

ORIGINAL ARTICLE

Subjective sleep disturbances and quality of life in chronic tetraplegia

J Spong¹, M Graco¹, DJ Brown², R Schembri¹ and DJ Berlowitz¹**Study design:** This is a cross-sectional survey.**Objectives:** The objective of this study was to evaluate the subjective sleep disturbances and quality of life in chronic tetraplegia.**Setting:** This study was conducted in a community sample from Victoria, Australia.**Methods:** People with tetraplegia were mailed a survey battery including the following: demographic questions; Karolinska Sleepiness Scale (KSS); Basic Nordic Sleepiness Questionnaire; Functional Outcomes of Sleep Questionnaire (FOSQ); Multivariate Apnoea Prediction Index and Assessment of Quality of Life (AQoL) Questionnaire. Scores were compared with the best available normative data.**Results:** A total of 163 of 424 (38%) surveys were returned (77% male; 39% sensory and motor complete; mean age \pm s.d. = 46 \pm 14 years; mean years since injury = 11 \pm 8 years). The AQoL health utility score (0.31 \pm 0.29) was significantly lower than published population norms. FOSQ total (17.55 \pm 2.57) and KSS (3.93 \pm 2.27) scores were no different from the best available population data. People with tetraplegia reported worse sleep habits, symptoms and quality than a normal population, as indicated on 17 of 21 questions on the Basic Nordic Sleep Questionnaire. Multivariate analysis found that greater injury severity (coefficient (95% CI) = 0.14 (0.10, 0.18)), increasing age (–0.004 (–0.008, –0.001)) and worse sleep symptoms (–0.005 (–0.009, –0.0003)) were all significantly associated with reduced quality of life.**Conclusion:** People with chronic tetraplegia experience more subjective sleep problems and worse quality of life than their able-bodied counterparts. Quality of life is related to injury severity, age and sleep symptoms. Treating the sleep disorders experienced by people living with tetraplegia has the potential to improve their health and well-being.*Spinal Cord* (2015) 53, 636–640; doi:10.1038/sc.2015.68; published online 21 April 2015

INTRODUCTION

It is increasingly apparent that people living with tetraplegia have a higher prevalence of sleep disorders than the general population.^{1–3} Although the aetiologies remain unclear, obesity, sleeping in supine, nasal congestion, disruption of the melatonin pathway, medications, pain and spasm all likely contribute to the increased prevalence.⁴ Because the majority of spinal cord injuries (SCIs) occur in the young, people with SCI typically live with secondary complications for many decades. Understanding the impact of secondary conditions, such as sleep disorders, will enable researchers, policy-makers and funders to direct resources to areas in which they are most likely to have an impact on the quality of life and health outcomes.

The Stockholm spinal cord study of a regional SCI population found that 35% regularly experience sleep disturbances, and that the odds of having a sleep disturbance was 3.53 times higher in people with SCI than the general population.³ A Danish postal survey evaluating subjective sleep disturbances in SCI found that individuals with SCI experienced more problems falling asleep and waking during the night, used more sleeping pills, slept longer at night and during the day and snored more than the general population.¹ This study used the Basic Nordic Sleep Questionnaire (BNSQ) to compare sleep disturbances in a traumatic SCI population and a normal population, and the published results have been used for comparison with the

tetraplegic sample in this study. Similarly, in another large survey in the United States of America, people with SCI experienced worse sleep disturbance, more snoring, more night time respiratory problems, less sleep, poorer sleep adequacy and greater daytime sleepiness than a normative population.²

The most common and widely studied sleep disorder in tetraplegia is obstructive sleep apnoea (OSA), with an estimated prevalence of 50–53% in the chronic population.^{5,6} This is significantly higher than in the able-bodied population, which is estimated to be 9% in men and 4% in women.⁷ Importantly, the presence of OSA in tetraplegia has been found to independently reduce health utility scores and thus quality of life.⁵ OSA has been associated with impaired cognition in people with tetraplegia, particularly in the areas of attention, concentration, memory and learning skills.⁸ Other serious health consequences of OSA in the able-bodied population include increased risk of cardiovascular disease, diabetes and premature death.⁹

This observational study describes the subjective sleep disturbances and quality of life of a chronic tetraplegic population and, where possible, compares the results with the best available published able-bodied (normative) data. The study also explores the relationships between quality of life, subjective sleep disturbances and injury severity in chronic tetraplegia.

