

## ORIGINAL ARTICLE

# Personal assistance, income and employment: the spinal injuries survey instrument (SISI) and its application in a sample of people with quadriplegia

D Rowell<sup>1</sup> and LB Connelly<sup>1,2</sup>

<sup>1</sup>Australian Centre for Economic Research on Health (ACERH), Mayne Medical School, The University of Queensland, Brisbane, Australia and <sup>2</sup>Centre of National Research on Disability and Rehabilitation Medicine (CONROD), The University of Queensland, Brisbane, Australia

**Introduction** Our aim was to ascertain what effect access to personal care package (PCP) has on the labour market activities of people who have a spinal cord injury (SCI). We developed a new instrument called the spinal injuries survey instrument (SISI). The SISI is a 35-item instrument, which contains items on health, education, employment, along with measures of personal assistance, mobility and psychological attribution style.

**Materials and methods** The SISI was administered, with the Short Form 36 (SF-36) health status instrument, to 250 people with an SCI. The response rate was 72%. A retrospective, matched case-control sampling approach matched individuals who received a PCP, with a cohort who did not. The matching criteria included the site and severity of spinal lesion, age and gender.

**Results** Although data on the reliability of the instrument are currently lacking, our empirical results are consistent with other studies: (1) mean annual health care costs (AUD\$8741) are comparable with Walsh's estimates (2) SF-36 data support Kreuter's contention that mental health is resilient to SCI and (3) a post-injury employment rate of 29.7% corroborates Murphy *et al.* We present additional data describing income, educational attainment and family support.

**Discussion** Our discussion borrows a conceptualization of disability by Sen, that includes both an 'earning handicap' (an impediment to earn income) and a 'conversion handicap' (an impediment to the enjoyment of income). Our application of the SISI provides evidence of both. The labour income of people with quadriplegia is AUD\$10 007 per annum, while diminished health status, increased out-of-pocket health expenditure and loss of time suggest a conversion handicap.

*Spinal Cord* (2008) 46, 417–424; doi:10.1038/sj.sc.3102157; published online 8 January 2008

**Keywords:** quadriplegia; economics; employment; quality of life

## Introduction

This article presents the results of designing a new 35-item instrument—the Spinal Injuries Survey Instrument (SISI)—and administering it to 250 Queensland residents with a spinal cord injury (SCI). The motivation for the construction of this instrument was to undertake a study of the impact of the provision of government support for people with an SCI on their labour market activities and outcomes. The resulting instrument, however, may have much wider application, since it contains items on a comprehensive range of health, education, income, health care utilization, psychological and other dimensions. For this reason, other researchers are

likely to find the SISI useful. Thus, the purpose of this article is to present the instrument to researchers (Appendix 1), and to report descriptive statistics from its initial application in Queensland, Australia.

The Queensland State Government funds an initiative that supports the re-integration of people with an SCI into the community. The recipients of a personal care package (PCP) receive paid personal care to assist them with activities of daily living, such as showering and meal preparation and to enable educational, vocational and social participation. Access to a PCP is rationed on the basis of assessed need. For this application of the SISI, we constructed a sample of people who receive government financial support for activities of daily living, matched with people who do not receive such support. Working with the Spinal Injuries Association (SIA) Queensland, and using a range of completion options (telephone, written and web) and incentives

Correspondence: D Rowell, Australian Centre for Economic Research on Health (ACERH), Mayne Medical School, The University of Queensland, Herston Road, Herston, Brisbane, Queensland 4006, Australia.  
E-mail: d.rowell@uq.edu.au

Received 17 July 2007; revised 19 November 2007; accepted 22 November 2007; published online 8 January 2008

(instant lottery tickets plus a small cash lottery draw for all respondents), we achieved a 72% response rate. We simultaneously administered the Short Form 36 (SF-36),<sup>1</sup> and a modified version of the SF-36 items that concern locomotion, along with the SISI in this study. The primary aim of the article is to present the instrument (Appendix 1) and describe the characteristics of the sample, including pre- and post-SCI education, employment and income, as well as post-SCI health-related quality of life (HRQoL), health services use, the provision of paid and unpaid care and indicators of the psychological 'attribution style' of this sample. Where comparison was possible our results were consistent with other reported findings in the Australian SCI literature.<sup>2-4</sup> We briefly describe the design and pilot test of the instrument along the methods of its administration in this study. Because our sampling frame was not constructed as a random sample of the population and due to the inference problems with small numbers of some types of spinal injury (for example, paraplegia), we focus on quadriplegia rather than people with SCI generally. The results of this study contribute to the literature on the achievements of, and challenges faced by people with quadriplegia. We conclude the article by inviting others to apply the SISI—which is available to *bona fide* researchers at zero charge—to advance our understanding of the social, economic and workplace achievements of and challenges faced by people with SCIs in other jurisdictions.

