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ORIGINAL REPORT

REFLECTING ON SUBJECTIVE WELL-BEING AND SPINAL CORD INJURY*

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Objective: **The aim of this study was to examine factors associated with the subjective well-being of individuals with spinal cord injuries, while acknowledging theories that describe the subjective well-being tendency to homeostasis.**

Methods: **A representative community cross-sectional cohort of 443 adults with traumatic and non-traumatic spinal cord injury completed a self-report survey (by internet, telephone or hard copy) that included reliable and valid measures of quality of life, depression, anxiety and stress, post-traumatic stress disorder, coping strategies, and emotional consequences.**

Results: **The subjective well-being of half of the population with spinal cord injury lay above the normative subjective well-being set-point threshold. Despite the inclusion of many biopsychosocial factors, only Intimacy, Safety, Acceptance, and Helplessness were significantly associated with normative subjective well-being.**

Conclusion: **Comparatively few factors were significantly associated with normative subjective well-being, but the results help to explain observed contradictions noted in previous research into subjective well-being after spinal cord injuries. The results highlight the resilience of individuals in general and are in keeping with the disability paradox. However, many individuals with spinal cord injuries do not live satisfactory lives. It is for them that further psychological care and rehabilitation is necessary to create a good life after spinal cord injury.**

Key words: spinal cord injury, subjective well-being, quality of life.

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INTRODUCTION

Quality of life (QoL) after spinal cord injury (SCI) is an essential aspect of rehabilitation. Studies of objective measures of QoL, such as health (1) or productivity (2), in persons with SCI reveal a tendency for poorer outcomes and represent important areas for rehabilitation intervention. It is likely that subjective QoL, at least as far as the person with the SCI is concerned, will be at least as important as objective QoL. Subjective QoL includes the persons' sense of happiness and their perception of living a "good life" (3). In this paper, subjective QoL, subjective well-being, satisfaction with life as a whole and living a good life are synonymous.

Measures of objective QoL in persons with disabilities are likely to be significantly below that found in persons without disabilities, but this is less likely for subjective well-being. Albrecht & Devlieger (4) coined the term *disability paradox* to describe how many people with persisting serious disability report living good or excellent lives, including individuals with SCI. Even individuals with a very high level of SCI impairment, such as tetraplegia requiring ventilator assistance, have been found to report excellent subjective well-being (5).

This phenomenon is consistent with the general literature on QoL research, which demonstrates that subjective well-being is a stable phenomenon linked to the personality traits of extraversion and neuroticism (3, 6). Theories such as Adaptation Theory (7), Personality Theory of Subjective Well-being (8), Dynamic Equilibrium Theory (9), Set-Point Theory (10) and Subjective Well-being Homeostasis (11) have been developed and refined over a 30-year period to describe this phenomenon. Central to each of these theories is that subjective well-being is a fairly robust set-point within us all and that any acute changes brought about by major life events, for better or worse, are temporary and are followed by a gradual return to the original level of subjective well-being.

Cummins (11) has noted the high level of consistency across ecological studies conducted in western countries that asked, "How satisfied are you with your life as a whole?" or something similar. The results lay within a very narrow band of mean 75% (standard deviation (SD) 2.5%) of the scale maximum (SM) (11). These results have also been replicated in studies that aggregated the 7 life satisfaction domains comprised within the Comprehensive Quality of Life Scale (COMQoL) (12, 13).

In general, objective QoL measures demonstrate positive but low correlations with subjective QoL measures, especially compared with the inter-correlation of QoL measures (14). For example, objective QoL domains, such as education and wealth, are more highly correlated with each other than with a subjective QoL domain, such as happiness. This suggests that individuals who are satisfied with their lives can experience low levels of negative affect irrespective of their level of

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education. This relative independence of subjective well-being from objective QoL tends not to apply within populations living under stressful conditions, such as care-giving, unemployment and chronic poor health (15). Cummins (15) has suggested that this breakdown is due to a failure of subjective well-being homeostasis, a hypothesized system borrowed from biology that describes the normal steady-state system of subjective well-being achieved by the actions of self-regulating compensatory systems of response to external stimuli.

These findings have important implications for measures of QoL after SCI. Literature on the QoL after SCI has not acknowledged sufficiently the effects of the subjective well-being set-point theories and tendency for homeostasis described above. The aim of this study was therefore to examine 3 questions: (*i*) Is the subjective well-being of those with SCI significantly different from that of the general population? (*ii*) What is the proportion of adults with SCI living in the community whose subjective well-being lies at or above the 70% SM (or normative subjective well-being set point as proposed by Cummins (15))? (*iii*) What psychological, social and biological factors are associated with normative subjective well-being?