¹Institute for Breathing and Sleep, Bowen Centre, Austin Hospital, Heidelberg, Victoria, Australia and ²Spinal Research Institute, Melbourne, Australia
Correspondence: Dr DJ Berlowitz, Institute for Breathing and Sleep, Bowen Centre, Austin Hospital, Heidelberg, Victoria 3084, Australia.
E-mail: david.berlowitz@austin.org.au

Received 2 December 2014; revised 14 March 2015; accepted 19 March 2015; published online 21 April 2015

MATERIALS AND METHODS

The methods for this study have been detailed previously⁵ but briefly, people with tetraplegia (T1 lesion or higher on hospital discharge) between 18 and 70 years of age, living in Victoria, Australia, were identified from Victorian Spinal Cord Service records. Potential participants were mailed a survey battery encompassing demographic data; state sleepiness (Karolinska Sleepiness Scale, KSS); general sleep symptoms and behaviour BNSQ; the impact of sleepiness on daily function (Functional Outcomes of Sleep, FOSQ); the likelihood of undiagnosed OSA (Multivariate Apnoea Prediction Index, MAPI); and health-related quality of life including health utility (Assessment of Quality of Life, AQoL). The questionnaires and scoring scales are detailed more fully online.

The study was approved by the institutional human ethics and research committee and is registered at <http://www.anzctr.org.au> (ACTRN12606000397516). The relationship between these questionnaire data and objective sleep studies in a subset of this sample has been published previously.⁵

Data analysis

Demographic and questionnaire data are presented descriptively. Questionnaire results from the study were compared with summary statistics from previously published normal and SCI samples using the Welch (unequal variance) *t*-test and χ^2 test as appropriate. Univariate and multivariate regression analyses were performed to investigate associations between sleep, demographic and injury severity variables and quality of life. Co-linearity and linearity assumptions were tested before multivariate analysis. Statistical significance was considered to be $P < 0.05$.

RESULTS

A database search of the Victorian Spinal Cord Service incident cases of SCI between 1984 and 2007 identified 1902 people with SCI; 1395 did not meet the inclusion criteria; 507 surveys were mailed and of these 424 were delivered and 163 (38%) surveys were returned. (Figure 1).

Description of the sample

There were no significant differences in gender or proportion with a complete (American Spinal Injury Association Impairment Scale (AIS) A) injury between those who responded to the survey compared with those who did not. The responders were 3.1 years older ($P = 0.01$) and had 1.6 fewer years since their SCI ($P = 0.03$) than the non-responders (Table 1).

Severity of injury was categorised into five groups according to the recommendations of DeVivo *et al.*¹⁰ AIS E was added as a sixth

category to account for the nine AIS E participants in the study. The majority of responders were C5–C8 AIS A, B or C (44%; Table 2).

Assessment of quality of life

Of the 163 responders, 121 completed the AQoL. The AQoL utility score was significantly lower than the published population norms (Table 3).¹¹

Functional outcomes of sleep questionnaire

The FOSQ was completed by 162 participants. Our tetraplegic population scored significantly worse than the normal sample in the activity level and intimate and sexual activity domains, but there was no difference in the total score and other three domains (Table 3).^{12,13}

Basic Nordic Sleep Questionnaire

The BNSQ was completed by 163 participants. Tables showing the entire distribution of responses to the 14 ordinal and 7 quantitative questions on the BNSQ, and how these compare to the Danish SCI and normal population responses,¹ can be found online (Supplementary Table 1). On 11 of the 14 questions, the current sample was significantly ($P < 0.05$) worse than the normal population values. The current sample was better than normal values in BNSQ question 1 (falling asleep; $P < 0.001$), and there was no difference between the samples in BNSQ questions 8 and 10 (excessive sleepiness in the morning and tendency to fall asleep at work). Similarly, the current sample scored significantly worse ($P < 0.05$) than the normal values in five of the seven quantitative questions in the BNSQ (Supplementary Table 3).

The final BNSQ question asks participants to describe any sleep problems they may have (Table 4). The three problems most commonly described by our participants were as follows: pain and paraesthesia; other somatic problems and breathing problems. In contrast, the top three problems listed by the Danish SCI population were pain and paraesthesia; voiding and spasms.