## Materials and methods

The SISI was initially developed to collect detailed information on pre- and post-SCI employment status and income, along with a variety of factors that are known or expected to confound this relationship. The economic literature on this subject, much of which has used existing administrative data sets, has employed sophisticated econometric/statistical techniques in an attempt to control for these confounders (see, for example, the review by Heckman<sup>5</sup>). The SISI, at least in part, represents an attempt to collect data that may assist in the statistical endeavour of disentangling the effect of government assistance *per se* on employment, from other factors (for example, physical function, mental health status, motivation or attitude to work) that are often not available from administrative data sets.

The SISI is a 35-item survey instrument which we pilot tested on a convenience sample of nine members of the SIA, along with the SF-36<sup>1</sup> and a modified version of the SF-36. The SISI includes questions regarding pre- and post-injury educational attainment, employment and income; and post-SCI sources of income, employment, paid and unpaid care, age, gender, marital status, location of residence, type of residence, health care utilization (outpatient, inpatient, pharmaceutical quantities and expenditures), conditions associated with hospitalizations, perceptions of discrimination by employers against people with disabilities, time preferences and psychological measures of 'attributional style' (Appendix 1).

The Australian version of the SF-36 was applied in unmodified form. However, we also created an 'enabled' version of the SF-36 by modifying (with permission) several items. Our rationale for creating the 'enabled' version of the SF-36 was that some of the SF-36 items that pertain to locomotion use terminology that is ill-suited for our sample. Specifically, whereas question 3 from the SF-36 uses verbs such as 'running' (3(a)), 'climbing' (3(d), 3(e)), 'bending, kneeling or stooping' (3(f)) and 'walking' (3(g)–(i)), we substituted verbs such as 'wheeling', 'going up', 'bending, or kneeling' and 'going', respectively.<sup>6</sup> The SF-36, the SISI and the modified forms of SF-36 questions 3(a)–(i) were presented, in that order, as a single booklet. Thus, the original and modified forms of question were considerably separated in our application of them.

### *The sample*

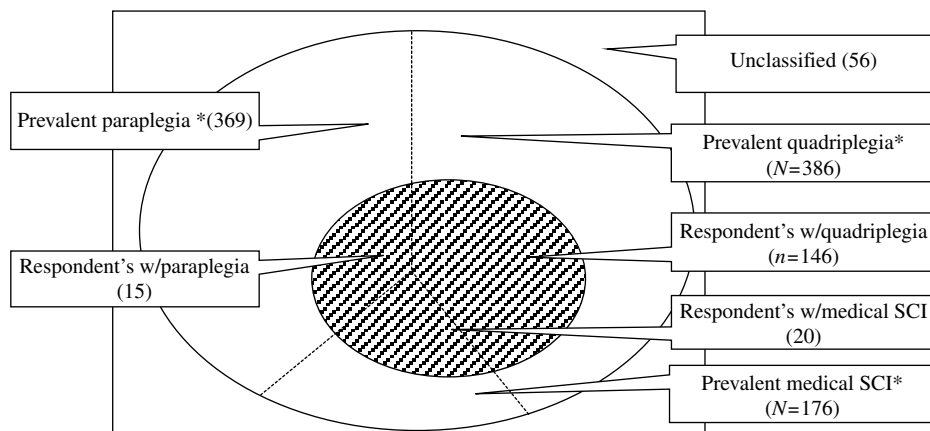
The SIA (Queensland) has 978 members. The membership list is, in fact, believed to encompass most people with serious spinal injuries in Queensland, Australia. People with an SCI are invariably treated by the specialist Spinal Injuries Unit at the Princess Alexandra Hospital in the capital city, Brisbane, and are routinely referred to the SIA for post-discharge support. An examination of the SIA database revealed that only 13.4% of the membership received a PCP. We then used the matched-sampling approach developed by Rubin<sup>7</sup> to compose the sample with individuals who did not receive a PCP. Specifically, each individual who received a PCP was matched to one control subject. Controls were matched on the basis of the level (for example, C3) and type ('complete'/'incomplete') of spinal lesion, age and sex.

In total, 250 individuals were surveyed in this application of the SISI. Non-respondents were followed up by phone, encouraged to complete the survey and again offered the options of completing the survey via telephone interview, or web-based response. In addition, as an incentive to participate, we offered all participants instant lottery tickets and entry in a cash draw of AUD\$500. These methods produced a response rate of 72% ( $n = 181$ ).

Since the public PCPs are rationed by Disability Services Queensland according to a judgement about the level of 'need' of an applicant, the resulting sample is characterized by a greater-than-average level of impairment than the SIA membership at large. Figure 1 illustrates the nature of this bias, by presenting the number of respondents and the estimated prevalent numbers of individuals with quadriplegia and paraplegia, and with SCI of medical (that is, non-traumatic) origin. The shaded region of Figure 1 represents the sample respondents.