SUBJECTS AND METHODS

Ethics

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, Austin Health and Bayside Health Ethics Committees. The surveys were strictly confidential but not anonymous. Each subject whose survey results indicated they were probably experiencing emotional distress, was approached and offered referral for psychological care.

Participants

The sample consisted of 443 adults with sudden-onset SCI who were 18 years and older and 6 months or more post-onset of the SCI. The majority of SCI was caused by trauma, but 62 (14%) had non-traumatic aetiology. Participation of respondents with non-traumatic SCI was restricted to those whose SCI occurred over a period of less than 36 h. Two recruitment sites were used: the outpatient register of the only hospital in Victoria with a dedicated traumatic SCI unit that also treats some non-traumatic SCI (Austin Hospital, Victoria, Australia), and the outpatient clinic of the only other hospital in Melbourne with a dedicated SCI rehabilitation unit that focuses on treating non-traumatic SCI (Caulfield Hospital, Victoria, Australia). Participants could complete the survey on the internet, by telephone or on hard-copy.

Survey instruments

The survey consisted of demographic and injury-related questions and self-report scales that included: the Comprehensive Quality of Life scale for adults, 5th edition (COMQoL-A5) (13), the short form Depression, Anxiety and Stress Scale (DASS-21) (16), the Impact of Events – Revised (IES-R) (17), the Spinal Cord Lesion Coping Strategies Scale v1 Australia (Coping Strategies Scale) (18), and the Spinal Cord Lesion Emotional Well-being Scale v1 Australia (Emotional Consequences Scale) (18).

Injury-related information was obtained from the participants using terminology with which they were familiar. Complete was defined as having no feeling or movement at and below the injury site, on both sides of the body; incomplete was defined as have some feeling and/or movement below the injury site, on one or both sides of the body.

The COMQoL-A5 (13) consists of objective and subjective subscales, measured separately since they are usually poorly related. Both the objective and subjective subscales define life quality using the 7 domains: Material, Health, Productivity, Intimacy, Safety, Place within the Community, and Emotional Well-being. Each objective domain is comprised of a summary score derived from 3 items. Higher scores indicate higher QoL. The subjective satisfaction subscales comprise a single score for each domain. The COMQoL-A5 is a reliable and valid scale that is designed to be used with any section of the adult population, including populations with SCI (13, 19).

The reliable and valid self-report short form of the DASS-21 was used to discriminate between symptoms of depression, anxiety and clinically significant-level of stress using the scoring system and cut-offs published in the manual (16). Each subscale (Depression, Anxiety and Stress) consists of 7 questions, has a clinical cut-off score and 4 levels of symptoms severity (mild, moderate, severe, and extremely severe). Respondents are asked to indicate on a 0–3 scale how much each statement has applied to them over the previous week. The DASS-21 has previously demonstrated very good internal consistency (20).

The IES-R (17), is a reliable and valid self-report measure of the symptoms of post-traumatic stress disorder (PTSD) that uses a 5-point, 0–4 response format. A cut-off score (mean IES-R = 1.5, equivalent to a total IES-R score of 33) (21) indicates a likely diagnosis of PTSD.

Both the DASS-21 and the IES-R, and their earlier versions, have been used successfully within general populations (20, 22), clinical populations with psychological disorders (20, 23) populations with significant physical illnesses (24, 25) and populations with physical disabilities including SCI (26, 27).

The Spinal Cord Lesion Coping Strategies Questionnaire v1 Australia (Coping Strategies Scale) (18) is a recently developed scale that provides a succinct indication of condition-specific (that is SCI) coping mechanisms being utilized by respondents. It consists of 12 items, representing 3 domains of Acceptance, Fighting Spirit and Social Reliance. The domain Acceptance indicates re-evaluation of life values. The domain Fighting Spirit reflects efforts to minimize the effects of the SCI. The domain Social Reliance indicates tendencies towards dependent behaviour.

The Spinal Cord Lesion Emotional Well-being Questionnaire v1 Australia (Emotional Consequences Scale) (18) is a recently developed scale that provides a succinct indication of condition-specific (that is SCI) emotional consequences being experienced by respondents. It consists of 12 items, representing 3 domains of Helplessness, Intrusion and Personal Growth. The domain Helplessness reflects perplexity, lack of control and loss of self-esteem. The domain Intrusion indicates bitterness and brooding on the consequences of having a SCI. The domain Personal Growth reflects crisis growth, that is, positive outcomes of life crises.

