Research article

Secondary conditions in a community sample of people with spinal cord damage

Peter W. New^{1,2,3}

¹Spinal Rehabilitation Service, Caulfield Hospital, Alfred Health, Melbourne, VIC, Australia, ²Principal Researcher, Epworth-Monash Rehabilitation Medicine Unit, Southern Medical School, Monash University, Melbourne, VIC, Australia, ³Department of Epidemiology and Preventive Medicine, School of Public Health & Preventive Medicine, Monash University, VIC, Australia

Objective: To compare secondary conditions in people with traumatic spinal cord injury (SCI) and non-traumatic spinal cord dysfunction (SCDys).

Design: Survey; completed August 2012 – June 2013.

Setting: Community, Australia.

Participants: Adults with spinal cord damage from any cause.

Interventions: Nil.

Outcome Measures: Demographic and clinical variables and the SCI-Secondary Conditions Scale (SCI-SCS).

Results: Survey completed by 150 people: 112 (74.7%) with traumatic SCI and 38 (25.3%) with non-traumatic SCDys a median of 10 years post onset. No significant difference ($t = -0.6$, $P = 0.6$) in the total SCI-SCS score between those with SCI (mean 13.7) and SCDys (mean 14.4). Except for bladder problems (SCDys mean = 1.5, SD = 1.1; SCI mean = 1.0, SD = 1.1; $t = -2.6$, $P = 0.01$) there were no significant differences between the aetiology groups regarding the conditions comprising the SCI-SCS (all other P values >0.1). The most common significant or chronic problems from the SCI-SCS were: sexual problems 41%; chronic pain 24%; bladder dysfunction 17%; spasms 17%; joint and muscle pain 15%; bowel dysfunction 14%; circulation problems 14%; contractures 9%; urinary tract infections 9%; pressure ulcer 7% and postural hypotension 5%. A linear regression analysis found that tetraplegia and higher disability were the only variables that significantly influenced ($R^2 = 0.13$; $P = 0.005$) the total SCI-SCS score and that sex, age, years post injury and etiology of spinal cord damage had no influence.

Conclusions: Secondary conditions following spinal cord damage do not appear to be influenced by etiology. Prevention and management of secondary conditions following need to consider people with non-traumatic SCDys as well as those with traumatic SCI.

Keywords: Spinal cord diseases, Complications, Survey, Psychometrics

Introduction

Secondary medical complications are common after spinal cord damage (SCD).^{1,2} They can exacerbate the experience of disability by negatively impacting on long-term health, quality of life,³ mobility, and independence. These complications are also costly in terms of health care resources, increasing the chance of rehospitalization⁴ and reducing participation in work, social and recreational activities for the person with SCD.

The most common secondary conditions reported following SCD are pressure ulcers,^{5,6} pain,^{7,8} spasticity,^{9,10}

urinary tract infections and other bladder problems,¹¹ bowel functioning (including incontinence),^{12,13} and problems with musculoskeletal,¹⁴ respiratory (e.g. pneumonia),¹⁵ and cardiovascular systems.¹⁶

Studies to date on secondary conditions following SCD have focused on people with traumatic spinal cord injury (SCI) and no studies have been located that report on the secondary complications in people with non-traumatic spinal cord dysfunction (SCDys). It is important to address this because the demographic characteristics and functional outcomes for people with SCDys are quite different from those with traumatic SCI.^{17,18} In addition, reports indicate that in developed countries the incidence of non-traumatic SCDys is

Correspondence to: Peter New, Spinal Rehabilitation Service, Caulfield Hospital, 260 Kooyong Rd, Caulfield 3162, VIC, Australia. Email: p.new@cgmc.org.au

higher than traumatic SCI^{19,20} and that the incidence of SCDys is expected to increase dramatically in the coming decades with population aging.¹⁹ Because people with non-traumatic SCDys tend to be older than those with traumatic SCI they are likely to have a lower physiological reserve.²¹ This can potentially influence the occurrence of many of the secondary conditions associated with SCD. For example, older people with SCDys would have less resilient skin due to reduced collagen and elastin, placing them at higher risk of pressure ulcers.²² Age-related degeneration of joints and soft tissues potentially increase the chance of muscular-skeletal pain from over-use injuries to the upper limbs. In addition, physiological differences in the etiology of SCD may also have an influence on the development of secondary conditions.