### *Statement of ethics*

We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers/animals were followed during the course of this research. Approval for the administration of the SISI was granted by the Medical Research Ethics Committee the Behavioural and Social Sciences Ethical Review Committee and the School of



**Figure 1** The sample frame. Constructed from data supplied by the Spinal Injuries Association (SIA) (2006). \* Prevalent numbers are estimates and assume that the SIA membership represents a complete enumeration of people with spinal cord injuries (SCIs). ‘Medical SCI’ is used here to connote SCI of non-traumatic, or congenital, origin. (e.g., *spina bifida*). Our survey is characterized by an over-sampling of people with quadriplegia ( $n = 146$ ) and an under-sampling of people with paraplegia ( $n = 15$ ) and medical SCIs ( $n = 20$ ). Therefore in this article we focus exclusively on respondents with quadriplegia.

**Table 1** Pre- and post-SCI labour force participation rates

Employment status	Murphy <i>et al.</i> <sup>4</sup>		Quadriplegia only	
	Pre-injury (%)	Post-injury (%)	Pre-injury (%)	Post-injury (%)
Employed	73	37	77.9	29.2
Unemployed and looking for work	5	4	5.0	11.1
Total in labour force	78	41	82.9	40.3
Unemployed and not looking for work	22	59	8.6	54.2
In training	NA	NA	8.6	5.6
Total not in labour force	22	59	17.1	59.7

Abbreviation: NA, not applicable.

Total in labour force = Employed + Unemployed and looking for work.

Total not in labour force = Unemployed and not looking for work + In training.

Economics, Research Ethics Committee, The University of Queensland.

## Results

It is useful to commence with a brief overview of the demographic characteristics of our sample. A total of 80% of our sample is male. The average age of prevalent quadriplegia in our sample is 43 years, 8 months, while the estimated average age of ‘incident’ quadriplegia is 26 years and 9 months.

Now, we present results that focus on employment status, HRQoL, health care utilization and the use of informal care by people with quadriplegia. These variables are the focus of our initial application of the SISI. Table 1 presents labour market participation rates for respondents with quadriplegia, pre- and post-SCI, alongside results that were published by Murphy *et al.*<sup>4</sup> on the labour force characteristics of people pre- and post-SCI. Our results are naturally comparable with those reported by Murphy *et al.*<sup>4</sup> because

three of the questions used by Murphy *et al.*<sup>4</sup> were also used in the SISI.

Table 2 presents means with confidence intervals for data supplied by respondents with quadriplegia. Two sets of results on the HRQoL of our sample are presented in the table: one set is based on the 11 standard subscales of the SF-36 (v.2), and another is based on our ‘modified/enabled’ version of the instrument. The physical function scale and summary component scores from the ‘enabled’ SF-36 were included to reflect the impact of a wheelchair on the true quality of life experienced by individuals with an SCI.

The health care cost estimates are based on a ‘bottom-up’ approach to calculating the expenditures on inpatient and outpatient care and pharmaceutical consumption. This method includes publicly and privately insured expenditures as well as patient out-of-pocket costs, but does not include any shadow prices for waiting times or other transaction costs. The estimates in Table 2 are based on respondents’ stated health care consumption in the SISI, in conjunction with the service price estimates that are presented in Appendix 2.

**Table 2** Summary statistics from an application of the SISI; quadriplegia

Variables	Quadriplegia (n = 146)		
	Mean	95% CI	
<i>SF-36 (V. 2)</i>			
Physical function SCALE	14.87	13.39	16.35
Role physical scale	31.18	29.16	33.19
Bodily pain scale	41.57	39.97	43.17
General health	40.17	38.35	41.98
Vitality scale	43.81	42.22	45.40
Social function scale	37.13	34.88	39.38
Role emotion scale	38.02	34.92	41.13
Mental health scale	43.07	40.96	45.19
Physical component score	27.35	26.17	28.54
Mental component score	47.68	45.03	50.34
<i>SF-36 (modified/'enabled')</i>			
Physical function scale	22.35	20.64	24.06
Physical component score	30.67	29.31	32.02
Mental component score	45.92	43.24	48.59
<i>Annual health care costs, by type \$pa (2005 prices)</i>			
Outpatient costs	1496	974	2018
Inpatient costs	3764	2125	5403
Pharmaceutical costs	1689	1451	1928
Out-of-pocket expenses	1792	1025	2559
Total health care costs	8741	6601	10881
<i>Annual income, by source \$pa (2005 prices)</i>			
Employment	10 007	6443	13 570
Disability pension	8225	7111	9340
Compensation	1910	222	3599
Paid assistance	15 717	11 447	19 987
Other income	4416	2331	6501
Total income	40 275	35 125	45 425
Income conditional upon employment	36 524	27 643	45 405
<i>Activity, by type (hours per fortnight)</i>			
Paid work	17.6	12.1	23.0
Unpaid work	5.3	3.2	7.3
Education	4.0	1.8	6.2
Domestic work	5.4	3.3	7.6
Other activity	26.0	20.8	31.2
Total activity	56.9	50.4	63.4
<i>Unpaid care</i>			
Number of hours per fortnight	80.46	61.14	99.78
Estimated shadow price of unpaid care \$ p.a. (2005 prices)	13 262	11 169	15 356

Abbreviation: SF-36, Short Form 36.

