
Spinal Cord Injury Community Survey: Understanding the Needs of Canadians with SCI

Luc Noreau, PhD,¹ Vanessa K. Noonan, PhD, PT,^{2,3} John Cobb, BSc, OT,^{2,4}
Jean Leblond, PhD,¹ and Frédéric S. Dumont, PhD¹

¹Center for Interdisciplinary Research in Rehabilitation and Social Integration (CIRRIS) and Université Laval, Quebec City, Canada;

²Rick Hansen Institute, Vancouver, Canada; ³Division of Spine, Department of Orthopedics, University of British Columbia, Vancouver, Canada; ⁴Vancouver General Hospital, Vancouver, Canada

Background: There is a lack of literature regarding service needs of people with SCI living in the community. Better assessment of expressed and met and unmet needs would help in the development of effective service delivery. **Objective:** From a national SCI Community Survey in Canada, the aim was to identify the most critical service needs of people living in the community at least 1 year post discharge from rehabilitation and the support they received to meet their needs. **Method:** Data were collected mainly through a secure Web site and encompassed demographics, personal and household income, an SCI severity measure, and an SCI community needs measure containing information on 13 SCI-related needs. **Results:** A total of 1,549 persons with SCI (traumatic lesion, $n = 1,137$; nontraumatic lesion, $n = 412$) across Canada completed the survey. Most critical needs for community integration were expressed by a substantial proportion of survey participants, but significantly more expressed and met needs were reported by persons with a traumatic than a nontraumatic lesion. Personal and environmental characteristics influenced the probability of expressing and meeting needs (eg, severity of injury and household income). Help and support to meet expressed needs were received from government agencies, community organizations, and friends or family. **Conclusion:** Better assessment of expressed and met or unmet needs for services remains a challenge but will serve as a tool to optimize service delivery in the community. Environmental barriers to services, particularly the process of getting needs met and associated costs, remain an issue that requires a reconsideration of some aspects of access to services. **Key words:** community living, environmental barriers, income, nontraumatic spinal cord injury, SCI-related needs, spinal cord injury

Traditionally, research on the continuum of care and services after spinal cord injury (SCI) focused largely on the initial rehabilitation phase (acute management and inpatient rehabilitation) in terms of intervention efficacy, medical and functional outcomes, and prognosis.¹⁻⁵ However, there is a paucity of literature regarding service needs after discharge from rehabilitation, even though effective service planning for persons with SCI living in the community requires determining what specific service needs they express and then determining whether their needs are met in a satisfactory manner.

Studies investigating the expressed needs of persons with SCI suggest that areas related to the greatest needs include physical changes such as strength and mobility (31%), transportation

(24%), work issues (22%), and ongoing education (19%). Among significant barriers preventing needs from being met, study participants mainly reported limited local expert knowledge of SCI (81%) and insufficient funding (56%).⁶ Kennedy and colleagues^{7,8} also reported unmet needs in the areas of sexual activity and pain relief, and subjects identified a need for specialized treatment to address those needs. Access to employment has also been recognized as a problematic area for persons with SCI in many other studies.⁹⁻¹² In Canada, national surveys examined self-reported needs as well as service availability for individuals with SCI living in the community.^{13,14} The most important unmet need that was identified most often by respondents was accessible infrastructure, specifically accessible public buildings (58%), adequate enforcement of disabled parking (57%),

Corresponding author: Luc Noreau, PhD, CIRRIS/IRDPQ, 525 Boulevard Wilfrid-Hamel, Québec, QC Canada, G1M 2S8; phone: 418-529-9141 ext. 6489; e-mail: Luc.Noreau@rea.ulaval.ca

Top Spinal Cord Inj Rehabil 2014;20(4):265-276
© 2014 Thomas Land Publishers, Inc.
www.thomasland.com

doi: 10.1310/sci2003-265

sufficient disabled parking (45%), and accessible streets and sidewalks (curb cuts or ramps) (38%).

Overall, these studies reported various types of needs (eg, health or disability issues) and influencing factors (eg, accessible infrastructure), but they did not specifically report on needs for services in major domains that foster community integration or those that seem to be prerequisites for achieving optimal participation and citizenship (housing, attendant care, primary health care access, vocational training, etc). Moreover, until recently, they did not systematically report expressed needs as well as met needs,¹⁵ and none indicated sources of support or help to ensure that service needs are met. It is mainly by determining perceived gaps in service delivery and the association with other factors that policy makers and service providers will be able to provide appropriate services to support community living after SCI.

The SCI Community Survey (SCICS) was designed to better understand the service needs of persons with a traumatic or nontraumatic SCI, and it goes beyond previous studies. The aim of this article was to identify the most critical service needs of people living in the community at least 1 year post discharge from rehabilitation. Specifically, the article focuses on the frequency of expressed needs for services, the extent to which they are met or unmet, type of help and support received to meet needs, degree of satisfaction, and environmental barriers affecting the fulfilment of expressed needs.

Methods

A more in-depth description of the methodology of the survey is presented in the first article in this issue.¹⁶ Overall, the SCICS is a series of measures used by Canadian collaborators, including people with SCI, researchers, health care professionals, and service providers, to assess important aspects of community living. Recruitment was done through national organizations (eg, SCI Canada, Rick Hansen Registry, rehabilitation facilities) and used the following inclusion criteria to identify eligible participants: ≥ 18 years of age, living in a community setting for at least 1 year after discharge from hospital/rehabilitation, having an SCI of traumatic or nontraumatic origin,

and understanding English or French. Data were collected mainly through a secure Web site (including the informed consent form) developed by a market research organization with experience conducting online surveys. A telephone interview was also offered to eligible participants.

Questionnaires

Demographic measure

Demographics included age, time since injury, gender, relationship status, ethnic origin, language, location of residence through postal code, level of education, living setting, living arrangement, personal and household income, and sources of income. An SCI classification measure provided information on the type and severity of injury as well as the cause (traumatic/nontraumatic) of the SCI.