The aim of this study was to compare the secondary medical complications reported by people with traumatic SCI to those with non-traumatic SCDys. It was also planned to assess factors influencing the occurrence of these complications.

Methods

Study design

People with SCD living in the community completed a comprehensive survey.

Setting

The survey commenced on 1st August 2013 and data collection ceased on the 30th June 2014. Only people with SCD residing in Australia were included.

Participants

The survey was targeted at adults aged 18 years of age and older with SCD from any aetiology—that is both traumatic SCI and non-traumatic SCDys were included. The following people were excluded from the study: those with inadequate English language skills, Multiple Sclerosis, congenital aetiology, or residing in a nursing home or hospital.

Participants were recruited from people with SCD who attended the spinal review clinic at the rehabilitation hospital where the author is based and through various Australian State-based organisations that support people with SCD in the community (see Acknowledgements). These organisations used their websites, newsletters, emails, and social media to inform readers of the survey, along with the URL for the web-based version of the survey.

The participants in this study were recruited as part of a larger project focusing on sexuality issues after SCD.²³

Outcome measures included in survey

Demographic and clinical information was collected from participants. This included sex, age, number of years since

SCD, level of SCD (paraplegia or tetraplegia) and a self-report of the etiology of their SCD. Participants self-report of their etiology was made by them selecting from either traumatic SCI (e.g. motor vehicle accident, fall, sport or recreational, assault) or non-traumatic SCDys (disc prolapse or canal stenosis and other degenerative causes, tumor, infarction, hemorrhage, infection, or inflammation including transverse myelitis) and then subsequently selecting from the main causes of each. For the purposes of analysis in this paper etiology was classified as either traumatic or non-traumatic.

The Spinal Cord Injury Secondary Conditions Scale (SCI-SCS)²⁴ was used to record the impact of secondary conditions following SCD. This is a reliable and valid scale, with 16 items that cover problems with skin, musculoskeletal system, pain, bowel and bladder, metabolic, respiratory and cardiovascular functioning. Items comprising the SCI-SCS are physiological in nature (i.e. not psychological or environmental); they can be self-reported by patients; and they can be prevented or managed. The SCI-SCS uses a 4-point ordinal scoring that ranges from 0 (not experienced/insignificant problem never limiting activity) to 3 (significant/chronic problem). The total score ranges from 0 to 48 and is derived by adding the problem ratings, such that higher scores indicate greater overall problem with secondary conditions.²⁴

Some questions in the survey were developed specifically for this project and not based on previously published outcome measures. These questions were developed in an iterative process involving clinicians experienced in spinal cord rehabilitation, a nurse and six people with SCD living in community. These questions included a brief and simple self-report of key functional abilities typically affected by SCD. These questions were developed because to the best of my knowledge there is no existing scale had these features. Questions were asked about bladder functioning, bowel incontinence, mobility, transfers, and self-care. These questions were combined to form a Spinal Functional Abilities Scale (S-FAS). In the S-FAS questions participants were asked to self-report their functioning in the above domains, with their responses corresponding to a numerical rating from 1 to 3, 4 or 5 (1 = highest functioning). A total S-FAS score (5–19) was calculated by summing the responses (higher the total the lower the functioning) as explained in the appendix. A full copy of the survey is available for the author upon request.

Sample size

There was no predetermined sample size as this was an exploratory study.

Statistical methods

The total SCI-SCS was normally distributed so analysed using the Students *t*-test when assessing relationship with categorical variables and central tendency reported using the mean and standard deviation (SD). Continuous variables not normally distributed were summarised using the median and inter-quartile range (IQR) and the Wilcoxon rank-sum (Mann-Whitney) test was used to calculate differences in the population distributions. Categorical variables were compared using Pearson's χ^2 test, with the Fisher exact correction used when small numbers in subgroups indicated that this was appropriate.