Derived from an application of the Spinal Injuries Survey Instrument. Health care cost estimates also employ data from various published sources (see Appendix 2).

All dollar values are expressed in 2005 Australian dollars (AUD\$1.00 = US\$0.77); SF-36 indices were normalized to a mean of 50 and a standard deviation of 10 using an algorithm provided by Prof Graham Hawthorn in correspondence. The algorithm used for the Australian SF-36 norms derived from the South Australian Omnibus Health Survey.<sup>8</sup>

Summary of financial data including wage rate, pension income and compensation packages were collected in our application of the SISI and are also presented in Table 2. Hours of paid care were treated as income-in-kind and valued at the SIA's service provision price for such care (that is, AUD\$26 per hour). Data were collected on activity by type, which included time spent in paid and unpaid work, education, domestic activity and other activities that the

respondents considered important (for example, participation in sporting activities, hobbies). Finally, the number of hours of unpaid family care is presented, and valued using a 'shadow price'. This computation was based on a wage rates determined by age and gender<sup>9</sup> and the hours of care, with an upper bound of 38 h per working week, to reflect the opportunity cost of time lost to the labour force.

In our sample, educational attainment is an important correlate of employment.<sup>4,10</sup> Pre-SCI, 38.6% of people with quadriplegia had completed high school and 57.7% had completed some further education. Post-SCI, 51.4% of the respondents with quadriplegia had commenced additional education. Figure 2, below, blends data from questions 17–19 to compare the educational achievement of people with quadriplegia and those of the broader community.

### Employment

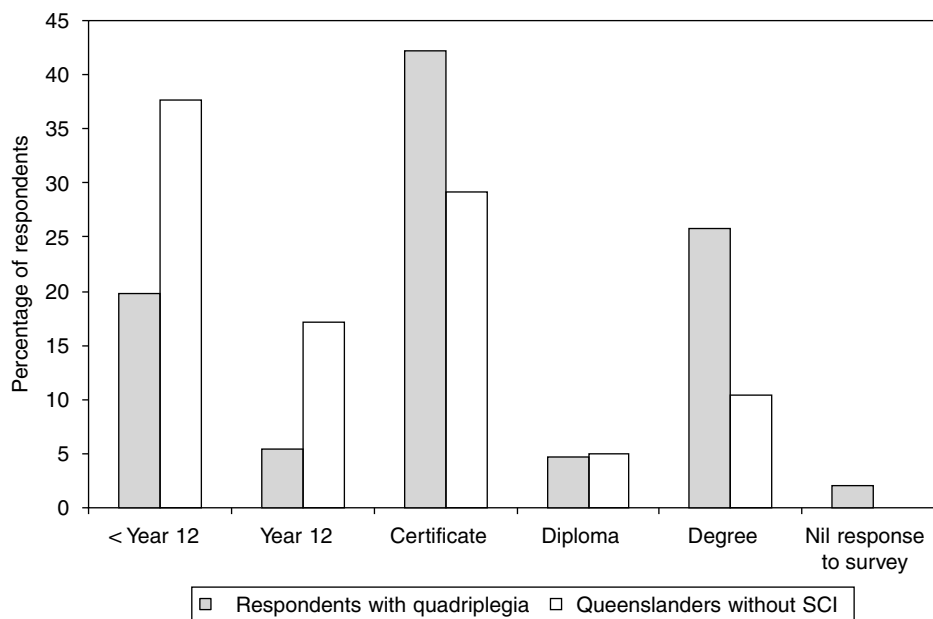
Table 1 shows that labour force participation rates for the respondents with quadriplegia declined from 83 to 40% and employment rates declined from 78 to 29% pre- and post-SCI. An unplanned exit from the labour market due to injury or health may, *Ceteris paribus*, be expected to have a deleterious impact on welfare.<sup>12</sup> Whereas Murphy *et al.*<sup>4</sup> modelled employment as either a dichotomous variable or continuous measure of hours worked, the SISI includes an open-ended question about labour earnings and about hours worked. The average labour income conditional on being employed was AUD\$36 524 per annum; however the average labour income for the entire (employed and unemployed) sample was only AUD\$10 007 per annum. PCPs were excluded from the income estimate because our sample was explicitly matched on this criterion, thereby limiting our ability to draw inference regarding income from this source. When only money income was considered, the mean gross income of the sample was estimated to be AUD\$24 558 per annum. This figure is approximately half the mean annual earnings of people living in Queensland.<sup>13</sup>

