



# SELF-REPORTED HEALTH PROBLEMS AND PRIORITIZED GOALS IN COMMUNITY-DWELLING INDIVIDUALS WITH SPINAL CORD INJURY IN SWEDEN

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**Objective:** To explore self-reported health problems and functional goals in community-dwelling individuals with spinal cord injury in Sweden.

**Design:** Cross-sectional descriptive study that used a survey designed by an experienced peer mentor with spinal cord injury.

**Subjects:** Community-dwelling individuals with spinal cord injury from Sweden.

**Methods:** The survey was distributed online by the community peer-based organization RG Active Rehabilitation.

**Results:** A total of 203 individuals (55% males, 90% acquired spinal cord injury) from all regions in Sweden completed the survey. Of these, 33% reported living with >2 unbearable physical or psychological problems. While some problems (e.g. problems related to bladder and balance) were consistently ranked to be common across all years since injury and type of spinal cord injury, distribution of some other unbearable problems (e.g. type of pain, excessive weight) varied between subgroups. Years since injury, level of acquired spinal cord injury and sex, but not age-group or type of spinal cord injury, explained some of the variation in the goals.

**Conclusion:** The high proportion of reported “unbearable” problems point to the stronger need for systematic, comprehensive, life-long, multi-disciplinary follow-up for people with spinal cord injury. The high rate of goals related to improving strength and fitness across all participants independently of their characteristics highlight the important role of community organizations that offer such lifetime services.

**Key words:** spinal cord injuries; goals; independent living; complications; community rehabilitation; peer support; pain.

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People living with functional sequels of a spinal cord injury (SCI) typically are prone to secondary conditions and complications that may have a signifi-

## LAY ABSTRACT

This study confirms that people with spinal cord injury (SCI) often live with unbearable health problems and need ongoing support and services. The study also showed that there is an enduring need for programs focusing on strength, fitness and balance training. Findings highlight the importance of involving peer mentors in strategies to manage these problems and needs. We used data that were collected online by a community organisation offering peer-based training programs for people with SCI in Sweden. The survey was designed by a peer mentor and asked people with SCI to identify their health problems and prioritize their goals. Providers of community rehabilitation programs for people with SCI in Sweden can use the information presented in this study to inform the design and focus of their services. The design of this study is an example of how community organisations can play a key role in reaching and evaluating people with SCI in the community.

cant negative impact on their independence, quality of life (QoL), and often lead to an increased utilization of healthcare throughout their lives (1). In addition, as mean age at injury has increased and survivors live longer, ageing further increases this vulnerability (2). Ongoing systematic follow-up services that address all aspects of physical and psychosocial well-being are therefore essential in the prevention and management of secondary complications (1–3). Furthermore, involvement in regular physical activity (4) including recreation and sports (5), social networking activities and peer support services (6) also counteract vulnerability leading to disease. While the provision of lifelong support is expensive, it may minimize long-term costs through prevention of complications and improvements in participation (7).

In this context, community organizations are gaining an increasingly important role in health promotion, long-term skills training and provision of education after discharge from initial care. In fact, community organizations have been reported as being the single major provider for SCI peer support services and the second most important provider for healthy living and leisure programmes, second only to friends and family (8). Service needs tend to change due to the changing

profile of the newly injured and survivors, as well as the changing healthcare systems that shorten initial in-patient hospitalization and transfer responsibilities to out-patient services and community organizations. It is therefore important for community organizations to continuously evaluate the contemporary needs of their service users, so as to adapt their programmes to suit these needs.

While large, well-designed, population-based studies such as the Stockholm Spinal Cord Injury Study (9) can provide detailed and reliable information, they are often expensive and difficult to conduct longitudinally. More recent studies from Sweden have reported that pain (10–13), bladder and bowel problems (10, 12), pressure ulcers (10, 11) and cardiovascular diseases (14) were common problems in individuals with SCI. However, these studies had a narrow focus either related to a specific medical condition or to a specific phase of life after injury, or to a specific age-group.