Karolinska sleepiness scale

The KSS was completed by all 163 participants. The mean score was 3.93, which equates to between 'alert' and 'neither alert nor sleepy' on the scale. This is within the range of normal 'middle of the day' values from several studies investigating sleepiness in daytime workers, and detailed in a recent review of the KSS (Table 3).¹⁴

The influence of sleep, demographics and injury severity on quality of life (AQoL utility)

Univariate analysis identified BNSQ total, BNSQ Q2b, age, years since injury and injury severity as significantly associated with mean health utility values. None of these variables were collinear. Multivariate analysis revealed that reduced quality of life was associated with more severe injury (coefficient (95% CI) = 0.14 (0.10, 0.18)), increasing age

Table 1 Difference in gender, completeness of injury, age and years since injury between responders and non-responders

	Responder	Non-responder	P-value
N (%)	163 (32.1)	344 (67.9)	
Males, N (%)	126 (77.3)	272 (79.1)	0.65
Complete (AIS A), N (%)	66 (39.1)	103 (32.3)	0.07
Mean age (s.d.), years	45.9 (13.5)	42.8 (12.7)	0.01
Years since injury (s.d.)	10.8 (7.5)	12.4 (7.4)	0.03

Abbreviation: AIS A, American Spinal Injury Association Impairment Scale.

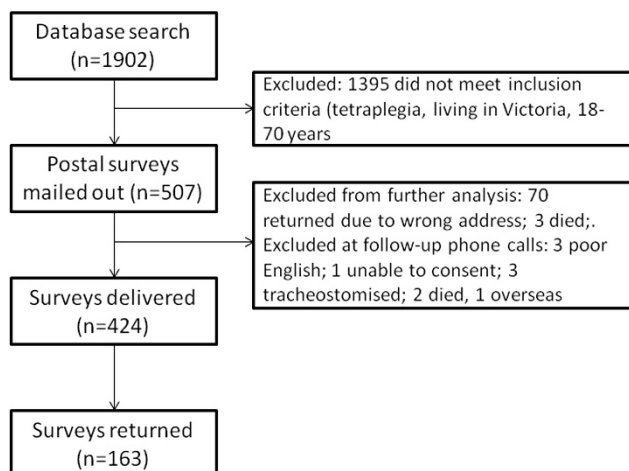


Figure 1 Participant recruitment.

Table 2 Severity of injury of the participants

Categories of injury severity	N (%)
C1-4 AIS A, B or C	22 (13.50)
C5-8 AIS A, B or C	72 (44.17)
T1-S5 AIS A, B or C	6 (3.68)
AIS D at any level	54 (33.13)
Ventilator dependent at any level	0 (0)
AIS E at any level	9 (5.52)

Abbreviation: AIS, ASIA Impairment Scale.

Table 3 AqoL utility, FOSQ total and domain scores, and KSS from this study and published populations norms

	Mean (s.d.)	Population norms ¹¹⁻¹⁴	P-value
AQoL utility	0.31 (0.29)	0.81 (0.22)	<0.0001
FOSQ general productivity	3.64 (0.46)	3.64 (0.51)	1.0
FOSQ social outcome	3.67 (0.61)	3.80 (0.46)	0.26
FOSQ activity level	3.32 (0.61)	3.61 (0.54)	0.04
FOSQ vigilance	3.45 (0.67)	3.51 (0.67)	0.71
FOSQ intimate relationships and sexual activity	3.47 (0.81)	3.93 (0.17)	<0.0001
FOSQ mean overall score	17.55 (2.57)	17.87 (3.08)	0.66
KSS	3.93 (2.27)	3-4	—

Abbreviations: AQoL, Assessment of Quality of Life; FOSQ, Functional Outcomes of Sleep Questionnaire; KSS, Karolinska Sleepiness Scale.

(- 0.004 (-0.008, -0.001)) and worse sleep symptoms on the BNSQ (-0.005 (-0.009, -0.0003)). The strongest utility score predictor was injury severity. Figure 2 shows the difference in AQoL by injury severity groupings. The multivariate model R^2 was 0.37, and a simpler model not incorporating the sleep symptoms (BNSQ) was 0.32.

DISCUSSION

The results of this study confirm previous reports that people with SCI experience more subjective sleep disturbances overall than the healthy, able-bodied population. Initiating sleep was not perceived to be as a significant problem for people with tetraplegia, despite the fact that people with tetraplegia reported staying awake in bed for longer. However, maintaining sleep was a significant issue. Both of these findings are similar to those of the Danish study comparing an SCI population with an able-bodied control group.¹ General sleep quality, use of sleeping pills, excessive daytime sleepiness, snoring and breathing pauses (sleep apnoea) were also significantly worse in our population than the published able-bodied data, again replicating differences found in the Danish questionnaire study. Similar to the Danish study, we found no difference between our participants with tetraplegia and the able-bodied in the number of hours they usually sleep at night, and whether responders feel excessively sleepy in the morning.

