

ORIGINAL RESEARCH

Describing Functioning in People Living With Spinal Cord Injury in Switzerland: A Graphical Modeling Approach

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Abstract

Objective: To describe functioning in people living with spinal cord injuries (SCI) in Switzerland.

Design: Secondary analysis of cross-sectional survey data.

Setting: Community, Switzerland.

Participants: Individuals (N=1549) 16 years of age or older with a history of traumatic or nontraumatic SCI and permanently residing in Switzerland.

Interventions: Not applicable.

Main Outcome Measures: Functioning was operationalized through 4 domains: (1) impairments in body functions; (2) impairments in mental functions; (3) independence in performing activities; and (4) performance problems in participation.

Results: Univariate analysis indicated a high prevalence of problems in 5 areas: (1) housework; (2) climbing stairs; (3) tiredness; (4) spasticity; and (5) chronic pain. Graphical modeling showed a strong association among the four domains of functioning. Moreover, we found that the differences in the dependence structures were significant between the paraplegia SCI population and the tetraplegia SCI population.

Conclusions: This study is a first study in the epidemiology of functioning of people living with SCI in Switzerland. Using univariate and graphical modeling approaches, we proposed an empirical foundation for developing hypotheses on functioning in each domain and category that could inform health systems on people's health needs.

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A prerequisite for responding to the needs of community-based people living with spinal cord injuries (SCI) is a better knowledge of their everyday ability to function. The World Health Organization's report *International Perspectives on Spinal Cord Injury* promotes functioning as an essential outcome of medical and rehabilitation services.¹ According to the World Health

Organization's International Classification of Functioning, Disability and Health (ICF), functioning is the outcome of the interaction between health conditions and associated impairments in physiological and mental functions and environmental and personal contextual factors that may result in limitations in performing simple or complex activities.² An epidemiology of functioning is needed to deepen our knowledge of functioning. An epidemiological approach documents the prevalence of problems in functioning, as well as the complex relationships involved in human functioning.^{3,4}

The epidemiology of functioning has been scarcely studied in the context of SCI. Previous research documented the prevalence of complications after SCI, such as pain,⁵ sexual dysfunction,⁶ depression,⁷ and spasticity.⁸ The consequences of pain, sadness, and the number of complications in activities of everyday living or

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performance in social activities were studied using regression analysis.^{9,10} Therefore, research that creates a comprehensive picture of the overall experience of functioning among people living with SCI is essential.

Graphical modeling is a powerful tool for comprehensively studying the functioning of people living with a variety of health conditions, including SCI.¹¹⁻¹⁴ Compared to other multivariate exploratory methods (eg, multiple regression analysis, structural equation modeling, and factor analysis), graphical modeling has many advantages: it provides an interpretable representation of complex relationships by considering all functioning categories¹³; it makes no a priori assumptions about directionality when it portrays associations between items¹²; and it identifies a minimum set of functioning variables (including confounder and intermediate functioning variables) that make 2 functioning variables conditionally independent.¹³

The first community survey of the Swiss Spinal Cord Injury Cohort Study (SwiSCI) provides sufficient data for comprehensively describing the experience of functioning in people living with SCI in Switzerland.¹⁵ The ICF was used to identify categories of functioning relevant for assessment and appropriate measurement instruments for operationalization.¹⁶ These data have already been successfully used to describe the prevalence of secondary health conditions¹⁷ and the role of psychological resources and social skills in everyday activities.^{18,19}

In the present study, we used data from the SwiSCI community survey to further our knowledge of functioning in people living with SCI in Switzerland. This study had 2 aims: (1) to determine the prevalence of functioning problems in this population; and (2) to identify and, more important, visualize the relationships among all categories of functioning.

Methods

Study Design

This study is a secondary analysis of cross-sectional survey data from the SwiSCI community survey.

Participants

We included in our survey Swiss residents with traumatic or non-traumatic SCIs aged 16 years or older.¹⁵ We collected data between September 2011 and March 2013, and we will conduct the survey again every 5 years after it was first completed. An unofficial estimate of the Swiss SCI population is about 6000 people.¹⁶ We contacted 3144 eligible people by mail and asked them to provide informed consent and answer an initial short questionnaire (starter module) about their socio-demographics, lesion characteristics, and care situation. We recruited participants by using a contact database established by the Swiss Paraplegics Association for people living with SCI, three specialized SCI rehabilitation centers and a SCI-specific

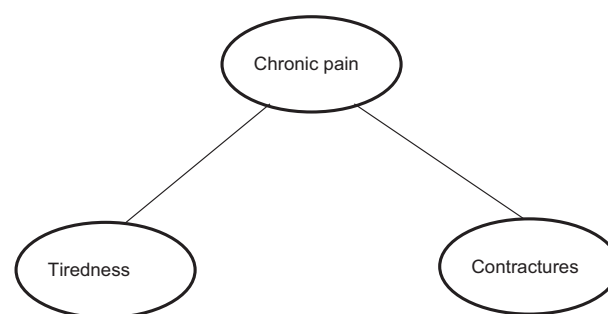


Fig 1 A simple skeleton of a DAG model. The nodes represent the functioning categories *Tiredness*, *Chronic pain*, and *Contractures*. The undirected edge between *Tiredness* and *Chronic pain* indicates that *Tiredness* includes the effect of *Chronic pain* (and vice versa). *Contractures* and *Tiredness* are conditionally independent, given the knowledge of *Chronic pain*. Thus, *Contractures* does not have a direct effect on *Tiredness*, and its effect is already contained in *Chronic pain* (and vice versa).

home-care institution. We sent a longer questionnaire (basic module) on functioning and environmental factors to 1549 people who had completed the starter module. A previous study evaluating the non-responders showed a minimal impact of response bias on survey results pertaining to characteristics of the people.¹⁶ We applied the

Table 1 Characteristics of study participants (N=1549)

| Characteristics | n(%) |
|-------------------------------|-------------|
| Sex | |
| Male | 1107 (71.5) |
| Female | 442 (28.5) |
| Agey | 52 (42-63) |
| 16-30 | 129 (8.3) |
| 31-45 | 377 (24.3) |
| 46-60 | 571 (36.9) |
| 61-75 | 378 (24.4) |
| ≥76 | 94 (6.1) |
| Education, y | 13 (12-15) |
| Language | |
| German | 1105 (71.3) |
| French | 376 (24.3) |
| Italian | 68 (4.4) |
| Etiology | |
| Traumatic | 1217 (78.5) |
| Non-traumatic | 332 (21.5) |
| Lesion characteristics, n (%) | |
| Paraplegia, incomplete | 582 (37.5) |
| Paraplegia, complete | 490 (31.6) |
| Tetraplegia, incomplete | 316 (20.4) |
| Tetraplegia, complete | 161 (10.4) |
| Time since injury, y | 14 (6-25) |
| 1 y | 56 (3.6) |
| 1-5 y | 278 (17.9) |
| 6-10 y | 277 (17.9) |
| 11-15 y | 218 (14.1) |
| 16-20 y | 180 (11.6) |
| 21-25 y | 168 (10.8) |
| 26-30 y | 131 (8.5) |
| 31-35 y | 88 (5.7) |
| ≥36 y | 153 (9.9) |

List of abbreviations:

| | |
|---------|--|
| DAG | directed acyclic graph |
| ICF | International Classification of Functioning, Disability and Health |
| SCI | spinal cord injuries |
| SCIM-SR | Spinal Cord Injury Independence Measure Self-Report |
| SwiSCI | Swiss Spinal Cord Injury Cohort Study |

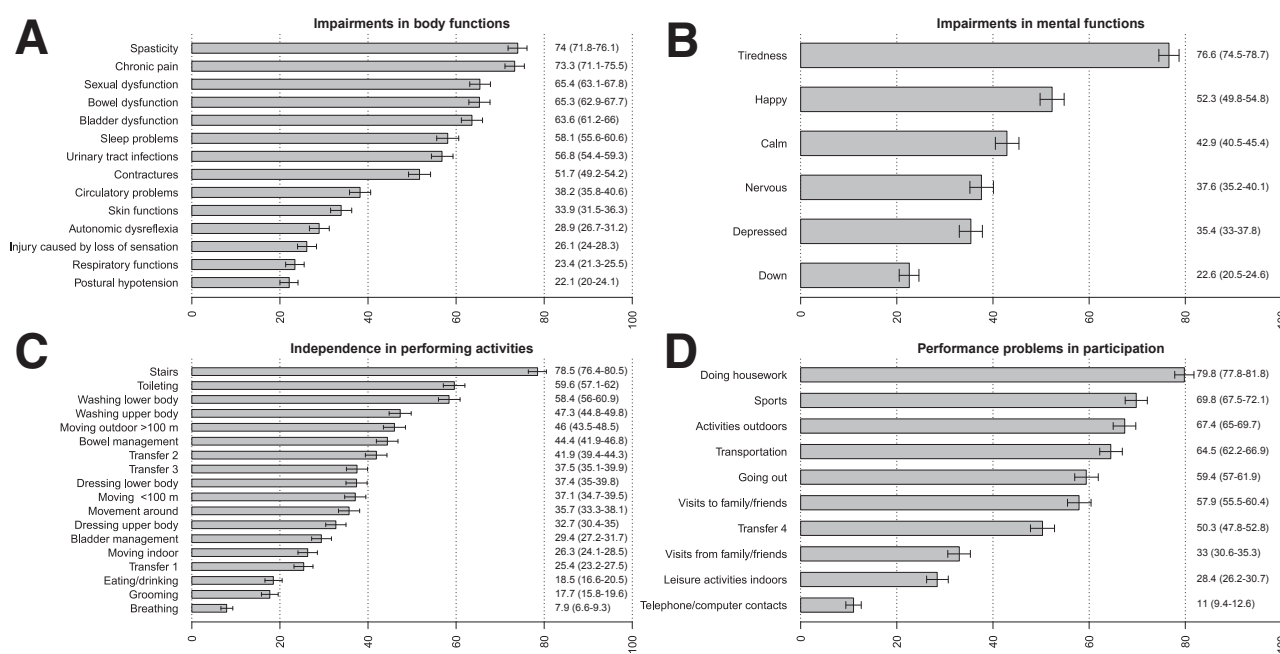


Fig 2 The prevalence of reported functioning problems in each ICF functioning domain. Abbreviations: 95% CI, 95% confidence interval; Transfer 1, transfer bed—wheelchair; Transfer 2, transfer wheelchair—toilet/tub; Transfer 3, transfer wheelchair—car; Transfer 4, transfer floor—wheelchair.

inverse probability weights available to correct for the nonresponse bias in this study. We collected data by written or online questionnaires and, in special cases, telephone interviews. This survey was approved by the ethics committee on research involving humans of Cantons Lucerne, Basel-Stadt and Valais.