A regression analysis was performed to determine the influence of demographic and clinical variables on the total SCI-SCS score. Participants' age, years since SCD, sex, level of SCD and the total S-FAS score were the covariates.

The face validity of the S-FAS was determined by the process of developing the questions to target key functions related to the consequences of SCD. The internal consistency was assessed using Cronbach α and the construct validity was assessed using the Spearman ρ correlation between the total S-FAS score and the International SCI quality of life dataset question on physical health.²⁵ The proportion of patients who had a S-FAS score of 5 (floor) and 19 (ceiling) was calculated. A notable floor or ceiling effect was considered to be 15% or higher.²⁶

Ethics approval for this project was obtained from the local Human Research and Ethics Committee. *P* values < 0.05 were deemed statistically significant. Stata version 12 for Windows (StataCorp LP, College Station, TX, USA) was used for statistical analysis.

Results

One hundred and fifty people with SCD completed the survey with SCI-SCS scores. There were almost twice as many males (*n* = 100, 66.7%) as females (*n* = 49, 32.7%) and one participant reported that they were transgender (0.7%). The median age was 50 years (IQR 38–58) and respondents were a median of 10 years (IQR 4–20) following their SCD. Most people

(*n* = 88, 58.7%) had a paraplegic level of injury. There were significant differences between those with traumatic SCI and non-traumatic SCDys regarding sex, level of injury, age and number of years since SCD (Table 1).

The proportion of people with SCD reporting the secondary conditions comprising the items of the SCI-SCS and their severity is shown in Table 2. The mean of the total SCI-SCS score was 13.9 (SD = 7.0, range 3–33). Except for bladder problems (SCDys mean = 1.5, SD = 1.1; SCI mean = 1.0, SD = 1.1); *t* = −2.6, *P* = 0.01), there were no significant differences between the aetiology of SCD (traumatic SCI and non-traumatic SCDys) and the conditions comprising the SCI-SCS (*P* values all > 0.1). There was no difference in the total SCI-SCS between the different etiologies of SCD (*t* = −0.55, *P* = 0.6). There was no relationship between the total SCI-SCS and age (Spearman's ρ = 0.15, *P* = 0.07) or years post SCD (Spearman's ρ = 0.03, *P* = 0.7).

The reliability of the S-FAS score assessed by determining the internal consistency using Cronbach α was 0.71 (inter-item covariance = 0.33). The construct validity of the total S-FAS score was confirmed by correlation with the International SCI quality of life dataset question on physical health (Spearman ρ = −0.34; *P* < 0.001). The range of S-FAS scores was 5 to 19 and the distribution was normal, with a mean of 10.9 (SD = 3.1). There was no notable floor (3.3%) or ceiling (0.7%) effect.

The linear regression analysis found that tetraplegia and higher disability, as measured using the S-FAS, were the only variables that significantly explained the variance the total SCI-SCS score (R^2 = 0.13; *P* = 0.006) while sex, age, years post injury and etiology had no influence. Table 3.

Discussion

This study found that there was no significant difference between people with traumatic SCI and those with non-traumatic SCDys regarding their total SCI-SCS scores. Among the individual components of the SCI-SCS, the only significant difference between the etiologies was for bladder problems, which had a higher score in

Table 1 Comparison of gender, level, age and time since spinal cord damage according to the etiology of spinal cord damage

	Traumatic SCI <i>n</i> =112, 74.7%	Non-traumatic SCDys <i>n</i> =38, 25.3%	<i>P</i>
Male	81, 72.3%	19, 50%	$\chi^2=6.4$, <i>P</i> = 0.01
Paraplegia	57, 50.9%	31, 81.6%	$\chi^2=11.0$, <i>P</i> = 0.001
Age (years), IQR, (range)	46.5, 33–55.5, (19–75)	58, 51–68 (35–81)	<i>Z</i> = −5.0, <i>P</i> < 0.001
Years since SCD, IQR, (range)	13, 5–23, (0.6–52)	6, 2.5–14.5, (0.3–38)	<i>Z</i> = 3.1, <i>P</i> = 0.002

SCI=spinal cord injury, SCDys=spinal cord dysfunction, IQR=interquartile range.

