

ORIGINAL ARTICLE

Quality of life in adults with spinal cord injury living in the community

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Study design: The study design used is cross-sectional descriptive survey.

Objectives: The aim of this study is to describe the subjective and objective quality of life (QoL) of adults with chronic non-traumatic spinal cord injury (NT-SCI) and to compare the objective and subjective QoL of adults with chronic NT-SCI with adults who have a chronic traumatic spinal cord injury (T-SCI) and the general population.

Setting: Living in the general community (non-residential care), Australia.

Participants: The study included 443 adults with SCI (T-SCI, $n = 381$) (NT-SCI, $n = 62$), all SCI ≥ 6 months duration.

Intervention: Not applicable.

Main Outcome Measures: Objective and subjective QoL domains—Comprehensive QoL Scale for Adults, version 5 (COMQoL-A5); *acceptance* subscale—the Spinal Cord Lesion Coping Strategies Questionnaire, version 1 Australia (SCL CSQ v1.0 Australia).

Results: Despite demographic differences, only the objective QoL domain material (higher in NT-SCI) and the subjective QoL domain health (lower in NT-SCI) were significantly different between the SCI subgroups. In contrast, five of the seven objective domains and four of the seven subjective domains were significantly lower in the SCI sample as a whole, compared with the general population. *Post hoc* analyses suggested that aetiology of the SCI was not responsible for QoL differences within the cohort with SCI.

Conclusion: On the whole, aetiology makes little difference to QoL outcomes after SCI. The QoL of adults with chronic T-SCI and NT-SCI fall significantly below that of the general population in most domains.

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Introduction

People who acquire a traumatic spinal cord injury (T-SCI) are more likely to be young, single men. People who acquire a non-traumatic spinal cord injury (NT-SCI) tend to be older, married and occur in similar numbers in men and women.¹ Though both groups appear to start rehabilitation with comparable levels of function, improvements in function

have been reported to be similar in one study² and smaller in those with NT-SCI in another.³

Advances in medical technologies and treatments at the time of onset and subsequent rehabilitation have led to a subgroup of persons with chronic SCI that is increasing in terms of both size and age. To more fully represent longer-term outcomes post-rehabilitation, it is necessary to consider the quality of life (QoL) of these people.

Objective QoL measures such as employment status⁴ and health⁵ have been found to be significantly lower in people with chronic SCI compared with the general population. This is less likely for subjective QoL in which even those with high level complete tetraplegia have been reported to be very satisfied with their lives.⁶ However to date, the focus of most studies of the QoL of people with an SCI has been on those with T-SCI.^{7–10} Few study samples have included people

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with NT-SCI;^{11,12} however, those studies did not differentiate between aetiologies in their analyses. In the general population, having an older age¹³ and being married^{13,14} is associated with higher satisfaction with life. There is some evidence that these variables may not apply to those with SCI.¹⁵ It is unknown if this trend is also found in Australian adults with NT-SCI, who also tend to be older and married.

An electronic literature search was made of the databases Medline, CINAHL, PsycINFO and EMBASE, to explore whether the above trend is associated with adults with NT-SCI. The search terms used were nontraumatic or non-traumatic, as both spellings have been noted in the literature, and spinal cord for the years 1974 to 2008 inclusive. One study used a single question to represent the QoL of people with NT-SCI.¹⁶ No studies were located that described in detail the QoL in people with chronic NT-SCI. Therefore, one aim of this paper was to describe the subjective and objective QoL of adults with chronic NT-SCI who are living in the community. A second aim was to put these results into context, so a comparison with those with T-SCI and the general population was made.

Methods

Participants

All adults who were 18 years and over and had chronic SCI defined as 6 months or more post-injury and who were on the Victorian Spinal Cord service (Austin Hospital) database were mailed an invitation to participate in the study. The database includes most of the people in Victoria who have a severe SCI. Individuals could participate using either a paper-based or online survey or as a telephone interview. Adults with an NT-SCI who attended the outpatient clinic of the only other dedicated SCI rehabilitation unit in the state (Caulfield Hospital) were also approached to participate.