Measures

Demographic and injury characteristics

We collected self-reported data on gender, age at the time of the questionnaire (in years), length of education (in years), etiology (traumatic or nontraumatic), lesion level (paraplegia or tetraplegia), lesion completeness (complete or incomplete), and time since SCI diagnosis (in years). A previous study¹⁶ confirmed reliability of the data by linking this self-reported information with available medical-record data.

Functional characteristics

We used reliable and valid instruments to operationalize relevant categories of functioning as defined by the ICF Core Set for SCI.^{20,21} For body functions, we used a selection of 14 items from the SCI Secondary Condition Scale,²² and, for mental functions, the Mental Health subscale from the Medical Outcomes Study Short-Form Health Survey. We used the SCI Independence Measure Self-Report (SCIM-SR) to assess independence in performing activities.²³ We used the Utrecht Scale for Evaluation Rehabilitation-Participation to evaluate performance problems in participation.²⁴ A previous study confirmed the internal construct validity and reliability of the SCIM-SR and USER-Participation instruments from the Utrecht Scale for Evaluation Rehabilitation-Participation.^{25,26} For this study, we operationalized each category of functioning in terms of the items in these instruments.²⁷ We present a detailed description of each item in [appendix 1](#).

Statistical analyses

We used descriptive statistics to summarize the study's sample characteristics. To categorize etiology, severity of injury, time

since injury, and age, we followed recommendations by the International Spinal Cord Society on standardized reporting for comparison with other epidemiological studies.²⁸

Prevalence of reported functioning problems

We calculated the prevalence of functioning problems (with 95% binomial confidence interval) by measuring the severity of the present functioning problem standardized for age and sex. For each functioning item, we dichotomized the answers into 0, for *not existing or insignificant problems/difficulty*, and 1, for *existing and significant problems/difficulty*, as described in [appendix 1](#). Consistent with previous research using these data, we used the following approaches: (1) we coded the response option *mild/infrequent problem* was coded as 1 (*existing and significant problems/difficulty*) for impairments in body functions; (2) we derived 4 age groups (16-30, 31-45, 46-60, and 61 and older); (3) we categorized time-since-injury variables as *less than 6 years*, *6-15 years*, *16-25 years*, and *26 years and more*.¹⁷ We generated 10 versions of the original data sets, and used the random forest imputation technique to deal with item nonresponses.²⁹ We excluded the functioning categories *Partner relationship* and *Work/education* from the analysis, because 21.3% and 15.3%, respectively, of individuals in the sample were restricted from participating in these activities (although not due to the injury). We examined the prevalence of functioning problems in relation to etiology, lesion characteristics, time since injury, age, and sex.

Association structure of functioning categories

We used the undirected graphical model, called the skeleton of the directed acyclic graph (DAG) model, to identify and visualize associations among categories of functioning. The model consists of nodes (circles) representing our variables of interest and undirected edges (lines) representing conditional dependency. The skeleton of a DAG is its undirected fundament, in which the relation between 2 variables is determined but not its direction. The skeleton of a DAG is valuable for exploratory analysis mainly

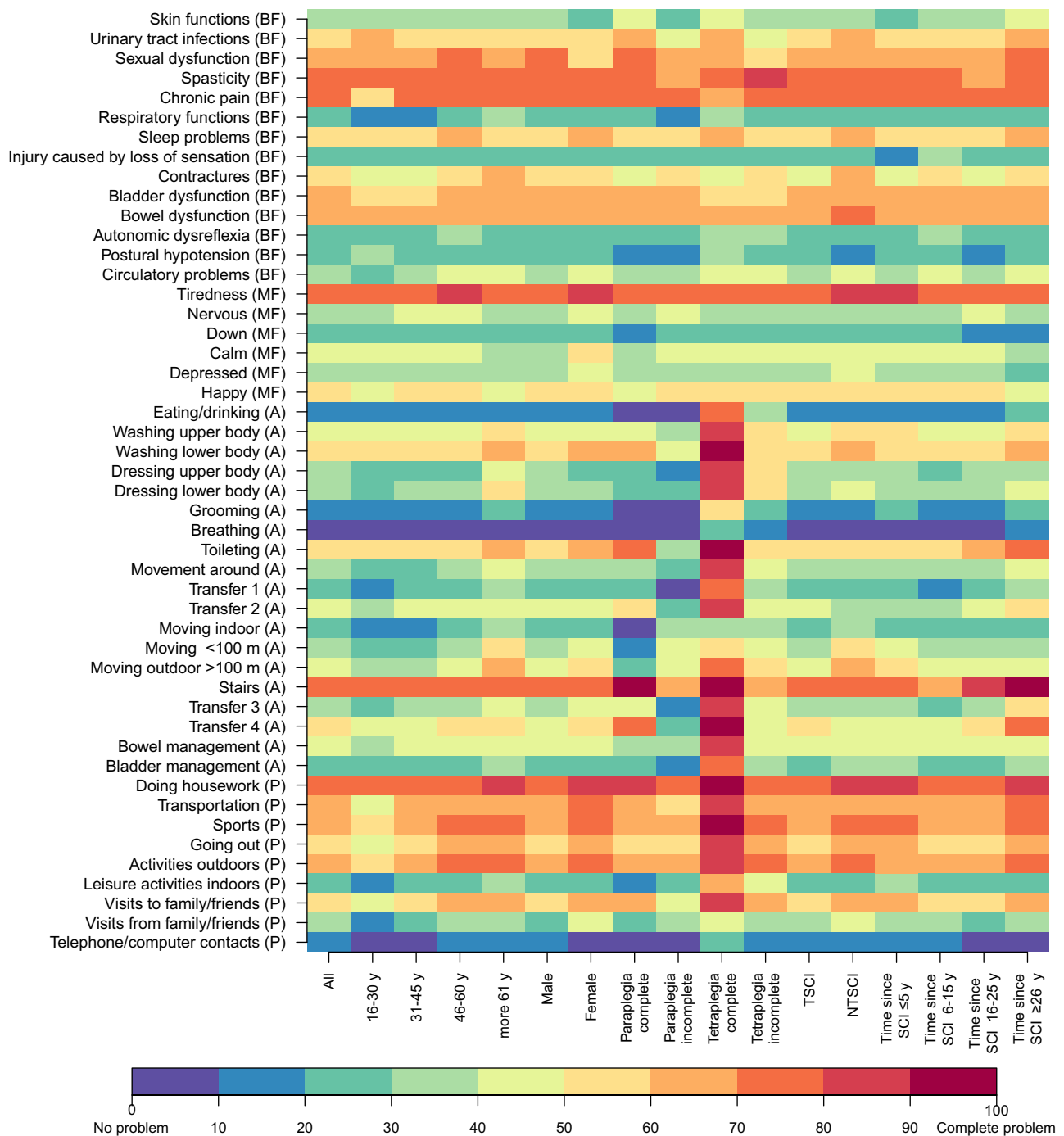


Fig 3 Functioning profile showing the prevalence of reported problems in functioning for the overall SCI sample and stratified by demographic characteristics, lesion characteristics, and time since injury. Abbreviations: Transfer 1, transfer bed—wheelchair; Transfer 2, transfer wheelchair—toilet/tub; Transfer 3, transfer wheelchair—car; Transfer 4, transfer floor—wheelchair; A, independence in performing activities; BF, impairments in body functioning; MF, impairments in mental functions; P, performance problems in participation; TSCI, traumatic SCI; NTSCI, nontraumatic SCI.

because it can be easily interpreted—every edge indicates some strong dependence which cannot be explained by accounting for other variables. Figure 1 shows a simple example of a skeleton of a DAG. The nodes in the figure represent the functioning categories *Tiredness*, *Chronic pain*, and *Contractures*. The absence of an edge between *Tiredness* and *Contractures* indicates conditional independence, given the knowledge of *Chronic pain*. The concept of conditional independence means that the information about *Contractures* does not give us information about *Tiredness* once

we have knowledge of *Chronic pain* (and vice versa). If *Tiredness* and *Contractures* are conditionally independent, we cannot infer that they are also marginally independent.³⁰ We study the marginal relation between *Tiredness* and *Contractures*, only and completely ignoring knowledge of *Chronic pain*.

The skeleton model is a first product of the PC algorithm in obtaining the DAG implemented by Kalisch et al.³¹ We tested any 2 functioning categories for conditional independence (significance level $\alpha=0.01$), given any subset of the remaining