SCI-related needs measure

The SCI community needs measure was developed for this study. This measure collects information on 13 SCI-related needs: accessible housing, attendant care, income support, short-distance transportation, long-distance transportation, SCI-specialized health care, general health care, emotional counselling, case management, SCI peer support, job training, healthy living (recreational and leisure programs), and equipment (medical supplies, communication devices, and technical aids).

The SCI community needs measure consists of 5 sections. In the first section, participants indicated whether or not they had some of 13 needs (yes/no) since discharge. Only those who expressed a specific need completed the remaining sections. In the second section, participants indicated to what extent an expressed need was met (1 = *completely* to 5 = *not at all*). The third and fourth sections focus on support received from family and friends and from governments, community organizations, or other organizations. The fifth section comprises 9 common environmental obstacles that can hinder individuals when accessing services to meet their needs (eg, availability, affordability and features of services, physical accessibility, lack of information, service providers' knowledge of SCI, etc).

Ethics

Ethical approval was obtained from an independent Canada-wide institutional review board (Institutional Research Board Services), in addition to approval from the Research Ethics Board of Université Laval and local research ethics boards, as required in order to cooperate with local researchers to promote the survey in the recruitment process.

Statistics

Statistical analysis was performed using IBM SPSS version 21.0 (IBM Corp., Armonk, NY) and R software version 2.14.

To describe sample characteristics, measures of central tendency (mean and median) and variability (confidence interval and *SD*) were used. Crosstabs were used to demonstrate interrelationships between variables. Pearson's chi-square test was used to verify significance (significance level set at .05). When comparing the central tendency of 2 samples, the Mann-Whitney test was used; the Kolmogorov-Smirnov test was used to compare the whole distribution of 2 samples.

Results

Participants

A total of 1,549 persons with SCI (traumatic lesion [TR], $n = 1,137$; nontraumatic lesion [NT], $n = 412$) across Canada completed the survey (age, 49.6 ± 13.9 years; time since injury, 18.5 ± 14.3 years). Most of the Canadian regions were represented in the sample, and survey participants came from large cities as well as small communities. Most of the participants were Caucasian (91%) and more than 40% lived with a spouse (plus an additional 10% with spouse and children). Differences were observed in some demographics between the type of lesion (TR vs NT), such as percentage of people living with a spouse (39% vs 44%), being female (29% vs 43%), and being older (48 ± 13 vs 53 ± 15 years). Overall, differences in the type of lesion suggested that expressed and met needs for services should be examined separately

among these subsamples, when applicable and relevant. A more in-depth description of the sample characteristics is provided in the first article in this issue (see **Table 1** in that article).¹⁶ (Given the limited space in this journal to present additional methodological information and all significant results, the research team developed a section on their Web site called "Extra data" that presents additional information and findings [cirris.ca/tscir.html].)

Illustrations of expressed vs met needs

As reported in the first article in this issue (see **Table 2** in that article),¹⁶ most critical needs for community integration were expressed by a substantial proportion of survey participants since discharge from rehabilitation, with differences based on the type of lesion. On average, participants with a TR lesion indicated significantly more expressed needs (8.3 ± 2.6 vs 7.1 ± 3.0 ; $P < .001$) as well as met needs (5.5 ± 2.8 vs 4.5 ± 2.7 ; $P < .001$) compared to participants with an NT lesion. However, the mean ratio of met to expressed needs is similar between the TR and NT lesion groups ($67\% \pm 28\%$ vs $67\% \pm 31\%$; Kolmogorov-Smirnov test, $Z = 0.769$; $P = .595$). This means, for example, that even though people with a TR lesion expressed more needs, they also had more needs met than people with an NT lesion.

Although the mean proportion of met to expressed needs showed a ratio of 2:3, an important variation was observed among the participants, as indicated by large standard deviations (see above). To get a comprehensive picture of expressed compared to met needs for services, a graphic illustration of their interrelationships was created with a bubble chart in which data points are replaced by bubbles, the size of which represents the number of observations (a larger bubble indicates a greater number of participants). **Figure 1** shows the significant variation in the relationships between the numbers of expressed needs compared to met needs, suggesting that some participants were able to find support to meet most of their expressed needs since discharge from rehabilitation while others did not. The dashed line (middle of the graph) reflects the number

Table 1. Relative risks^a of expressing a need or having a need met according to type of lesion or level of household income in people with a traumatic SCI

Needs	Lesion groups ^b				Household income ^c			
	Expressed needs (<i>n</i> = 1007)		Met needs ^d (<i>n</i> = 310 to 934)		Expressed needs (<i>n</i> = 930)		Met needs ^d (<i>n</i> = 289 to 862)	
	Tetra ABC vs AIS D	Para ABC vs AIS D	Tetra ABC vs AIS D	Para ABC vs AIS D	> \$60K vs < \$30K	\$30K-\$60K vs < \$30K	> \$60K vs < \$30K	\$30K-\$60K vs < \$30K
Attendant care	2.66		1.23		0.87		1.27	
Long-distance transportation	1.95	1.79			1.17		1.57	1.47
Accessible housing	1.91	1.91	1.14				1.31	1.21
SCI peer support	1.72	1.61					1.37	
Case management	1.58	1.38		1.36	0.80		1.46	
Equipment and technical aids	1.46	1.45					1.27	
Short-distance transportation	1.31	1.24		1.13			1.30	1.25
Income support	1.30				0.60	0.75	2.65	2.02
SCI-specialized health care	1.14	1.09					1.23	
General health care	1.14	1.10	1.15	1.18				
Emotional counselling							1.41	1.38
Job training							1.52	
Healthy living and leisure programs					1.21		1.59	

Note: Only statistically significant relative risks (RR) are presented ($P \leq .05$). Data are listed in decreasing order of RRs of expressing a need in a tetraplegia ABC lesion. Income is given in Canadian dollars.

^aRR is the probability of an event occurring (expressing a need or meeting a need) in a group with a specific characteristic (tetra ABC or income >\$60,000) divided by the probability of the same event occurring in a group with another characteristic (AIS D or income <\$30,000).