### Health-related quality of life

A number of Australian social scientists have attempted to measure HRQoL in the SCI population and their findings have been mixed. Hancock *et al.*<sup>14</sup> used validated psychological instruments to conclude that people with SCI were more anxious and depressed than a control group.<sup>14</sup> Kreuter<sup>3</sup> used the SF-36 and reported a mean 'physical functional scale' (PFS) score that was well below the population mean. Interestingly, the mean Mental Health Scale score in his sample was only marginally lower than that of the general population.<sup>3</sup>

Our findings on these subscales are similar to those of Kreuter.<sup>3</sup> The estimates of the physical component score (27.35), reported in Table 2, place our sample in the bottom 2.5% of the Australian population. The mental component score (47.68), on the other hand, suggests that the mental health of our sample of people with quadriplegia is resilient to the challenges of this disability.

The 'enabled' version of the SF-36 produced a statistically significant difference in both the PFS (14.87–22.35) and the



**Figure 2** Highest level of educational participation, (SISI (spinal injuries survey instrument) sample with quadriplegia compared to Queenslanders without spinal cord injuries (SCI)). The SISI and Persons Aged 15 Years and Over, Level of highest attainment by selected characteristics, Education and Training Experience, Australia 2005.<sup>11</sup> The highest level of educational attainment is derived from questions 17–19 on the SISI. However question 19 concerns education undertaken, but not necessarily completed. Approximately 49% of our sample indicated that they had enrolled in some form of education post SCI.

physical component score (27.35–30.67) when compared to the responses to the standard SF-36. This is due to the ‘enabled’ version’s propensity to accommodate the routinely use of wheelchairs in this population to ambulate. Of course, a disadvantage of our ‘enabled’ measure is that no population norms have been established for it. This presents an opportunity for further development.

#### Health care

Respondents with quadriplegia spent an average of AUD\$8741 per annum on health care, approximately twice the community average of AUD\$4319 per annum.<sup>15</sup> Health care costs were dominated by hospital services (42.0%), followed by medical services (19.2%) and pharmaceuticals (18.8%). By comparison, the health care costs by service category for the general population were composed of lower proportions of expenditure on hospital services (34.8%), medical services (17.1%) and pharmaceuticals (14.4%).<sup>15</sup>

#### Informal care

Families play an important ongoing role caring for people with an SCI. A total of 70% of respondents with quadriplegia receives some unpaid care. The average for this group was 80 h per fortnight. Based on a carer’s wage rate determined by age, gender<sup>9</sup> and an upper bound of a 38-h working week, the shadow price of family care was estimated to be AUD\$13 262 per annum. The burden of care falls disproportionately on women, no doubt due to the higher prevalence of SCIs in males, 80% of the carers are females and their ages range from 17 to 91 years, with a mean of 54 years.

## Discussion

Sen asserts that ‘[t]here is something immediate and poignant in the recognition of disability that calls for reflection and response’.<sup>16</sup> We therefore conclude by using Sen’s conception of an ‘earning handicap’ and ‘conversion handicap’ to draw together our quantitative results, into a narrative which describes the full socioeconomic impact of quadriplegia in Queensland, Australia.

#### Earning handicap

For persons with quadriplegia the average labour income conditional upon being employed is AUD\$36 524 per annum. However, the employment participation rate of this group was only 29.7% post-SCI, which reduces the (unconditional) average labour income for the entire cohort to just AUD\$10 007 per annum. We contend that this is *prima facie* evidence of an earning handicap.

Another important determinant of earnings potential is the human capital stock, which, although negatively correlated with an SCI, is generally positively correlated with education. Figure 2 indicates that in gross terms, the level of educational attainment for people with SCI compares favourably with community standards. Until labour market participation rates increase, income transfers, such as the disability pension which raise mean income to AUD\$24 558 per annum, will remain an important measure of earning handicap mitigation. We cannot quantify the potential mitigating role of education and re-training on earning handicaps though.