A recent international initiative targeting community-dwelling individuals with SCI used the International SCI Community Survey (InSCI) to collect data from 28 countries (15). Because Sweden did not take part in the InSCI, it was deemed of high priority to plan for a study that would explore the contemporary needs of people with SCI. While international studies can provide some insight into the contemporary characteristics and needs of people with SCI, national studies are necessary to inform the design and delivery of community services due to inherent differences between settings.

The aims of this study were to explore self-reported health problems and functional goals in community-dwelling individuals with SCI in Sweden.

## MATERIAL AND METHODS

### *Study design and ethics*

This is a cross-sectional descriptive study involving a retrospective analysis of de-identified data collected through a purpose-made survey. The reporting for this study was guided by the STROBE statement (16) for cross-sectional studies. The research proposal was reviewed and approved by the Human Research Ethics Committee at Central Queensland University (H17/04-069).

### *Context*

“RG Active Rehabilitation” (RG AR) is a peer-based community organization, which provides services addressing aspects of physical, emotional, independent living and lifestyle needs of individuals with SCI in Sweden. Typically, these services are provided by experienced peer mentors with personal experience of living with the sequels of SCI. Services include one-on-one individual counselling and coaching, training programmes, follow-up activities, as well as activities aimed at increasing

knowledge, understanding and public awareness relating to living with a disability. The primary focus of this consumer-driven intervention, is to support individuals with SCI to improve their independent living skills and self-esteem, and subsequently to reach their full potential as regards activity and participation. During the past 40 years, components of the RG AR concept have been adopted by organizations in over 20 countries in Europe, Asia and Africa (17).

RG AR undertook a quality assurance initiative, involving an electronic survey in order to identify areas for service improvement and to assess service user satisfaction.

### *Survey*

The survey was developed by a board member of RG AR who had participated in many AR training programmes, both as participant early after sustaining tetraplegia, and later as a peer mentor and general programme manager, as well as in a number of “train-the-trainers” workshops. The current paper presents data from the following 3 sections of the survey: (i) basic demographics, including age-group, sex, area of living, type and cause of injury and years since injury (YSI); (ii) questions relating to physical and/or psychological problems, as well as perceptions as to who participants believed best could help them solve these problems; and (iii) questions relating to prioritized functional goals related to becoming better in wheelchair skills, transfers, gait, balance, strength and fitness, dressing and managing bowel and bladder.

### *Subjects and procedure*

The RG AR database and a closed group on social media were used to identify participants. These predominantly include individuals with SCI, but also include individuals with other disabilities, relatives, carers and health professionals. While there are approximately 1,300 entries in these databases, we were not able to make a reliable estimation of the number of individuals with SCI. Individuals with a congenital SCI (CSCI) or acquired SCI (ASCI) were openly invited to complete an online survey that was developed in Survey Monkey. Participation to the survey was voluntary. Data were collected during a 6-month period (April–November 2016). Responses were then de-identified by the organization by deleting name, address, email, and IP addresses before sending them to the first author.

### *Data analysis*

Sample characteristics were analysed using descriptive statistics. With regard to physical and psychological problems, respondents were asked to report whether each of the listed problems was a problem at all, and whether it was at a bearable or unbearable degree. The “not a problem” and “bearable” problem categories were dichotomized against the “unbearable” problems. These variables were analysed and presented based on YSI and type of injury (i.e. ASCI and CSCI).

Multiple logistic regression was performed in order to explore which respondent characteristics were more strongly associated with any of the 9 functional goals (Section 3 of the survey). The independent variables were tested all at once and included age group, sex, residential location, YSI, CSCI/ASCI and type of injury (tetraplegia complete, tetraplegia incomplete, paraplegia complete and paraplegia incomplete). All statistical analyses were performed using the Statistical Package for Social Sciences (SPSS) software (v. 22.0; SPSS, Chicago, IL, USA).