^bParticipants were grouped according to type of lesion based on the level of injury (tetraplegia vs paraplegia) and severity of injury (AIS grade ABC vs D).

^cParticipants were grouped according to household income (>\$60,000; \$30,000 to \$60,000; <\$30,000).

^dSample sizes depend on the number of participants who reported having this need.⁴

of participants (as shown by the bubble size) for whom all expressed needs were met according to the number of expressed needs. Precisely, 21.4% of participants with a TR lesion had all their needs met (**Figure 1a**) compared to 25.7% in the NT lesion group (**Figure 1b**) (Pearson's $\chi^2 = 3.28$, $P = .07$). Conversely, in participants located in the bottom and right side of the graph (shaded area), there is a decreasing proportion of met to expressed needs (ratio $\leq 50\%$), suggesting that they were less able to find ways to meet their needs.

Personal and environmental variables associated with expressed and met needs

The expression and meeting of needs for services seem to be influenced by various personal characteristics: Severity of the lesion, years since

injury, and level of education were associated with a difference in the expression of needs and proportion of met to unmet needs. For example, **Table 1** reports the relative risks (RRs) of expressing a need or having a need met, based on the severity of the traumatic lesion. Paraplegia or tetraplegia (American Spinal Injury Association Impairment Scale [AIS] ABC) significantly increases the likelihood of expressing a significant number of needs compared to a less severe injury (AIS D). In people with tetraplegia, the probability of expressing needs related to attendant care (RR, 2.66), long-distance transportation (RR, 1.95), and accessible housing (RR, 1.91) seems to be particularly influenced by the severity of the lesion. For meeting needs, such a probability is reduced as statistically significant RRs appear in only a few needs with a lesser magnitude.

Table 2. Percentages (and confidence intervals) of participants who reported receiving help to meet their needs from government agencies, friends and family, community organizations, or other organizations

Needs (<i>n</i> = respondents expressing the needs)	All participants (traumatic and nontraumatic lesions)			
	Government agencies % (95% CI)	Friends and family % (95% CI)	Community organizations % (95% CI)	Other organizations ^a % (95% CI)
General health care (<i>n</i> = 1,377)	91.6 (90-93)	59.0 (56-62)	32.7 (30-35)	38.8 (36-41)
Income support (<i>n</i> = 824)	85.7 (83-88)	47.8 (44-51)	13.0 (11-16)	36.2 (33-40)
SCI-specialized health care (<i>n</i> = 1,296)	85.0 (83-87)	56.2 (53-59)	34.7 (32-37)	38.0 (35-41)
Case management (<i>n</i> = 764)	77.2 (74-80)	50.8 (47-54)	40.6 (37-44)	16.5 (14-19)
Attendant care (<i>n</i> = 808)	73.1 (70-76)	78.7 (76-81)	18.4 (16-21)	17.8 (15-21)
Equipment and technical aids (<i>n</i> = 1,390)	69.4 (67-72)	51.8 (49-54)	25.8 (24-28)	40.7 (38-43)
Emotional counselling (<i>n</i> = 568)	65.5 (61-69)	46.0 (42-50)	25.4 (22-29)	23.4 (20-27)
Short-distance transportation (<i>n</i> = 1,307)	59.5 (57-62)	69.1 (66-72)	12.9 (11-15)	49.3 (47-52)
Job training (<i>n</i> = 460)	59.3 (55-64)	43.0 (38-48)	39.6 (35-44)	27.4 (23-32)
Accessible housing (<i>n</i> = 1,277)	45.2 (42-48)	64.6 (62-67)	19.2 (17-21)	25.3 (23-28)
SCI peer support (<i>n</i> = 464)	39.0 (35-44)	56.5 (52-61)	77.2 (73-81)	17.9 (15-22)
Healthy living and leisure programs (<i>n</i> = 809)	35.6 (32-39)	56.7 (53-60)	54.4 (51-58)	30.2 (27-33)
Long-distance transportation (<i>n</i> = 1,057)	27.1 (24-30)	62.6 (60-66)	7.9 (6-10)	49.7 (47-53)

Note: Data are listed in decreasing order of participants receiving support from government agencies.

^aInsurance companies, private donations, legal settlements.

Such a pattern of influence on needs is also noticeable for environmental conditions (eg, region of residence, living arrangement, and income). Household income seems to be an important variable in the probability of meeting needs for services. Higher household income (>60,000 Canadian dollars) reduces the probability of expressing a need for income support, attendant care, and case management but increases the probability of having long-distance transportation and healthy living and leisure program needs. On the other hand, a higher income drastically increases the possibility of meeting most needs for services with statistically significant RRs (1.27–2.65) compared to people with a low income (<\$30,000/year). The exception is the general

health care need, probably due to the public health care system in Canada. The impact is less marked when comparing the other income groups (\$30,000–\$60,000 vs < \$30,000), but the likelihood of 5 needs being met still increases (from 21% to 102%) in the former group. Similar patterns were observed in the NT lesion group (findings are reported in the online “Extra data” sections [cirris.ca/tscir.html].)