Table 2 Proportion of people with SCD reporting secondary conditions and their severity

Secondary condition	Significant or chronic problem*	Moderate or occasional problem	Mild or infrequent problem	Not a problem
Sexual dysfunction	40.7%	20.7%	20.0%	18.7%
Chronic pain	24.0%	21.3%	24.0%	30.7%
Bladder dysfunction	16.7%	18.7%	25.3%	39.3%
Spasticity	17.3%	28.0%	31.3%	23.3%
Joint and muscle pain	15.3%	28.7%	35.3%	20.7%
Bowel dysfunction	14.0%	18.7%	38.7%	28.7%
Circulation problems	14.0%	14.7%	28.0%	43.3%
Contractures	9.3%	12.7%	24.7%	53.3%
Urinary tract infections	9.3%	20.0%	29.3%	41.3%
Pressure ulcers	7.3%	6.0%	12.0%	74.7%
Postural hypotension	4.7%	4.7%	33.3%	57.3%
Autonomic dysreflexia	2.7%	14.0%	24.7%	58.7%
Diabetes	4.7%	2.0%	2.7%	90.7%
Injury caused by loss of sensation	4.0%	8.7%	23.3%	64.0%
Respiratory problems	3.3%	4.0%	16.7%	76.0%
Heterotopic ossification	1.3%	0.7%	6.7%	91.3%

* Ranked by the most to least percent reporting significant or chronic problem.

those with SCDys. Furthermore, there was no significant relationship between the total SCI-SCS score and age of participants, years post SCD, or sex. The linear regression analysis found that only tetraplegia and lower functional abilities significantly influenced the total SCI-SCS score.

In comparing the findings from this study to those in the initial publication that described the development of the SCI-SCS the results overall were quite similar in both studies in respects of the general order and prevalence of the most significant and moderate problems.²⁴ The only exceptions are that in the present study the prevalence of spasticity and sexuality problems was notably higher. A possible explanation for the higher prevalence of sexuality problems in the present study is that participants were recruited for a project that focused on sexuality, raising the possibility of responder bias (see below) but no explanation is available for the greater prevalence of spasticity in our sample.

The initial report of the SCI-SCS suggested that future development of the scale should consider rewording of the question on sexual dysfunction as it was

worded in a way that in part refers to dissatisfaction.²⁴ It has previously been reported that there is a moderate correlation between the sexual dysfunction question of the SCI-SCS and the self-reports of the male and female International SCI Sexuality Datasets that were also collected as part of the project that included this study (males: Spearman $\rho = 0.40$, $P = 0.0002$; females: Spearman $\rho = 0.41$, $P = 0.01$).²³ This suggests that the survey respondents interpreted the sexuality question in the SCI-SCS as generally referring to sexual dysfunction. Nevertheless, this author agrees that it would be appropriate to alter the wording to remove the reference to dissatisfaction from the SCI-SCS.

An important implication of this study is that it provides further support for the use of the SCI-SCS as a patient reported outcome measure in spinal cord research when considering secondary conditions that potentially arise after SCD.²⁷ The SCI-SCS is able to record the subjective experience of problems related to SCD that can be used in research—to make comparisons between samples and to examine the association between secondary conditions and other aspects of health.²⁴ The SCI-SCS may be useful in studies that involve only self-reports (e.g. no physical examination to determine secondary conditions objectively) or where the focus is on the experience of secondary conditions and its' relationship to other self-reports. By confirming the validity of the SCI-SCS in people with SCDys a broader sample of people with SCD can be included in studies that use this scale.