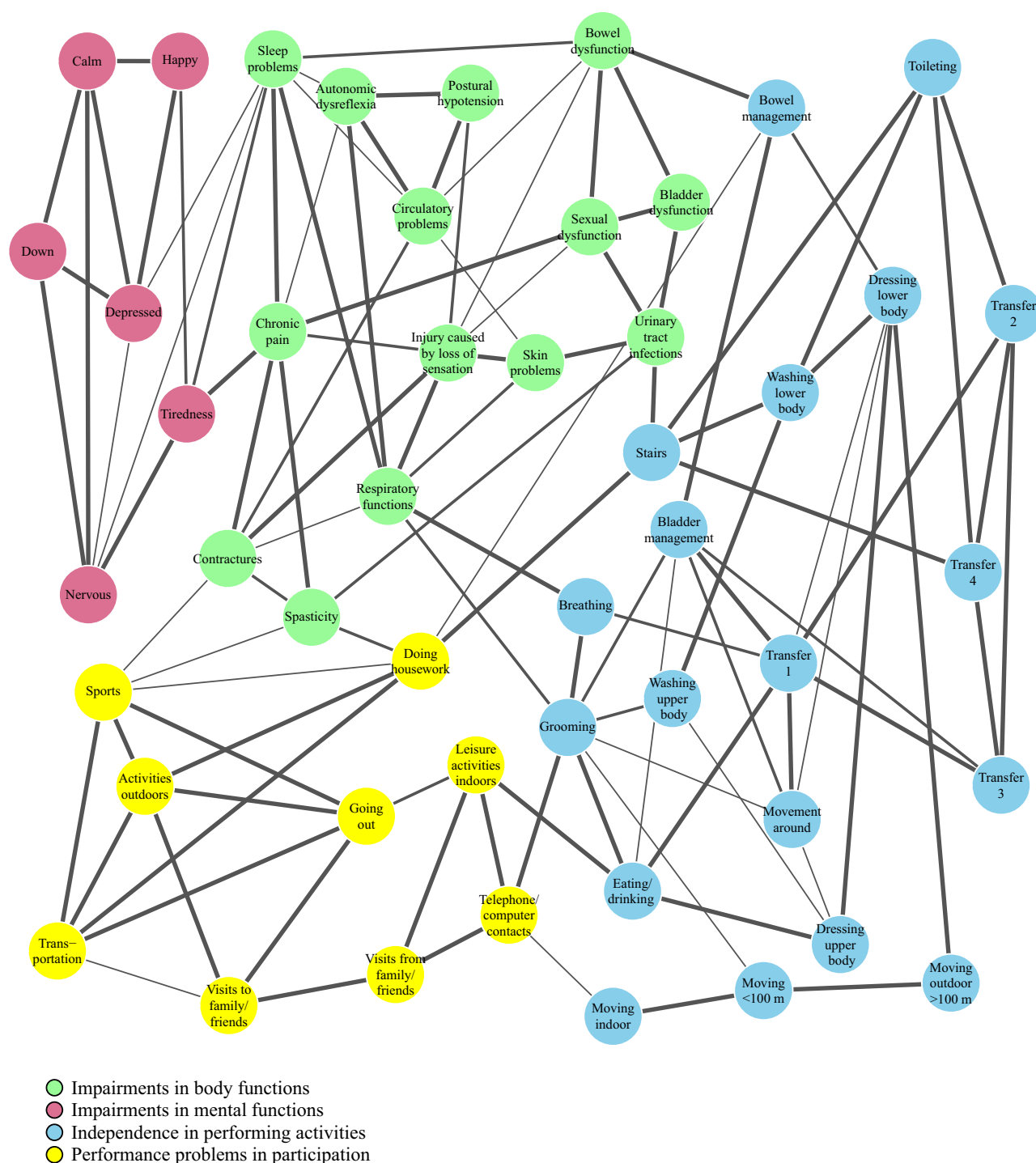


Fig 4 The association structure identified for the overall SCI sample among the categories of functioning. The thickness of an edge represents the reliability of the edge (light weighted: edge identified in 50-74 generated samples; middle weighted: edge identified in 75-90 generated samples and heavy weighted: edge identified in ≥ 90 generated samples). Abbreviations: Transfer 1, transfer bed—wheelchair; Transfer 2, transfer wheelchair—toilet/tub; Transfer 3, transfer wheelchair—car; Transfer 4, transfer floor—wheelchair.

functioning categories.³² Because this algorithm was developed only for dichotomous data, we used the dichotomization strategy from the prevalence analysis.

To enhance the stability of the estimated associations, we repeated the PC algorithm for 100 bootstrap samples generated from resampling, with replacement 10 times from each of the 10 imputed data sets used in the prevalence analysis.³³ We

aggregated the results in a summary graph that included only edges that appeared in the skeleton of at least 50 generated samples (we considered 50 samples the minimum number necessary for reducing random fluctuations and keeping the meaningful associations).¹² The thickness of an edge indicates the reliability of the edge (light weighted, edge identified in 50-74 generated samples; middle weighted, edge identified in 75-90

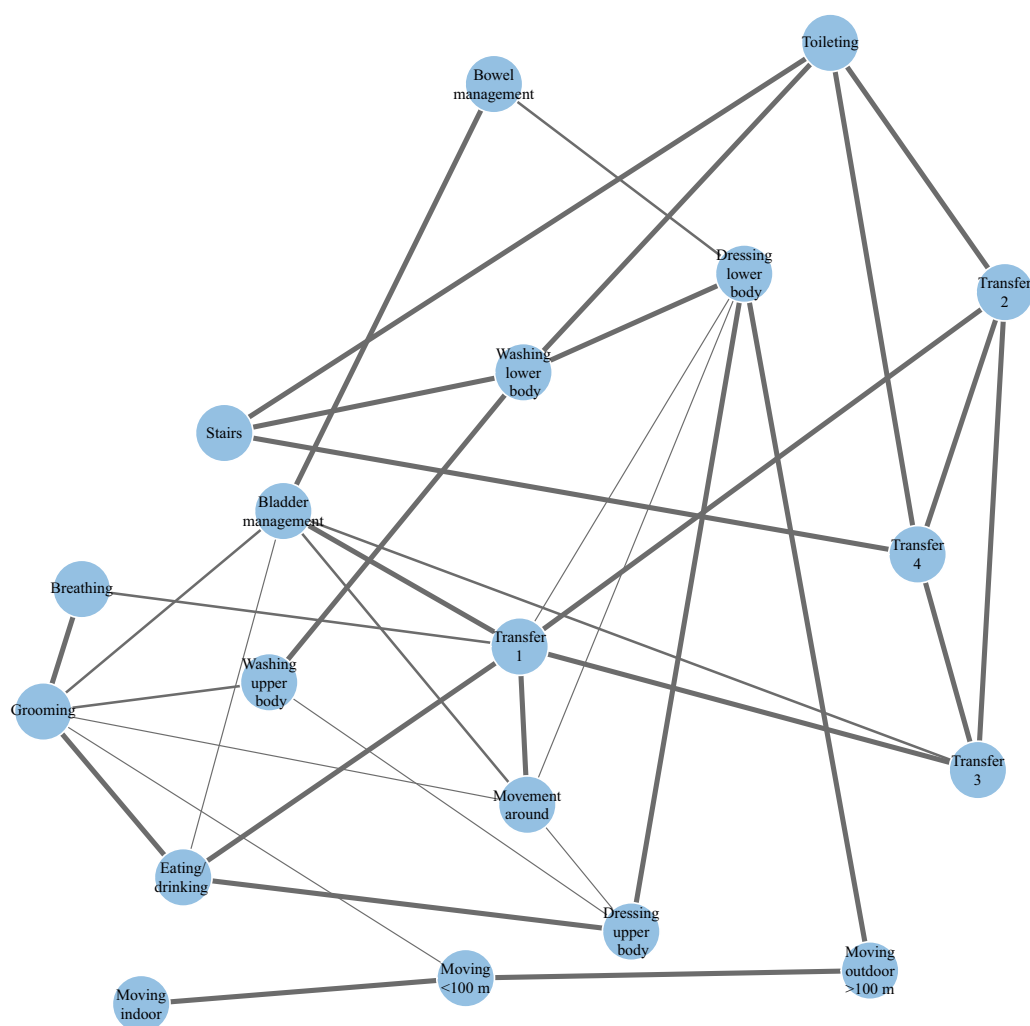


Fig 5 The association structure identified for the overall SCI sample among categories of functioning from the domain: independence in performing activities. This figure is a close-up look at part of figure 4 in the functioning categories from the domain: independence in performing activities. The thickness of an edge represents the reliability of the edge (light weighted: edge identified in 50-74 generated samples; middle weighted: edge identified in 75-90 generated samples and heavy weighted: edge identified in ≥ 90 generated samples). Abbreviations: Transfer 1, transfer bed—wheelchair; Transfer 2, transfer wheelchair—toilet/tub; Transfer 3, transfer wheelchair—car; Transfer 4, transfer floor—wheelchair.

generated samples, and heavy weighted, edge identified in ≥ 90 generated samples).

To visualize the differences in the association structure between the paraplegia SCI population and the tetraplegia SCI population, we estimated the association structure for each subgroup, as previously described. To quantify the overall difference between the groups, we used the Structural Hamming Distance, which is the number of edge insertions or deletions required to transform the graph of the paraplegia SCI population to the graph of the tetraplegia SCI population.

Results

Sample Characteristics

Sample descriptive information is provided in table 1. Most of the participants (71.5% [n = 1107]) were male with a median age of 52 years. More than half (58% [n = 898]) had an incomplete lesion, and over two-thirds (69% [n = 1072]) were individuals with paraplegia.

Prevalence of reported functioning problems

Figure 2 shows the prevalence means across the 10 imputed data sets adjusted for nonparticipants for each domain of functioning. The functioning categories with the highest prevalence of reported problems were *Doing housework* (performance problems in participation) (79.8% [n = 1280]), *Stairs* (independence in performing activities) (78.5% [n = 1263]), *Tiredness* (impairments in mental functions) (76.6% [n = 1187]), and *Spasticity* and *Chronic pain* (impairments in body functions) (74% [n = 1149] and 73.3% [n = 1135, respectively]). The prevalence of functioning problems stratified by SCI-specific subgroups and the 95% confidence interval are presented in figure 3. Appendices 2 and 3 provide complementary information on the relative frequency of functions categories. Compared to the other age groups, the 46-60 and 60+ age groups showed a higher prevalence of problems under the categories of *Sexual functions*, *Chronic pain*, *Respiratory functions*, *Circulatory functions*, independence in *Dressing upper body*, and problems with movement and performance in participation. People with SCIs for more than 15 years reported greater need for assistance with mobility. People with complete SCIs reported a higher

