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Satisfaction with life, health and well-being: comparison between non-traumatic spinal cord dysfunction, traumatic spinal cord injury and Australian norms

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Abstract

Study design Cross-sectional survey.

Objectives The objective of this study is to compare self-reported satisfaction with life, and self-reported health and well-being of people with NTSCD, to that of people with TSCI, and with Australian population.

Setting Victoria, Australia.

Methods Participants completed surveys by post or email. The Satisfaction with Life Scale (SWLS) and the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36) were used to assess self-reported satisfaction with life, and health and well-being. Descriptive statistics are reported including median and interquartile range (IQR). The Mann–Whitney U-test was used to investigate differences between groups.

Results There were 41 participants: NTSCD ($n = 14$) and TSCI ($n = 27$). There were no significant differences in the median scores on the SWLS for NTSCD and TSCI, but both groups scored lower than the Australian non-disabled sample mean. There were significant differences between NTSCD and TSCI for SF-36 domains physical functioning, role limitations physical and vitality ($p < 0.05$). Median scores for both groups in all eight domains were lower than the means of the comparative Australian sample, except for role limitations emotional.

Conclusions There were more apparent difficulties for people with NTSCD in completing desired functional tasks than those with TSCI. Both groups had lower self-reported satisfaction with life, and lower reported health and well-being in comparison to samples of non-disabled Australians.

Introduction

Traditionally, spinal cord injury (SCI) has been classified according to the cause of injury. The term traumatic spinal cord injury (TSCI) is used when the cause is due to an external event such as a motor vehicle accident, fall or

violence. Acquired damage to the spinal cord from pathology such as spinal cord myelopathy, spinal cord infections, vascular causes such as blood clot, and triple aortic aneurysm or transverse myelitis is commonly referred to as non-TSCI or dysfunction [1–3]. Internationally, incidence rates for TSCI are estimated to range from 16 to 40 people per million population per year [2]. While difficult to accurately ascertain due to lack of consistent recording, the incidence of acquired non-traumatic spinal cord dysfunction (NTSCD) appears to be higher in developed countries than the incidence of TSCI [1, 3].

Due to the aetiology of the spinal cord damage, people with acquired NTSCD tend to be older, are more likely to have incomplete injuries and are equally likely to be female, in comparison to those with TSCI [3]. In addition, they are less likely to be funded by work insurance or transport accident compensation schemes, being more likely reliant on government pensions [4]. Given the differing profiles, it is possible that there may be differences in the health and

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well-being of the two groups. There have been numerous studies that have investigated employment [5], mental health [6], secondary health conditions [7], quality of life (QoL) [8] and satisfaction with life among people with TSCI [9]. However, while there is some research regarding the functional outcomes of people with NTSCD [10, 11], and secondary health conditions [12], there is limited information available regarding satisfaction with life, and long-term health and well-being outcomes of this group [13, 14]. The only study located that specifically reported on the QoL of people with NTSCD was conducted by Migliorini et al. [15] who utilised the Comprehensive QoL Scale for Adults V5, a standardised scale that consists of objective and subjective subscales [16]. Their sample of 443 included 62 (14%) people with NTSCD. After adjusting for level of injury, they found that the NTSCD participants were less satisfied with their health than the TSCI participants, and significantly less satisfied with their health than the general Australian population. There were no other significant differences between the two SCI samples in the other subjective areas of material, productivity, intimacy, safety, community or emotional well-being [15].

In order for the needs of people with acquired NTSCD to be adequately addressed during rehabilitation and subsequently when they are living in the community, more information regarding their satisfaction with life, health and well-being is needed. The primary aim of this study was to compare self-reported satisfaction with life of people with NTSCD, to that of people with TSCI and with the Australian population. The second aim was to compare self-reported health and well-being of people with NTSCD, to that of people with TSCI and with the Australian population.

Methods

Ethical approval for the project was obtained from Monash University, Victoria, Australia.

Participants

Initially participants were recruited through advertisements in online organisational newsletters inviting interested people to contact the lead researcher. Due to the limited number of people with NTSCD who responded to these advertisements ($n = 2$), an additional recruitment strategy was used. People with NTSCD who had participated in a previous study [13], and had consented to being contacted for further research, were sent a letter of invitation to participate. Recruitment occurred between August 2016 and November 2017. Inclusion criteria were: aged over 18 years, had an acquired SCI (of traumatic or non-traumatic

aetiology), were living in the community, and able to complete surveys in English. Information was not sought from potential participants regarding their cognitive or mental health status, therefore people with cognitive issues or mental health issues were not excluded.