## RESULTS

*Demographics*

Out of 203 respondents with SCI, 55% were males. Ten percent had CSCI, while the 90% of respondents with ASCI were equally distributed between the sub-groups of <5, 5–20 and >20 YSI, respectively. While all regions in Sweden were represented in the sample, the largest sub-group of the cohort (25%) came from the capital region (Greater Stockholm area). The distribution for age, type of injury and residential location are shown in Table I.

*Number of physical and psychological problems*

The majority (70%) of individuals with SCI reported experiencing at least one unbearable physical problem, with a large proportion (30%) experiencing >2 unbearable physical problems. At the same time, 85% responded experiencing >2 bearable physical problems, while half of the cohort (50%) reported experiencing >5 bearable physical problems. Nearly half of the cohort reported experiencing more than 2 bearable psychological problems. Reported unbearable psychological problems were far less common (20%). Overall, 85% of respondents reported experiencing >5 bearable physical or psychological problems and 33% reported living with >2 unbearable physical or psychological problems.

**Table I.** Self-reported sample characteristics

	Descriptive data (n = 203) n (%)
Sex	
Male	111 (54.7)
Female	92 (45.3)
Age group	
< 25 years	16 (7.9)
25–44 years	65 (32.2)
44–64 years	101 (50.0)
> 64 years	20 (9.9)
Missing	1 (0.5)
Residential location	
City	76 (37.4)
Town	85 (41.9)
Rural	42 (20.7)
Time since injury	
< 5 years	56 (27.6)
5–20 years	69 (34.0)
> 20 years	59 (29.1)
Since birth	19 (9.4)
Type of injury	
Acquired spinal cord injury	
Tetraplegia complete	31 (15.3)
Tetraplegia incomplete	29 (14.3)
Paraplegia complete	59 (29.1)
Paraplegia incomplete	65 (32.0)
Congenital spinal cord injury	19 (9.4)