Survey instrument

The survey consisted of demographic and injury-related questions and the Comprehensive QoL Scale for Adults, version 5 (COMQoL-A5).¹⁷ This is a standardized scale based on a representative normative Australian population that consists of objective and subjective subscales, which are measured separately as they are usually poorly related. Both the objective and subjective satisfaction subscale define life quality using the seven domains: material, health, productivity, intimacy, safety, place within the community and emotional well-being. A summary score represents an aggregate score of 3 objective indices relevant to each particular domain. Higher scores indicate higher QoL. Interested readers are referred to www.deakin.edu.au/research/acqol/instruments/ for further reading. Each domain of the subjective subscale—satisfaction—is represented by a single score using a 7-point response (7 = delighted, 6 = pleased, 5 = mostly satisfied, 4 = mixed, 3 = mostly dissatisfied, 2 = unhappy or 1 = terrible).

This scale is designed to be used with any section of the adult population. The scale is psychometrically sound and has been reported as reliable, stable, valid and sensitive.¹⁷ The

scale has shown very good content, convergent, discriminant validity and internal consistency. Summary QoL normative data was obtained from the COMQoL-A5 manual.¹⁷

A characteristic that has been significantly and positively associated with higher overall satisfaction with life is acceptance.¹⁸ Therefore, acceptance was used to examine potential variations *post hoc*. The domain acceptance was a subscale of the Spinal Cord Lesion Coping Strategies Questionnaire (SCL CSQ v1.0 Australia),¹⁹ which was developed specifically for use with the SCI population.¹⁹ Higher scores indicate a higher affirmation of the domain. Acceptance represents the extent of reevaluation of life values.

Analyses

Raw data was examined for systematic patterns of missing data using missing value analysis in SPSS,²⁰ normative distribution and the presence of outliers. Preliminary univariate analyses were used to observe basic differences in demographic and injury-related variables between the NT-SCI and T-SCI samples.

Univariate analyses were used to compare the levels of QoL across the QoL domains between the NT-SCI and T-SCI groups. Comparisons with general population normative controls were executed to place the results into context. Where significant differences between the two SCI groups were found, analysis of variance was used to place the levels into context by comparing with the normative control group. Where no significant differences between the two SCI groups were found, then the two SCI groups were combined into one group and compared with the normative control group.

Two standard linear regression analyses were used to explore the degree of variance in the two dependent variables (objective QoL domain material and subjective QoL domain health) that could be explained by the independent variables of demographic and injury-related characteristics. Further *post hoc* analyses examined potential biases or confounds.

All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research. The research project was approved by Monash University and both participating hospitals ethics committees.

Results

The total sample consisted of 443 adults. Sixty-two (14%) had an NT-SCI, which, if not immediate in onset, developed within 36 h. The range of traumas responsible for the SCI have been described more fully in a previous report that focused on the mental health outcomes of persons with chronic T-SCI and NT-SCI and published in this journal.²¹

The overall response rate was 48%: 61% paper-based, 23% web, 16% telephone interview. It is not possible to determine why some chose not to participate, but the participants did not differ significantly from non-participants by current age or gender. Missing value analysis²⁰ revealed no systematic patterns in missing data.

Participants with NT-SCI were significantly older than participants with T-SCI. Substantially more participants with NT-SCI had incomplete paraplegia and no one with NT-SCI had a complete tetraplegia lesion. There was a more even distribution of males and females with NT-SCI (Table 1).

There were comparatively few statistically significant QoL differences between the two SCI groups (Table 2). Participants with NT-SCI were materially better off, but were less satisfied with their health compared with those with T-SCI. In contrast, there were noticeably more differences between

the SCI cohort as a whole and the general population averages (Table 3). Objective QoL domains health, productivity, safety and emotional well-being were each significantly below the general population. The objective QoL domain place in the community, however, was higher than the general population.

Post hoc analyses revealed that only participants with T-SCI were materially worse off (general population vs NT-SCI, $t=0.315$ (df, 852) $P=0.753$). Satisfaction with health differed between the three groups with participants with T-SCI less satisfied with their health than the general population. Those with NT-SCI were less satisfied with their health compared with both those with T-SCI (Table 3) and the general population (general population vs T-SCI, $t=6.99$ (df, 1171) $P=0.000$).

