

Community Needs of People Living With Spinal Cord Injury and Their Family

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Returning to the community after intensive functional rehabilitation can be a challenge for people who have sustained a traumatic spinal cord injury (SCI) and for their family members.¹⁻⁴ They may need different services in order to facilitate their social participation and improve their quality of life.^{3,5,6} Research was conducted to better understand the role of the environment in community reintegration in the first years post rehabilitation. This article focuses on the needs from the perspective of persons with SCI and their family members. A more complete understanding of unmet needs will help better address them in future intervention and policies.

Method

Participants with SCI were recruited through the main intensive rehabilitation centers in the province of Quebec. Selection criteria were age 18 years or older, to have reintegrated the community in the past year, and to be able to answer questions in French or English. Family members were recruited through the person with SCI.

To evaluate the needs of participants with SCI during the first year post rehabilitation, a questionnaire was created. A similar questionnaire was produced for the family members specific to the needs they might have. For persons with SCI, the questionnaire included 13 needs based on preliminary work of the Spinal Cord Injury Solutions Network (Rick Hansen Institute) under the direction of Dr. Luc Noreau (see **Figure 1** for list of needs). The questionnaire for family

members included 7 needs that were selected based on literature⁷⁻⁹ (see **Figure 2** for list of needs). For each item, the participants were asked if they had this need. If so, they were asked to rate to what degree it had been met (met, partially met, or not met). Questionnaires were completed via a telephone survey with a research assistant.

Participants

The questionnaires were completed by 35 persons with SCI and 21 family members. Most of the respondents with SCI were men (80%), with an average age of 47.6 years (± 17.8 years). The main causes of trauma were motorized vehicle and being hit by an object or falling (40%) (**Table 1**). About half of participants (52%) had an ASIA Impairment Scale (AIS) D, while the other half had an AIS A (23%), B (11%), or C (14%). Family members were 86% female, with an average age of 50 years (± 16.2 years). More than half of the participants (57.1%) were the spouse of the person with SCI. Others were mothers (24%), siblings (14%), or daughters (5%).

Needs of participants with SCI

The most frequently mentioned needs for participants with SCI are SCI specialized health care,

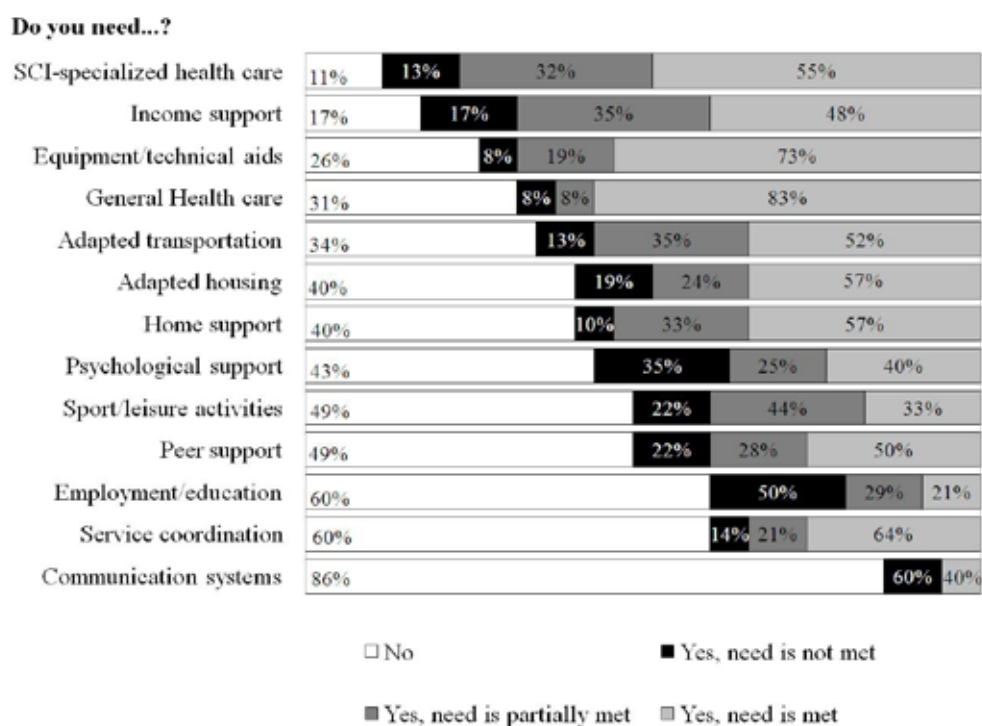


Figure 1. Needs of participants with SCI (n=35). Percentages expressed in the graphic can be understood in the following manner: first percentage on the left represents participants who do not have the need mentioned in the list. Other percentages (on 100%) include all participants who stated having the need and correspond to the degree in which they say their need is met.