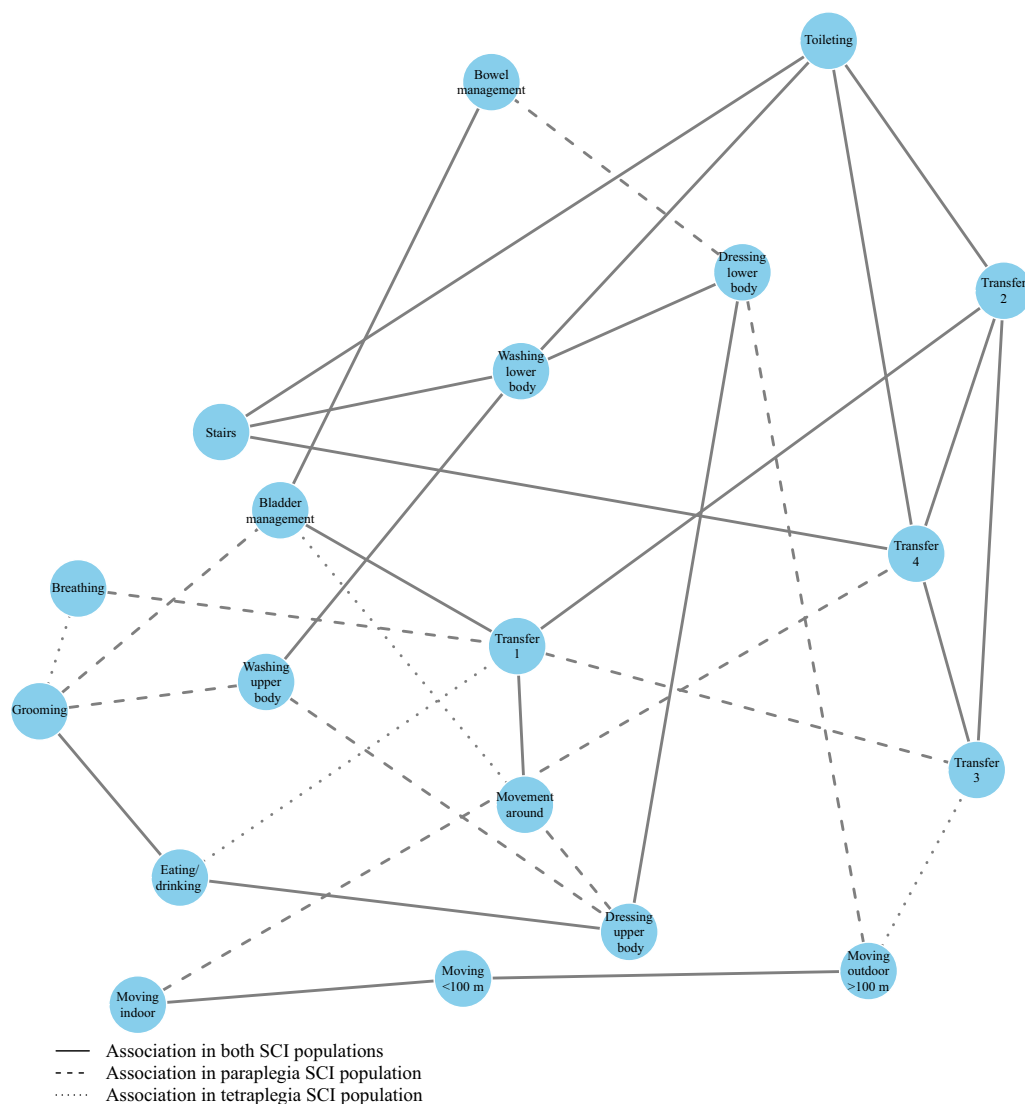


Fig 6 Comparison of association structures of functioning categories addressing independence in performing activities between the respective paraplegia and tetraplegia SCI populations. Abbreviations: Transfer 1, transfer bed–wheelchair; Transfer 2, transfer wheelchair–toilet/tub; Transfer 3, transfer wheelchair–car; Transfer 4, transfer floor–wheelchair.

prevalence of problems with independence in performing activities and performance problems in participation than those with incomplete lesions, irrespective of lesion levels.

Association structure of functioning categories

Graphical models revealed a strong association within and across variables operationalizing the same domain of functioning: impairments in body functions, impairments in mental functions, independence in performing activities, and performance problems in participation (fig 4). This finding confirmed the dynamic among the domains of functioning described in the ICF. For example, impairments in body functions, such as *Contractures* and *Spasticity*, provide information about performance in *Sports* (and vice versa).

For illustrative purposes, figure 5 presents a closer look at part of figure 4 to illustrate associations among the items of the SCIM-SR. The dynamic among the subdomains of SCIM-SR, mobility, self-care, and sphincter and respiration was revealed. For example, *Toileting* (item from the sphincter and respiration subscale)

contains the effect of mobility activity *Transfer wheelchair–toilet/tub* (and vice versa). A triangle formed by 3 functioning categories (eg, *Toileting*, *Transfer wheelchair–toilet/tub*, and *Transfer floor–wheelchair*) indicated that 1 variable was strongly dependent on the other 2, and thus, each of these 3 functioning categories was a confounding variable in association with the other 2 variables.

The association structures the paraplegia SCI population differ significantly from the association structure for the tetraplegia SCI population (Structural Hamming Distance = 82). Figure 6 illustrates the comparison of association structures among the items in the SCIM-SR. For variables addressing mobility, most of the associations were similar in both SCI populations, with the exception of 2 edges identified only for the paraplegia SCI population: (1) edge connecting *Transfer 1* (transfer bed–wheelchair) and *Transfer 3* (transfer wheelchair–car); (2) edge connecting *Transfer 4* (transfer floor–wheelchair) and *Moving indoor*. The association between *Transfer 1* (transfer bed–wheelchair) and *Eating/drinking* and between *Movement around* and *Bladder management* were identified only for the SCI population with tetraplegia.

Discussion

This analysis is a first study in the epidemiology of functioning among people living with SCI in Switzerland. We identified the categories of functioning with the highest prevalence of reported problems using univariate analysis. Then, employing graphical modeling, we provided empirical evidence of a strong association between the categories of functioning that address the same functioning domain, including impairments in body functions, impairments in mental functions, independence in performing activities, and performance problems in participation. Graphical modeling was useful for visualizing the differences in the association structures according to lesion level.

The categories of functioning problems with the highest prevalence in the Swiss SCI population reported in this study were acknowledged in previous SCI population-based studies; these categories included *Doing housework* duties,³⁴ climbing *Stairs*,³⁵ *Tiredness*,³⁶ *Spasticity*, and *Chronic pain*.^{8,37,38} They are also comparable with the SwiSCI data in response to the open-ended question *What causes you the most problems since your spinal cord injury?*³⁹ The graphical modeling approach provided empirical evidence to explain these results. For example, the high percentage of people reporting limitations in *Doing housework* duties may be explained by the presence of *Spasticity* impairments and limitations in climbing *Stairs* (see fig 4). The distribution of the prevalence of problems across different subgroups reflects physiological differences and the complexity of the functioning category for each SCI subgroup; it also reflects people's responses to the rehabilitation programs. For example, *Doing housework* duties was a complex activity for all SCI people,³⁴ whereas climbing *Stairs* was impossible for most of the SCI people with complete injury (although individuals in the latter group were mobile with a manual or electric wheelchair).³⁵ The low problem prevalence for independence in *Breathing* could be explained by impairments in *Respiratory functions* (see fig 4), which are predominantly reported by individuals with tetraplegia.⁴⁰

The skeleton model produced a single cluster of functioning categories, i.e. each functioning category is connected with all other functioning categories through a path. Thus, graphical modeling demonstrates the unidimensionality of functioning. However, the construction of one summary score for an overall outcome of functioning is challenging. Using Rasch modeling, a functioning profile for each individual was constructed by reporting an interval score for mental functions, functioning of body systems, mobility, self-care and involvement in life situations.²⁵

The identified association structure provided empirical evidence for a basic description of functioning in each category. For example, any study of *Spasticity* in people living with SCI should consider the functioning categories that are directly associated with *Spasticity*: *Chronic pain*; *Contractures*; *Urinary tract infections*; *Doing housework*; and *Sports* (see fig 4). In line with the evidence from a SCI study using the same methodology and functioning data from 14 countries, we confirmed that the study of *Doing housework* duties should consider performance in different *Activities outdoors* and in using *Transportation*, but also the indirect effect of impairments in mental-functions (*Tiredness*, *Nervous*).¹² Future longitudinal studies should verify our results.

Using graphical modeling, we confirmed the differences in functioning between people with tetraplegia and paraplegia not only in mobility, self-care, and domestic life but also in body functions, because the graphical models identified for each subgroup vary significantly.⁴¹ Such a comparison of the association structures between different SCI sub-groups can be useful to develop hypotheses about functioning. For example, when studying independence in

Movement around, its association with *Bowel management* should be considered in the tetraplegia SCI population, while its association with *Dressing upper body* was relevant in the paraplegia SCI population.

Study Limitations

We note several limitations to our study. First, because we assumed missing data noninformative, and because we dichotomized the available discrete functioning variables, we could not investigate nonlinear associations. Coding the response option *mild problems* in impairments in body functions items as *not existing or insignificant* resulted in slight changes in the association structure. Second, we applied graphical modeling to cross-sectional and self-reported data; graphical modeling is an explorative statistical approach without an imposed a priori assumption about associations, and, therefore, in our study, may not reveal some of the previously identified associations (eg, between *Urinary tract infection* and *Bladder management*⁴² or the reliability of some associations, such as *Depressed* and *Sleep problems*⁴³). Third, we excluded the *Partner relationship* and *Work/education* functioning categories from our analysis. We conducted additional analyses using data from people who also rated these items. *Work/education* was conditionally dependent on *Nervousness (type of mood)* and limitations in *Sports*, *Leisure activities outdoors*, *Going out*, and *Doing housework*, whereas *Partner relationship* was associated with problems in the categories of *Sexual functions*, *Happy*, *Leisure activities outdoors*, and *Going out*. When longitudinal data from this survey are available, we plan to include these variables when studying the relations among the 4 domains of functioning; we will use Markov chain Monte Carlo methods.⁴⁴ Fourth, the small sample for the SCI population with tetraplegia could lead to a sparse graph for this population.³² Finally, we did not collect the exact level and completeness of lesion based on the American Spinal Injury Association system.⁴⁵

Conclusions

Using univariate and graphical modeling approach, we proposed an empirical foundation for developing hypotheses on functioning in each domain and category that could inform health systems about people's health needs. We showed that graphical models are helpful in discovering and visualizing the effect of lesion characteristics in the functioning of people living with SCI. By combining graphical models with other statistical concepts, we should contribute to greater knowledge about the functioning of people living with SCI.

