International Journal of Physical Medicine & Rehabilitation

Guest, et al., Int J Phys Med Rehabil 2014, 2:5
DOI: 10.4172/2329-9096.1000222

Research Article Open Access

A Prospective Study of the Change in Quality of Life in Adults with a Newly Acquired Spinal Cord Injury

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Received date: 09 July 2014; **Accepted date:** 21 Aug 2014; **Published date:** 25 Aug 2014

Abstract

Objective: Spinal cord injury (SCI) is a catastrophic injury impairing body systems and functions with secondary conditions like infections, chronic pain and fatigue having major negative impacts on functionality and well-being. The objective of this research was to conduct a prospective study of the change in health related quality of life (HR-QOL) from the hospitalization stage to six months following discharge in adults with SCI.

Methods: Participants included 91 adults with SCI, admitted over two-years into three SCI Units in Sydney, Australia. Multiple measures were taken, including socio-demographic and injury-related variables. Health related quality of life (HR-QOL) was assessed using the Short-Form Health Survey (SF-36) on three occasions, the first soon after admission to rehabilitation, the second within 2 weeks of discharge and the third six-months after discharge.

Results: After six months of living in the community, QOL of the SCI sample was significantly lower than Australian adult norms for all SF-36 domains except mental health. QOL domains such as physical functioning and vitality significantly improved from admission to discharge and 6 months after discharge. In contrast, SF-36 general health scores had deteriorated significantly 6 months after discharge. There was a non-significant trend for emotional functioning to also deteriorate 6 months after discharge. No improvement in the SF-36 pain interference scores were found over the time of the three assessments.

Conclusion: SCI has a substantial negative impact on QOL for domains such as physical functioning, physical role, pain and health. While participants showed some improvement in HR-QOL at discharge and 6 months after discharge, it is a concern that adults with SCI living in the community continue to have significantly lower QOL. Considered advancements in rehabilitation and community strategies will be required to address deficits in QOL in the long-term following SCI.

Keywords: Quality of life; Rehabilitation; Spinal cord injury; Mental health; Chronic pain; Vitality; Emotional functioning

Introduction

Chronic spinal cord injury (SCI) is a catastrophic injury that occurs when the spinal cord is severely bruised, lacerated, or severed due to traumatic injury or disease [1,2]. Depending on the level (tetraplegia versus paraplegia) and extent (completeness) of the lesion, significant impairment follows the injury, including a variable loss of sensation, muscle paralysis, and autonomic dysfunction associated with major effects on the functioning of multiple body systems [2]. While SCI is comparatively uncommon, its short and long-term management presents a considerable cost to the individual and society, largely due to its life-long burden and ongoing medical and ancillary treatment [1]. Ongoing problems and conditions like frequent hospitalization, pressure ulcers, autonomic dysreflexia, bladder and bowel dysfunction, pulmonary health complications, spasticity, circulatory problems, sexual problems, chronic pain, chronic fatigue, and psychological morbidity (such as depression and anxiety disorders), are known to challenge and diminish QOL in people with SCI [3-11].

Physical measures of SCI rehabilitation outcome assess aspects of the injury such as level or extent of impairment and activity limitation related to the disability. However, these measures alone are insufficient for explaining much of the variation in health outcomes after discharge following rehabilitation [11]. Health-related quality of life (HR-QOL) is viewed as an important and sensitive outcome measure when assessing the well-being of people with SCI, as they complement physical assessments [5]. Thus, the construct of QOL has been developed and become widely used in health related research in particular [12], assessing health from a multidimensional perspective, including physical, psychological, social, and vocational aspects [10-12].

The Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) is a reliable measure of HR-QOL and has frequently been used

Citation: Guest R, Perry KN, Tran Y, Middleton J, Craig A (2014) A Prospective Study of the Change in Quality of Life in Adults with a Newly Acquired Spinal Cord Injury . Int J Phys Med Rehabil 2: 222. doi:10.4172/2329-9096.1000222

in measuring the impact of disease [5], with a number of studies using the SF-36 having now shown that SCI negatively impacts multiple health domains [3,4,9,12]. For instance, chronic severe pain has been shown to have a toxic influence on QOL in people with SCI [3,8], while psychological morbidity such as depressive mood and related symptoms like chronic fatigue have also been found to be associated with diminished QOL [7,9,13-18]. Factors such as level of lesion, age, time since injury and completeness of the lesion have not been consistently found to be associated with lower QOL [5]. While numerous studies have shown SCI results in diminished QOL across a broad range of health and social domains, few, if any studies, have assessed changes in QOL prospectively over time, from the early inpatient period through to rehabilitation, discharge from hospital and after a period of time of living in the community. Therefore, this study had two objectives: first to confirm that HR-QOL is reduced in comparison to community norms in the sample being studied, and second, to assess prospectively the change, if any, in HR-QOL in adults with a newly acquired SCI as they progress from hospitalization and into the community. It is hypothesized that HR-QOL will improve over this time period given the broad goals of rehabilitation are to enhance QOL through the improvement of functionality, self-efficacy and capacity for self-management.

Characteristics	Participants
Age: mean years (sd min max)	42.6 (17.8, 18-81)
Male: n (%)	62 (70.4%)
Education: mean years (sd)	12.8 (2.5)
Relationship:	
Married or defacto n (%) Single: n (%) Widowed/separated/divorced: n (%)	45 (51.1) 34 (38.6) 9 (10.3)
Weeks since accident: mean weeks (sd)	7.3 (6.1)
Level and extent of lesion	
Tetraplegia: n (%) Paraplegia: n (%)	34 (39) 54 (61)
Complete lesion n (%)	41 (46.5)
Cause of SCI	
Road crash: n (%) Fall: n (%) Sport: n (%) Assault/shooting: n (%) Non traumatic (disease): n (%) Other: n (%)	26 (29.5) 27 (30.6) 10 (11.4) 2 (2.3) 10 (11.4) 13 (14.8)
Traumatic brain injury: n (%)	19 (21.5)
Compensation: n (%)	29 (32.9)
Prior psychiatric/psychological treatment: n (%)	28 (31.8)

Table 1: Socio-demographic and injury characteristics of the SCI sample participants (N=88). sd=standard deviation.

Methods

Participants

Participants included 91 adults with acute SCI who were consecutively admitted to the three adult SCI units in Sydney, Australia, over a period of almost two years (from March 2010 to January 2013). However, three chose not to take part in the study, resulting in 88 participants, and one participant could not be assessed for their SF-36 scores, leaving a total of 87 at admission. A further five were not able to be assessed at discharge, making a total of 82 participants at discharge, while a further 11 could not be assessed in the community, making a total of 71 participants for the 6 months measure. Inclusion criteria for the study consisted of: (a) the presence of an established acute SCI; (b) a recent first time admission to a SCI unit; (c) aged 18 or more and less than 85 years at the time of interview, and (c) able to speak English.

Demographic and injury characteristics for the sample are shown in Table 1. Completeness of the lesion was assessed by a medical specialist based on International Standards for Neurological Classification of SCI (http://ais.emsci.org/). All participants received standard medical and psychosocial rehabilitation treatment that is similar across the three SCI Units. Full compliance with the Code of Ethics of the World Medical Association occurred when conducting this study and research ethics approval was granted by the local institutional human research ethics committee. Written consent was obtained prior to participation in the study.

Study design and procedure

A repeated measures design was employed. The SCI group was assessed on three occasions, the first within 4 weeks of admission to inpatient rehabilitation, the second, within two weeks of discharge from hospital having completed the rehabilitation program, and the third after six months of living in the community. The first two assessment sessions were conducted when participants were inpatients in the SCI unit, while the third assessment session was conducted in the community in the participants' home.