For the independent dichotomous variable, Presence of Psychopathology, any score from the DASS-21 and/or IES-R that was above the published cut-off, thus indicating a likely clinical diagnosis, was coded as 1. Participants who scored below the threshold for DASS-21 and IES-R, thus falling within the non-clinical range, were coded 0. This variable indicates that the participant has a high probability of a clinical diagnosis and not an actual clinical diagnosis.

The dependent outcome variable Normative Subjective Well-being ($\geq 70\%$ SM) was calculated as follows: the mean of the 7 subjective QoL domains was converted into a percentage of scale maximum score (satisfaction % SM) using the following formula:

$$\text{Satisfaction \% SM} = (\text{score } y-1) \times 100/(7-1)$$

where y is the sum of the satisfaction scores divided by 7 (Formula 1 (13; p. 28)).

Satisfaction % SM was then dichotomized into 0 = satisfaction $< 70\%$ SM and 1 = satisfaction $\geq 70\%$ SM and the variable renamed Normative Subjective Well-being.

Statistical analyses

The proportion of the sample whose overall subjective well-being score lay at or above the 70% SM (normative subjective well-being) addressed the first question. A *t*-test for equality of means, comparing the proportion of the sample with normative subjective well-being with the normative proportion as published within the COMQoL-A5 manual addressed the second question. A single, binary logistic regression was used to explore the relative association of a range of independent psychological, social and biological variables with the dependent outcome variable (satisfaction $\geq 70\%$ SM) in this study. *Post-hoc* analyses, investigating the impact of outliers, potential confounds and biases were conducted.

RESULTS

Characteristics of the cohort

The cohort consisted of 443 individuals with SCI living in the community (345 males; 78%). The mean age of respondents was 51.78 years (age range 18–86 years). The mean time since injury was 19.20 years (range 1–66 years). The proportion of the cohort with incomplete paraplegia was 33.6% ($n = 149$), complete paraplegia 30.7% ($n = 136$), incomplete tetraplegia 25.3% ($n = 112$) and complete tetraplegia 10.2% ($n = 45$). Most subjects were in a relationship (married/defacto/living with partner; $n = 260$, 58.7%), some had been in a relationship (divorced/widowed/separated; $n = 68$, 15.3%) and 25.7% ($n = 114$) were single. Approximately half (51.5%, $n = 222$) of the cohort scored within the normal non-clinical range for Depression, Anxiety, Stress and PTSD. However, as measured by the DASS-21, 37% scored above the threshold for clinical Depression, 30% for Anxiety and 25% for Stress. Thirty-seven participants (8.4%) were above the cut-off score for a diagnosis of PTSD, as measured by the IES-R when the mean (IES-R Total score = 1.5 or Total summed IES-R score = –33) was used. Further discussion concerning psychopathology of the cohort is reported elsewhere (28). The response rate was 48% of those invited to participate. Individuals who completed the survey did not differ significantly from non-completers in current age or gender (current age $t = 1.55$ (*df*, 927), $p = 0.12$; gender $\chi^2 = 1.81$ (*df*, 1), $p = 0.18$). Table I provides descriptive statistics of the cohort grouped by normative subjective well-being membership.

Research questions

Question 1: Is the overall subjective well-being of those with SCI significantly different from that of the general population? Compared with the normative population, the overall COMQoL-A5 score for the cohort of this study (mean = 70.07% SM) was significantly below that of the normative data (mean = 73% SM; $t = 3.78$, $p < 0.001$).

Question 2: What is the proportion of adults with SCI living in the community whose subjective well-being falls at or above the 70% SM? Around half of those with SCI (53%, $n = 236$) were satisfied with their life as a whole since their subjective well-being was equal to or above 70% SM.

Question 3: What psychological, social and biological factors are associated with normative subjective well-being? The probability of normative well-being is associated positively with the objective QoL domains Intimacy and Safety, with the emotional consequence Intrusion and with the coping strategies Acceptance scale, and negatively with the emotional consequences Helplessness, after age, gender, marital status and level of SCI are accounted for (Table II).

Table I. *Descriptive statistics of the cohort grouped by normative satisfaction membership*