The prevalence of secondary conditions in this study is generally within the range of typical findings from other reports regarding people with SCD.^{2,5–16}

Table 3 Linear regression analysis of variables influencing the total SCI-SCS score.

Variable	Coefficient, 95%CI	β	P*
Male	−1.64, −4.11–0.83	−0.11	0.2
Age	0.07, −0.03–0.18	0.15	0.2
Years post SCD	−0.03, −0.14–0.09	−0.04	0.7
Etiology SCD	1.85, −1.71–5.41	0.11	0.3
Tetraplegia	2.62, 0.11–5.12	0.18	0.04
S-FAS	0.66, 0.22–1.11	0.29	0.004
Constant	−1.54, −9.63–6.54		0.7

* $R^2 = 0.13$; $P = 0.005$.

The strengths of this study include the much larger sample size than the 65 in the initial sample used to validate the SCI-SCS.²⁴ The initial study had a mixed sample of people with both SCI and SCDys, however, the etiology of participants was not recoded and therefore no comparisons between these groups was possible (personal communication Claire Kalpakjian). This study also assessed the influence on the total SCI-SCS score of variables not previously explored.

The epidemiological characteristics and level of injury, both for traumatic SCI and non-traumatic SCDys participants included in this study are similar to those from a large population-based study of SCD in Australia.¹⁸ Therefore, the results here may be generalizable to other people with SCD in Australia, within the limitations outlined below.

Limitations of this study need to be acknowledged. As with every survey there is a degree of responder bias. It is relevant to note that the participants in this study were recruited for a project that focused on sexuality issues and it is reported that responder bias is even greater in studies of sexuality.²⁸ The study sample was biased towards a higher socio-economic cohort as the main mode of survey completion was via the internet. Furthermore, only those with adequate English language skills were able to participate. The findings of this study may not apply to people of a lower socio-economic standing, without computer literacy, and with poor English language skills. The age, sex, and level of damage of participants suggests that in many respects our sample is fairly typical of those with SCD.¹⁸ The American Spinal Injury Association (ASIA) Impairment Scale (AIS) was not recorded because it was believed that many people would not know their grade and instead the S-FAS was used as a proxy measure for the severity of SCD.

Future research should explore the further use of the SCI-SCS in people with SCD. In addition, performing factor analysis on the SCI-SCS to reduce the number of items by grouping related items that have similar impact and identifying groups of inter-related components is one possible direction. Furthermore, research should further explore the validity and the utility of the S-FAS as a brief patient reported outcome of key functional abilities typically affected by SCD. There remains a need to assess the scale's construct validity, for example, by determining the agreement between clinical examination and response to the scale items.

Conclusion

Secondary conditions following SCD do not appear to be influenced by the etiology of SCD. The prevention

and management of secondary conditions need to consider people with non-traumatic SCDys as well as those with traumatic SCI. The SCI-SCS is a patient reported outcome measure that appears to be useful for research involving people with SCD.

Acknowledgments

Some of the information in this manuscript was presented at the International Spinal Cord Society and American Spinal Injury Association 4th combined Annual Scientific Meeting, 14th May 2015, Montreal, Canada.

Dr Kim Currie is thanked for her assistance with developing the S-FAS.

Merilyn Seddon (Monash University) and the following organisations are thanked for their assistance with distribution of the survey: AQA (Victoria), Spinal Injuries Association (Queensland), Spinal Cord Injuries Australia (New South Wales), Paraplegic-Quadriplegic Association of WA, ParaQuad NSW, Paraplegic and Quadriplegic Association of South Australia, Spinal Cord Injury Network (Australia).

Finally, the author would like to thank all the participants who completed the survey.

