

ORIGINAL ARTICLE

# Development of a comprehensive survey of sexuality issues including a self-report version of the International Spinal Cord Injury sexual function basic data sets

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**Study design:** Questionnaire development, validation and completion.

**Objectives:** Develop comprehensive survey of sexuality issues including validated self-report versions of the International Spinal Cord Injury male sexual function and female sexual and reproductive function basic data sets (SR-iSCI-sexual function).

**Setting:** People with spinal cord damage (SCD) living in the community, Australia from August 2013 to June 2014.

**Methods:** An iterative process involving rehabilitation medicine clinicians, a nurse specialising in sexuality issues in SCD and people with SCD who developed a comprehensive survey that included the SR-iSCI-sexual function. Participants recruitment through spinal rehabilitation review clinic and community organisations that support people with SCD.

**Results:** Surveys completed by 154 people. Most were male ( $n=101$ , 65.6%). Respondents' median age was 50 years (interquartile range (IQR) 38–58), and they were a median of 10 years (IQR 4–20) after the onset of SCD. Sexual problems unrelated to SCD were reported by 12 (8%) respondents, and 114 ( $n=75.5%$ ) reported sexual problems because of SCD. Orgasms were much less likely ( $\chi^2=13.1$ ,  $P=0.006$ ) to be normal in males ( $n=5$ , 5%) compared with females ( $n=11$ , 22%). Males had significantly worse ( $\chi^2=26.0$ ,  $P=0.001$ ) psychogenic genital functioning (normal  $n=9$ , 9%) than females (normal  $n=13$ , 26%) and worse ( $\chi^2=10.8$ ,  $P=0.013$ ) reflex genital functioning. Normal ejaculation was reported in only three (3%) men. Most ( $n=26$ , 52%) women reported reduced or absent menstruation pattern since SCD.

**Conclusion:** The SR-iSCI-sexual function provides a useful tool for researchers and clinicians to collect information regarding patient-reported sexual functioning after SCD and to facilitate comparative studies.

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## INTRODUCTION

Sexual health and sexual functioning are recognised as important domains of health in general and are vital for well-being and quality of life<sup>1</sup> but often neglected in people with disability.<sup>2,3</sup> Sexuality changes after spinal cord damage (SCD) from any cause (traumatic or non-traumatic) are common, complex, confounding<sup>4,5</sup> and are a major priority for people with SCD.<sup>6</sup> For example, a large survey of people with traumatic spinal cord injury (SCI) from the American National Spinal Cord Injury Database found that sexual functioning was the highest priority for those with paraplegia and the second highest priority (after upper limb function) for people with tetraplegia.<sup>7</sup>

Studies of sexuality after SCD published to date have focused on people with traumatic SCI. As there is no internationally accepted term for the group of conditions that can cause non-traumatic SCD,<sup>8</sup> we will use the term spinal cord dysfunction (SCDys) to describe these conditions throughout this article. Although some studies of sexuality have included people with non-traumatic SCDys,<sup>9</sup> no studies have been located that report separately on the sexual changes in this group. This is important to address because the demographic characteristics and functional outcomes for people with non-traumatic SCDys are

different from traumatic SCI,<sup>10,11</sup> and these differences could potentially impact sexual health outcomes. Furthermore, evidence suggests that in many developed countries the incidence of non-traumatic SCDys is higher than traumatic SCI,<sup>12,13</sup> and this difference is expected to increase markedly in the coming decades with population ageing.<sup>12</sup>

In recent years, the International Spinal Cord Society (ISCoS) developed the International SCI male sexual function<sup>14</sup> and female sexual and reproductive function basic data sets.<sup>15</sup> These are designed to enable a standardised format for collecting and reporting of a minimal amount of information regarding sexual functioning in order to facilitate comparisons between studies, in accordance with the purpose and vision of the International SCI Data Sets project.<sup>16</sup> The sexual function data sets, however, are worded in a way that is directed at clinicians not patients; hence, they are not appropriate for use as a patient-reported outcome.

The aims of this study were as follows: (1) to develop a self-report version of the International SCI male sexual function and female sexual and reproductive function (SR-iSCI-sexual function) basic data sets, and (2) to include the SR-iSCI-sexual function data sets in a

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study of people with SCD residing in the community as part of a comprehensive study of sexuality issues in people with SCD. The objectives were to compare the responses to the SR-iSCI-sexual function data sets from people with traumatic SCI with those who have non-traumatic SCDys and to assess the psychometric properties of the SR-iSCI-sexual function.