Sources of help and support to meet expressed needs

For each expressed need, the survey participants received help and support from multiple sources (Table 2) without any significant differences between the TR and NT lesion groups. Government

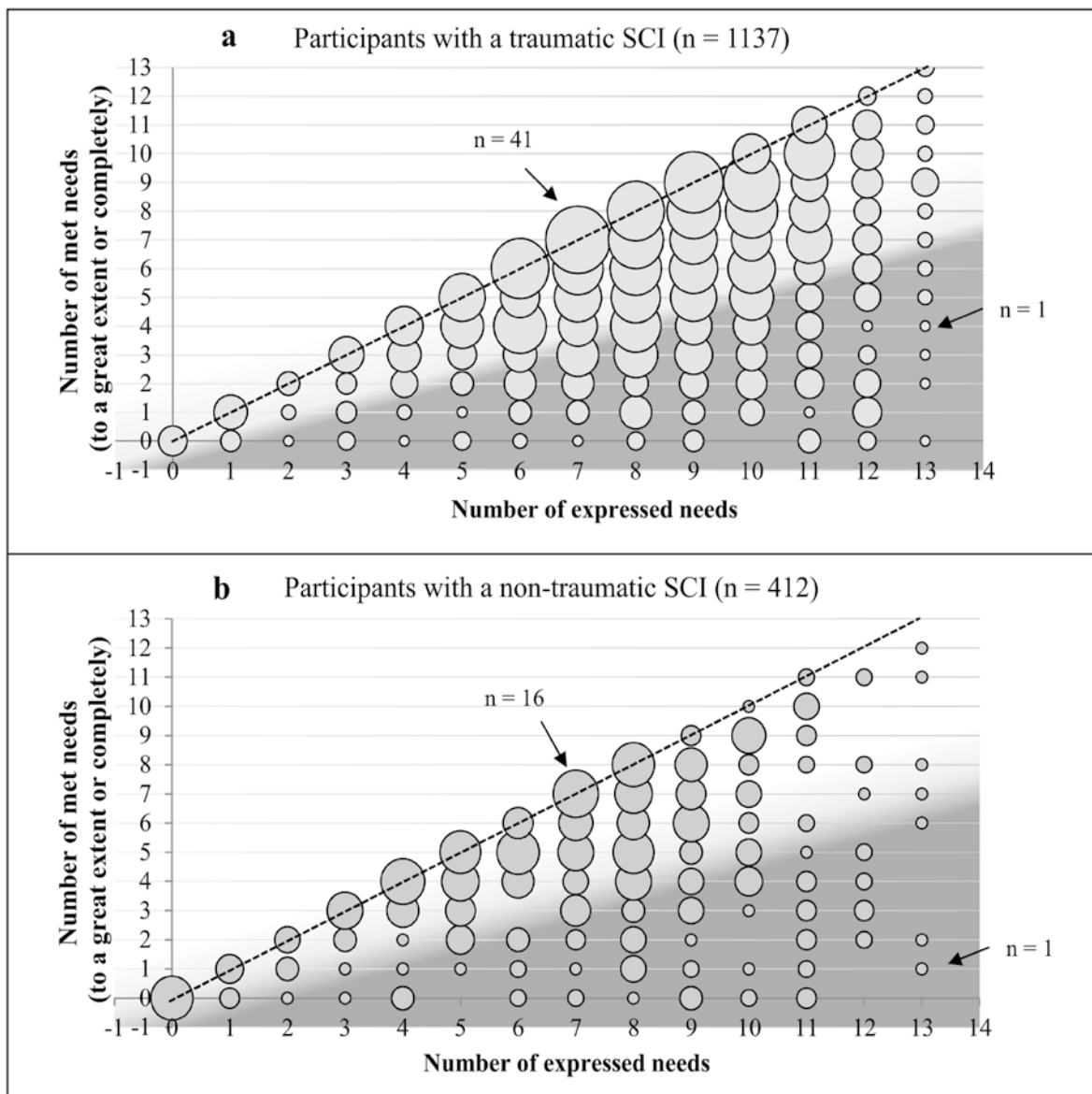


Figure 1. Graphic illustration of the relationships between number of expressed needs and needs met (to a great extent or more) in survey participants with a traumatic and nontraumatic SCI. Each circle (bubble) represents the data points between a specific number of expressed and met needs. The size of each bubble represents a specific number of participants and examples are given in the graphs (largest circle: $n = 41$, traumatic lesion, $n = 16$, nontraumatic lesion; smallest circle: $n = 1$, both lesions). Shaded area comprises participants for whom the number of met needs corresponds to 50% or less of expressed needs.

agencies were the main source of support for 7 out of 13 expressed needs, and the proportion of participants who received this type of support was between 77% and 91% for 4 specific needs (general health care, SCI-specialized health care, income support, and case management). Despite such important support from agencies, help

and support from friends and family remained substantial for these specific needs (reported by 50%-60% of the sample). In fact, family and friends were identified as the main source of support by participants for 5 critical needs for community integration (attendant care, 78%; short-distance transportation, 69%; accessible

Table 3. Level of satisfaction of participants with a traumatic lesion (percentages and confidence intervals) regarding help and support received from government agencies, community, and other organizations (insurance companies, etc) to meet their needs

Needs	Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat or very dissatisfied
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
SCI peer support	37.5 (32-43)	35.1 (30-41)	18.2 (14-23)	9.2 (6-13)
Attendant care	28.4 (25-32)	47.2 (43-51)	10.0 (8-13)	14.4 (12-18)
Equipment and technical aids	28.2 (25-31)	46.0 (43-49)	11.4 (10-14)	14.3 (12-17)
Case management	24.9 (21-29)	42.9 (39-47)	18.0 (15-22)	14.3 (11-18)
Job training	24.3 (20-30)	41.7 (36-47)	17.8 (14-23)	16.2 (12-21)
General health care	24.0 (21-27)	51.2 (48-54)	11.7 (10-14)	13.2 (11-16)
SCI-specialized health care	23.3 (21-26)	46.8 (44-50)	15.2 (13-18)	14.7 (12-17)
Accessible housing	23.0 (20-26)	37.4 (34-41)	20.0 (17-23)	19.6 (17-23)
Short-distance transportation	22.4 (20-25)	38.1 (35-42)	21.2 (18-24)	18.3 (16-21)
Emotional counselling	19.9 (16-25)	38.5 (33-44)	23.9 (19-29)	17.7 (14-22)
Healthy living and leisure programs	18.8 (15-23)	42.9 (38-48)	19.5 (16-24)	18.8 (15-23)
Long-distance transportation	16.3 (13-20)	38.8 (35-43)	27.2 (24-31)	17.7 (15-21)
Income support	14.6 (12-18)	38.4 (34-42)	18.6 (16-22)	28.4 (25-32)

Note: Data are listed in decreasing order of the “very satisfied” level.

housing, 64%; long-distance transportation, 62%; healthy living and leisure, 56%). Not surprisingly, community organizations provided peer support for 77% of people who expressed this need. Other organizations (insurance companies, private donations, legal settlements) also provided support for a substantial proportion of the respondents, particularly to meet needs related to transportation, equipment, and technical aids (reported by 40% of the sample).

