of many persons with SCI. Although there are some studies<sup>15,54</sup> that have noted fatigue as a problem in SCI populations, very little is known about the nature, course, or treatment of fatigue in persons with SCI. The current findings, when considered in light of the limited research on SCI-related fatigue, suggest that such research is urgently needed.

Other symptoms and complaints, such as weakness, numbness, memory loss, vision loss, and shortness of breath, have not been previously systematically studied in samples of persons with SCI. The current findings indicate that, of these other symptoms, weakness and numbness are the most common, but that weakness and memory loss are most closely linked to important functioning domains. Thus, although numbness may be relatively common, it may not be particularly problematic for most patients with SCI. On the other hand, although memory loss was endorsed only by a little more than a quarter of participants, it showed a strong association with both mental health and social integration. Readers should keep in mind, however, that prevalence rates of cognitive problems in the general population, particularly memory loss, show a large variability in epidemiologic studies (probably because of differences in samples and assessment procedures), ranging from a low of 3.2% to as much as 53.8%.<sup>55-59</sup> Thus, one cannot assume that the memory problems, or even the other symptoms, reported by participants in this sample are necessarily related to SCI.

Of course, patient-reported symptoms are not the only factors that contribute to decreased patient functioning. Previous research has identified a number of predictors of both psychologic functioning (eg, recent urinary infections,<sup>60</sup> spasticity,<sup>61</sup> bowel problems,<sup>61</sup> receiving family care,<sup>60</sup> catastrophizing,<sup>62</sup> preinjury history of depression,<sup>63</sup> marital status,<sup>61</sup> employment status<sup>61</sup>) and community and social integration (eg, pain,<sup>64</sup> neurologic classification and injury level,<sup>65</sup> locus of control,<sup>64</sup> family support<sup>66</sup>) in subjects with SCI. As a group, this research is consistent with biopsychosocial models of functioning in persons with SCI, which argue that biologic, psychologic, and social factors all can contribute to patient functioning. Patient care and functioning are likely maximized when clinicians assess and then treat as appropriate each of the biologic, psychologic, and social problems or issues that may be contributing to dysfunction in any one patient. Perhaps pain, weakness, fatigue, and memory loss might be considered an important (but not the exclusive) part of addressing the biologic portion of the whole person with SCI.

### Study Limitations

There are a number of limitations of this study that should be considered when interpreting the results. First, we only measured 2 primary domains of functioning (community integration, psychologic functioning). Although the measure of community integration used in this study, the CIQ, has evidence of good reliability and validity,<sup>36,37</sup> it has been criticized given that scoring favors respondents who (1) have able-bodied friends over those whose friends are not able-bodied, (2) spend more time with friends than family, and (3) tend to do household activities alone rather than with others.<sup>67</sup> It is possible that some of the symptoms that did not evidence significant associations with the criterion variables used would show significant and strong relationships with other functioning or QOL domains or with other measures of community integration or psychologic functioning. Future research on the nature, scope, and impact of symptoms in persons with SCI should therefore assess additional functioning domains, such as physical functioning, social role functioning, and participation, and examine the association between these symptoms and community integration and psychologic functioning assessed with different measures.



A second limitation of the current study is that only some secondary complications—those focusing on perceived symptoms—were assessed and not other secondary complications common to persons with SCI such as spasms, bladder and bowel dysfunction, pressure ulcers, insomnia, and obesity, among others. Thus, we were not able to determine the relative contribution of the symptoms studied to patient functioning over and above any effects of these other complications. Also, we did not examine any of the signs associated with the secondary complications to help verify and quantify the extent of these problems. Future researchers should include measures of additional secondary complications to examine their relative frequency, severity, and potential role in patient functioning.

It is also possible that some study participants may have been confused about the consequences of SCI (eg, paralysis) and the symptoms we assessed (eg, weakness or numbness). To the extent that such confusion occurred, the associations between the symptoms and functioning, in particular, may be overestimated. Future researchers could potentially control for extent of paralysis in the analyses when measures of this are available. Similarly, the domains of pain and other symptoms are multidimensional; they consist not only of magnitude, which was assessed in this study, but can include spatial, quality, and temporal components. Simple 0-to-10 magnitude estimates do not provide a thorough evaluation of these symptoms. On the other hand, the fact that significant effects emerged for pain and some of the other symptoms at all, despite this limitation, supports the importance of these symptoms as they relate to patient functioning. Nevertheless, future research could examine how the location(s) of these symptoms, their quality, and their frequency might moderate the associations between symptom severity and QOL or even themselves show significant direct associations with measures of patient functioning.