### Conversion handicap

The capacity of people with quadriplegia to convert income into good living is subject to the constraints imposed, not only by their wealth and income, but also by their health status. The SISI provides circumstantial evidence of a conversion handicap of this kind. Firstly, out-of-pocket health care expenses of AUD\$1792 per year directly reduce the income available for other consumption. Second, despite health care expenditure of AUD\$8741 per annum, which is twice the community average; the health status of our sample remains poor. While the mental component score (47.68) of the group was only marginally below that of the community mean, the physical component score of (27.35) was much lower than the community mean of 50. Third, spinal injury imposes average family costs of 80.5 h per fortnight in carer time, which according to our method of estimation, amounts to approximately in AUD\$13 262 per annum of lost wages. This estimate assumes that the time of informal carers would otherwise have been applied in the workforce. Finally, the conversion handicap is affectingly illustrated by Oi's often quoted assertion that 'disability steals time'.<sup>17</sup> People with quadriplegia engage in only 56.9 h per fortnight of activity, where we define activity as paid or unpaid work, education, domestic duties or any other activity nominated as worthwhile by the respondent.

However, the value of the SISI is not limited to description of quadriplegia. The SISI contains data on a variety of other dimensions of potential interest to researchers interested in SCI. These include labour market participation, health care utilization, family support and social participation. Additionally the SISI also gathers data on a comprehensive set of potential covariates, some of which are uniquely relevant to individuals with an SCI; physical disability, psychological status and hours of formal and informal assistance. Data collection from small cohorts such as people with SCI is costly. The standardization of data collection offers the prospect of data sharing by researchers with diverse range of questions for investigation.

A limitation of the newly developed SISI is that we lack reliability and validity data. In addition, the test-retest properties of the SISI itself and the modified SF-36 have not yet been explored. These are avenues for further research. Where comparison with the published Australian literature is possible, the results derived from the SISI are, however, broadly comparable with forgoing studies. While our estimates for chronic health care costs are slightly lower than the cost assumptions used by Walsh 18 years ago,<sup>2</sup> a post-injury employment rate of 29.7% corroborates the results published by Murphy *et al.*<sup>4</sup> We therefore present the SISI (Appendix 1) as a new, freely available, instrument that may be useful to social scientists who are interested in SCIs and their economic and social effects. We encourage others to apply the SISI to extend our knowledge of the properties of the instrument (for example, validity, reliability) and of the relationships between post-SCI support and activities (for example, education) and the well-being of people with SCIs.

### Acknowledgements

This study was jointly funded by the Spinal Injuries Association of Queensland and Disability Services of Queensland with each organization contributing \$2000 towards the costs of the survey. Professor Justin Kenardy provided helpful advice on the design of the SISI, which enabled us to develop items that elicit data on the psychological attribution style of individuals.

### References

- 1 Ware JE, Sherbourne CD. The MOS 36-Item Short-Form Health Survey (SF-36). *Med Care* 1992; **30**: 473–481.
- 2 Walsh J. Costs of spinal cord injury in Australia. *Paraplegia* 1988; **26**: 380–388.
- 3 Kreuter M, Siosteen A, Erholm B, Bystrome U, Brown DJ. Health and quality of life of persons with spinal cord lesion in Australia and Sweden. *Spinal Cord* 2005; **43**: 123–129.
- 4 Murphy G, Brown D, Athanasou J, Foreman P, Young A. Labour force participation and employment among a sample of Australian patients with a spinal cord injury. *Spinal Cord* 1997; **35**: 238–244.
- 5 Heckman JJ. The Economics and Econometrics of Active Labor Market Programs. In: Ashenfelter O, Card D (eds). *Handbook of Labor Economics*. Elsevier: Amsterdam, 1999, pp. 1865–2097.
- 6 Meyers AR, Anderson EM. Enabling our instruments: accommodation, universal design, and access to participation in research. *Arch Phys Med Rehabil* 2000; **81** (Suppl 2): S5–S9.
- 7 Rubin DB. Using multivariate matched sampling and regression adjustment to control bias in observational studies. *J Am Stat Assoc* 1979; **74**: 318–328.
- 8 Behavioural Epidemiology Unit. *South Australian Population Norms for the Short Form 36(SF-36) Health Status Questionnaire*. South Australian Health Commission August: Adelaide, 1995.
- 9 Australian Bureau of Statistics. *Basic Community Profile Queensland (State 3) B13 Weekly individual Income by Age by Sex Canberra ABS 2002*. Report no. 2001.0.
- 10 Krause JS, Terza JV. Injury and demographic factors predictive of disparities in earnings after spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 2006; **87**: 1318–1326.
- 11 Australian Bureau of Statistics. *Education and Training Experience, Australia, 2005*. Canberra Australian Bureau of Statistics 2006 29 May 2006. Report no. 6278.
- 12 Saunders P. *Disability, Poverty and Living Standards: Reviewing Australian Evidence and Policies SPRC Discussion Paper No. 145*. Sydney, 2005.
- 13 Australian Bureau of Statistics. *Average Weekly Earnings, Australia*. Report no. 6302.0.
- 14 Hancock KM, Craig AR, Dickson HG, Chang E, Martin J. Anxiety and depression over the first year of spinal cord injury: a longitudinal study. *Paraplegia* 1993; **31**: 349–357.
- 15 Australian Institute of Health and Welfare (AIHW). *Australia's health 2006*. Canberra; 2006 2003. Report no. AIHW cat. no. AUS 73.
- 16 Sen A. Disability and justice. *Disability and Inclusive Development: Sharing, Learning and Building Alliances*. Washington, D.C.: The World Bank, 2004 pp 1.
- 17 Oi W. Employment and benefits for people with diverse disabilities. In: Mashaw JL, Reno V, Berkhauser RV, Berkowitz M (eds). *Disability, Work and Cash Benefits*. W.E. Upjohn Institute for Employment Research: Kalamazoo, 1996, pp 108.
- 18 Marino RJ, Goin JE. Development of a short-form quadriplegia index of function scale. *Spinal Cord* 1999; **37**: 289–296.
- 19 Furnham A, Sadka V, Brewin CR. The development of an occupational attributional style questionnaire. *J Organ Behav* 1992; **13**: 27–39.