No participant with a NT-SCI had a complete tetraplegia level of injury, which may have introduced a bias in the results. Excluding participants with complete tetraplegia T-SCI and rerunning the univariate analyses resulted in only minor shifts in the univariate statistics and the P -values and, therefore, made little difference to the results. The significance of objective QoL safety subscale was driven by the responses to two of the three items that made up the subscale: ‘How often do you sleep well?’ and ‘How often are you worried or anxious at home?’ Response to a third item, ‘Are you safe at home?’, did not differ between groups.

Standard linear regression analysis was used to explore the relative impact made by the demographic and injury-related variables associated with satisfaction health and objective QoL domain material within the SCI cohort (Table 4). Being in better health, having a complete SCI and higher levels of acceptance of their SCI were each associated with higher satisfaction with health after marital status, age, gender and aetiology of the SCI were controlled. Higher objective QoL domain material resources was associated with being older, married and having a complete SCI after gender, health, aetiology of the SCI and acceptance were controlled.

None of the major assumptions of multiple regression analysis (normality, linearity, homoscedasticity, independence of the residuals) were violated. Method of survey completion did not significantly impact on any of the dependent variables (not shown). In the regression analyses, injury was represented by complete and incomplete only, because of the low representation of higher injuries in the cohort with NT-SCI. Time since injury was initially included within the regression analyses, but was found to be non-significant. Time since injury was also moderately correlated with age, which showed a stronger association with both dependent variables. For these reasons, time since injury was not included in the models. The positive coping strategy acceptance has been significantly associated with positive outcomes previously,²² so was included within these exploratory analyses.

Discussion

Despite demographic differences, only the objective QoL domain material (higher in NT-SCI) and the subjective QoL domain health (lower in NT-SCI) were significantly different

Table 1 Demographic characteristics of adults with SCI, count (per cent) and comparative analyses

	NT-SCI (n = 62)	T-SCI (n = 381)	Comparative analysis	P-value
Gender			$\chi^2 = 8.330$	0.004
Male (n)	39 (62.9%)	305 (80.5%)		
Female (n)	23 (47.1%)	76 (19.5%)		
Age (years)			$t = 4.596$	0.000
M (s.d.)	59.8 (14.9)	50.5 (14.0)		
Years post-injury			$t = 1.637$	0.102
M (s.d.)	16.4 (15.0)	19.7 (12.9)		
Level of SCI			$\chi^2 = 44.492$	0.000
IC Para (n)	43 (70.5%)	106 (27.9%)		
C Para (n)	11 (18.0%)	125 (32.9%)		
IC Tetra (n)	7 (11.5%)	104 (27.4%)		
C Tetra (n)	0	45 (11.8%)		
Marital status^a			$\chi^2 = 2.492$	0.288
Married	41 (66.1%)	219 (57.6%)		
Single	11 (17.7%)	103 (27.1%)		
Divorced	10 (16.1%)	58 (15.3%)		

Abbreviations: C, complete; IC, incomplete; M, mean; NT-SCI, non-traumatic spinal cord injury; Para, paraplegia; s.d., standard deviation; Tetra, tetraplegia; T-SCI, traumatic spinal cord injury.

^aMarried also includes *de facto*, divorced also includes widowed and separated.

Table 2 Comparison of QoL domains between NT-SCI and T-SCI

	NT-SCI M (s.d.)	T-SCI M (s.d.)	t-test	P-value
Objective QoL domain				
Material	9.93 (2.16)	9.17 (2.77)	2.502	0.014
Health	8.16 (2.04)	8.47 (2.35)	-1.104	0.273
Productivity	9.64 (2.72)	9.45 (2.91)	0.617	0.538
Intimacy	11.23 (2.45)	11.09 (2.79)	0.461	0.645
Safety	11.87 (1.82)	11.76 (2.09)	0.364	0.717
Community	8.26 (2.35)	8.50 (2.20)	-0.626	0.531
Emotional well-being	10.43 (2.49)	10.02 (2.57)	1.229	0.220
Subjective QoL domain				
Material	5.56 (0.79)	5.63 (0.96)	0.106	0.916
Health	4.15 (1.44)	4.61 (1.46)	-2.305	0.022
Productivity	4.95 (1.22)	5.02 (1.26)	-0.390	0.697
Intimacy	5.69 (1.11)	5.57 (1.17)	0.801	0.424
Safety	5.47 (0.78)	5.57 (0.91)	-0.826	0.409
Community	5.19 (1.24)	5.07 (1.28)	0.715	0.475
Emotional well-being	5.19 (1.23)	5.00 (1.36)	1.053	0.293

Abbreviations: M, mean; NT-SCI, non-traumatic spinal cord injury; QoL, quality of life; s.d., standard deviation; T-SCI, traumatic spinal cord injury.