## MATERIALS AND METHODS

### Study design

A comprehensive survey was planned that focused on numerous aspects of sexuality in people with SCD living in the community. Principles of good survey design were followed in the design and conduct of this study.<sup>17</sup>

### Setting

The survey commenced on 1 August 2013, and data collection ceased on 30 June 2014. Only people residing in Australia were included.

### Participants

The survey was targeted at adults aged over 18 years of age with SCD from any aetiology—that is both traumatic SCI and non-traumatic SCDys were included. The exclusion criteria were inadequate English language skills to read the consent and survey, multiple sclerosis (because of association with brain damage), congenital aetiology (because the unique circumstances regarding sexual development are very different from those with an acquired SCD), residing in a nursing home or were in a hospital (because these situations adversely impact on establishing and maintaining a sexual relationship and sexual functioning). Potential participants were made aware of these criteria in the survey documentation.

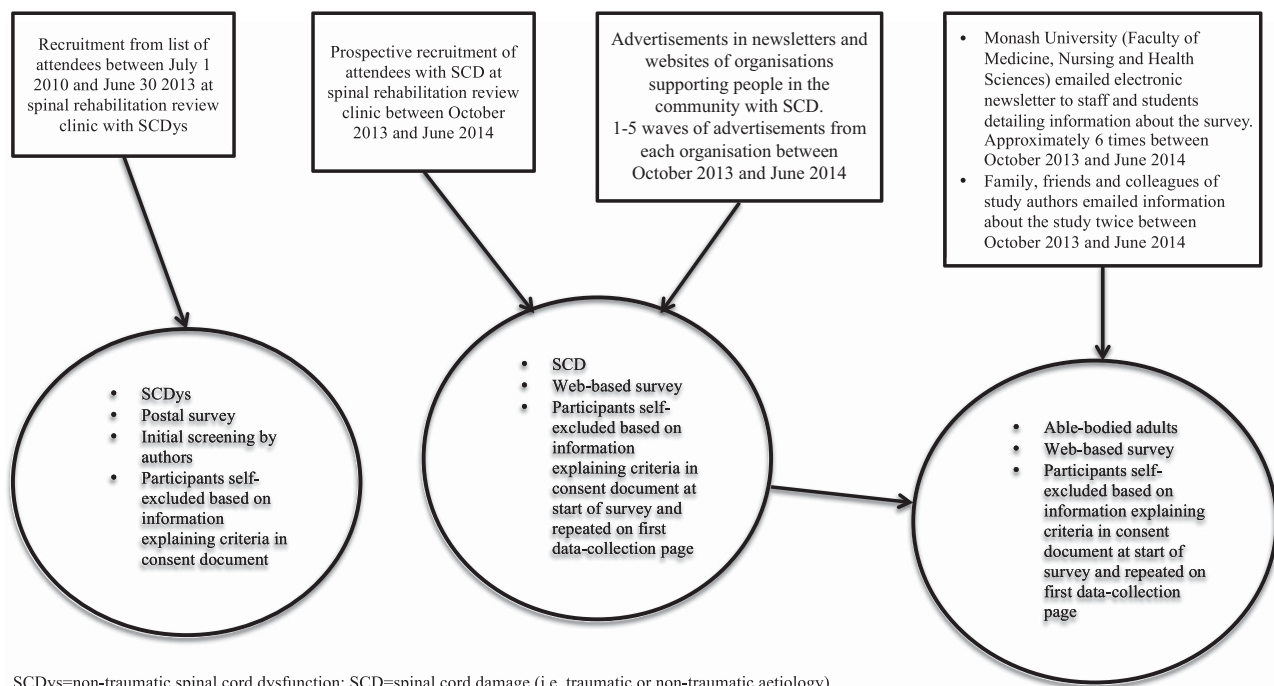
Three methods were used to recruit people with SCD to complete the survey (Figure 1). Patients who had attended the spinal rehabilitation review clinic at the rehabilitation hospital where the authors are based were targeted in two ways. First, those with SCDys who attended the clinic between 1 July 2010 and 30 June 2013 ( $n=136$ ) were twice posted (August and September 2013) information about the study, a consent form, a paper version of the survey and a post-paid envelope. Second, from October 2013 a notice about the study was placed in the clinic waiting room (targeting all eligible adults with SCD) that

included a URL that directed people to a web-based version of the survey. The web-based version of the survey included information about inclusion and exclusion criteria in the consent section, and this was also repeated on the first data collection page. Third, between October 2013 and June 2014 participants were recruited with the assistance of various Australian State-based organisations that support people with SCD (see Acknowledgements section). These organisations used their websites, newsletters, emails and social media to make readers or members aware of the survey, with the URL for the web-based version of the survey included in these communications. Organisations included information about the study between one and five times in their various communications over the study period.