Keywords

International Classification of Functioning, Disability and Health; Prevalence; Rehabilitation; Spinal cord injuries; Unirected graph

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Appendix 1 The Functioning Items and the Dichotomization Strategy

| Instrument | Instrument Label | Study Label | Dichotomization Strategy |
|--------------------------------------|--|------------------------------------|--|
| SCI Secondary Conditions Scale | Injury caused by loss of sensation | Injury caused by loss of sensation | 0=No problem; 1=Mild/infrequent problem/Moderate/occasional problem/Significant/chronic problem. |
| | Chronic pain | Chronic pain | |
| | Postural hypotension | Postural hypotension | |
| | Circulatory | Circulatory | |
| | Respiration | Respiration | |
| | Bowel dysfunction | Bowel dysfunction | |
| | Urinary tract infection | Urinary tract infections | |
| | Bladder dysfunction | Bladder dysfunction | |
| | Sexual dysfunction | Sexual dysfunction | |
| | Contractures | Contractures | |
| | Spasticity | Spasticity | |
| | Decubitus | Skin functions | |
| | Sleep | Sleep problems | |
| | Autonomic dysreflexia | Autonomic dysreflexia | |
| 36-item Short Form (SF-36) | Type of mood: Nervous | Nervous | 0=None of the time/A little of the time; 1=All of the time/Most of the time/A good bit of the time/Some of the time. |
| | Type of mood: Down | Down | |
| | Type of mood: Depressed | Depressed | |
| | Type of mood: Calm | Calm | 0=All of the time/A little of the time; 1=Most of the time/A good bit of the time/Some of the time/None of the time. |
| SCI Independence Measure Self-Report | Type of mood: Happy | Happy | |
| | Movement around (Turning upper body in bed; Turning lower body in bed; Sitting up in bed; Doing push ups in wheelchair [with or without adaptive devices]) | Movement around | 0=All of them; 1=None, I need assistance in all these activities/One activity/Two or three activities. |
| | Transfers: wheelchair-car | Transfer wheelchair-car | 0=I do not need assistance or adaptive devices/I do not use a wheelchair; 1=I need total assistance/I need partial assistance, supervision or adaptive devices. |
| | Transfers: floor-wheelchair | Transfer floor-wheelchair | 0=I do not need assistance/I do not use a wheelchair; 1=I need total assistance. |
| | Transfers: bed-wheelchair | Transfer bed-wheelchair | 0=I transfer independently/I do not use a wheelchair; 1=I need total assistance/I need partial assistance, supervision or adaptive devices. |
| | Transfers: wheelchair-toilet/tub | Transfer wheelchair-toilet/tub | 0=I transfer independently/I do not use a wheelchair; 1=I need total assistance/I need partial assistance, supervision or adaptive devices. |
| | Ascending or descending stairs | Stairs | 0=I ascend or descend at least 3 steps without any assistance, supervision or devices; 1=I am unable to ascend or descend stairs/I ascend or descend at least 3 steps |

(continued on next page)

Appendix 1 (continued)

| Instrument | Instrument Label | Study Label | Dichotomization Strategy |
|--|--|---|--|
| | Moving around indoor Moving around moderate distances (10m-100m) Moving around outdoor for more than 100 m | Moving indoor Moving <100 m Moving outdoor >100 m | but only with assistance or supervision/I ascend or descend at least 3 steps but only with devices (e.g. handrail, crutch, cane). 0=I use a wheelchair and move independently in a manual wheelchair/I walk indoors and I walk without aids; 1=I use a wheelchair and I need total assistance/I use a wheelchair and I need an electric wheelchair or partial assistance to operate a manual wheelchair/I walk moderate distances and I need supervision while walking (with or without aids)/I walk indoors with a walking frame or crutches, swinging forward with both feet at a time/I walk indoors and I walk with crutches or two canes, setting one foot before the other/I walk indoors and I walk with one cane)/(I walk indoors and I walk with a leg orthosis only (e.g. leg splint). 0=I am completely independent and don't need adaptive devices or a specific setting; 1=I need total assistance/I need partial assistance/I do not need assistance, but I need adaptive devices or a specific setting. 0=I use the toilet independently without adaptive devices or a special setting; 1=I need total assistance/I need partial assistance and cannot clean myself/I need partial assistance but I can clean myself/I use the toilet independently but I need adaptive devices (e.g. bars) or a special setting (e.g. wheelchair accessible toilet). 0=I am completely independent in dressing my upper body; 1=I need total assistance/I need partial assistance, even with easy-to-dress clothes/I do not need assistance with easy-to-dress clothes, but I need adaptive devices or a specific setting with them/I am independent in dressing my upper body with easy-to-dress clothes and only need assistance or adaptive devices or a specific setting with difficult-to-dress clothes. 0=I am completely independent in dressing my lower body; 1=I need total assistance/I need partial assistance, even with easy-to-dress clothes/I do not need assistance with easy-to-dress clothes, but I need adaptive devices or a specific setting with them/I am independent in dressing my lower body with easy-to-dress clothes and only need assistance or adaptive devices or a specific setting with difficult-to-dress clothe. 0=I eat/drink independently without assistance or adaptive devices; 1=I need parenteral feeding or I have a gastrostomy/I need total assistance with eating/drinking/I need partial assistance with eating/drinking or for putting on/taking off adaptive devices/I eat/drink independently, but I need adaptive devices or assistance for cutting food, pouring or opening containers. 0= Without difficulty; 1= With difficulty/With assistance/Not possible; NA= Not applicable. |
| | Washing upper body and head Washing lower body Grooming | Washing upper body Washing lower body Grooming | |
| | Toileting | Toileting | |
| | Dressing upper body | Dressing upper body | |
| | Dressing lower body | Dressing lower body | |
| | Eating and drinking | Eating and drinking | |
| Utrecht Scale for Evaluation Rehabilitation-Participation | Limitation in household duties Limitation in outdoor mobility | Doing housework Transportation | |

(continued on next page)

Appendix 1 (continued)

| Instrument | Instrument Label | Study Label | Dichotomization Strategy |
|------------|--|-----------------------------|--------------------------|
| | Limitation in relationship | Relationships | |
| | Limitation in contacting others | Telephone/computer contacts | |
| | Limitation in work or education | Work/Education | |
| | Limitation in sports | Sports | |
| | Limitation in going out | Going out | |
| | Limitation in day trips | Activities outdoors | |
| | Limitation in leisure activities at home | Leisure activities indoors | |
| | Limitation of visiting family or friends | Visits to family/friends | |
| | Limitation in being visited by family or friends | Visits from family/friends | |

Appendix 2 Relative frequency (percentage with 95% confidence interval) of reported functioning problems stratified by demographic characteristics of participants