Degree of satisfaction with the help and support received varied greatly among participants and between expressed needs (Table 3). The proportion of people with a TR lesion who reported being very satisfied with the help and support received (regardless of the source) was under 30% (except for SCI peer support, which was 37%) and as low as 16% and 14% for long-distance transportation and income support, respectively. However, there was no general trend toward dissatisfaction but rather a low level of satisfaction as a substantial proportion of participants indicated they were somewhat satisfied (35% to 50%) with the help and support they received to meet their needs. No significant differences were observed between the TR and NT lesion groups.

Environmental barriers limiting needs fulfillment

Among the 9 environmental obstacles that could limit the fulfillment of needs, 2 are noteworthy: the process of and the financial affordability of getting needs met. These obstacles seem to affect the fulfillment of most expressed needs (Figure 2a-b). This is particularly clear for needs such as accessible housing, income support, and attendant care, where few participants totally agree that the process is easy or can afford to pay to meet their needs. Conversely, a substantial number of participants reported that they know how to find help and information to meet most of their needs and that availability and quality of features to meet specific needs exist.

Another approach to examining the relationships between environmental obstacles and expressed needs is to determine the needs that are most or least hindered by the 9 obstacles. For example, accessible housing (Figure 3a) is one of the needs with the most obstacles overall. The process of obtaining accessible housing, amount of services, and physical obstacles in the environment make it much more problematic than other needs. To some extent, meeting needs for SCI-specialized health

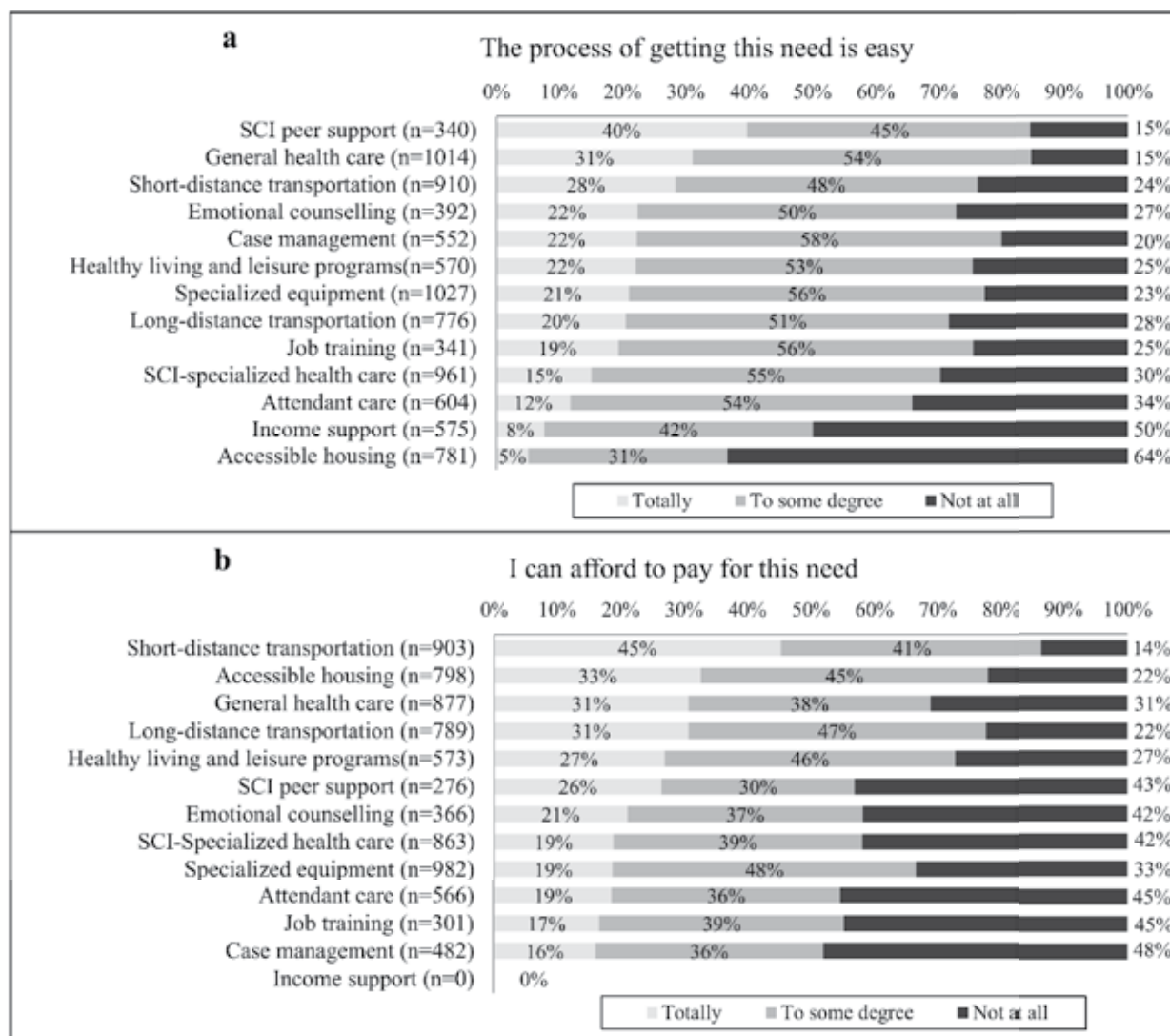


Figure 2. Bar graphs representing level of agreement regarding the characteristics of 2 environmental factors (ease of getting a need met, financial affordability) that influence the fulfilment of a need. Data are listed in decreasing order of total agreement.

care, income, and long-distance transportation is also hindered by environmental obstacles. On the other hand, a majority of people totally agree that general health care exists and is available where they live (**Figure 3b**), but some participants seem to only partly agree as to the quantity of this service, its affordability, and ease of getting it. The SCI knowledge of service providers seems to be an important barrier to ensuring that general health care needs are met. A similar pattern was observed in meeting the need for equipment, medical

supplies, communication devices, and technical aids. (Other findings related to environmental obstacles are reported in the online resource [cirris.ca/tscir.html].)