## Appendix

### Appendix 1: Items from the spinal injuries survey instrument

- (1) If you choose to complete the following questionnaire you will be given a choice of “scratch-it” lottery tickets as a token of our appreciation. Which would you prefer? (i) \$4.00 worth of scratch-it tickets now, (ii) \$8.00 worth of scratch-it tickets in [ × ] weeks’ time.
- (2) The following questions are about activities you might perform during a typical day using normal mobility devices (wheelchair/cane/mobility aid). Does your health now limit you in these activities? (i) Yes limited a lot, (ii) Yes limited a little, (iii) No, not limited at all.
- (a) Vigorous activities, such as wheeling, lifting heavy objects, participating in strenuous sports.
  - (b) Moderate activities, such as moving a table, pushing a vacuum cleaner, or bowling.
  - (c) Lifting or carrying groceries.
  - (d) Going up several flights of stairs.
  - (e) Going up one flight of stairs.
  - (f) Bending, or kneeling.
  - (g) Going more than a kilometre.
  - (h) Going several hundred metres.
  - (i) Going one hundred metres.
  - (j) Bathing or dressing yourself
- (3) Which type of wheelchair do you use? (i) Manual wheelchair, (ii) Electric wheelchair, (iii) No wheelchair.
- (4) When did your spinal cord injury or disease occur?
- (5) After your spinal cord injury or disease occurred, for how many months were you initially in hospital for?
- (6) How much assistance do you require with the following activities? (i) Dependent, (ii) Assistance needed, (iii) Supervision, (iv) Independent with devices, (v) Independent.
- (a) Wash and dry hair
  - (b) Turn supine to side in bed
  - (c) Put on lower body clothing
  - (d) Open a carton or jar
  - (e) Transfer from bed to chair
  - (f) Lock wheelchair<sup>18</sup>
- (7) In the last month how many times have you used the following health services? (i) Emergency ward, (ii) General Practitioner, (iii) Specialist Doctor, (iv) Physiotherapist, (v) Other service.
- (8) During the last year how many times were you treated in a public or private hospital for the following medical problems? (i) Urinary, (ii) Skin, (iii) Digestive, (iv) Musculo-skeletal, (v) Psychiatric, (vi) Other.
- (9) In total how many nights did you spend in a hospital during the last year?
- (10) How many medications are you using today? Answer for each drug type. (i) Antibiotics, (ii) Urinary antiseptics, (iii) Pain medications, (iv) Anti-depressants, (v) Muscle relaxants, (vi) Other prescribed medications.
- (11) How much of your own money did you spend on medical care last year?
- (12) What is your current employment status? (i) Employed, (ii) Unemployed and looking for work, (iii) Not looking for work, (iv) In training.
- (13) I feel my employer underestimates my productivity because of my disability. (i) Strongly agree, (ii) Agree, (iii) Undecided, (iv) Disagree, (v) Strongly disagree.
- (14) I feel employer discrimination has prevented me from getting a job. (i) Strongly agree, (ii) Agree, (iii) Undecided, (iv) Disagree, (v) Strongly disagree
- (15) What was your employment status prior to your injury? (i) Employed, (ii) Unemployed and looking for work, (iii) Not looking for work, (iv) In training
- (16) If you were employed before your accident how would you best describe your job? (i) Professional, (ii) Clerical & sales, (iii) Trade, (iv) Manual, (v) Other
- (17) What level of secondary school did you complete prior to your spinal cord injury? (i) Year 9 or less, (ii) Year 10, (iii) Year 11, (iv) Year 12.<sup>4</sup>
- (18) What other qualifications, if any did you hold prior to your injury? (i) No Other, (ii) Trade, (iii) Certificate, (iv) Diploma, (v) Degree.<sup>4</sup>
- (19) What, if any education did you undertake after your spinal cord injury? (i) No additional studies, (ii) High school, (iii) Technical and further education, (iv) University.<sup>4</sup>
- (20) Do you receive the Adult Lifestyle Support Package funded by the Queensland Government?
- (21) Do you receive an alternative type of personal support package, for example a workers compensation payment?
- (22) If you receive any personal support package, when did it first begin?
- (23) On average how many hours of assistance do you currently receive for your activities of daily living?
- (24) Do you feel the total personal assistance you receive is? (i) Very Satisfactory, (ii) Satisfactory, (iii) Undecided, (iv) Unsatisfactory, (v) Very unsatisfactory.
- If you rely on unpaid assistance from your family
- (25) How old is your primary unpaid care provider?
- (26) What gender is your primary unpaid care provider?
- (27) What is the minimum compensation you would accept, to give up one year’s access to your personal care package? (i) \$5000, (ii) \$30 000, (iii) \$60 000, (iv) \$90 000, (v) \$120 000, (vi) \$150 000, (vii) > \$150 000.
- (28) Before income tax is taken out, how much do you currently earn? (i) Employment, (ii) Disability pension, (iii) Compensation, (iv) Personal Support Package, (v) Other income.
- (29) How satisfied are you with the income that you receive now? (i) Very satisfied, (ii) Satisfied, (iii) Undecided, (iv) Dissatisfied, (v) Very Unsatisfied.
- (30) What was your before-tax income immediately prior to your spinal cord injury or disease? (i) Employment (ii) Government payment, (iii) Other.
- (31) How many hours do you currently spend on the following activities? (i) Paid work, (ii) Voluntary work, (iii) Education and training, (iv) Housekeeping, (v) Any activity important to you.
- (32) What is your marital status? (i) Single, (ii) Married or de facto, (iii) Separated, (iv) Divorced.
- (33) Where do you live now? (i) My home, (ii) Nursing Home.
- The final two questions will present you with a brief story. While you may feel that not every relevant detail has been included, please try your best to circle a number from (i) to (vii) to indicate how you feel about each statement.