Non-disabled controls were also recruited to complete questions relevant to them (but not the SR-iSCI-sexual function data sets) for comparison with people with SCD in subsequent publications. These non-disabled controls were recruited by a number of means: participants completing the web-based survey were asked to forward the URL for the study to family and friends; the lead investigator emailed professional and social contacts; and Monash University included information in newsletters emailed to staff and students in the Faculty of Medicine, Nursing and Health Sciences on approximately six occasions over the study period.

### Outcome variables included in survey

Numerous patient-reported outcomes were included in the survey. These were selected on the basis of the clinical expertise of the lead author, a published review of the literature in this area<sup>18</sup> and our own literature search. The main focus of the project was aspects of sexuality—both spinal cord specific and general disability-related sexuality scales were selected. We included the International SCI core data set,<sup>19</sup> a self-report classification of non-traumatic SCDys based on the International SCI non-traumatic data sets (available on request)<sup>20</sup> and the International SCI quality of life basic data set.<sup>21</sup> Questions were asked about the following areas: gender, including the option for transgender, which was not included in the International SCI core data set; sexual orientation; functional abilities; secondary conditions and complications that are related to SCD;<sup>22</sup> sexual education during rehabilitation; sexual and body esteem;<sup>23</sup> sexual interest, desire, activities, satisfaction and relationship issues;<sup>24–27</sup> and sexual abuse. The findings from the above outcomes not



SCDys=non-traumatic spinal cord dysfunction; SCD=spinal cord damage (i.e. traumatic or non-traumatic aetiology)

Figure 1 Flowchart illustrating methods of patient recruitment.

included in the article will be presented in future publications. A copy of the full survey is available from the first author on request.

Some questions in the survey were developed specifically for this project and not based on previously published outcome measures. These included questions

**Table 1 Demographic and clinical characteristics**

	n, %
<i>Sexual orientation</i>	
Exclusively heterosexual	146, 94.8%
Gay or lesbian	2, 1.3%
Bisexual	6, 3.9%
<i>Current accommodation</i>	
Private residence	151, 98.0%
Assisted living residence (hostel type)	1, 0.7%
Group living situation (for example, community residential unit)	2, 1.3%
<i>Current living arrangement<sup>a</sup></i>	
Live at home alone	54, 35.3%
Live at home with partner and/or children	62, 40.5%
Live at home with family or friend	35, 22.9%
Live in hostel or supported residential service	2, 1.3%
<i>Highest level of education<sup>a</sup></i>	
Primary school level only	0
Secondary school level only	54, 35.5%
Apprentice, trade certificate or similar	41, 27.0%
University degree	57, 37.5%
<i>Employment and income source<sup>a,b</sup></i>	
Employed	60, 39.0%
Volunteer	11, 7.1%
Student	16, 10.4%
Home duties	10, 6.5%
Unemployed	22, 14.3%
Age pension	10, 6.5%
Disability pension	54, 35.1%
Self-funded retiree	17, 11.0%
Accident insurance income	3, 1.9%
<i>Traumatic SCI</i>	
Motor vehicle accident (passenger, driver or pedestrian)	115, 74.7%
Fall	55, 47.8%
Sport or recreational	21, 18.3%
Assault (include with weapon)	26, 22.6%
Other trauma	2, 1.7%
Other trauma	11, 9.6%
<i>Non-traumatic SCDys</i>	
Disc prolapse or other degenerative causes	39, 25.3%
Tumour	11, 28.2%
Ischaemia	6, 15.4%
Haemorrhage	4, 10.3%
Infection	4, 10.3%
Inflammation including transverse myelitis	4, 10.3%
Other	5, 12.8%
Other	5, 12.8%
<i>Current relationship status<sup>a</sup></i>	
Never married	45, 29.6%
Married or <i>de facto</i>	68, 44.7%
Widowed	5, 3.3%
Separated or divorced	34, 22.4%