*Type of unbearable physical and psychological problems*

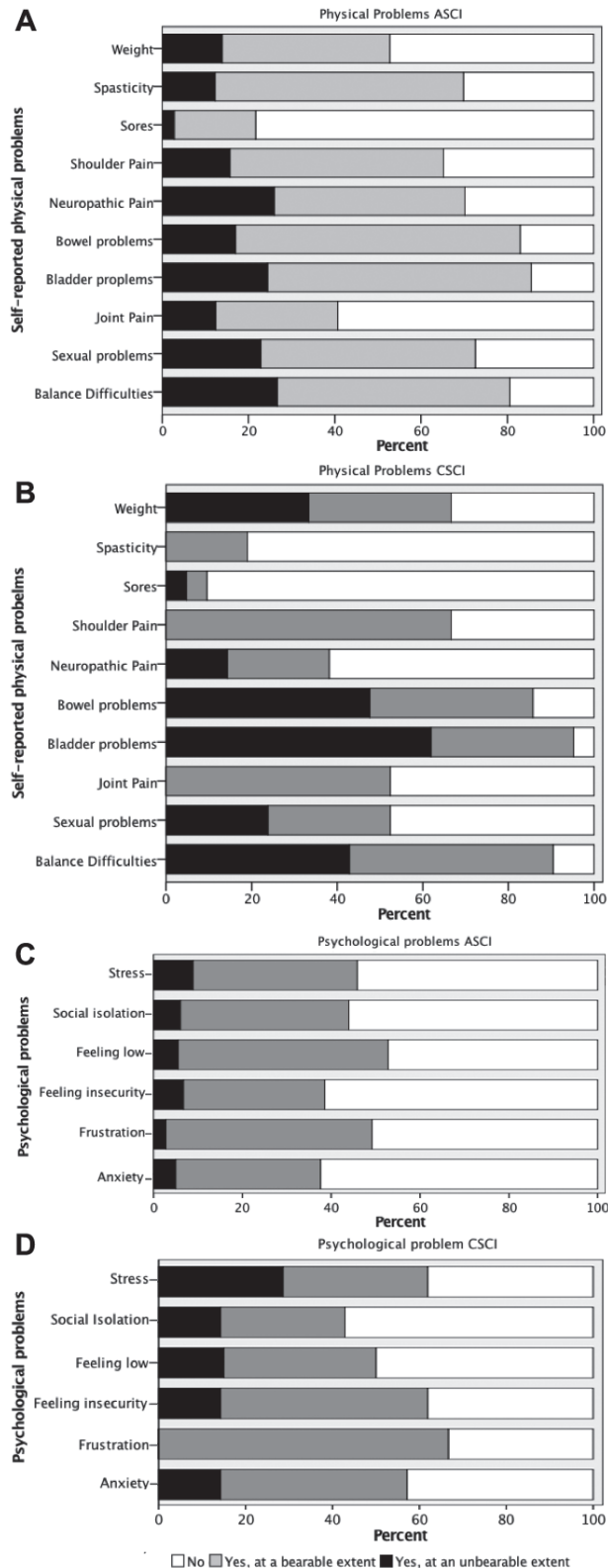
The self-reported effect of physical and psychological problems in individuals with ASCI and CSCI is presented in Fig. 1. In individuals with ASCI, pain was the most commonly reported “unbearable” physical problem; individuals <20 YSI more commonly reported unbearable neurogenic-type pain, whereas individuals >20 YSI more commonly reported shoulder (musculoskeletal-type) pain. The most common forms of pain in individuals with CSCI were shoulder and other joint pain, and both of these were reported to be at bearable levels. Problems related to bladder dysfunction and balance (i.e. problems with maintaining sitting or standing position, or losing balance while walking) were commonly reported as “unbearable” among both ASCI and CSCI individuals. In addition, half of the individuals with CSCI reported having unbearable bowel problems and 1 out of 3 reported having problems with excessive weight. While ASCI and CSCI respondents reported a similar profile of psychological problems, the latter group reported being affected at a considerably higher rate.

Respondents with ASCI reported that they would choose health professionals as most suitable to manage their physical problems (41%), compared with talking to a peer (30%) or looking at educational and online resources. At the same time, meeting and talking to peers was perceived as more suitable to manage psychological problems (44%) compared with meeting health professionals (27%) or educational and online resources. The majority of respondents with CSCI reported that they perceived health professionals as being the most suitable to manage both their physical and psychological problems.

*Prioritized functional goals*

For respondents with ASCI, some goals were reported as decreasing in importance across the YSI subgroups (i.e. improve balance, wheelchair skills, walking), whereas other goals retained their importance throughout the years after injury (i.e. improve strength, fitness, transfer skills). Some other areas such as manage bladder and bowel independently were not reported to be common goals in any of the stages post-injury. Finally, dressing was an important goal for individuals <5 YSI and for those >20 YSI, but not as important for those 5–20 YSI.

Table II presents data relevant to the multiple logistic regression analysis of functional goals and respondent characteristics (i.e. age group, sex, residential loca-



**Fig. 1.** Physical (A and B) and psychological (C and D) problems in patients with acquired spinal cord injury (ASCI) (A and C) and congenital spinal cord injury (CSCI) (B and D).

**Table II.** Regression analysis of functional goals and personal characteristics

	p-value	OR	CI lower	CI upper
Dressing				
< 5 years since training	0.001	17.7	3.1	101.0
Wheelchair skills				
Females	0.015	2.4	1.2	5.0
< 5 years since training	0.009	3.1	1.3	7.2
Transfers				
Females	0.031	2.8	1.1	7.3
Town	0.01	4.5	1.4	14.3
Tetraplegia complete	< 0.00	25.8	4.9	135.3
Paraplegia complete	0.006	7.2	1.8	29.0
Gait training				
> 20 years since training	0.004	0.04	0.01	0.36

Based on 203 participants

Included independent variables in the logistic model: type of injury ("Paraplegia incomplete" referent); cause of injury ("ASCI" referent); age group ("25–44 years" referent); sex ("male" referent); years since injury ("5–20 years since training" referent); residential location ("city" referent). Only significant adjusted odds ratio (OR) presented.