(34) You have decided to apply for a job. The application process involves sitting a written test and providing the names of two referees. Good news, one week later you get the job.

(a) Is the cause of your successful job search due to something about you or something about other people or circumstances? (i) *Totally due to other people or circumstances -thru- (vii) Totally due to me.*<sup>19</sup>

(b) In future when looking for a job, will this cause again be present? (i) *Will never again be present -thru- (vii) Will always be present.*<sup>19</sup>

(c) Is the cause something that just influences looking for a job or does it also influences other areas of your life? (i) *Influences just this situation in particular -thru- (vii) Influences all situations in my life.*<sup>19</sup>

(d) How important would this situation be if it happened to you? (i) *Not at all important -thru- (vii) Influences all situations in my life.*<sup>19</sup>

(35) You have a job interview. On the day of the interview the traffic is heavier than usual and you arrive late for the interview. Although the interview appeared to go well you are not offered the jobs.

(a) Is the cause of your unsuccessful job search due to something about you or something about other people or circumstances?

(i) *Totally due to other people or circumstances -thru- (vii) Totally due to me.*<sup>19</sup>

(b) In future when looking for a job, will this cause again be present? (i) *Will never again be present -thru- (vii) Will always be present.*<sup>19</sup>

(c) Is the cause something that just influences looking for a job or does it also influences other areas of your life? (i) *Influences just this situation in particular -thru- (vii) Influences all situations in my life.*<sup>19</sup>

(d) How important would this situation be if it happened to you? (i) *Not at all important -thru- (vii) Influences all situations in my life.*<sup>19</sup>

Note: A formatted version of the SISI is available from the Centre of National Research on Disability and Rehabilitation medicine, (CONROD) <http://www.uq.edu.au/conrod/>.

## Appendix 2: Cost estimates for episodes of medial care consumed by people with SCI

Categories of health care	Estimate
<i>Annual Inpatient costs</i>	
Cost per bed day for inpatient with chronic SCI (B60A & B60B)	\$1031
<i>Annual Outpatient costs</i>	
Emergency ward	\$265
General practitioner visit	\$35
Specialist visit	\$74
<i>Annual pharmaceutical costs</i>	
Price per script	\$30
Duration of script (days)	30
Out-of-pocket costs	NA

Source: Cost estimates have been sourced from the Australian public health literature. References will be provided upon request to [d.rowell@uq.edu.au](mailto:d.rowell@uq.edu.au).

Note: The estimates were calculated as follows:

Annual Inpatient Costs = Cost per inpatient bed day × Bed days per year;

Annual Outpatient Costs =  $\sum$  (Episode of outpatient care × Average cost);

Annual Pharmaceutical Costs = Number of scripts × Price per script  
× (365 days / Duration of script).