Study design

Participants were sent surveys to complete by post or email. Two validated questionnaires, the Satisfaction with Life Scale (SWLS) [17], and the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36) [18], were used to assess self-reported satisfaction with life, health and well-being. In addition, demographic data were collected which included: age; gender; cause of injury; level of injury; age at time of injury; age at time of survey, and additional questions related to social participation, which will be reported elsewhere.

Measures

Satisfaction with life

The SWLS [17] is one of the most widely used scales for measuring well-being. The SWLS is a well-validated measure with high internal consistency and good test–retest correlations [19]. Since it was first introduced in 1985, the SWLS has been widely used as a measure of subjective well-being (SWB) among a range of groups, including people with SCI [9, 20]. The tool consists of five items on a 7-point Likert self-report scale ranging from one (strongly agree) to seven (strongly disagree). (For example, Item 1: in most ways my life is close to ideal). The five items are keyed in a positive direction, so the five responses can be added together to obtain a final overall score. Scores between five and nine indicate the respondent is “extremely dissatisfied” with life; a score of 20–30 is considered an indication of a “good” level of satisfaction with life; while a score 31–35 indicates the respondent is “extremely satisfied” with life [21]. To provide a comparison with non-disabled Australian adults, study scores from a sample of 107 Australian adults aged 16–64 years, recruited from the general community were used [22].

Health and well-being

The Medical Outcomes study 36-Item Short Form Health Survey (SF-36) is a self-report survey designed to provide information regarding the physical and mental well-being of the participant [18]. Scores on the SF-36 have been shown to have acceptable reliability and validity in various populations, including the Australian population [23], and have been widely used in health outcomes research [24]. The

SF-36 assesses eight health related concepts or domains: general health perception; physical functioning; physical role limitations; social functioning; bodily pain; emotional role functioning; vitality; mental health [25]. Each question contributes a score to one of the health domains. Raw data for each of the eight domains is obtained by summing and transformed using the formula outlined in the SF-36 Manual [26]. The scores for each of the eight concepts are added to form a total score out of 100. A higher score indicates a better state of health or well-being. To provide a comparison with non-disabled Australian adults for the eight subscales, scores from the South Australian Department of Human Services study conducted in 2004, ($n = 3012$) were used [27].

Data collection and analysis

Data were analysed using SPSS version 25 statistical package. Data were non-normally distributed. Descriptive statistics were reported including mean, standard deviation, median and interquartile range (IQR). In addition, given the small sample size and exploratory nature of the study, and that no corrections for multiple analysis were made, the Mann–Whitney U-test was used to investigate differences between groups.

Results

Fourteen people with NTSCD and 27 people with TSCI participated in the study. Causes of spinal damage for those with non-traumatic aetiology were triple aortic aneurysm ($n = 4$), transverse myelitis ($n = 3$), other vascular cause ($n = 3$), infection/abscess ($n = 2$), virus ($n = 1$) and canal stenosis ($n = 1$). Cause of injury for those with traumatic injuries were primarily motor vehicle accidents ($n = 14$), followed by diving ($n = 4$), falls ($n = 3$), other accidents ($n = 3$), sport injuries ($n = 2$) and work injury ($n = 1$). Demographic information for the 41 participants is described in Table 1.

Satisfaction with Life (SWLS) and Health and Well-being (SF36) scores for both participant groups (NTSCD and TSCI) and the Australian population are outlined in Table 2.

Satisfaction with life

There were no significant differences in the median scores on the SWLS for NTSCD and TSCI. Both groups had mean scores lower than the Australian non-disabled sample mean, but neither group was greater than one standard deviation below the Australian sample mean (Table 2).

Table 1 Sample demographics

Characteristic	NTSCD ($n = 14$)	TSCI ($n = 27$)
Level of injury (n)		
C1–C4	0	2
C5–C8	4	12
T1–T6	2	11
T7–T12	6	2
Lumbar or sacral	2	0
Age: mean; median (IQR)		
Age at injury (years)	53.2; 60.0 (36.0–69.5)	29.6; 24.0 (18.0–39.0)
Age at survey (years)	56.0; 66.6 (49.5–74.0)	47.9; 49.0 (36.0–60.0)
Time injury to survey (months)	96.1; 72.0 (48.0–111.0)	204.0 (86.0–336.0)
Gender		
Female	7 (50%)	5 (19%)
Male	7	22
Funding (n)		
Compensation (traffic accident insurance/work insurance) ^a	2	14
National Disability Insurance Scheme ^b or disability services	5	8 (52%)
Aged care funding ^c	5 (36%)	1
Other/not indicated	2	4