Independent variable	Subjective well-being < 70% SM (not satisfied), *n*	Subjective well-being ≥ 70% SM (normative satisfaction), *n*
Gender		
Male	164	181
Female	43	55
Marital status		
Married/defacto	113	147
Single	55	59
Divorced/separated/widowed	38	30
SCI level of injury		
Incomplete paraplegia	74	75
Complete paraplegia	58	78
Incomplete tetraplegia	56	56
Complete tetraplegia	19	26
Presence of psychopathology		
Present	144	65
Not present	58	164
	Mean (SD)	Mean (SD)
Subjective well-being, % SM	58.11 (10.17)	80.55 (7.33)
Age (years)	51.31 (15.01)	52.20 (13.95)
Time since injury (years)	17.03 (12.55)	21.09 (13.61)
Objective QoL scale domains		
Material	9.12 (2.66)	9.41 (2.74)
Health	8.00 (2.23)	8.83 (2.33)
Productivity	8.80 (2.88)	10.08 (2.75)
Intimacy	9.95 (2.70)	12.14 (2.34)
Safety	10.90 (1.99)	12.54 (1.78)
Place in the Community	7.92 (2.13)	8.94 (2.20)
Emotional Well-being	8.91 (2.45)	11.09 (2.19)
Emotional Consequences scale		
Helplessness	2.47 (0.59)	1.81 (0.50)
Intrusion	2.38 (0.82)	1.86 (0.71)
Personal Growth	2.45 (0.54)	2.66 (0.50)
Coping scale		
Acceptance	2.73 (0.57)	3.29 (0.49)
Fighting Spirit	3.13 (0.43)	3.35 (0.41)
Social Reliance	2.71 (0.74)	2.67 (0.66)

SM: scale maximum; SCI: spinal cord injury; QoL: quality of life; SD: standard deviation.

The Emotional Consequences Scale variable Intrusion proved an unusual variable. Intrusion was a statistically significant variable in the regression, but in the opposite direction to that which might be expected. Intrusion is a composite variable resulting from 3 items: (*i*) I often wonder just why I was injured; (*ii*) I will probably never get over feeling bitter and resentful that I was injured; and (*iii*) my injury feels like an undeserved punishment. It seems wrong that strong agreement with those items would be associated with normative subjective well-being. Face validity of Intrusion suggests a negative relationship with normative subjective well-being with which univariate correlation concurs ($r = -0.33$, $p < 0.001$, $n = 443$). Intrusion was also highly correlated with Helplessness ($r = 0.68$, $p < 0.001$, $n = 440$), suggesting that Helplessness provides a much stronger explanation for normative subjective well-being membership. For these reasons, Intrusion will not be considered any further.

Table II. *Relative association of biopsychosocial variables with normative subjective well-being (≥70% SM) outcome*

	Single logistic regression; odds ratio	Level of significance; *p*-value
Gender		
(reference – male)		
Female	1.65	0.150
Age	0.99	0.263
Marital status		
(reference – married)		
Single	0.79	0.539
Separated/divorced/widowed	0.35	0.267
SCI level of injury		
(reference – incomplete paraplegia)		
Complete paraplegia	1.01	0.982
Incomplete tetraplegia	1.41	0.362
Complete tetraplegia	0.65	0.422
Time since injury	1.01	0.455
Objective QoL scale domains		
Material	0.91	0.130
Health	1.10	0.171
Productivity	1.02	0.793
Intimacy	1.21	0.001
Safety	1.45	0.000
Place in the Community	1.11	0.168
Emotional Well-being	1.12	0.108
Emotional Consequences scale		
Helplessness	0.24	0.001
Intrusion	1.96	0.013
Personal Growth	0.89	0.701
Coping scale		
Acceptance	3.46	0.001
Fighting Spirit	0.99	0.977
Social Reliance	1.34	0.249
Presence of psychopathology		
(reference – not present)		
Psychopathology present	0.60	0.106

SM: scale maximum; SCI: spinal cord injury; QoL: quality of life.

Outliers had no impact on the regression analysis. Examination for potential confounds introduced by the physical sequelae of SCI with the physical symptoms diagnostic of psychological disorders (autonomic items) was conducted. The results indicated that the autonomic items did not confound the results, but that they did play a legitimate role in diagnoses, which is congruent with previous research (29). *Post-hoc* analyses revealed that the mode of survey completion made no significant impact on the odds of normative satisfaction. Univariate correlation analysis revealed a small to moderate relationship (not reported) between Safety and Anxiety (a component of the composite variable Presence of Psychopathology); therefore Safety is unlikely to be acting as a proxy for Anxiety in the regression analysis. The potential issue created by including a score representing the degree of impairment within the calculation of the objective QoL Health score was also found not to have significantly impacted on the results.

DISCUSSION

This large-scale study of an Australian community population of adults with SCI found that subjective well-being of roughly half of the cohort lay above the minimum level for normative subjective well-being in western countries. Many were well satisfied with their lives as a whole. Four variables affected the odds of normative subjective well-being. Relatively few variables were statistically significant, which is congruent with both the disability paradox (4) and normative subjective well-being homeostasis theory (11). It is possible to have chronic ill health and low material assets and still be satisfied with your life as a whole. Yet, as the subjective well-being homeostasis theory predicts when living under challenging conditions, many in the cohort were not satisfied.