Assessment

Sessions involved up to two hours of interview and assessment during which socio-demographic, injury and psychosocial factors were determined. HR-QOL was also measured in the three assessment sessions. Assessment was conducted by psychologists experienced with psychiatric interview practice and psychometric measurement techniques. HR-QOL was measured by the SF-36 [19,20]. Advantages include that: (i) it employs multiple dimensions or domains to assess QOL, (ii) it is considered a reliable and valid measure of QOL, and (iii) it has been frequently used in measuring the impact of many diseases allowing standardized comparisons of disease impacts [20]. The SF-36 measures eight QOL dimensions including: (a) physical functioning, indicating the extent to which a person's health limits their day to day physical activities; (b) role limitations at work or in the home due to physical health problems, (c) pain, indicating the extent to which pain interferes with daily activities; (d) general health status and perception of health; (e) vitality, a measure of a person's energy levels or fatigue; (f) social functioning, indicating the extent to which health limits social activities; (g) role limitations due to emotional problems, indicating the extent to which a person's emotional problems impact on daily and work activities, and (h) mental health, indicating the amount of time a person experiences feelings of nervousness, depression, happiness and so on [19,20]. The SF-36 has been shown to have acceptable reliability and validity with a variety of populations including Australia [21,22], and normative Australian data are available [23]. The SF-36 questionnaire was scored by summing and transforming raw data for each of the eight domains as per the formula in the SF-36 manual [20], and higher scores on the eight domains suggest higher QOL.

Statistical methods

Descriptive statistical analyses generated central tendency and breakdown statistics for the socio-demographic and injury study variables (Table 1). Mean values for the eight SF-36 domain scores were calculated and SF-36 comparisons made to Australian population norms standardized for age and sex [23]. Differences between the SCI sample SF-36 scores (at 6 months after discharge) and Australian norms were calculated using one-sample t-tests and Cohen's d effect sizes were also calculated to indicate the standardized difference between the sample means and Australian norms [24]. To determine significance of changes over time, repeated measures multivariate analysis of variance (MANOVA) was employed to determine overall within-group differences, and this was followed by univariate repeated measures ANOVA to establish in which SF-36 domains differences existed [25]. Bonferroni contrasts were then calculated to determine where significant differences occurred [25]. Effect sizes for the MANOVA are provided, in the form of eta-squared ($\eta 2$) values, as an indication of the size of the difference over time [24]. An $\eta 2$ of around .03 is considered small, .13 is considered a medium difference and over .2 or above is considered a large and substantial difference. Post-hoc statistical power was also provided for the MANOVA. All analyses were performed using Statistica Software (Version 12, Statsoft).

Results

Table 2 shows descriptive statistics for the eight SF-36 domains in the SCI sample at 6 months after discharge as well as able-bodied Australian SF-36 community norms. The SCI sample was found to have significantly lower QOL scores (p<.01) for all the SF-36 domains except for mental health, when compared to Australian norms standardized for age and sex. Effect sizes for these differences range from 2.1 for physical function (very large), to moderate to large effect sizes for the remaining six domains that were significant. Mental health was only marginally lower than community norms.