Abbreviations: SCDys, spinal cord dysfunction; SCI, spinal cord injury.  
<sup>a</sup>Missing data: current relationship status  $n=2$ ; current living arrangement  $n=1$ ; highest level of education  $n=2$ ; employment and income source  $n=2$ .  
<sup>b</sup>Total not add up to 100% as more than one answer possible.

that covered functional abilities, sexual education during rehabilitation, sexual abuse and the self-report versions of the International SCI male sexual function<sup>14</sup> and female sexual and reproductive function data sets.<sup>15</sup> These novel questions including the rewording of the International SCI sexual function data sets for the SR-iSCI-sexual function data sets were developed in an iterative process involving clinicians experienced in spinal cord rehabilitation (the authors), a nurse specialising in sexuality issues in SCD and six people with SCD living in community. The clinicians did the initial writing of the questions and first rounds of revision. The SR-iSCI-sexual function data sets were reworded to change from a clinician-focused assessment to a more accessible patient-reported outcome using simple to understand explanations for the clinical terms. Feedback was obtained from the nurse and then after further changes from the people with SCD. Further changes were made in response to suggestions from each person before circulating the revised version to the next person with SCD. There were no additional suggestions made from the last two people with SCD regarding the SR-iSCI-sexual function data sets (final version shown in appendix 1).

### Sample size

As this was an exploratory study, there was no predetermined sample size.

### Statistical methods

Continuous variables were not normally distributed and hence were summarised using the median and interquartile range (IQR). The Wilcoxon rank-sum (Mann-Whitney) test was used to calculate differences in the population distribution between continuous variables. Categorical variables were compared using Pearson's chi-square test, with the Fisher exact correction used when small numbers in subgroups indicated that this was appropriate.

It was determined that survey responses would only be included in the analysis if at least one complete sexuality-related outcome measure was completed.

Construct validity of the SR-iSCI-sexual function data sets was assessed using the Spinal Cord Injury Secondary Conditions Scale (SCI-SCS),<sup>22</sup> which is a valid and reliable scale for self-reporting the impact of secondary conditions following SCD. The scale uses a four-point ordinal rating of how people are affected by various conditions, ranging from 0 (not experienced/insignificant problem) to 3 (significant/chronic problem). The scale includes an item on sexual dysfunction. The sexual function items in the SR-iSCI-sexual function data sets were given scores as follows: 0 = normal, 1 = reduced or altered and 2 = absent. The total score was calculated for men (psychogenic erection, reflex erection, ejaculation and orgasm) and women (psychogenic arousal, reflex arousal and orgasm). Menstruation was not included in the scoring of the SR-iSCI-sexual function data sets for assessment of construct validity as it relates to reproduction not sexual function. The Spearman  $\rho$  correlations were calculated between the SCI-SCS item on sexual dysfunction and the total scores from the SR-iSCI-sexual function male and female data sets. The reliability of the SR-iSCI-sexual function data set scores was assessed by testing the internal consistency using Cronbach  $\alpha$  with an acceptable level deemed to be 0.70.

$P$ -values of  $<0.05$  were deemed statistically significant.

### Ethics and software

All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research. Stata 12 for Windows (StataCorp, College Station, TX, USA) was used for statistical analysis.

### RESULTS

There were 154 surveys completed by people with SCD included in the analysis. There were 24 completed surveys returned by post (response rate 18%). There were 469 surveys initiated via the website, but 123 were excluded (70 provided no data at all, 37 failed to complete the specified minimum amount of data and 16 self-reported that they did not meet the inclusion criteria). Non-disabled people completed 220 surveys.

**Table 2 Comparison of demographic and clinical characteristics by cause of spinal cord damage**

	Traumatic SCI n = 115	Non-traumatic SCDys n = 39	P-value
Male	82, 71.9%	19, 48.2%	$\chi^2 = 7.0, P = 0.008$
Current relationship status			
Never married	43, 37.7%	2, 5.3%	$\chi^2 = 15.2, P = 0.002$
Married or <i>de facto</i>	47, 41.2%	21, 55.3%	
Widowed	3, 2.6%	2, 5.3%	
Separated or divorced	21, 18.4%	13, 34.2%	
Paraplegia	60, 52.2%	31, 79.5%	$\chi^2 = 9.0, P = 0.003$
Age (years), IQR, (range)	46, 32–55 (19–75)	58, 51–68 (35–81)	$Z = -5.2, P < 0.001$
Years since SCD, IQR, (range)	12, 5–23 (0.6–52)	6, 2–14 (0.3–38)	$Z = 3.0, P = 0.003$

Abbreviations: IQR, interquartile range; SCD, spinal cord damage; SCDys, spinal cord dysfunction; SCI, spinal cord injury.