The differences observed in the self-reported sleep problems (the final free text question of the BNSQ) between our sample and the Danish SCI sample may reflect differences in the demographics of these samples. The Danish SCI sample consisted of approximately 50% tetraplegic and 50% paraplegic individuals. For both groups, pain and paraesthesia were reported in the top three sleep problems. However, in our tetraplegic only population, problems with changing position in bed and breathing were also significant issues. Although

Table 4 BNSQ Q21: 'Please describe any other sleep problems you may have'

Problem number (%)	Primary problem ^a	Primary problem ^b	Total ^a	Total ^b
Spasms	5 (6.0)	32 (20.3)	10 (9.1)	33 (16.1)
Pain and paraesthesia	14 (16.7)	50 (31.7)	17 (15.5)	55 (26.8)
Voiding	7 (8.3)	28 (17.7)	8 (7.2)	40 (19.5)
Gastrointestinal problems	—	2 (1.3)	—	6 (2.9)
Sweating, warm or cold feeling	6 (7.1)	8 (5.1)	12 (10.9)	12 (5.9)
Other somatic problems; e.g., turning over in bed	15 (17.9)	10 (6.3)	17 (15.5)	16 (7.8)
Dreams, nightmares	5 (6.0)	9 (5.7)	6 (5.5)	10 (4.9)
Speculations/worries	5 (6.0)	8 (5.1)	8 (7.3)	15 (7.3)
Other	3 (3.6)	11 (7.0)	6 (5.5)	18 (8.8)
Breathing problems	15 (17.9)	—	16 (14.5)	—
Sleep initiation and maintenance	9 (10.7)	—	10 (9.1)	—
Total	84	158	110	205

Abbreviation: BNSQ, Basic Nordic Sleep Questionnaire.

Groupings of responses including results from the Danish study¹.

^aResults from this tetraplegia study

^bResults from the Danish SCI study. 'Total' is the number of times the problem was described regardless of whether it was the first, second or third listed problem.

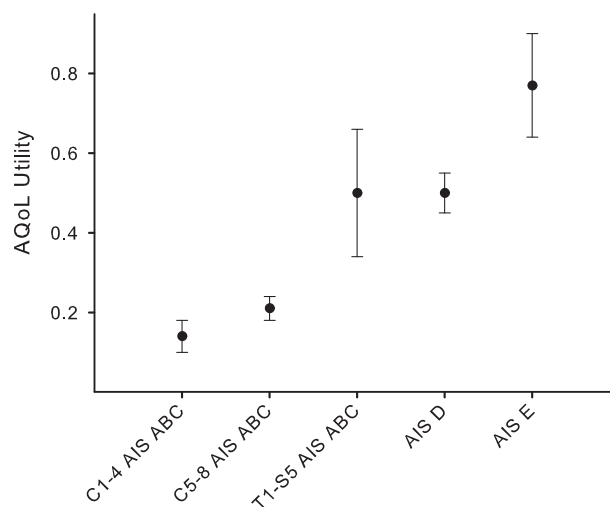


Figure 2 Average (and 95% confidence intervals) of the AQoL-derived health utility values across the range of injury severities.

the published data are sparse, it is believed that sleep-disordered breathing is more common in people with tetraplegia than paraplegia,⁴ and bed mobility is obviously more challenging in people with tetraplegia. It is possible that the addition of people with paraplegia in the Danish sample reduced the relative magnitude of these problems.

Health-related quality of life (AQoL) was substantially worse in our sample of people with tetraplegia compared with Australian population norms. The mean utility score from our sample is in the same range as people who report their mental health status as 'poor' and is worse than people who rate their physical health as 'poor'. This is consistent with the literature, which shows that people with SCI tend to experience lower quality of life than the able-bodied, with the largest deficits found in physical functioning and physical role

limitation domains.^{15,16} According to a review by Dijkers, this is particularly true when utility measures, which tend to focus on a relatively narrow concept of health, are used to measure the quality of life in SCI.¹⁵

There was no difference between our sample and the 'best available' normal value sample in the total FOSQ score, but significant differences were found on the 'activity' and 'intimate and sexual relationships' domains. However, with a sample size of 20 in the normal group, it is not possible to draw conclusions from these findings. Our data suggest that people living with tetraplegia experience poorer sleep quality and symptoms, and worse quality of life in general, than the normal population and hypothesise that the overall impact of sleep on daily functioning would also be worse in people with tetraplegia.