Funding No funding was provided for this research

Conflicts of interest No relevant conflicts of interest to declare

References

- 1 ISCoS textbook on comprehensive management of spinal cord injuries. Chhabra HS, editor. New Delhi: Wolters Kluwer; 2015
- 2 Lin V, editor. Spinal cord medicine: principles and practice. 2nd ed. New York, New York: Demos Medical Publishing; 2010.
- 3 Dijkers MJM. Quality of life of individuals with spinal cord injury: A review of conceptualization, measurement, and research findings. *J Rehabil Res Dev* 2005;42 Suppl 1:87–110.
- 4 Cardenas DD, Hoffman JM, Kirshblum S, McKinley W. Etiology and incidence of rehospitalization after traumatic spinal cord injury: A multicenter analysis. *Arch Phys Med Rehabil* 2004; 85(11):1757–63.
- 5 Priebe M, Wuermser L-A, McCormack HE. Medical management of pressure ulcers. In: Lin VW, editor. Spinal cord medicine: principles and practice. 2nd ed. New York, New York: Demos Medical Publishing; 2010. p. 659–672.
- 6 Gélis A, Dupeyron A, Legros P, Benaïm C, Pelissier J, Fattal C. Pressure ulcer risk factors in persons with spinal cord injury Part 2: the chronic stage. *Spinal Cord* 2009;47(9):651–61.
- 7 Bryce TN. Pain management in persons with spinal cord injury. In: Lin VW, editor. Spinal cord medicine: principles and practice. 2nd ed. New York, New York: Demos Medical Publishing; 2010. p. 500–522.
- 8 Dijkers M, Bryce T, Zanca J. Prevalence of chronic pain after traumatic spinal cord injury: a systematic review. *J Rehabil Res Dev* 2009;46(1):13–30.
- 9 Adams M, Hicks AL. Spasticity: pathophysiology, assessment, and management. In: Lin VW, editor. Spinal cord medicine: principles and practice. 2nd ed. New York, New York: Demos Medical Publishing; 2010. p. 534–544.
- 10 Adams MM, Hicks AL. Spasticity after spinal cord injury. *Spinal Cord* 2005;43(10):577–86.