There were almost twice as many males ( $n = 101, 65.6\%$ ) as females ( $n = 52, 33.7\%$ ) and one participant identified as 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 ( $n = 91, 59.1\%$ ) had a paraplegic level of injury. The demographic and clinical characteristics of respondents are shown in Table 1. No participants reported their aetiology as ‘unknown’. On the basis of the feedback received during the development of the survey from people with SCD, respondents were permitted to indicate more than one response regarding their employment and income sources. Although most respondents ( $n = 111, 72.1\%$ ) indicated only one category of employment or income, two categories were reported by 33 people (21.4%), three categories by 6 people (3.9%) and four categories were selected by 2 people (1.3%).

#### Differences according to aetiology of SCD

There were significant differences between those with traumatic SCI and non-traumatic SCDys regarding gender, current relationship status, level of SCD, age and number of years since SCD (Table 2).

#### Self-reports of male sexual function and female sexual and reproductive function data sets

One hundred fifty-one respondents with SCD completed the SR-iSCI-sexual function data sets. Comparisons between the responses for those with traumatic SCI and non-traumatic SCDys and males and females are shown in Table 3.

Sexual problems or issues unrelated to SCD were reported by 12 (8%) of respondents. These problems included the following: erectile dysfunction ( $n = 4$ ), infertility, over-weight, penis size, vaginismus, recent birth of a child, reduced libido and others not specified ( $n = 3$ ).

No differences were found between males and females regarding pre-existing sexual issues unrelated to SCD ( $\chi^2 = 1.7, P = 0.4$ ), but sexual dysfunction as a result of SCD was much more likely ( $\chi^2 = 6.5, P = 0.04$ ) to be reported by males (sexual dysfunction  $n = 82, 82\%$ ; no sexual dysfunction  $n = 11, 11\%$  unsure  $n = 7, 7\%$ ) than females (sexual dysfunction  $n = 32, 64\%$ ; no sexual dysfunction  $n = 13, 26\%$  unsure  $n = 5, 10\%$ ). Orgasms were also more likely ( $\chi^2 = 13.1, P = 0.006$ ) to be abnormal in males (normal  $n = 5, 5\%$ ; reduced  $n = 33, 33\%$ ; absent  $n = 52, 52\%$ ; unknown  $n = 10, 10\%$ ) than females (normal  $n = 11, 22\%$ ; reduced  $n = 20, 40\%$ ; absent  $n = 16, 32\%$ ; unknown  $n = 3, 6\%$ ). Males had significantly worse psychogenic genital functioning ( $\chi^2 = 26.0, P = 0.001$ ) and reflex genital functioning ( $\chi^2 = 10.8, P = 0.013$ ) than females (Table 3).

#### Psychometric properties of the self-report male and female sexual function data sets

There was a strong correlation between the SCI-SCS sexual dysfunction item and the total scores from the SR-iSCI-sexual function for males ( $n = 83$ , Spearman  $\rho = 0.40$ ;  $P = 0.0002$ ) and females ( $n = 37$ , Spearman  $\rho = 0.41$ ;  $P = 0.01$ ).

For males, the internal consistency of the SR-iSCI-sexual function was  $\alpha = 0.73$  (inter-item covariance = 0.16) and for females  $\alpha = 0.76$  (inter-item covariance = 0.28).

The face validity of the sexual function data sets was confirmed by the process of developing these, as outlined previously.<sup>14,15</sup> The male SR-iSCI-sexual function score (range 4–12) had a very low floor (1%) but a mild ceiling (21%) effect, whereas the female SR-iSCI-sexual function score (range 3–9) had a low floor (13%) and a low ceiling (11%) effect.