| Conditions, Disorders, and Injuries | Age at the Time of Questionnaire | | | | P | Sex | | P |
|-------------------------------------|----------------------------------|----------------------|-----------------------|----------------------|--------|--------------------|----------------------|--------|
| | 16-30 y % (95% CI) | 31-45y % (95% CI) | 46-60 y % (95% CI) | ≥ 61 y % (95% CI) | | Male % (95% CI) | Female % (95% CI) | |
| Skin functions | 30.2 (22.3-38.1) | 31.6 (26.9-36.3) | 34.8 (30.9-38.7) | 36.1 (31.8-40.4) | .380 | 35.7 (32.9-38.6) | 29.3 (25-33.5) | .019 |
| Urinary tract infections | 61.4 (53-69.8) | 57.4 (52.4-62.4) | 58 (54-62.1) | 53.9 (49.4-58.3) | .330 | 55.6 (52.7-58.6) | 59.8 (55.3-64.4) | .153 |
| Sexual functions | 61.1 (52.7-69.5) | 61.1 (56.2-66) | 71.8 (68.1-75.4) | 63.4 (59.1-67.8) | .001 | 70.7 (68-73.4) | 52.2 (47.6-56.9) | <.001 |
| Spasticity | 77.8 (70.6-84.9) | 72.8 (68.3-77.3) | 70.5 (66.8-74.2) | 77.6 (73.9-81.4) | .045 | 73.7 (71.1-76.3) | 74.5 (70.4-78.5) | .802 |
| Chronic pain | 54.9 (46.3-63.5) | 71.6 (67.1-76.2) | 76 (72.5-79.5) | 77.1 (73.3-80.9) | <.001 | 72.4 (69.7-75) | 75.7 (71.7-79.7) | .205 |
| Respiratory functions | 18.9 (12.2-25.7) | 17.4 (13.6-21.3) | 21.9 (18.6-25.3) | 31.5 (27.3-35.7) | <.001 | 23.5 (21-26) | 23.1 (19.2-27.1) | .912 |
| Sleep problems | 52 (43.3-60.6) | 53.2 (48.2-58.3) | 63.4 (59.4-67.3) | 58.3 (53.8-62.7) | .006 | 56.2 (53.3-59.1) | 62.8 (58.3-67.3) | .023 |
| Injury caused by loss of sensation | 25.3 (17.8-32.8) | 27.4 (22.9-31.9) | 27.8 (24.2-31.5) | 23.5 (19.6-27.3) | .358 | 26.4 (23.8-29) | 25.5 (21.5-29.6) | .772 |
| Contractures | 42 (33.5-50.5) | 42.2 (37.2-47.2) | 53.2 (49.1-57.3) | 60.8 (56.4-65.2) | <0.001 | 51.2 (48.2-54.1) | 53 (48.3-57.6) | .561 |
| Bladder dysfunction | 58.2 (49.7-66.8) | 59.9 (55-64.9) | 65.2 (61.3-69.1) | 66.5 (62.3-70.8) | .097 | 61.5 (58.7-64.4) | 68.8 (64.4-73.1) | .010 |
| Bowel dysfunction | 68.1 (60.1-76.2) | 63.5 (58.6-68.3) | 66.8 (63-70.7) | 64.4 (60.1-68.7) | .533 | 63.7 (60.9-66.6) | 69.3 (65-73.6) | .049 |
| Autonomic dysreflexia | 30 (22.1-37.9) | 28 (23.5-32.5) | 32.2 (28.4-36.1) | 25.9 (21.9-29.8) | .139 | 28.7 (26-31.3) | 29.5 (25.3-33.8) | .783 |
| Postural hypotension | 30.1 (22.2-38.1) | 21.3 (17.2-25.4) | 20.3 (17-23.6) | 22.4 (18.6-26.1) | .094 | 20.7 (18.4-23.1) | 25.4 (21.3-29.4) | .059 |
| Circulatory problems | 25.4 (17.9-32.9) | 31.9 (27.2-36.6) | 40.6 (36.6-44.7) | 44.6 (40.1-49.1) | <0.001 | 34.3 (31.5-37.1) | 47.8 (43.1-52.5) | <0.001 |
| Tiredness | 77.5 (70.3-84.7) | 75.7 (71.3-80) | 80.3 (77.1-83.6) | 73.1 (69.1-77.1) | 0.041 | 74.7 (72.2-77.3) | 81.2 (77.5-84.8) | 0.009 |
| Nervous | 35.9 (27.6-44.2) | 40.8 (35.9-45.8) | 40.2 (36.2-44.2) | 32.8 (28.5-37) | 0.042 | 35.7 (32.9-38.5) | 42.5 (37.9-47.2) | .014 |
| Down | 21 (14-28.1) | 23.9 (19.6-28.2) | 23.3 (19.8-26.8) | 21.1 (17.4-24.8) | .637 | 21.2 (18.8-23.6) | 25.9 (21.8-30) | .058 |
| Calm | 44.9 (36.3-53.5) | 49.6 (44.6-54.7) | 44.5 (40.5-48.6) | 35.1 (30.8-39.4) | <0.001 | 39 (36.1-41.8) | 53 (48.3-57.6) | <0.001 |
| Depressed | 34 (25.8-42.2) | 38.9 (33.9-43.8) | 35.4 (31.5-39.3) | 33.1 (28.9-37.4) | .327 | 31.6 (28.9-34.4) | 44.9 (40.3-49.6) | <0.001 |
| Happy | 41.4 (32.9-49.9) | 57.5 (52.5-62.5) | 54.7 (50.7-58.8) | 48.5 (44-53) | .002 | 51.7 (48.8-54.6) | 53.9 (49.3-58.6) | .463 |
| Eating/drinking | 17.5 (11-24.1) | 19.3 (15.3-23.3) | 17.8 (14.6-20.9) | 19.1 (15.6-22.7) | .814 | 19.1 (16.8-21.4) | 17.1 (13.6-20.6) | .384 |
| Washing upper body | 44.4 (35.8-53) | 45.9 (40.8-50.9) | 45.6 (41.5-49.7) | 51.4 (46.9-55.9) | .183 | 47.1 (44.1-50) | 47.9 (43.3-52.6) | .796 |
| Washing lower body | 53.7 (45.1-62.3) | 54.8 (49.8-59.9) | 58.5 (54.5-62.5) | 62.8 (58.4-67.2) | .067 | 57.4 (54.5-60.3) | 61 (56.5-65.6) | .209 |
| Dressing upper body | 21.9 (14.8-29.1) | 27.4 (22.9-31.9) | 28.2 (24.5-31.8) | 45.3 (40.8-49.8) | <.001 | 33.9 (31.1-36.6) | 29.8 (25.5-34) | .136 |
| Dressing lower body | 24.4 (17-31.8) | 30.2 (25.6-34.8) | 33.7 (29.8-37.6) | 51.4 (46.9-55.9) | <.001 | 37.8 (35-40.7) | 36.4 (31.9-40.9) | .633 |
| Grooming | 13.1 (7.3-19) | 16.9 (13.1-20.7) | 16.7 (13.6-19.7) | 20.8 (17.1-24.4) | .124 | 18.6 (16.3-20.9) | 15.4 (12-18.8) | .158 |
| Breathing | 5.7 (1.7-9.8) | 8.2 (5.4-11) | 7.1 (5-9.2) | 9.2 (6.6-11.8) | .418 | 8 (6.4-9.6) | 7.7 (5.2-10.2) | .918 |
| Toileting | 56 (47.5-64.6) | 58 (53-63) | 60 (56-64.1) | 61.5 (57.1-65.9) | .534 | 59.1 (56.2-62) | 60.7 (56.1-65.3) | .605 |
| Movement around | 29.6 (21.8-37.5) | 30 (25.4-34.6) | 34.3 (30.4-38.2) | 43.9 (39.4-48.4) | <.001 | 35.6 (32.8-38.4) | 35.9 (31.4-40.4) | .958 |
| Transfer bed—wheelchair | 17.4 (10.9-24) | 21.9 (17.7-26) | 22.4 (19-25.8) | 34.1 (29.8-38.3) | <.001 | 24.5 (22-27.1) | 27.4 (23.3-31.6) | .268 |
| Transfer wheelchair—toilet or tub | 33.5 (25.3-41.6) | 41.3 (36.4-46.3) | 42.8 (38.8-46.9) | 43.8 (39.4-48.3) | .171 | 40.1 (37.2-43) | 46.4 (41.7-51) | .027 |
| Moving indoor | 15.9 (9.6-22.2) | 18.8 (14.8-22.7) | 23.3 (19.8-26.8) | 39 (34.6-43.4) | <.001 | 24.9 (22.3-27.4) | 29.8 (25.5-34) | .058 |
| Moving <100 m | 21.6 (14.5-28.7) | 28.3 (23.7-32.8) | 33.9 (30-37.8) | 52.7 (48.2-57.2) | <.001 | 34.8 (32-37.6) | 43 (38.3-47.6) | .003 |
| Moving outdoor >100 m | 32.3 (24.3-40.4) | 34.6 (29.8-39.4) | 43.8 (39.7-47.8) | 62.1 (57.7-66.4) | <.001 | 42.7 (39.8-45.7) | 54.2 (49.5-58.8) | <0.001 |
| Stairs | 74.9 (67.4-82.4) | 78.5 (74.4-82.7) | 79.4 (76.1-82.7) | 78.5 (74.8-82.2) | .658 | 77.9 (75.5-80.3) | 79.9 (76.2-83.7) | .418 |
| Transfer wheelchair—car | 28.2 (20.5-36) | 32.4 (27.7-37.1) | 36.1 (32.2-40.1) | 46.1 (41.7-50.6) | <.001 | 34.9 (32.1-37.8) | 43.9 (39.2-48.5) | .001 |
| Transfer floor—wheelchair | 40.7 (32.2-49.2) | 47 (42-52.1) | 50.7 (46.6-54.8) | 55.5 (51-60) | .008 | 48.7 (45.7-51.6) | 54.4 (49.8-59.1) | .049 |
| Doing housework | 72 (64.3-79.8) | 79.5 (75.4-83.5) | 80 (76.8-83.3) | 81.9 (78.5-85.4) | .101 | 76.6 (74.1-79.1) | 87.8 (84.7-90.8) | <.001 |

(continued on next page)

Appendix 2 (continued)

| Conditions, Disorders, and Injuries | Age at the Time of Questionnaire | | | | <i>P</i> | Sex | | <i>P</i> |
|-------------------------------------|----------------------------------|----------------------|-----------------------|----------------------|----------|--------------------|----------------------|----------|
| | 16-30 y % (95% CI) | 31-45y % (95% CI) | 46-60 y % (95% CI) | ≥ 61 y % (95% CI) | | Male % (95% CI) | Female % (95% CI) | |
| Transportation | 47.4 (38.8-56.1) | 60.4 (55.4-65.3) | 68.2 (64.4-72.1) | 68.9 (64.7-73.1) | <.001 | 61.6 (58.7-64.4) | 72 (67.8-76.2) | <.001 |
| Sports | 52.2 (43.5-60.8) | 66.9 (62.2-71.7) | 71.7 (68-75.4) | 75.3 (71.4-79.2) | <.001 | 67.9 (65.1-70.6) | 74.6 (70.6-78.7) | .013 |
| Going out | 43.7 (35.2-52.3) | 53.6 (48.6-58.7) | 62.2 (58.2-66.2) | 65.8 (61.5-70) | <.001 | 57.3 (54.4-60.2) | 64.7 (60.3-69.2) | .009 |
| Activities outdoors | 53.5 (44.9-62.1) | 63.1 (58.3-68) | 71.4 (67.7-75.1) | 70.5 (66.4-74.6) | <.001 | 64.8 (62-67.6) | 73.7 (69.6-77.8) | .001 |
| Leisure activities indoors | 16.8 (10.3-23.2) | 25.3 (20.9-29.7) | 28.4 (24.7-32.1) | 34.4 (30.1-38.7) | <.001 | 29.8 (27.1-32.5) | 24.9 (20.9-28.9) | .066 |
| Visits to family/friends | 43.6 (35.1-52.2) | 53.1 (48-58.1) | 61.4 (57.4-65.4) | 62.4 (58.1-66.8) | <.001 | 55.5 (52.6-58.5) | 63.9 (59.4-68.4) | .004 |
| Visits from family/friends | 14.7 (8.6-20.8) | 27.9 (23.4-32.4) | 38 (34-41.9) | 37.2 (32.8-41.5) | <.001 | 29.9 (27.2-32.6) | 40.6 (36-45.1) | <0.001 |
| Telephone/computer contacts | 5.5 (1.6-9.5) | 7.7 (5-10.4) | 10.1 (7.6-12.5) | 16.6 (13.3-20) | <.001 | 12 (10-13.9) | 8.6 (6-11.2) | .072 |
| Bowel management | 37.1 (28.7-45.4) | 43.9 (38.9-48.9) | 43.3 (39.3-47.4) | 47.9 (43.4-52.4) | .123 | 44.4 (41.5-47.3) | 44.3 (39.6-48.9) | .940 |
| Bladder management | 23.2 (15.9-30.5) | 24 (19.7-28.3) | 26.7 (23.1-30.3) | 38.9 (34.5-43.3) | <.001 | 29.5 (26.9-32.2) | 29.2 (25-33.4) | .930 |

Abbreviation: CI, confidence interval.