Table 3 Comparative analyses of QoL domains between those with SCI and non-disabled population

	NT-SCI and T-SCI M (s.d.)	NT-SCI M (s.d.)	T-SCI M (s.d.)	Non-disabled population M (s.d.) ^a	Comparative analysis	P-value
<i>Objective QoL domain</i>						
Material		9.93 (2.16)	9.17 (2.77)	10.04 (1.86)	F(2,1222) = 20.098	0.000
Health	8.44 (2.32)	NA	NA	12.87 (1.95)	t = 34.052	0.000
Productivity	9.48 (2.88)	NA	NA	10.79 (2.63)	t = 7.911	0.000
Intimacy	11.11 (2.74)	NA	NA	11.34 (2.38)	t = 1.477	0.140
Safety	11.77 (2.05)	NA	NA	12.33 (1.85)	t = 4.764	0.000
Community	8.47 (2.22)	NA	NA	7.72 (2.37)	t = 5.552	0.000
Emotional well-being	10.08 (2.55)	NA	NA	10.62 (2.25)	t = 3.710	0.000
<i>Satisfaction QoL domain</i>						
Material	5.63 (0.94)	NA	NA	5.49 (0.92)	t = 2.531	0.012
Health		4.15 (1.44)	4.61 (1.46)	5.21 (1.18)	F(2,1232) = 41.18	0.000
Productivity	5.00 (1.25)	NA	NA	5.10 (1.02)	t = 1.438	0.151
Intimacy	5.58 (1.16)	NA	NA	5.63 (1.12)	t = 0.736	0.462
Safety	5.55 (0.89)	NA	NA	5.64 (0.89)	t = 1.705	0.088
Community	5.09 (1.27)	NA	NA	5.26 (1.00)	t = 2.426	0.015
Emotional well-being	5.02 (1.34)	NA	NA	5.33 (1.08)	t = 4.164	0.000

Abbreviations: M, mean; NA, not applicable; NT-SCI, non-traumatic spinal cord injury; QoL, quality of life; s.d, standard deviation; T-SCI, traumatic spinal cord injury.

^aCOMQoL A5 normative data.

Table 4 Linear regression analyses exploring associations with dependent variables satisfaction with health and objective material QoL

Dependent variable	Satisfaction with health		Objective material QoL	
	Standardized coefficient	P-value	Standardized coefficient	P-value
Age	0.035	0.436	0.153	0.002
Female	-0.019	0.656	0.081	0.082
Married	0.063	0.155	-0.235	0.000
Health	0.178	0.000	0.015	0.746
Traumatic aetiology	0.069	0.127	-0.072	0.139
Complete injury	0.106	0.017	0.152	0.001
Acceptance	0.362	0.000	0.048	0.300

Abbreviation: QoL, quality of life.

*Married also includes *de facto*.

between the SCI subgroups. In contrast, five of the seven objective domains and four of the seven subjective domains were significantly lower in the SCI sample as a whole, compared with the general population.

Aetiology made little difference to the impact of SCI on QoL in our findings except for the availability of material resources and satisfaction with health. The implication of this is that therapists and rehabilitation programmes working with NT-SCI patients need to be aware that these patients are just as likely to have a QoL that is less than that of the general population as are T-SCI patients. The staff working with these patients need to try and take appropriate steps to help optimize the patients' independence and return to roles and community participation that can improve their QoL.

We believe that a possible explanation for the differences noted in objective material QoL could be due to the variation in age at the time of injury, otherwise known as a cohort effect. People with NT-SCI tend to be older when acquiring their SCI. This would give them more opportunity to

participate in the wider community without disability including the potential to earn and accumulate material resources before having to contend with an SCI. The proportion of women with NT-SCI was substantially higher, but female was not significant in the regression. The material resource levels of women with SCI maybe less affected by SCI as historically women have been less likely to be the main or sole breadwinners of their households. Further exploration suggested that this was neither because of the higher proportion of women *per se* nor because of the length of time before injury, but because as the years accumulate so do material resources and because two people can earn more than one. This occurred regardless of the aetiology of the SCI.