#### DISCUSSION

This study has reported on the development of self-report versions of the International SCI male sexual function and female sexual and reproductive function basic data sets. These were used in a sample of people with traumatic and non-traumatic SCD as part of a comprehensive study of sexuality. We found numerous significant differences in the sexual functioning of people with traumatic SCI compared to those with non-traumatic SCDys, as well as gender-related differences. Our assessment of the psychometric properties of the SR-iSCI-sexual function data sets found no issues of concern.

In this exploratory study there were a number of noteworthy differences in the sexual functioning of people with non-traumatic SCDys and those with traumatic SCI. People with SCDys are more likely to have pre-existing sexual issues and retain the ability to have orgasms and are less likely to be able to ejaculate or menstruate following their SCDys. These differences may be explained by the older age and the greater likelihood of incomplete SCD in people with SCDys.

There are a number of implications of our findings. First, others have suggested that people with SCDys are more likely to have worse sexual adjustment because of the higher likelihood of medical complications that could interfere with a sexual rehabilitation program.<sup>28</sup> Our results, however, do not support this assertion. If it is accepted that people with SCDys are more likely to have worse sexual adjustment they may be excluded from sexuality rehabilitation programs. We strongly believe that there is no justification for

**Table 3 Results of the self-report versions of the International SCI male sexual function and female sexual and reproductive function basic data sets**

	Traumatic SCI n = 113	Non-traumatic SCDys n = 38	P-value	Total, n = 151 n, %
<i>Sexual problems or issues unrelated to SCDys</i>				
Yes	5, 4.4%	7, 18.4%	$\chi^2 = 8.7, P = 0.01$	12, 8.0%
No	98, 86.7%	30, 79.0%		128, 84.8%
Unsure	10, 8.9%	1, 2.6%		11, 7.3%
<i>Sexual problems or issues due to SCDys</i>				
Yes	82, 72.6%	32, 84.2%	$\chi^2 = 4.3, P = 0.1$	114, 75.5%
No	22, 19.5%	2, 5.3%		24, 15.9%
Unsure	9, 8.0%	4, 10.5%		13, 8.6%
<i>Ability to have orgasms</i>				
Normal	12, 10.6%	5, 13.2%	$\chi^2 = 7.5, P = 0.04$	17, 11.3%
Reduced or altered	34, 30.1%	19, 50.0%		53, 35.1%
Absent	58, 51.3%	10, 26.3%		68, 45.0%
Unknown	9, 8.0%	4, 10.5%		13, 8.6%
Male data set (n = 100) <sup>a</sup>				
	n = 81	n = 19		
<i>Ability to have psychogenic erections</i>				
Normal	8, 9.9%	1, 5.3%	$\chi^2 = 9.2, P = 0.06$	9, 9.9%
Reduced or altered	21, 25.9%	3, 15.8%		24, 24.4%
Absent	51, 63.0%	12, 63.2%		63, 63%
Unknown	1, 1.2%	3, 15.8%		4, 4%
<i>Ability to have reflex erections</i>				
Normal	15, 18.5%	3, 15.8%	$\chi^2 = 0.9, P = 0.7$	18, 18%
Reduced or altered	44, 54.3%	9, 47.4%		53, 53%
Absent	20, 24.7%	6, 31.6%		26, 26%
Unknown	2, 2.5%	1, 5.3%		3, 3%
<i>Ability to ejaculate</i>				
Normal	3, 3.7%	0, 0%	$\chi^2 = 7.7, P = 0.04$	3, 3%
Reduced or altered	25, 30.9%	10, 52.6%		35, 35%
Absent	46, 56.8%	5, 26.3%		51, 51%
Unknown	7, 8.4%	4, 21.1%		11, 11%
Female data set (n = 50) <sup>a</sup>				
	n = 31	n = 19		
<i>Ability to have psychogenic genital arousal</i>				
Normal	8, 25.8%	5, 26.3%	$\chi^2 = 2.0, P = 0.6$	13, 26.0%
Reduced or altered	12, 38.7%	9, 47.4%		21, 42.0%
Absent	8, 25.8%	2, 10.5%		10, 20.0%
Unknown	3, 9.7%	3, 15.8%		6, 12.0%
<i>Ability to have reflex genital arousal</i>				
Normal	6, 19.4%	4, 21.1%	$\chi^2 = 1.7, P = 0.7$	10, 20.0%
Reduced or altered	14, 45.2%	7, 36.8%		21, 42.0%
Absent	7, 22.6%	3, 15.8%		10, 20.0%
Unknown	4, 12.9%	5, 26.3%		9, 18.0%
<i>How would you rate your menstruation pattern since your spinal cord damage</i>				
Normal	14, 45.2%	4, 21.1%	$\chi^2 = 10.9, P = 0.01$	18, 36.0%
Reduced or altered	11, 35.5%	3, 36.8%		14, 28.0%
Absent	5, 16.1%	7, 26.3%		12, 24.0%
Unknown	1, 3.2%	5, 26.3%		6, 12.0%