The coping subscale Acceptance and the objective QoL domains Intimacy and Safety were positively associated with normative subjective well-being. The emotional consequences subscale Helplessness was negatively associated with normative subjective well-being. The objective QoL domain of Intimacy represents the frequency of interactions in close relationships with family and/or friends (in both talking and in activities) and the frequency of displays of empathy from others towards feelings of sadness. Thus, Intimacy embodies how an individual is placed or bonded socially with others. The domain Safety measured sleeping well, feeling safe at home and frequency of feeling worried or anxious during the day. Safety seems to embody how comfortable and relaxed at home individuals with SCI may or may not feel. Intuitively, it makes sense that these factors would have a significant impact on subjective well-being.

Both Acceptance and Helplessness were significantly associated with normative subjective well-being, albeit in opposite directions. The coping strategies subscale Acceptance indicated the degree of re-evaluation within one's life after injury; not by passively giving-up but rather by absorbing the SCI into one's own schema of self. The emotional consequences subscale Helplessness indicated confusion and lack of control in one's life after injury. Therefore, their relationship with subjective well-being makes sense. They were also moderately related to each other. The process of re-evaluation of your life, allowing the injury to no longer dominate your thinking must also mean being able to take some sort of control over your life. This is congruous with the activation of the cognitive buffers of adaptation and habituation within the subjective well-being homeostatic system, as proposed by Cummins et al. (3).

It is reasonable to expect the Presence of Psychopathology variable, representing strong negative emotions, to show a significant negative relationship with normative subjective well-being. However, in the regression analysis it did not. It did have a strong negative univariate relationship with subjective well-being (not reported here), but the regression results suggest that the absence of one (normative subjective well-being) does not automatically indicate the presence of the other (psychopathology). This also is in keeping with general knowledge of subjective well-being, which posits emotions and subjective well-being as closely related but not the same (30).

There were a number of other non-significant variables in the regression that included the objective QoL domains Health, Productivity, and Place in the Community as well as various demographic and injury-related items variables. These variables have been studied previously in a variety of guises, such as various aspects of physicality, community integration such as volunteering and employment, environmental factors, age, time since injury and so on. Those factors have varied in statistical significance between studies.

For example, Brillhart (31) found satisfaction with life did not vary according to the type of urinary management system, whereas Hicken et al. (32) found those who required assistance with bowel and bladder management had a significantly lower satisfaction with life (effect size = 0.68). Anderson et al. (33) found those who were married had significantly higher satisfaction with life (odds ratio (OR) = 24.98 (95% confidence interval (CI): 1.60–383.15)), whereas Roach (34) found intimate ties were not associated with satisfaction.

Differences in the design of the study, power to identify significant factors, types of research tools and effect sizes are some potential explanations for the disparity in results. Recent research has addressed many of the methodological concerns expressed in a previous review (35). Sample sizes are often small, but some studies have used much larger samples. The range of instruments used to measure subjective well-being has reduced substantially. However, restricting the above examples to studies that have employed the same high-quality scale, the Satisfaction with Life Scale (36), has not restricted discrepancies within findings.

There is, however, an issue that has not been recognized previously. This concerns the acknowledgement of the robustness and stability of subjective well-being homeostasis (15, 37). The failure to appreciate the stability and robustness of subjective well-being could be responsible for many of the contradictory results in QoL after SCI research. If the subjective well-being of many individuals within a sample had returned to their well-being set-point then any statistically significant difference within the cohort could give rise to spurious results. This explanation could have considerable implications on adaptation theory and rehabilitation research in general. Corroborative evidence is still needed.

Potential confounds and biases were considered, but no significant results were found. Though response rates could always be better, responders did not differ in gender or age from non-responders and we have no evidence that the participants were unrepresentative. Additionally, there was a reasonable distribution of participants across the range of demographic and injury-related characteristics, which should increase confidence to generalize from the results.

The results of this study support the robustness of subjective well-being and demonstrate that individuals can be measured as unhealthy and/or unproductive, in the conventional sense, and still have high subjective well-being. Overall, this study also supports the resilience of individuals in general and is in keeping with the *disability paradox* (3). The theories that incorporate subjective well-being are still evolving. It would seem that the recency of events that modify subjective well-being is important (38). Also, where once it was thought that all changes to subjective well-being were temporary, it is now recognized that downward changes can be more permanent (39), consistent with the findings that there are individuals with SCI living in the community who do not experience a good enough QoL. It is for them that psychological care and further rehabilitation is necessary in order to create a good life after SCI.

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