OR: odds ratio; CI: confidence interval.

tion, YSI, CSCI/ASCI, level-completeness) in order to explore which of the latter were more strongly associated with specific goals. Individuals with <5 YSI had 18 times higher odds of having dressing as their functional goal, compared with individuals 5–20 YSI. Females and individuals <5 YSI had 2 times and 3 times higher odds of having wheelchair skills as their functional goal compared with males and individuals 5–20 YSI. Improving on transfers was reported more often as a goal in women (3 times higher odds than men), in complete tetraplegics and complete paraplegics (26 times and 7 times, respectively, higher odds than incomplete paraplegics), as well as in people living in small towns (5 times higher odds than those living in cities). Age-group and type of injury (ASCI or CSCI) were not significant factors in determining the functional goals of the respondents. Also, strength, fitness and balance were common functional goals for all participants independently of age, YSI, type of injury, level of injury, sex, and residential location. In contrast, becoming independent in bladder and bower management were uncommon functional goals regardless of age, years since injury, type of injury, level of injury, sex, and residential location.

## DISCUSSION

This study analysed data routinely collected by a community peer-based organization to identify service needs and inform service design. Despite this survey being non-standardized and non-validated, it does provide a unique perspective on perceived problems, needs, goals and priorities of community-dwelling individuals with SCI, especially because it was deve-



loped by a peer-mentor with SCI. It has been reported that people with SCI perceive peer mentors as being credible and effective because they use the right language and they have a lived experience of SCI (18).

#### *Reported unbearable physical and psychological problems*

The presence of secondary health conditions per se may not necessarily have a negative impact on activity, participation, life satisfaction and QoL (12, 19). For these reasons, it would be meaningful to identify those conditions that are perceived as unbearable, as those require immediate attention and could potentially make a difference in activity and participation level, as well as QoL.

In agreement with other studies, our findings indicate that pain, bowel and bladder problems are the most common problems in long-term SCI (1, 12, 20, 21). More specifically, neurogenic pain early after injury and shoulder pain in long-term SCI, were the most commonly reported unbearable problems in ASCI. Similarly, unbearable bowel and bladder problems were commonly reported across all sub-groups, and tended to be more frequent the longer the YSI. These 3 problems have also been described as the most common reasons for community-dwelling individuals to visit their family physician (22).

Feeling stressed, feeling low (i.e. feeling a depressed mood) and feeling isolated were the most commonly reported unbearable psychological problems. Individuals with ASCI and CSCI reported having similar type of unbearable psychological problems, but the rates in individuals with CSCI were considerably higher. While these were self-reported feelings through a non-standardized survey, they warrant further evaluation and potentially more attention when designing follow-up services for people with CSCI. Other similar studies excluded individuals with CSCI and reported that among people with ASCI, individuals who were older (>32 years) and sustained their injury more recently (<14 years) experienced more depressed mood, less positive affect and challenge appraisals, lower life satisfaction, purpose in life and self-efficacy (23).

Many of these physical and psychological secondary conditions and complications have been associated with low activity and participation levels, such as difficulties with leaving from home and involvement in active recreation, as well as with low QoL (24–26). Our findings echo the conclusions of other studies for the high need for systematic, comprehensive, life-long, multi-disciplinary follow-up for people with SCI as a way to prevent and manage these secondary conditions (24, 25). In addition, our findings, and in particular

the preference of many respondents for peer mentors as most suitable to manage some of their problems, highlight the need for including peer mentors as an integral component of the multi-disciplinary team in all stages of SCI management.