^aCompensation—recipients receive comprehensive cover for all medical, therapy, care and equipment needs

^bNational Disability Insurance Scheme (NDIS) is a no-fault social insurance scheme that provides people with disabilities under the age of 65 years with individually funded support across the lifespan. Some limitations to services provided

^cAged care funding—basic level of funding for people over the age of 65 years not eligible for compensation or NDIS. Basic care, therapy and equipment provided

Health and well-being

There were no significant differences in the median scores on the bodily pain, general health, social functioning, role limitations emotional and mental health domains between the NTSCD and TSCI groups ($p > 0.05$). There were, however, significant differences between NTSCD and TSCI participants for the domains physical functioning, role limitations physical and vitality ($p < 0.05$). Mean scores for both groups in all eight domains were lower than the means of the comparative Australian sample. In the physical function domain, the mean of the TSCI group was three standard deviations below the Australian sample mean, and the mean of NTSCD group was two standard deviations below. In the role limitations physical domain, the mean of

Table 2 Summary data for the measures of Satisfaction with Life (SWLS) and Health and Well-being (SF36) between NTSCD and TSCI (significant results in bold, $p < 0.05$)

Scale	NTSCD	TSCI	U value	P value	Australian scores Mean (SD)
	(<i>n</i> = 14) Mean(SD) Median (IQR)	(<i>n</i> = 27) Mean (SD) Median (IQR)			
SWLS	15.7 (6.6) 16 (10.0–20.5)	19.1 (6.0) 19.0 (15.0–24.0)	128.5	0.14	23.6 (12.2)
SF-36					
General health perception	50.2 (21.2) 57.0 (28.8–62.0)	58.6 (24.1) 62.0 (47.0–72.0)	141.5	0.19	72.4 (21.7)
Physical functioning	24.3 (28.2) 12.5 (3.8–38.8)	8.7 (15.7) 0.0 (0.0–10.0)	106.5	0.02	84.7 (22.0)
Role limitations, physical	16.1 (28.8) 0.0 (0.0–25.0)	48.2 (42.7) 50.0 (0.0–100.0)	113.0	0.03	76.8 (37.1)
Role limitations, emotional	59.5 (37.4) 66.7 (33.3–100.0)	66.7 (40.1) 100.0 (33.3–100.0)	166.0	0.50	86.8 (30.2)
Bodily pain	58.6 (22.6) 62.0 (42.0–74.0)	63.3 (20.8) 62.0 (52.0–84.0)	161.0	0.43	75.9 (25.3)
Vitality	43.2 (12.3) 45.0 (33.8–50.0)	56.9 (18.9) 60.0 (45.0–70.0)	97.5	0.01	63.3 (21.8)
Mental health	68.3 (12.7) 68.0 (59.0–78.0)	69.8 (19.6) 72.0 (52.0–84.0)	166.0	0.53	80.0 (17.4)
Social functioning	65.2 (17.8) 62.5 (50.0–75.0)	70.4 (27.1) 75.0 (50.0–100.0)	161.0	0.43	87.1 (22.6)

^aSignificant results in bold, $p < 0.05$

the NTSCD group was one standard deviation below the Australian sample mean.

Discussion

This study compared life satisfaction, health and well-being, of people with a TSCI to that reported by people with NTSCD. Self-reported satisfaction with life (as measured with the SWLS) of the two SCI groups was not significantly different. However, there were significant differences between the two groups in health and well-being, as measured by scores attributable to the physical and vitality domains of the SF-36.

The lack of difference between scores on life satisfaction as measured by the SWLS of the two SCI groups supports the finding of Migliorini et al. [15] that aetiology of SCI makes little difference to QoL outcomes after SCI. While neither of the two SCI groups in this study had a mean score more than one standard deviation lower than the Australian population sample, they did score below the cut point of 20. According to the SWLS scale instructions, a score between 20 and 24 is considered an ‘average’ score, and a score between 15 and 19 is considered a ‘below average’ score [21]. People who score in this range usually have small but significant problems in several areas of their lives, or have

many areas where they are doing well but one area that represents a substantial problem for them [21]. A literature review, examining the subjective well-being (SWB; mental health and life satisfaction) and psychological and social support factors associated with these outcomes in people with SCI, found that on average people with SCI experience lower levels of life satisfaction compared with the general population. However, the studies included in this review, did not differentiate people with NTSCD from those with TSCI, it is assumed that the samples were either mixed or only TSCI [28].