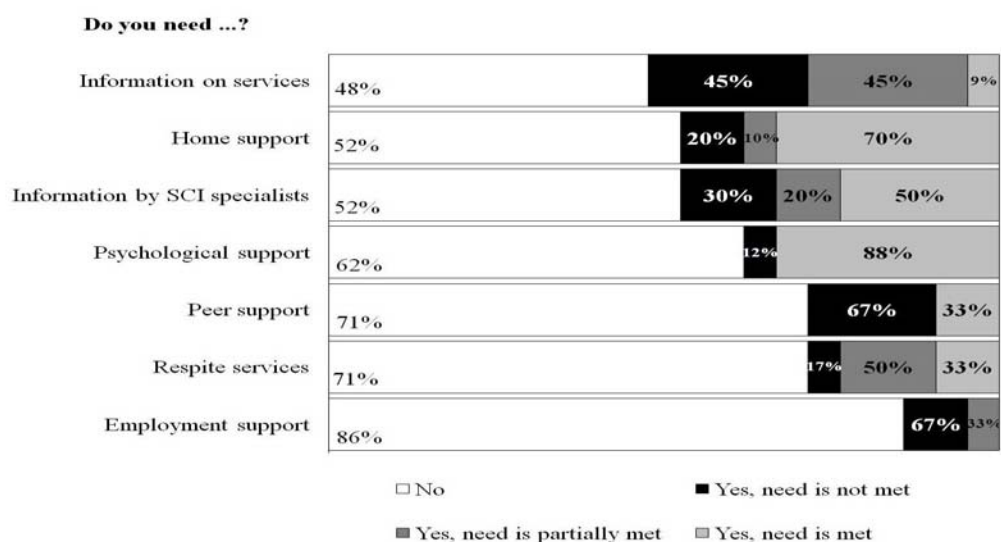


Figure 2. Needs of family members (n=21). Percentages expressed in the graphic can be understood in the following manner: first percentage on the left represents participants who do not have the need mentioned in the list. Other percentages (on 100%) include all participants who stated having the need and correspond to the degree in which they say their need is met.

Table 1. Cause of accident

Motorized vehicle	46%
Being hit by an object or falling	40%
Sport or leisure activities	6%
Dive	3%
Other	6%

income support, equipment and technical aids, general health care, adapted transport, home support, and adapted housing. Needs regarding equipment and technical aids as well as general health care seem to be well met. However, needs less frequently mentioned by participants are often unmet, such as emotional and psychological support or employment, education, and training (Figure 1).

Fisher analyses were conducted to determine whether any of these needs could be related to some variables, such as gender, living alone or with someone, type of compensation received, and severity of the lesion. The only associations found were with severity of lesion, as measured by AIS (Figure 3). As shown in Figure 3, 100% of

participants with an AIS A, B, or C said that they need some equipment and technical aids, whereas only 50% of those with an AIS D said that they have this need. Each need presented in Figure 3 was associated with AIS grade. No association with severity was found with other needs.

Needs of family members

The most frequently mentioned need by family members is for information on social programs and services that exist in the community (Figure 2). However, it is met for only 9% of them. Some other needs, also important, seem to be well met, in particular home support and emotional and psychological support, which are met for 70% and 88% of participants, respectively. However, the small number of participants limits the interpretation of this result.

What Did We Learn From This Research?

Many needs were encountered the first year post rehabilitation by people with SCI and their family members. Results show that some of these needs

Do you need...?

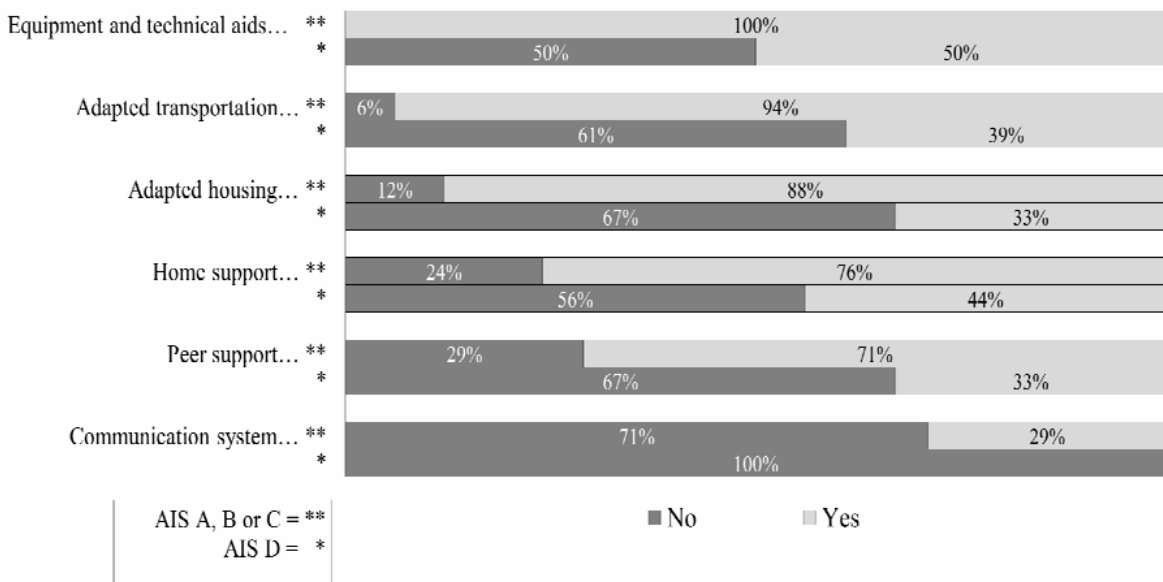


Figure 3. Association between needs and AIS grade (n=35). Seventeen out of 35 participants had an AIS A, B, or C.

are well met for participants. It is important to acknowledge these needs and to continue to offer services that meet them. At the same time, we must consider and improve services for the needs evaluated as being less met, such as psychological support and employment or education support for people with SCI. Regarding needs of family members, results indicate the importance of increasing information on social programs and services.

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