A recent RCT study reported that a peer-led, community-based telephone intervention for individuals with chronic SCI achieved a positive impact on self-management to prevent secondary complications in adults with chronic SCI (27). Online self-management programmes organized either by a community organization or rehabilitation centre have been reported to be an effective and cost-effective method to educate and facilitate behaviour change (22). Another option is community peer-based courses, such as those organized by RG AR. Retro Courses are short residential programmes targeting individuals with a long-standing SCI. The aim of these face-to-face programmes is to promote active and healthy living through provision of education, training and peer support.

#### *Functional goals*

“Goals” may be operationalized as “realistic unmet needs”. Our findings indicate that improving strength, fitness and balance were common functional goals for all participants independent of age, YSI, type of injury, level-completeness of injury, sex, and residential location. This supports the recommendations from other studies that services providing resistance and fitness training opportunities are highly needed and should therefore be readily available for all individuals with SCI (4, 19, 28, 29). Transfers were more likely to be reported as a goal by women, potentially due to their body composition (short arms proportionally to torso, larger pelvis and smaller muscle bulk). Furthermore, respondents from small towns had a higher likelihood of reporting transfer as a functional goal, potentially due to a less accessible environment compared with larger cities, and maybe also fewer opportunities for effective training. This is an area where further research is needed. Females and individuals <5 YSI were more likely to report wheelchair skills as their functional goal, which is an indication for the high need for services in this area during the transitioning phase after initial discharge, but also throughout life.

While bowel and bladder problems were commonly reported to be unbearable, being able to manage bowel and bladder independently were not reported to be common functional goals in any subgroup. This may indicate that these problems were not related to lack of skill, but rather to complications, such as recurrent infections and constipation. At the same time, managing bowel and bladder independently have been reported

as goals that are typically more relevant in the earlier phases of community life, compared with medical care, psychosocial support and recreational goals that may be more relevant as the person spends longer time in the community (30).

### Study limitations

As with many online surveys, it was not possible to know how many individuals were invited and what was the actual response rate in this study. This is a known issue with surveys that are made freely available on the internet. Therefore, our sample cannot be considered as representative of the Swedish SCI population. More specifically, we could see an over-representation of women, as well as individuals with paraplegia. Representative community samples are difficult to obtain and necessitate either large population-based studies or a randomized method to identify respondents. Nevertheless, this is an exploratory study that used a sample of 203 individuals with SCI living in all areas in Sweden, which can serve as a basis for designing further research.

Selection bias was yet another limitation of the current study. Our sample probably comprised individuals who were well enough to participate in recreational programmes, but also individuals who may have an interest and need for such programmes. In other words, individuals who may experience severe problems and individuals who have a satisfactory lifestyle and do not need the support of the community organization may have chosen not to complete the survey. At the same time, because the survey was anonymous, we cannot exclude the scenario that some respondents may have sent more than one response.

Some variables, such as age and YSI, were reported as ranges, rather than as a continuous variable. That limited the type of analysis we could conduct and also made it difficult to compare the demographic information with other studies. Given that the primary purpose of this survey was quality assurance, we chose not to alter the questions for that reason.

When considering these findings, it is important to bear in mind that the current study focused on goals related to body functions and structures, activity and participation, rather than environment (e.g. equipment, psychosocial support, services, personal assistants, accommodation, family support, financial/legal support, medication). Because our survey was developed by a peer-led community organization, the focus was primarily on aspects that the organization could assist its members, rather than on aspects that were outside the scope of community peer-based organizations.

### Conclusion

The high proportion of respondents reporting “unbearable” problems point to the stronger need for systematic, comprehensive, life-long, multi-disciplinary follow-up for people with SCI. Furthermore, our findings suggest the active involvement of peer mentors in such services, as this was indicated by respondents. Some goals were found to correlate more with specific personal characteristics, something which warrants further research and can inform the focus of community interventions. The high rate of goals related to improving strength and fitness across all participants independently of their characteristics highlight the important role of community organizations that offer such lifetime services.

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