A recent review of subjective sleepiness found that in four studies investigating sleepiness in day workers the average KSS value during the middle of the day was 3–4.¹⁴ Data from our study are within this range. We have previously published the relationship between the questionnaire data described in this paper and the objective sleep measures that were made in a subset of this sample. We performed sleep studies in 78 of the 163 survey responders and showed that sleep symptoms were related to objectively measured sleep apnoea, particularly in those with complete lesions. Overall, 50% were found to have OSA–hypopnea syndrome. This study also found that sleepiness, as measured by the KSS, was related to frequent arousal from sleep and awakenings in those with complete but not incomplete tetraplegia.⁵ This is consistent with other research showing a relationship with severity of sleep apnoea and daytime sleepiness.^{6,17,18} Although our KSS scores may be within the normal range, the known relationship between objective sleep disturbances and daytime sleepiness suggests that therapies that treat sleep-disordered breathing could result in clinically significant improvements in sleepiness; however, this remains speculative.

Although the MAPI was also collected for this study, we chose not to analyse and compare the MAPI scores with published normal data in this paper. Our group previously published data showing that the MAPI, which was developed for the able-bodied population to measure likelihood of OSA, has high specificity but poor sensitivity in chronic tetraplegia.⁵ A comparison of MAPI scores between the able-bodied and those with tetraplegia would therefore not be valid. Further research is required to understand the predictive factors of OSA that are specific to SCI, and to develop a tool that accurately predicts both OSA and its functional impact in this population.

This study also identified associations between quality of life and other factors in chronic tetraplegia, and in particular whether sleep quality or symptoms are associated with quality of life. We did not include the FOSQ in the analysis because the FOSQ measures the impact of symptoms on daily functioning, which in itself is a component of quality of life. Instead, we assessed the impact of sleep quality and symptoms on quality of life through inclusion of the BNSQ and KSS. Worse sleep symptoms and quality were associated with worse quality of life. Other factors strongly associated with reduced quality of life included increasing age, increasing years since injury and increasing severity of injury. After controlling for all of these factors in a multivariate model, injury severity, age, sleep quality and symptoms remained quality-of-life predictors. The R^2 for this model was 0.37, suggesting that 37% of the variance in AQoL utility is attributable to these factors. When the sleep variables were removed, the R^2 fell to 0.32, implying that sleep symptoms account for 5% of the variance in utility scores, a modest but important effect size.

In our study, increasing injury severity was strongly associated with lower quality of life in chronic tetraplegia. However, a review of studies using the SF-36 in SCI found that the relationship between injury severity and quality of life was unclear, with the majority of studies reporting no association between injury completeness and injury level with quality of life. Those studies that did find an association reported lower quality of life in higher injuries, as was the finding in our study.¹⁹ The strong association that we found between injury severity and quality of life may be owing to measurement differences between the AQoL and the SF-36. It is also possible that there are significant but subtle impacts of injury severity within the tetraplegic population, and that including those with paraplegia in the sample dilutes the effect.

Limitations

We did not collect data from a normal sample for direct comparison and are therefore comparing our results with published summary data. Differences in methodology between studies and cultural differences in the samples could affect the validity of our findings. However, reassurance that our findings are valid is provided by the observation that the differences in the BNSQ between our tetraplegic sample and the published normal data are similar in magnitude to those previously reported between the Danish SCI sample and their associated able-bodied controls. The low response rate may have introduced a non-responder bias. However, only small and clinically insignificant differences in basic demographic information were found between responders and non-responders, suggesting that the data obtained were likely to be representative of the population. It is possible that the questionnaires were preferentially completed by those with sleep problems, which may have introduced a selection bias to the study.

CONCLUSION

In general, people with chronic tetraplegia experience more problems with sleep quality and symptoms, and report worse quality of life than their able-bodied counterparts. Quality of life is related to injury severity, age and sleep. Growing evidence suggests that poor sleep affects the health and quality of life of this population, highlighting the importance of more research to find new and effective treatments for people with SCI suffering from sleep disorders.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ACKNOWLEDGEMENTS

This project was proudly supported by the Transport Accident Commission (TAC). All authors are employed by organisations that have received competitive research funding from the TAC. The TAC played no role in the design, analysis or interpretation of the project.