Discussion

To our knowledge, this study is the first to thoroughly explore the needs (expressed and met) for services of people with long-standing SCI, which includes sources of help and support they

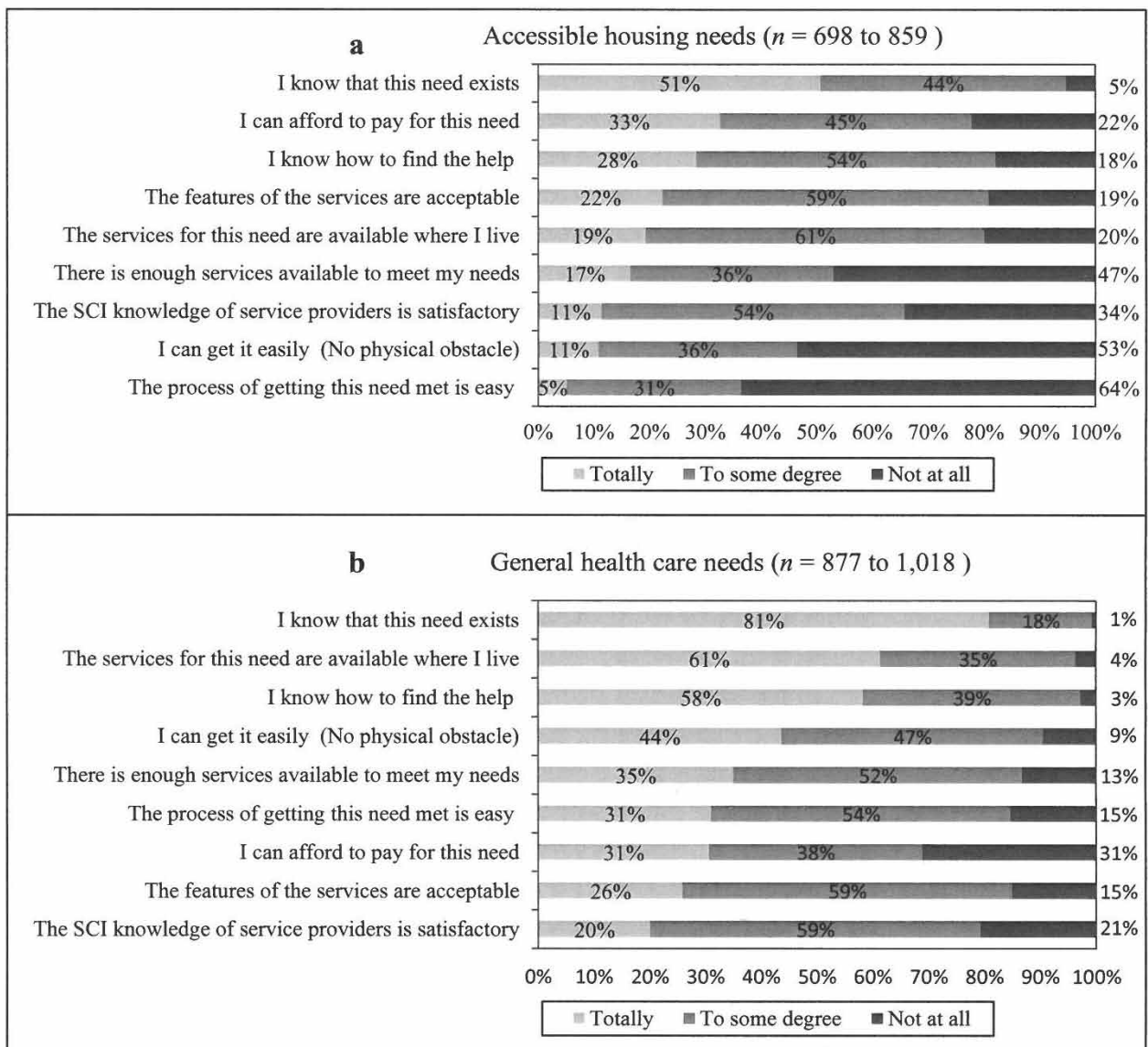


Figure 3. Bar graphs representing level of agreement regarding 9 environmental factors that influence the fulfilment of 2 specific needs or services (accessible housing and general health care). Data are listed in decreasing order of total agreement.

received and barriers that prevented them from meeting their needs. The main findings of the study suggest that people with SCI have a variety of needs, some more critical than others, to ensure community living and that some people receive enough help and support from various sources to meet most of their expressed needs. This supports the hypothesis that some community needs may be addressed relatively well.⁸ However, this would

occur gradually over the course of community living as fulfilment of critical needs (eg, accessible housing, transportation, home support) is lower in the first year post discharge¹⁷ and the services received in this early phase do not meet the needs identified at discharge for both health and social care in most people with neurological conditions.¹⁸

Despite some encouraging findings, a substantial proportion of people with SCI cannot meet 50%

of their needs, which has a potential impact on community living. This militates in favor of better access to support and help through various types of community outreach programs. The results show that perceived needs as well as the capacity to meet them vary greatly from one person to the next. A more sudden TR lesion seems to create significantly more needs for services than an NT lesion, but there are no differences in the proportion of met and expressed needs between the 2 types of lesion. This study confirms that the expression of needs tends to be related to some extent to personal and environmental characteristics. For critical needs, such as attendant care, transportation, and accessible housing, for example, people with more severe tetraplegia had a higher probability of expressing needs. Nonetheless, people with less severe injuries who recover some level of mobility or have NT lesions with potential additional functional decline require special consideration and interventions to address their needs, especially in terms of psychological support and peer support.¹⁹ Emotional counselling needs were reported by about one-third of the current survey participants, but only 43% of them considered this need as met, which makes it the third least met need.