Abbreviations: SCDys, spinal cord dysfunction; SCI, spinal cord injury.  
<sup>a</sup>Transgender (n = 1) did not complete either the male or female-specific questions.



excluding people with SCDys from future studies of sexuality or sexual health following SCD.

Another implication is that our results reinforce the need for sexuality research in people with SCD to include those who are gay, lesbian, bisexual or transgender, although our sample size was too small to report subgroup analyses for these people.

An additional implication of our findings is the justification of the approach taken to allow more than one response to the question regarding employment and income sources. People with SCD engaged in a number of employment and income roles, and these should be assessed with a multiple-response rather than a single-response answer.

Finally, the perspective of people with SCD is recognised as being important in spinal cord research,<sup>6</sup> and our findings further justify this in relation to sexuality research.

Rehabilitation clinicians working with people who have SCDys need to consider their unique sexuality issues. Careful assessment of sexuality concerns coupled with appropriate education and/or therapeutic intervention should be part of comprehensive SCDys rehabilitation. On the basis of our findings, there are a number of important areas for consideration. Understanding pre-existing medical conditions associated with ageing and how they can affect sexual functioning is important because SCDys is more common in older age and was reported by participants in this study. Given the trend for people with non-traumatic SCDys to be older,<sup>10,11</sup> they are more likely to have comorbidities that could potentially impact sexual health outcomes. Older men would be less likely to use or tolerate certain erectile dysfunction treatments. Optimising the ejaculatory potential and strategies for dealing with this dysfunction is particularly important for men with SCDys. Awareness of greater problems with menstruation in women with SCDys is needed. Fertility issues are less likely to be a focus of concern in people with SCDys, given the age of this group. Finally, given that involving the partner in assessment and management of sexuality issues is central to satisfaction of the person with SCDys, it is important to be aware of the differences in relationship status of people with SCDys (they are more likely to be married, in a *de facto*, separated or divorced) compared with those with SCI.

Our findings from the SR-iSCI-sexual function data sets are generally comparable with those from previous studies; however, in all the studies cited below direct comparisons are limited by a wide range in terminology, definitions and wording. This will hopefully be addressed by the uptake among clinicians and researchers of the International SCI data sets.<sup>16</sup> Erectile dysfunction has been reported by roughly half of men<sup>29,30</sup> and ejaculation in less than half.<sup>30–32</sup> Orgasmic function is typically better preserved in women<sup>33,34</sup> than in men.<sup>30,32</sup> Psychogenic arousal<sup>33,34</sup> and reflex genital arousal<sup>34</sup> are also typically reduced in women.

The strengths of this study are that it is the first to publish results of the International SCI basic sexual function data sets, and we have developed and validated a self-report version for males and females that can be used by others in future studies. This is also, to our knowledge, the first study to compare in detail the sexual functioning in people with non-traumatic SCDys to those with traumatic SCI.

The epidemiology and the level of injury, both for traumatic SCI and non-traumatic SCDys, are consistent with those from previous reports of SCD in Australia (median age: SCI=46, SCDys=67; males: SCI=72%, SCDys=53%; paraplegia: SCI=50%, SCDys=69%).<sup>11</sup> The proportions of people identifying as gay, lesbian or bisexual were similar to those in a large population-based study of the Australian population.<sup>35</sup> On the basis of the above, we believe that it is likely that

the results are largely generalisable to people with SCD in Australia, while acknowledging the limitations outlined below. Although we cannot generalise the results here to other countries, we believe that it is possible to use the SR-iSCI-sexual function data sets in other settings.