The main differences between the SCI groups in this study were in some health and well-being domains, as reported by the SF-36. Differences were evident in the physical function domain (higher for NTSCD), role limitations physical domain (lower for NTSCD) and vitality (lower for NTSCD). Although the results are from small samples, these differences warrant consideration and discussion. The physical function domain of the SF-36 reports on specific physical abilities, for example, running, lifting heavy objects, moving objects, lifting, carrying, walking and kneeling. More than half of the TSCI group had cervical injuries (51.9%) compared to only 28.6% in the NTSCD group. There were no lumbar or sacral injuries in the TSCI group, while the NTSCD group had only two. While no information is available on the degree of

completeness of the injuries in these samples, it is known that people with NTSCD typically have more incomplete injuries than those with TSCI, and more of them are ambulant than those with TSCI [11, 29]. Thus people with TSCI are likely to be more restricted in physical abilities such as climbing stairs, kneeling and walking than those with NTSCD.

The scores on the role limitations physical and vitality domains were significantly lower for the NTSCD group compared to the TSCI group. Questions in the role limitations physical domain relate to the ability to complete functional tasks including being able to spend time on work or other activities, accomplishment and difficulty performing work or other regular activities. While the vitality domain asks questions specifically related to feeling 'full of pep', having 'a lot of energy' or 'feeling tired'. In this study, mean age at time of injury for the NTSCD group was 53.2 years in comparison to the TSCI group whose mean age at time of injury was 29.6 years. Mean age at time of survey for the NTSCD group was 56 years compared to 47.9 years for the TSCI group. Being injured at an older age is typical for people with NTSCD [30], and as a result this group is more likely to suffer from age related co-morbidities, potentially resulting in greater fatigue and less ability to accomplish the tasks that they wish to. In addition, the TSCI group is younger, and even if wheelchair dependent, may be fitter and stronger and more able to compensate for their injuries using equipment or modifications until they are older and potentially suffer from age-related problems.

An additional contributor to the lower scores for the NTSCD sample in the role limitations physical and vitality domains, could be the differences in the rehabilitation and services the two groups receive. In many developed countries, for example Canada and Australia, persons with NTSCD are often neglected in the traditional rehabilitation process, with many not being admitted to specialist spinal rehabilitation units, but instead being admitted to general hospitals and slow stream rehabilitation [3, 7, 31]. In Australia more than 50% of people with TSCI have access to generous funding through motor vehicle insurance or work insurance [32], which can support them to return to education or retraining, and facilitate development of new life roles. In contrast, people who acquire a disability over the age of 65 years may receive government aged care funding which is limited in nature [33]. Of the NTSCD group 36% ($n = 5$) were receiving aged care funding, while 52% ($n = 14$) of the TSCI group were receiving generous compensation funding. Qualitative studies have found that people with NTSCD report feeling unsupported in managing their injury [7, 13], are socially isolated, and rely heavily on family members to support them in the absence of paid supports [13].

Both the NTSCD and TSCI groups had mean scores two or more standard deviations lower on the domain physical

function in comparison to the mean of Australian sample, while the NTSCD group scored one standard deviation lower on the domain role limitations physical. These findings are consistent with the physical limitations and activity restrictions people which SCI experience [34].

Limitations

One of the main limitations of this study was the small sample sizes, and the self-selected participant sampling. People with NTSCD living in the community were challenging to recruit for this study. Only two people with NTSCD responded to the online advertisements placed in the spinal association newsletters, while the remainder were people who had participated in a previous study conducted by the lead author. In addition, due to the participants completing the demographic details themselves, the information relating to their level of injury may not be accurate. No information was collected regarding completeness of injury, or co-morbidities, which may have impacted the results. In addition, potential bias is inherent in research that uses voluntary, self-selected participants. A further limitation was the version of the SF-36 used in this study. The SF-36 walk-wheel has been modified to improve its responsiveness in people with SCI [35], and may have produced different results in the physical function domain.

Conclusions

Although a pilot study with small numbers, the results of this study provide important information regarding the health and well-being of persons with NTSCD and TSCI, and raise some points for consideration. There were more apparent difficulties for people with NTSCD in completing desired functional tasks than those with TSCI, possibly accounted for by age at onset, but also potentially influenced by the rehabilitation services and community support they received. Both groups had lower self-reported satisfaction with life, and lower reported health and well-being in comparison to samples of non-disabled Australians. In future it is hoped that a database/register for people with NTSCD can be established in Australia, similar to that of people with TSCI, which will enable vulnerable people with NTSCD to be monitored. Further, qualitative studies could provide more detailed information regarding the health and well-being of people living in the community with NTSCD, contributing to the development of intervention strategies and changes to health services to more effectively assist them.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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