Of particular interest is the insight the study provides on the potential impact of income on the capacity to meet needs. In this study, people with access to a household income over \$60,000 clearly had a higher probability of meeting their needs than those with a lower income. Moreover, access to a better income seems to create opportunities to express needs, such as for long-distance transportation and healthy living/leisure programs that could have a positive impact on social participation. This raises the issue of ensuring adequate funding or income to meet needs for community living. Some studies indicate that lack of funding is a major concern among people with SCI,^{6,13,14} including access to health care.^{20,21} This is also consistent with other studies suggesting additional costs of living for people with disability,²²⁻²⁴ effect of a higher income on life satisfaction, and increased risk of health problems and environmental barriers in people with low incomes.²⁵

In addition to financial issues, 2 other factors, the complex process of getting needs met and service providers' knowledge of SCI, seem to be important barriers to ensuring that needs are met. Less than 40% of survey participants (and usually under 25%) agreed with the statement that the process of getting support to meet their needs is easy. For needs such as income support and accessible housing, 50% or more participants indicated that it was not at all easy. Only a few participants considered that the SCI knowledge of those providing services was satisfactory, and the majority considered it satisfactory to some extent. This is consistent with previous studies that examined environmental barriers to meeting needs.^{6,26}

The study results confirm that people with SCI received help and support from multiple sources. A combination of sources with predominantly government support for specific needs (eg, health care, income support, case management) seems to ensure a certain provision of services, but varying degrees of satisfaction and dissatisfaction with support from these organizations suggest that it should be enhanced. Even in a publicly funded system, government policies and availability of services were previously seen as barriers to community integration,²⁷ to meeting health care needs,²⁸ and to returning to work²⁹ among people with disabilities.

Given various limits on government jurisdictions to help meet expressed needs, support from family remains essential and highly predominant to meet needs such as attendant care, accessible housing, and short- and long-distance transportation. This confirms that a large proportion of people with SCI receive instrumental and emotional support from family,³⁰ which contributes to life satisfaction.^{31,32} While this high proportion of support from family and friends seems to be beneficial, a substantial percentage of partners who act as caregivers suffer from serious burden³³ and also need a great deal of support through various interventions.^{34,35}

Study limitations

There are some limitations in this survey that must be acknowledged. First, the recruitment

process did not allow participants to be selected through a randomized process and the level of participation was uneven across Canada, creating a potential selection bias and a nonresponse bias. Although the geographic distribution of participants approaches the distribution of the adult population in Canada, it was not possible to calculate a representational weight for each observation. Second, the study is based on self-reported data that cannot be validated by external data, and the high number of sections and questions may have induced fatigue or boredom in participants, leading to under- or overestimation of behaviors, beliefs, and knowledge and consequently to a potential information bias. Likewise, there is a subjective component in the assessment of needs (expressed and met) that is influenced by personal beliefs and social norms that can also create potential upward or downward bias. Third, the data collection period lasted more than a week or a month for 25% and 15% of respondents, respectively, which might have created a form of recall bias. Fourth, estimation of the severity of injury relied on self-reported information about motor and sensation recovery and is not as accurate as an actual medical assessment, leading to potential misclassification of the AIS grade.

Conclusion

The measurement of expressed and met needs for services is a challenge but is needed to ensure optimal service delivery for people with SCI living in the community. This study is among the first to thoroughly illustrate expressed and met and unmet needs for services in this population, as

well as the support received from various sources and obstacles encountered in meeting those needs. Results showed that overall about two-thirds of needs expressed by survey participants are met in a satisfactory manner, with significant interindividual variation, suggesting that some people are still in a precarious situation regarding their needs for services. The needs measure developed in this study might be very useful for service providers to detect individuals who require additional support and to prioritize actions to meet the most unmet needs. Environmental barriers to services, particularly the process of getting needs met and associated costs, remain an issue that requires a reassessment of some aspects of access to services, particularly for critical needs such as accessible housing, attendant care, transportation, and income support, that are prerequisites for people with SCI to live independently in the community and contribute to society like other citizens.

Acknowledgments

The study was supported by the Rick Hansen Institute (grant number: 2010-03) and the Ontario Neurotrauma Foundation (grant number: 2010-RHI-SURVEY-812). The authors are indebted to all participants who completed the Survey and to members of the Community Integration Practice Network of the Rick Hansen Institute (RHI) for their invaluable comments during the initial phase of survey design and development. We particularly thank RHI's Cathy McGuinness and Lydia Cartar for their support throughout the survey development phases.

The authors do not have any conflicts of interest to disclose.

REFERENCES

1. Sipski ML, Richards JS. Spinal cord injury rehabilitation: State of the science. *Am J Phys Med Rehabil.* 2006;85(4):310-342.
2. Wuermsier LA, Ho CH, Chiodo AE, Priebe MM, Kirshblum SC, Scelza WM. Spinal cord injury medicine. 2. Acute care management of traumatic and nontraumatic injury. *Arch Phys Med Rehabil.* 2007;88(3 Suppl 1):S55-61.
3. Kirshblum SC, Priebe MM, Ho CH, Scelza WM, Chiodo AE, Wuermsier LA. Spinal cord injury medicine. 3. Rehabilitation phase after acute spinal cord injury. *Arch Phys Med Rehabil.* 2007;88(3 Suppl 1):S62-70.
4. Santos A, Gurling J, Dvorak MF, et al. Modeling the patient journey from injury to community reintegration for persons with acute traumatic spinal cord injury in a Canadian centre. *PLoS One.* 2013;8(8):e72552.
5. Dijkers MP, Hart T, Tsaousides T, Whyte J, Zanca JM. Treatment taxonomy for rehabilitation: Past, present, and prospects. *Arch Phys Med Rehabil.* 2014;95(1 Suppl):S6-16.