#### Limitations and future directions

Limitations of this study need to be acknowledged, in particular the responder bias to surveys, which is reported to be greater in studies of sexuality.<sup>36</sup> Nevertheless, alternative study methods are not readily available. A reflection of this responder bias is that the education level reported was higher than that which we would expect to be typical of a population sample of people with SCD, although little is known about education standards in Australians with SCD. The nature of the recruitment methods, which were used for practical purposes, excluded people without computer skills and ready access to a computer, which would bias the sample toward a higher socio-economic cohort and partially account for the education level. This may also have biased against people with complete tetraplegia and reduced the hand function. However, the use of voice-activated software is readily available to allow people with SCD to use computers independently, and they would have also had the option of completing the survey with the aid of another person if they were comfortable with this. In addition, only those with adequate English language skills would have been able to complete the survey. We estimate that in our unit about 10–15% of patients admitted would not have adequate English skills to complete the survey. This would create additional bias in the sample. The age and gender mix of respondents, however, suggests that in many aspects our sample is typical of those with SCD.<sup>11</sup>

Additional limitations are that the number of respondents with non-traumatic SCDys was less than anticipated, and the number of females was also relatively low. This reduced the power of the analyses; however, as an exploratory study in this area the analyses serve as a useful benchmark for guiding further research. No American Spinal Injury Association Impairment Scale information was collected from participants because pilot testing indicated that most of the people attending our review clinic did not know this. The response rate from the mailed survey was relatively low, but we were not able to determine to what extent the responder bias influenced the results. There were many people who visited the web-based site without entering any data or the minimum amount of data, but we were not able to determine the reasons for this. No information was collected from women regarding parity or contraceptive use. No information was collected regarding whether participants had used any specific therapies for their sexual dysfunction or what these were. Finally, we cannot be absolutely certain that participants completing the SR-iSCI-sexual function data sets would correctly discriminate whether sexual problems were related or unrelated to their SCD apart from assuming that the unrelated sexuality problems existed before the SCD.

Additional studies are needed to address the dearth of research regarding sexuality issues in people with SCDys. Other directions for future research include using the SR-iSCI-sexual function data sets in other settings and with a larger number of respondents, particularly females and people with SCDys, in order to facilitate comparisons between these subgroups of people with SCD. Further assessment of the psychometric properties of the SR-iSCI-sexual function data sets is needed, in particular the test-retest reliability. Translation into other languages is also appropriate. We advocate for the inclusion of an option for transsexual gender identification in the ISCoS core data set and the addition of sexual orientation in a revised version of the International SCI basic sexual function data sets.

In conclusion, the SR-iSCI-sexual function data sets provide a useful tool for researchers and clinicians to collect information regarding patient-reported sexual functioning after SCD and to facilitate comparative studies.

#### DATA ARCHIVING

There were no data to deposit.

#### CONFLICT OF INTEREST

The authors declare no conflict of interest.

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#### APPENDIX 1

Self-report versions of the International Spinal Cord Society male sexual function and female sexual and reproductive function data sets

##### QUESTIONS IN BOTH MALE AND FEMALE DATA SETS

**Do you have any sexual problems or issues unrelated to your spinal cord damage?**

- Yes, please specify \_\_\_\_\_
- No
- Unsure

**Do you have any sexual problems or issues due to your spinal cord damage?**

- Yes
- No
- Unsure

**How would you rate your ability to have an orgasm?**

- Normal
- Reduced/altered
- Absent
- Unknown

##### MALES DATA SET

**How would you rate your ability to have psychogenic erections?**

(A psychogenic erection is an erection that occurs without any physical touching. This may occur if a man thinks of something sexual or sometimes it just happens on its own)?

- Normal
- Reduced/altered
- Absent
- Unknown

**How would you rate your ability to have reflex erections**

(This is an erection that occurs because of physical stimulation or touch)?

- Normal
- Reduced/altered
- Absent
- Unknown

**How would you rate your ability to ejaculate?**

- Normal
- Reduced/altered
- Absent
- Unknown

**FEMALES DATA SET**

**How would you rate your ability to have psychogenic genital arousal** (This is when genital changes and lubrication occur

without any physical touching. This may occur if a woman thinks of something sexual or sometimes it just happens on its own)?

- Normal
- Reduced/altered
- Absent
- Unknown

**How would you rate your ability to have reflex genital arousal**

(This is when genital changes and lubrication occur because of physical stimulation or touch)?

- Normal
- Reduced/altered
- Absent
- Unknown

**How would you rate your current menstruation pattern?**

- Normal
- Reduced/altered
- Absent
- Unknown