Appendix 3 Relative frequency (percentage with 95% confidence interval) of reported functioning problems stratified by lesion characteristics of participants and time since injury

| Conditions, Disabilities, or Injuries | Paraplegia | | Tetraplegia | | <i>P</i> |
|--|------------------------|--------------------------|------------------------|--------------------------|----------|
| | Complete % (95% CI) | Incomplete % (95% CI) | Complete % (95% CI) | Incomplete % (95% CI) | |
| Skin functions | 42.5 (38.2-46.9) | 26.2 (22.6-29.8) | 44.8 (37.1-52.5) | 31 (25.9-36.1) | <.001 |
| Urinary tract infections | 70 (66-74.1) | 49.2 (45.1-53.3) | 63.4 (55.9-70.8) | 49.5 (43.9-55) | <.001 |
| Sexual functions | 73.1 (69.2-77) | 64.3 (60.4-68.2) | 61 (53.5-68.6) | 58.8 (53.4-64.2) | <.001 |
| Spasticity | 73.3 (69.3-77.2) | 69 (65.3-72.8) | 75.9 (69.3-82.5) | 83.3 (79.2-87.4) | <.001 |
| Chronic pain | 76.2 (72.4-79.9) | 73.3 (69.7-76.9) | 64.4 (57-71.8) | 74.1 (69.2-78.9) | .034 |
| Respiratory functions | 20.9 (17.3-24.5) | 18.8 (15.6-21.9) | 38.9 (31.4-46.5) | 28.4 (23.4-33.4) | <0.001 |
| Sleep problems | 56.7 (52.3-61.1) | 60 (56-63.9) | 62.4 (54.9-69.8) | 54.9 (49.4-60.4) | .286 |
| Injury caused by loss of sensation | 24.9 (21-28.7) | 26.6 (23-30.2) | 24.7 (18-31.3) | 27.8 (22.9-32.8) | .757 |
| Contractures | 42.3 (37.9-46.6) | 56.9 (52.9-60.9) | 46.9 (39.1-54.6) | 57.4 (52-62.9) | <.001 |
| Bladder dysfunction | 69.6 (65.5-73.6) | 64.2 (60.3-68.1) | 58.4 (50.8-66) | 56.7 (51.2-62.2) | .001 |
| Bowel dysfunction | 67.3 (63.1-71.4) | 66 (62.2-69.9) | 60.8 (53.2-68.3) | 63.4 (58.1-68.7) | .400 |
| Autonomic dysreflexia | 28 (24-31.9) | 24.2 (20.7-27.7) | 37.2 (29.7-44.7) | 35.2 (29.9-40.4) | .001 |
| Postural hypotension | 17 (13.7-20.4) | 19 (15.8-22.2) | 38.4 (30.9-45.9) | 26.9 (22-31.8) | <.001 |
| Circulatory problems | 39.7 (35.4-44) | 33.8 (30-37.7) | 45.8 (38.1-53.5) | 40.5 (35.1-46) | .022 |
| Tiredness | 73.6 (69.7-77.5) | 78.3 (74.9-81.6) | 72.2 (65.3-79.1) | 79.5 (75.1-84) | .088 |
| Nervous | 35.2 (30.9-39.4) | 41.3 (37.3-45.3) | 36 (28.6-43.4) | 35.1 (29.8-40.4) | .131 |
| Down | 16.7 (13.4- 20) | 27 (23.4-30.6) | 20.7 (14.4-26.9) | 23.3 (18.6-28) | .001 |
| Calm | 39.6 (35.3-43.9) | 45.8 (41.8-49.9) | 41 (33.4-48.6) | 43.3 (37.8-48.8) | .216 |
| Depressed | 30.2 (26.1-34.3) | 37.4 (33.5-41.3) | 34.4 (27-41.7) | 39.5 (34.1-44.9) | .027 |
| Happy | 49.8 (45.4-54.2) | 52.4 (48.3-56.5) | 57.1 (49.4-64.7) | 53.4 (47.9-58.9) | .411 |
| Eating/drinking | 2.7 (1.3-4.1) | 6.8 (4.8-8.9) | 72.9 (66.1-79.8) | 36 (30.7-41.3) | <.001 |
| Washing upper body | 49.7 (45.3-54.1) | 33.7 (29.8-37.5) | 81.3 (75.3-87.4) | 53 (47.5-58.5) | <.001 |
| Washing lower body | 69 (64.9-73.1) | 41.4 (37.4-45.4) | 92.1 (88-96.3) | 59.4 (53.9-64.8) | <.001 |
| Dressing upper body | 21.6 (17.9-25.2) | 18.1 (15-21.2) | 84.3 (78.7-90) | 50.3 (44.7-55.8) | <.001 |
| Dressing lower body | 29.5 (25.5-33.5) | 23.6 (20.1-27) | 87.1 (81.9-92.3) | 50.4 (44.9-55.9) | <.001 |
| Grooming | 6.5 (4.3-8.7) | 9.1 (6.8-11.4) | 57.5 (49.9-65.2) | 29.7 (24.6-34.7) | <.001 |
| Breathing | 3.7 (2.1-5.4) | 3.7 (2.2-5.3) | 29.2 (22.2-36.2) | 11.4 (7.9-14.9) | <.001 |
| Toileting | 79.9 (76.4-83.5) | 38.9 (35-42.9) | 95.8 (92.7-98.9) | 52.8 (47.3-58.3) | <.001 |
| Movement around | 33.8 (29.6-38) | 21.3 (18-24.6) | 81.2 (75.1-87.2) | 43.4 (37.9-48.8) | <.001 |
| Transfer bed—wheelchair | 26.1 (22.2-30) | 9.5 (7.1-11.9) | 75.1 (68.4-81.7) | 30.3 (25.3-35.4) | <.001 |
| Transfer wheelchair—toilet or tub | 54.1 (49.6-58.5) | 20.8 (17.5-24.1) | 89.9 (85.2-94.5) | 41.7 (36.3-47.2) | <.001 |
| Moving indoor | 8.4 (6-10.9) | 33.9 (30-37.7) | 38.8 (31.3-46.3) | 31.1 (26-36.2) | <.001 |
| Moving <100 m | 15.6 (12.4-18.8) | 43.8 (39.8-47.9) | 56.5 (48.8-64.1) | 45.4 (39.9-50.9) | <.001 |
| Moving outdoor >100 m | 28.2 (24.2-32.2) | 48.2 (44.2-52.3) | 70.4 (63.4-77.5) | 55.1 (49.6-60.6) | <.001 |
| Stairs | 99 (98.1-99.9) | 64.9 (61-68.8) | 97.8 (95.6-100.1) | 66.6 (61.4-71.8) | <.001 |
| Transfer wheelchair—car | 42.5 (38.1-46.9) | 19.7 (16.4-22.9) | 80.3 (74.1-86.4) | 43.8 (38.4-49.3) | <.001 |
| Transfer floor—wheelchair | 71.1 (67.1-75.1) | 25.2 (21.7-28.8) | 93.3 (89.4-97.1) | 48.6 (43.1-54.2) | <.001 |
| Doing housework | 83.9 (80.7-87.2) | 72.3 (68.7-75.9) | 96.8 (94-99.5) | 80 (75.5-84.4) | <.001 |
| Transportation | 67.7 (63.6-71.9) | 55 (51-59.1) | 89.7 (85-94.4) | 66.1 (60.9-71.3) | <.001 |
| Sports | 64 (59.7-68.2) | 66.1 (62.2-69.9) | 91.2 (86.8-95.6) | 74.9 (70.1-79.7) | <.001 |
| Going out | 58.5 (54.1-62.9) | 50.2 (46.1-54.3) | 85.1 (79.6-90.6) | 65.8 (60.6-71.1) | <.001 |
| Activities outdoors | 67.1 (62.9-71.2) | 60.6 (56.6-64.6) | 88.9 (84.1-93.8) | 70.4 (65.3-75.4) | <.001 |
| Leisure activities indoors | 17.3 (13.9-20.6) | 21.7 (18.3-25) | 60.7 (53.2-68.3) | 40.7 (35.3-46.1) | <.001 |
| Visits to family/friends | 60.4 (56.1-64.7) | 46.8 (42.7-50.8) | 84.5 (78.9-90.1) | 63 (57.6-68.3) | <.001 |
| Visits from family/friends | 25.4 (21.5-29.2) | 31.1 (27.3-34.8) | 49.9 (42.2-57.7) | 39.1 (33.7-44.5) | <.001 |
| Telephone/computer contacts | 5.6 (3.6-7.7) | 8.1 (5.8-10.3) | 23.9 (17.3-30.4) | 17.8 (13.6-22.1) | <.001 |
| Bowel management | 37.4 (33.1-41.7) | 37.5 (33.5-41.4) | 84.7 (79.2-90.3) | 47.7 (42.2-53.2) | <.001 |
| Bladder management | 26.9 (23-30.8) | 16.5 (13.5-19.5) | 74 (67.2-80.7) | 35.9 (30.6-41.2) | <.001 |

Abbreviations: CI, confidence interval; TSCI, traumatic SCI; NSCI, nontraumatic SCI.