- 11 Singh M, Perakash I, Bodner DR. Urologic management in spinal cord injury. In: Lin VW, editor. *Spinal cord medicine: principles and practice*. 2nd ed. New York, New York: Demos Medical Publishing; 2010. p. 362–368.
- 12 Stiens SA, Singal AK, Korsten MA. The gastrointestinal system after spinal cord injury: assessment and intervention. In: Lin VW, editor. *Spinal cord medicine: principles and practice*. 2nd ed. New York, New York: Demos Medical Publishing; 2010. p. 382–408.
- 13 Krassioukov A, Eng JJ, Claxton G, Sakakibara BM, Shum S, and the SCIRE Research Team. Neurogenic bowel management after spinal cord injury: a systematic review of the evidence. *Spinal Cord* 2010;48(10):718–33.
- 14 Boninger ML, Collinger JL, Cooper RA, Koontz AM. Musculoskeletal pain and overuse injuries. In: Lin VW, editor. *Spinal cord medicine: principles and practice*. 2nd ed. New York, New York: Demos Medical Publishing; 2010. p. 627–635.
- 15 Baydur A, Sassoon CSH. Respiratory dysfunction in spinal cord disorders. In: Lin VW, editor. *Spinal cord medicine: principles and practice*. 2nd ed. New York, New York: Demos Medical Publishing; 2010. p. 215–229.
- 16 Sabbarwal S. Cardiovascular dysfunction in spinal cord disorders. In: Lin VW, editor. *Spinal cord medicine: principles and practice*. 2nd ed. New York, New York: Demos Medical Publishing; 2010. p. 241–255.
- 17 New PW. Functional outcomes and disability after nontraumatic spinal cord injury rehabilitation: results from a retrospective study. *Arch Phys Med Rehabil* 2005;86(2):250–61.
- 18 New PW, Simmonds F, Stevermuer T. A population-based study comparing traumatic spinal cord injury and non-traumatic spinal cord injury using a national rehabilitation database. *Spinal Cord* 2011;49(3):397–403.
- 19 New PW, Sundararajan V. Incidence of non-traumatic spinal cord injury in Victoria, Australia: a population-based study and literature review. *Spinal Cord* 2008;46(6):406–11.
- 20 Noonan VK, Fingas M, Farry A, Baxter D, Singh A, Fehlings MG, *et al.* The incidence and prevalence of SCI in Canada: a national perspective. *Neuroepidemiology* 2012;38(4):219–26.
- 21 Furusawa K, Tajima F. Geriatric spinal cord injuries: rehabilitation perspectives. In: Chhabra HS, editor. *ISCOs textbook on comprehensive management of spinal cord injuries*. New Delhi: Wolters Kluwer; 2015. p. 960–967.
- 22 New PW, Rawicki HB, Bailey MJ. Nontraumatic spinal cord injury rehabilitation: pressure ulcer patterns, prediction, and impact. *Arch Phys Med Rehabil* 2004;85(1):87–93.
- 23 New PW, Currie KE. Development of a comprehensive survey of sexuality issues including a self-report version of the International Spinal Cord Injury sexual function basic data sets. *Spinal Cord* 2015 Dec 8. [Epub ahead of print].
- 24 Kalpakjian C, Scelza W, Forchheimer M, Toussaint L. Preliminary reliability and validity of a spinal cord injury secondary conditions scale. *J Spinal Cord Med* 2007;30(2):131–9.
- 25 Charlifue S, Post MW, Biering-Sørensen F, Catz A, Dijkers M, Geyh S, *et al.* International spinal cord injury quality of life basic data set. *Spinal Cord* 2012;50(9):672–5.
- 26 McHorney C, Tarlov A. Individual-patient monitoring in clinical practice: are available health status surveys adequate? *Qual Life Res* 1995;4(4):293–307.
- 27 Simpson L, Eng J, Hsieh J, Wolfe D, Spinal Cord Injury Rehabilitation Evidence (SCIRE) Research Team. The health and life priorities of individuals with spinal cord injury: a systematic review. *J Neurotrauma* 2012;29(8):1548–55.
- 28 Strassberg DS, Lowe K. Volunteer bias in sexuality research. *Arch Sex Behav* 1995;24(4):369–82.

Appendix Questions in the Spinal Functional Abilities Scale (S-FAS) and the responses from participants

Questions*	Responses n, %
How would you best describe your bowel functioning?	
1. No bowel accidents in past year (or since discharge from rehabilitation if less than one year)	50, 33.3%
2. Less than one bowel accident per month	64, 42.7%
3. One or more bowel accident per month	21, 14.0%
4. One or more bowel accident per week	9, 6.0%
5. Colostomy	6, 4.0%
How would you best describe your bladder functioning?	
1. Continent on sensation and no catheters used at all	16, 11.1%
2. Some urine incontinence managed with pads or nothing	19, 13.2%
3. Intermittent self-catheterization	56, 39.0%
4a Suprapubic catheter	37, 25.7%
4b Indwelling catheter	16, 11.1%
How would you best describe your mobility status?	
1. Walking more than 100 meters with or without gait aid	30, 20.0%
2. Walking more than 10 meters with or without gait aid	13, 8.7%
3. Wheelchair independent in the community (either electric or manual)	90, 60.0%
4. Wheelchair dependent on another person in the community (either electric or manual)	17, 11.3%
How would you best describe your transfer ability?	
1. Independent for all transfers	89, 59.7%
2. Supervision or a little help needed with transfers	33, 22.2%
3. A lot of help needed with transfers, including needing a hoist or standing machine	27, 18.1%
How would you best describe your personal self-care abilities? (That involve washing and drying yourself, getting dressed or undressed)?	
1. Independent with all personal self-care	88, 58.7%
2. Needing help with a quarter of the effort needed for these activities or less	18, 12.0%
3. Needing help with more than a quarter of the effort needed for these activities	44, 29.3%

* Total S-FAS score obtained by summing number corresponding to each question except indwelling catheter and suprapubic catheter considered equivalent.