6. Cox RJ, Amsters DI, Pershouse KJ. The need for a multidisciplinary outreach service for people with spinal cord injury living in the community. *Clin Rehabil.* 2001;15(6):600-606.
7. Kennedy P, Lude P, Taylor N. Quality of life, social participation, appraisals and coping post spinal cord injury: A review of four community samples. *Spinal Cord.* 2006;44(2):95-105.
8. Kennedy P, Sherlock O, McClelland M, Short D, Royle J, Wilson C. A multi-centre study of the community needs of people with spinal cord injuries: The first 18 months. *Spinal Cord.* 2010;48(1):15-20.
9. Murphy GC, McDonald L, McDonald S. Test-retest reliability of information about employment provided in surveys by people with spinal cord injuries. *Psychol Rep.* 1997;81(1):25-26.
10. Conroy L, McKenna K. Vocational outcome following spinal cord injury. *Spinal Cord.* 1999;37(9):624-633.
11. Tomassen PC, Post MW, van Asbeck FW. Return to work after spinal cord injury. *Spinal Cord.* 2000;38(1):51-55.
12. Schonherr MC, Groothoff JW, Mulder GA, Eisma WH. Vocational perspectives after spinal cord injury. *Clin Rehabil.* 2005;19(2):200-208.
13. Rick Hansen Man-in-Motion Foundation (RHMIMF). SCI Community Survey overall results. *Ipsos Reid.* 2004:56.
14. Rick Hansen Man-in-Motion Foundation (RHMIMF). SCI Forum report. *Ipsos Reid.* 2005:66.
15. Turner-Stokes L, McCrone P, Jackson DM, Siegert RJ. The Needs and Provision Complexity Scale: A multicentre prospective cohort analysis of met and unmet needs and their cost implications for patients with complex neurological disability. *BMJ Open.* 2013;3(2).
16. Noreau L, Noonan V, Cobb J, Leblond J, Dumont F. Spinal Cord Injury Community Survey: A national, comprehensive study to portray the lives of Canadians with spinal cord injury. *Top Spinal Cord Inj Rehabil.* 2014;20(4):249-264.
17. Beauregard L, Guindon A, Noreau L, Lefebvre H, Boucher N. Community needs of people living with spinal cord injury and their family. *Top Spinal Cord Inj Rehabil.* 2012;18(2):122-125.
18. Siegert RJ, Jackson DM, Playford ED, Fleminger S, Turner-Stokes L. A longitudinal, multicentre, cohort study of community rehabilitation service delivery in long-term neurological conditions. *BMJ Open.* 2014;4(2):e004231.
19. Jannings W, Pryor J. The experiences and needs of persons with spinal cord injury who can walk. *Disabil Rehabil.* 2012;34(21):1820-1826.
20. Beatty PW, Hagglund KJ, Neri MT, Dhont KR, Clark MJ, Hilton SA. Access to health care services among people with chronic or disabling conditions: Patterns and predictors. *Arch Phys Med Rehabil.* 2003;84(10):1417-1425.
21. Guilcher SJ, Munce SE, Couris CM, et al. Health care utilization in non-traumatic and traumatic spinal cord injury: A population-based study. *Spinal Cord.* 2010;48(1):45-50.
22. Zaida A, Burchardt T. Comparing incomes when needs differ: Equalization for the extra costs of disability in the U.K. *Rev Income Wealth.* 2005;51(1):89-114.
23. Cullinan J, Gannon B, Lyons S. Estimating the extra cost of living for people with disabilities. *Health Econ.* 2011;20(5):582-599.
24. Wilkinson-Meyers L, Brown P, McNeill R, Patston P, Dylan S, Baker R. Estimating the additional cost of disability: Beyond budget standards. *Soc Sci Med.* 2010;71(10):1882-1889.
25. Cao Y, Krause JS, Saunders LL, Bingham W. Household income and subjective well-being after spinal cord injury: A longitudinal study. *Top Spinal Cord Inj Rehabil.* 2014;20(1):40-47.
26. van Loo MA, Post MWM, Bloemen JHA, van Asbeck FWA. Care needs of persons with long-term spinal cord injury living at home in the Netherlands. *Spinal Cord.* 2010;48(5):423-428.
27. Lysack C, Komanecky M, Kabel A, Cross K, Neufeld S. Environmental factors and their role in community integration after spinal cord injury. *Canadian J Occup Ther.* 2007;74 Spec No.:243-254.
28. McColl MA, Jarzynowska A, Shortt SED. Unmet health care needs of people with disabilities: Population level evidence. *Disabil Soc.* 2010;25(2):205-218.
29. Jongbloed L, Backman C, Forwell SJ, Carpenter C. Employment after spinal cord injury: The impact of government policies in Canada. *Work.* 2007;29(2):145-154.
30. Chun S, Lee Y. "I am just thankful": The experience of gratitude following traumatic spinal cord injury. *Disabil Rehabil.* 2013;35(1):11-19.
31. Holicky R, Charlifue S. Ageing with spinal cord injury: The impact of spousal support. *Disabil Rehabil.* 1999;21(5-6):250-257.
32. Mortenson WB, Noreau L, Miller WC. The relationship between and predictors of quality of life after spinal cord injury at 3 and 15 months after discharge. *Spinal Cord.* 2010;48(1):73-79.
33. Post MW, Bloemen J, de Witte LP. Burden of support for partners of persons with spinal cord injuries. *Spinal Cord.* 2005;43(5):311-319.
34. Schulz R, Czaja SJ, Lustig A, Zdaniuk B, Martire LM, Perdomo D. Improving the quality of life of caregivers of persons with spinal cord injury: A randomized controlled trial. *Rehabil Psychol.* 2009;54(1):1-15.
35. Dickson A, Ward R, O'Brien G, Allan D, O'Carroll R. Difficulties adjusting to post-discharge life following a spinal cord injury: An interpretative phenomenological analysis. *Psychol Health Med.* 2011;16(4):463-474.