Another limitation concerns the cross-sectional nature of the data, which makes it impossible to draw causal conclusions regarding the potential impact of symptoms on patient functioning. It is possible, for example, that higher levels of psychologic dysfunction may make patients more aware, or more ready to endorse, symptoms such as pain or memory loss.

A number of factors limit the potential generalizability of the findings. For example, the respondents came from 1 geographic region and received initial care at the same center. Also, as a group, the respondents reported a higher level of education than the nonrespondents. Finally, although the response rate of 48% (of possible surveys that could have been returned) to our survey is standard for this type of study, it still represents only a subgroup of the population. Additional research in other SCI samples is necessary to determine the generalizability of the findings.

## CONCLUSIONS

Despite the study's limitations, the current findings: (1) replicate previous research concerning the frequency and refractory nature of pain in persons with SCI; (2) indicate that other symptoms, such as weakness, fatigue, and numbness, are very common; and (3) indicate that a number of these symptoms, including pain but also weakness, fatigue, memory loss, and vision loss are associated with measures of social integration and psychologic functioning. Research is needed to replicate these findings in other samples of persons with SCI. A better understanding of the types of symptoms persons with SCI experience and their frequency, severity and impact on day-to-day functioning is an important step toward identifying effective treatments and improving the QOL of those living with SCI.

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**Table 1**

Frequency and Course of 7 Symptoms in the Sample of Patients With SCI

Symptom*	Frequency of Occurrence (% >1)	Frequency of Severe Symptom (% >6)	Average Severity (mean ± SD)	Course Since Onset (%)			Course Last 6 Months (%)		
				Worse	Same	Better	Worse	Same	Better
Pain	84	35	4.17±3.08	40	39	21	30	64	6
Weakness	64	18	3.21±3.10	35	30	35	26	64	10
Fatigue	67	18	3.23±2.91	41	31	28	26	66	9
Numbness	66	38	4.41±3.89	21	60	19	14	82	4
Memory loss	27	5	1.11±2.14	49	39	13	34	53	13
Vision loss	27	4	0.99±1.96	69	29	3	39	61	0
Shortness of breath	34	8	1.52±2.61	28	53	18	18	74	8

\* All symptoms rated by respondents on a 0 (none) to 10 (very severe) scale.

**Table 2**

Correlation Coefficients Between Patient-Rated Symptom Severity and Measures of Patient Functioning

Symptom	Community Integration (CIQ)			Psychologic Functioning (SF-36 mental health scale)
	Home Competency	Social Integration	Productive Activity	
Pain	-.05	-.33*	-.16	-.40*
Weakness	-.15	-.33*	-.14	-.32*
Fatigue	-.09	-.31*	-.17	-.34*
Numbness	-.03	-.11	-.14	-.23
Memory loss	-.13	-.32*	-.11	-.34*
Vision loss	.01	.00	-.08	-.08
Dyspnea (shortness of breath)	-.06	-.02	-.19	-.18

\*  $P < .002$ .

**Table 3**

Multiple Regression Analyses Predicting CIQ Social Integration and SF-36 Mental Health Scale Scores From 7 Symptom Severity Ratings

Step and Variables	Total $R^2$	$R^2$ Change	F Change	$\beta$
Criterion: CIQ social integration scale score				
Step 1: Demographic variables	.10	.10	5.05 <sup>‡</sup>	
Age				-.20*
Sex				.21*
Duration of SCI				-.03
Step 2: Symptom ratings	.33	.23	6.77 <sup>§</sup>	
Pain				-.22*
Weakness				-.23*
Fatigue				-.20 <sup>†</sup>
Numbness				.09
Memory loss				-.24 <sup>‡</sup>
Vision loss				.22*
Shortness of breath				.10
Criterion: SF-36 mental health scale				
Step 1: Demographic variables	.03	.03	1.20	
Age				-.03
Sex				.00
Duration of SCI				-.15 <sup>†</sup>
Step 2: Symptom ratings	.28	.25	6.70 <sup>§</sup>	
Pain				-.21*
Weakness				-.12
Fatigue				-.19 <sup>†</sup>
Numbness				-.11
Memory loss				-.26 <sup>‡</sup>
Vision loss				.17 <sup>†</sup>
Shortness of breath				.08

\*  $P < .05$ .

<sup>†</sup>  $P < .10$ .

<sup>‡</sup>  $P < .01$ .

<sup>§</sup>  $P < .001$ .