- 1 Biering-Sorensen F, Biering-Sorensen M. Sleep disturbances in the spinal cord injured: an epidemiological questionnaire investigation, including a normal population. *Spinal Cord* 2001; **39**: 505–513.
- 2 Jensen MP, Hirsh AT, Molton IR, Bamer AM. Sleep problems in individuals with spinal cord injury: frequency and age effects. *Rehabil Psychol* 2009; **54**: 323–331.
- 3 Levi R, Hultling C, Nash MS, Seiger A. The Stockholm spinal cord injury study: 1. Medical problems in a regional SCI population. *Paraplegia* 1995; **33**: 308–315.
- 4 Giannoccaro MP, Moghadam KK, Pizza F, Boriani S, Maraldi NM, Avoni P *et al*. Sleep disorders in patients with spinal cord injury. *Sleep Med Rev* 2013; **17**: 399–409.

- 5 Berlowitz DJ, Spong J, Gordon I, Howard ME, Brown DJ. Relationships between objective sleep indices and symptoms in a community sample of people with tetraplegia. *Arch Phys Med Rehabil* 2012; **93**: 1246–1252.
- 6 Leduc BE, Dagher JH, Mayer P, Bellemare F, Lepage Y. Estimated prevalence of obstructive sleep apnea-hypopnea syndrome after cervical cord injury. *Arch Phys Med Rehabil* 2007; **88**: 333–337.
- 7 Young T, Palta M, Dempsey J, Skatrud J, Weber S, Badr S. The occurrence of sleep-disordered breathing among middle-aged adults. *N Engl J Med* 1993; **328**: 1230–1235.
- 8 Sajkov D, Marshall R, Walker P, Mykytyn I, McEvoy RD, Wale J *et al*. Sleep apnoea related hypoxia is associated with cognitive disturbances in patients with tetraplegia. *Spinal Cord* 1998; **36**: 231–239.
- 9 Al Lawati NM, Patel SR, Ayas NT. Epidemiology, risk factors, and consequences of obstructive sleep apnea and short sleep duration. *Prog Cardiovasc Dis* 2009; **51**: 285–293.
- 10 DeVivo MJ, Biering-Sorensen F, New P, Chen Y. Standardization of data analysis and reporting of results from the International Spinal Cord Injury Core Data Set. *Spinal Cord* 2011; **49**: 596–599.
- 11 Hawthorne G, Korn S, Richardson J. Population norms for the AQoL derived from the 2007 Australian National Survey of Mental Health and Wellbeing. *Aust N Z J Public Health* 2013; **37**: 7–16.
- 12 Weaver TE, Maislin G, Dinges DF, Bloxham T, George CFP, Greenberg H *et al*. Relationship between hours of CPAP use and achieving normal levels of sleepiness and daily functioning. *Sleep* 2007; **30**: 711–719.
- 13 Weaver TE Personal Communication 2013.
- 14 Åkerstedt T, Anund A, Axelsson J, Kecklund G. Subjective sleepiness is a sensitive indicator of insufficient sleep and impaired waking function. *J Sleep Res* 2014; **23**: 240–252.
- 15 Dijkers MP. Quality of life of individuals with spinal cord injury: a review of conceptualization, measurement, and research findings. *J Rehabil Res Dev* 2005; **42**: 87–110.
- 16 Boakye M, Leigh BC, Skelly AC. Quality of life in persons with spinal cord injury: comparisons with other populations. *J Neurosurg Spine* 2012; **17**: 29–37.
- 17 McEvoy RD, Mykytyn I, Sajkov D, Flavell H, Marshall R, Antic R *et al*. Sleep apnoea in patients with quadriplegia. *Thorax* 1995; **50**: 613–619.
- 18 Stockhammer E, Tobon A, Michel F, Eser P, Scheuler W, Bauer W *et al*. Characteristics of sleep apnea syndrome in tetraplegic patients. *Spinal Cord* 2002; **40**: 286–294.
- 19 Ku JH. Health-related quality of life in patients with spinal cord injury: review of the short form 36-health questionnaire survey. *Yonsei Med J* 2007; **48**: 360–370.

Supplementary Information accompanies this paper on the Spinal Cord website (<http://www.nature.com/sc>)