Appendix 3 Continued

| Etiology | | | Time Since SCI | | | | |
|------------------|------------------|--------|------------------|------------------|------------------|------------------|--------|
| TSCI | NTSCI | P | ≤5 y | 6-15 y | 16-25 y | ≥26 y | P |
| % (95% CI) | % (95% CI) | | % (95% CI) | % (95% CI) | % (95% CI) | % (95% CI) | |
| 33.8 (31.2-36.5) | 34.1 (29-39.2) | .854 | 28.9 (24-33.7) | 32.4 (28.3-36.6) | 34.8 (29.8-39.8) | 40.1 (35.1-45.1) | .013 |
| 55.3 (52.5-58.1) | 61.9 (56.7-67.1) | .041 | 55.2 (49.9-60.5) | 54.5 (50.1-58.8) | 57.2 (52-62.4) | 62.9 (58-67.9) | .069 |
| 65.5 (62.9-68.2) | 64.7 (59.5-69.8) | .757 | 65.6 (60.5-70.7) | 65.2 (61-69.4) | 61.7 (56.6-66.8) | 70.8 (66.2-75.4) | .089 |
| 72.7 (70.2-75.2) | 78.4 (74-82.9) | .043 | 79.4 (75-83.7) | 75.9 (72.1-79.7) | 69.7 (64.9-74.5) | 70.6 (66-75.3) | .012 |
| 72.6 (70.1-75.1) | 76 (71.4-80.6) | .246 | 72 (67.1-76.8) | 75.2 (71.4-79) | 72.3 (67.6-77) | 72.2 (67.7-76.8) | .640 |
| 22.5 (20.1-24.8) | 26.7 (22-31.5) | .125 | 20.9 (16.5-25.2) | 24.1 (20.4-27.9) | 20.8 (16.6-25.1) | 27.6 (23.1-32.2) | .098 |
| 56.5 (53.7-59.3) | 63.8 (58.6-69) | .022 | 54.5 (49.2-59.9) | 58.9 (54.5-63.2) | 56.3 (51.1-61.5) | 62.6 (57.7-67.6) | .137 |
| 26.2 (23.7-28.6) | 25.8 (21.1-30.5) | .929 | 19.9 (15.6-24.1) | 30.1 (26.1-34.2) | 25.8 (21.2-30.4) | 25.9 (21.4-30.3) | .013 |
| 49.3 (46.5-52.1) | 60.2 (54.9-65.5) | .001 | 49.5 (44.2-54.9) | 51.3 (46.9-55.7) | 49.6 (44.4-54.9) | 56.4 (51.3-61.4) | .206 |
| 61.8 (59.1-64.5) | 69.7 (64.8-74.7) | .010 | 63.5 (58.4-68.7) | 64.1 (59.9-68.3) | 60.1 (55-65.2) | 67.6 (62.9-72.4) | .223 |
| 63 (60.3-65.7) | 73.2 (68.5-78) | .001 | 60.9 (55.6-66.1) | 66.5 (62.3-70.7) | 66.1 (61.1-71) | 66.8 (62-71.6) | .292 |
| 29.4 (26.8-31.9) | 27.3 (22.5-32.1) | .506 | 26.2 (21.5-30.9) | 31 (26.9-35) | 28.6 (23.9-33.4) | 28.4 (23.8-33) | .513 |
| 22.8 (20.5-25.2) | 19.5 (15.2-23.7) | .226 | 21.8 (17.4-26.2) | 24 (20.3-27.8) | 19.2 (15.1-23.4) | 22.8 (18.5-27.1) | .419 |
| 36.7 (34-39.4) | 43.6 (38.2-48.9) | .031 | 30.5 (25.5-35.4) | 41.3 (36.9-45.6) | 34.5 (29.5-39.5) | 45.1 (40-50.1) | <.001 |
| 75.3 (72.9-77.8) | 80.7 (76.5-84.9) | .054 | 82.2 (78.1-86.3) | 77.2 (73.5-80.9) | 76.2 (71.7-80.7) | 70.4 (65.7-75) | .003 |
| 37.1 (34.4-39.9) | 39.3 (34.1-44.6) | .523 | 37.6 (32.5-42.8) | 38.3 (34-42.6) | 40.1 (35-45.3) | 33 (28.2-37.8) | .222 |
| 21.5 (19.2-23.8) | 26 (21.3-30.7) | .102 | 26.8 (22-31.5) | 26 (22.1-29.9) | 18.5 (14.5-22.6) | 17.4 (13.5-21.2) | .001 |
| 42.5 (39.8-45.3) | 44.2 (38.9-49.6) | .630 | 42 (36.7-47.3) | 47.4 (43-51.8) | 42.4 (37.2-47.6) | 36.8 (31.9-41.7) | .020 |
| 33.9 (31.3-36.6) | 40.8 (35.5-46.1) | .026 | 38.2 (33-43.5) | 39.4 (35.1-43.7) | 33.5 (28.5-38.4) | 27.6 (23.1-32.2) | .002 |
| 51.9 (49.1-54.7) | 53.7 (48.3-59.1) | 0.603 | 55 (49.6-60.3) | 53.9 (49.5-58.3) | 50.5 (45.2-55.7) | 49.3 (44.2-54.4) | 0.352 |
| 19.5 (17.3-21.7) | 15.3 (11.4-19.2) | 0.096 | 18.6 (14.4-22.8) | 15.4 (12.2-18.6) | 18.8 (14.7-22.9) | 24 (19.7-28.4) | 0.016 |
| 46.3 (43.5-49.1) | 50.7 (45.3-56.1) | 0.178 | 50.2 (44.9-55.6) | 43.1 (38.7-47.4) | 46.5 (41.3-51.8) | 53.3 (48.2-58.4) | 0.019 |
| 57.8 (55.1-60.6) | 60.5 (55.3-65.8) | 0.411 | 59.5 (54.3-64.8) | 52.3 (47.9-56.7) | 59.5 (54.4-64.7) | 67.1 (62.3-71.9) | <0.001 |
| 31.6 (29-34.2) | 36.5 (31.3-41.6) | 0.111 | 32.6 (27.6-37.7) | 28.1 (24.2-32.1) | 33.1 (28.2-38) | 39.5 (34.5-44.4) | 0.006 |
| 35.5 (32.8-38.2) | 44.3 (38.9-49.6) | 0.004 | 37.2 (32-42.3) | 31.2 (27.1-35.3) | 39.2 (34.1-44.3) | 45.5 (40.5-50.6) | <0.001 |
| 17.9 (15.8-20.1) | 16.8 (12.8-20.8) | 0.691 | 20.2 (15.9-24.5) | 14.1 (11-17.2) | 18.5 (14.4-22.6) | 20.3 (16.2-24.3) | 0.056 |
| 8.3 (6.7-9.8) | 6.7 (4-9.4) | 0.424 | 9.1 (6-12.1) | 5.8 (3.8-7.9) | 7.2 (4.5-9.9) | 11.7 (8.4-14.9) | 0.016 |
| 59.5 (56.7-62.3) | 59.8 (54.5-65) | 0.955 | 55.8 (50.5-61.1) | 51.4 (47-55.8) | 63.2 (58.2-68.3) | 73.7 (69.2-78.2) | <0.001 |
| 36.5 (33.8-39.2) | 33.1 (28-38.1) | 0.275 | 38 (32.8-43.2) | 30.3 (26.3-34.4) | 34.2 (29.2-39.1) | 44.6 (39.6-49.7) | <0.001 |
| 25.8 (23.3-28.2) | 24.2 (19.6-28.8) | .614 | 25.3 (20.6-29.9) | 19.6 (16.1-23.1) | 25.1 (20.5-29.6) | 36.1 (31.2-41) | <.001 |
| 43 (40.2-45.8) | 38 (32.8-43.3) | .120 | 36.8 (31.6-42) | 34.7 (30.5-38.9) | 44.3 (39.1-49.5) | 57.5 (52.5-62.6) | <.001 |
| 22.9 (20.6-25.3) | 38.2 (33-43.4) | <0.001 | 28.7 (23.9-33.6) | 25.2 (21.3-29) | 27 (22.3-31.6) | 23.4 (19.1-27.7) | .395 |
| 33 (30.3-35.6) | 51.9 (46.5-57.2) | <0.001 | 41.6 (36.3-46.9) | 34.7 (30.5-38.9) | 36.6 (31.5-41.6) | 36.3 (31.4-41.2) | .235 |
| 41.9 (39.2-44.7) | 60.5 (55.2-65.7) | <0.001 | 51.8 (46.4-57.2) | 42.3 (37.9-46.6) | 43.9 (38.6-49.1) | 48.5 (43.4-53.6) | .031 |
| 78.8 (76.5-81.1) | 77.7 (73.2-82.2) | .742 | 74.6 (69.9-79.3) | 67.7 (63.6-71.8) | 83.1 (79.2-87) | 96.7 (94.9-98.5) | <.001 |
| 37.1 (34.3-39.8) | 39.3 (34-44.5) | .509 | 35.7 (30.6-40.9) | 29.9 (25.9-34) | 38.8 (33.7-43.9) | 51.1 (46-56.2) | <0.001 |
| 51.4 (48.6-54.2) | 46.8 (41.5-52.2) | .159 | 43.5 (38.2-48.8) | 41 (36.7-45.3) | 52.2 (46.9-57.4) | 72.5 (67.9-77) | <0.001 |
| 78.5 (76.2-80.8) | 84.2 (80.3-88.2) | .027 | 80.5 (76.3-84.8) | 78.5 (74.9-82.1) | 78.4 (74.1-82.7) | 83.3 (79.5-87.1) | 0.271 |
| 63.6 (60.9-66.3) | 68.2 (63.2-73.2) | .140 | 64.3 (59.2-69.4) | 61 (56.7-65.3) | 62.1 (57-67.2) | 74.5 (70-78.9) | <0.001 |
| 67.9 (65.3-70.5) | 76.5 (71.9-81.1) | .004 | 75.7 (71.1-80.3) | 67.7 (63.6-71.8) | 66.5 (61.5-71.4) | 71.7 (67.1-76.3) | 0.035 |
| 58 (55.2-60.8) | 64.4 (59.3-69.6) | .042 | 63.1 (57.9-68.2) | 56 (51.6-60.3) | 56.4 (51.2-61.6) | 65.7 (60.9-70.6) | 0.011 |
| 66.1 (63.4-68.7) | 71.9 (67.1-76.8) | .055 | 68.5 (63.5-73.5) | 64.4 (60.2-68.6) | 65.8 (60.8-70.7) | 73.7 (69.2-78.2) | 0.028 |
| 28.5 (25.9-31) | 28.2 (23.4-33) | .931 | 36.9 (31.7-42) | 27.7 (23.8-31.7) | 24 (19.5-28.5) | 26.6 (22.1-31.1) | 0.001 |
| 57.2 (54.4-60) | 60.6 (55.4-65.9) | .291 | 60.7 (55.4-65.9) | 55 (50.6-59.4) | 55 (49.8-60.2) | 64.4 (59.5-69.3) | 0.018 |
| 31 (28.4-33.6) | 40.1 (34.8-45.4) | .002 | 37 (31.8-42.2) | 32 (27.9-36.2) | 28.1 (23.3-32.8) | 37.1 (32.2-42) | 0.030 |
| 10.5 (8.8-12.2) | 12.9 (9.3-16.5) | .258 | 12.9 (9.3-16.5) | 12.7 (9.8-15.6) | 8.4 (5.5-11.3) | 8.9 (6-11.8) | 0.079 |
| 43.8 (41-46.6) | 46.3 (41-51.7) | .455 | 42.7 (37.4-48) | 41 (36.6-45.3) | 45.9 (40.7-51.1) | 50 (44.9-55.1) | 0.055 |
| 28.3 (25.7-30.8) | 33.5 (28.5-38.6) | .076 | 30.7 (25.7-35.6) | 25.6 (21.7-29.4) | 26.5 (21.9-31.2) | 39 (34-44) | <0.001 |

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