Participants with NT-SCI were less satisfied with their health despite there being no differences in their objective health from participants with T-SCI. As people with NT-SCI tended to be older, health satisfaction could also be subject to the cohort effect. It is reasonable to hypothesize that those with NT-SCI have lived longer without the burden of chronic illness or disability than those with T-SCI. In addition, as people age, they are more likely to experience co-morbid chronic ill health conditions,²³ so there could be a reluctance to accept the accumulative effect of their injury with other co-morbid conditions. Higher acceptance of their injury was significantly associated with higher satisfaction with health as was being healthier and having a complete injury. Further examination of the demographic profile of the overall cohort with SCI also hints at another explanation—the healthy worker survivor effect. There was a higher participation rate among those who were healthier and had complete injuries. These same people also tended to be more accepting of their injury.

Aside from satisfaction health and objective material, there were no QoL differences between the NT-SCI and T-SCI subgroups. In contrast, there were many more

differences between the non-disabled general population and those with SCI as a whole. This was not unexpected for the objective QoL domains health, productivity and emotional well-being, which concur with the previous research. It is important to note that the calculation of the objective QoL domain health was a composite score that included numerical representations of the degree of disability and/or medical conditions, number and types of medicines, and frequency of visits to the doctor. This could introduce a risk of confounding in the analyses, particularly in the regressions; however, this was deemed to be unlikely. Reducing the variable to only number and types of medication and frequency of visits to the doctor made only minor non-significant changes to both the univariate and multivariate analyses.

Responses to two items, one that looked at frequency of sleeping well and one that looked at frequency of feeling worried or anxious at home, were the reason why the objective QoL domain safety was lower in the SCI population. The reason that those items were significant is also supported by the previous research.²⁴

An interesting contrast was the objective QoL domain, place in the community that was higher in the population with SCI compared with the objective QoL domain productivity. The community subscale consists of items assessing frequency of participation in leisure activities and participation in unpaid positions of authority in community clubs or societies. The productivity subscale consists of more traditional indicators such as paid workforce participation. People with SCI participated in the community more than the non-disabled population, but not in the paid workforce.

Further exploration (not reported) indicates that the above finding was not simply reflecting the inclusion of persons past retirement age. It is unclear why productivity should be lower in those with SCI if they have the capability to participate so much in volunteer or leisure activities except possibly for attitudes within the wider community. In general, volunteer work is likely to have greater flexibility compared with paid employment, but the scale item referred specifically to positions of authority. This level of responsibility may not have the same degree of flexibility as a general helper. All the same, the need for some level of flexibility need not preclude paid workforce participation in many industries. The increase in leisure and volunteer activities trend is also similar to the previous research, notwithstanding the higher overall level of paid employment found by Schonherr *et al.*²⁵

Limitations

Fifty-two percent of people on the Victorian Spinal Cord Injury Service database who were approached and did not participate might have introduced a bias in the results. But participants did not differ by age or gender and this study had an equivalent or better participation rate than other studies that approached community residing individuals with SCI, for example Jensen *et al.* (43%)²⁶ and Bloemen-Vrencken *et al.* (45.5%).²⁷

The proportion of the sample with NT-SCI was relatively small (14%). Participants had similar demographic and injury-related characteristics to other Australian studies of T-SCI and NT-SCI SCI,^{28,29} which improves the generalizability. Nevertheless, it is recommended that future studies include larger proportions of persons with NT-SCI.

The participants were recruited from two centres that specialize in SCI rehabilitation and ongoing review. Potentially, different results may occur in samples that include people with SCI not managed in specialist units. This study has focused on the chronic phase after the acute injury and initial rehabilitation had been completed. Studies of the QoL of patients with NT-SCI in the early phases post-injury are also required.

Conclusions

The literature search called attention to the fact that very little is currently available that details the QoL of people with NT-SCI. Their QoL is also lower than the general population; therefore, both groups, T-SCI and NT-SCI, require support and services aimed at improving QoL. The regression analysis does point to the fact that those who are not married have fewer resources and complete injuries, so could be seen as more at risk and need more focus.

Conflict of interest

The authors declare no conflict of interest.

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