Table 3 shows mean SF-36 scores for all domains measured in the three time periods. Repeated measures MANOVA indicated that significant within group changes occurred over time in the eight SF-36 domains: Wilk's $\lambda=.48$; F (16,55)=3.6; p<.001; $\eta 2=.51$ (very large effect); post-hoc statistical power=99%. Univariate ANOVAs and Bonferroni post-hoc contrasts indicated that significant changes occurred in the following SF-36 domains: (i) Physical function (F(2,140)=10.9; p<.001); Bonferroni contrasts confirmed that the physical function score measured at discharge had significantly improved compared to physical function scores taken at admission and gains were maintained at 6 months after discharge (p<.05). (ii) General health (F(2,140)=6.1; p<.001); Bonferroni contrasts indicated that general health scores taken at admission and discharge were significantly higher than the 6 months score (p<.05). That is, general health after 6 months had significantly deteriorated. Figure 1 shows change in SF-36 general health scores over time. (iii) Vitality (F(2,140)=6.8; p<.001); Bonferroni contrasts indicated vitality scores taken at discharge were significantly improved compared to vitality scores taken at admission (p<.05), while a trend for vitality scores at admission to be lower than the 6 months score also occurred (p<.07). Figure 1 shows change in SF-36 vitality scores over time. (iv) Mental health (F(2,140)=3.5; p<.05); Bonferroni contrasts indicated that mental health scores taken at discharge were significantly improved compared to admission mental health scores (p<.05), while there was no difference between discharge and 6 month mental health scores. Figure 1 shows change in SF-36 Mental health scores over time. It is worth noting that a trend occurred for role limitations due to emotional functioning to deteriorate 6 month after discharge (F(2,140)=2.7; p<.07), while scores for the limitations due to pain showed little change over time.

SF-36 domain	SCI 6 months Mean (std error)	Aust. Norms Mean (std error)	t-test Effect size
Physical function	31.3 (2.8)	82.5 (0.2)	18.0 * 2.1
Role limit-physical	42.5 (4.8)	79.8 (0.4)	7.7* 0.9
Bodily pain	62.0 (3.1)	76.8 (0.3)	4.7 * 0.5
General health	61.4 (2.7)	71.6 (0.2)	3.7 * 0.4
Vitality	53.5 (2.3)	64.5 (0.2)	4.7 * 0.6
Social function	68.7 (2.9)	84.9 (0.2)	5.5 * 0.6
Role limit-emotion	63.0 (4.9)	82.8 (0.3)	3.9 * 0.5
Mental health	73.9 (2.0)	75.9 (0.2)	1.0 0.1

Table 2: Descriptive statistics for the SF-36 domains for the SCI sample (6 months after discharge, N=71) and the Australian adult able-bodied SF-36 norms standardized for age and sex; t-test values, probabilities of difference and Cohen's d effect sizes are also shown. *p<0.01.

SF-36 domain	Admission Mean (sd) 95%CI	Discharge Mean (sd) 95%CI	6 months Mean (sd) 95%CI
Physical function	22.2 (17) 19-26	32.2 (17) 28-36	31.3 (24) 33-52
Role limit-physical	32.7 (38) 24-41	35.2 (38) 27-44	42.5 (41) 33-52
Bodily pain	61.6 (28) 56-68	61.4 (26) 56-67	62.0 (26) 56-68
General health	67.9 (20) 64-72	69.2 (18) 65-73	61.4 (23) 56-67
Vitality	49.8 (19) 46-54	56.2 (17) 52-60	53.5 (19) 49-58
Social function	61.1 (32) 54-68	69.5 (26) 64-75	68.7 (25) 63-75
Role limit-emotion	73.5 (40) 65-82	76.7 (36) 69-84	63.0 (42) 53-73
Mental health	72.9 (20) 69-77	78.3 (17) 74-82	73.9 (17) 70-78

Table 3: Descriptive statistics for the SF-36 domains for the SCI sample at admission (N=87), just before discharge (N=82) and 6 months after discharge (N=71).

Change in QOL over time as a function of level of injury (paraplegia versus tetraplegia), completeness of the lesion, presence of a partner, pre-morbid psychological treatment and ASIA functional classification

(American Spinal Injury Association; www.asia-spinalinjury.org) were explored over the three time periods. Level of injury (F(16,54)=.89, p=0.58), completeness of the lesion (F(16,54)=0.52, p=0.92), presence of a partner (F(16,54)=.59, p=0.88), pre-morbid psychological treatment (F(16,54)=1.13, p=0.35) and ASIA level (F(64,201)=1.15, p=0.23) were not associated with significant changes in QOL over time.

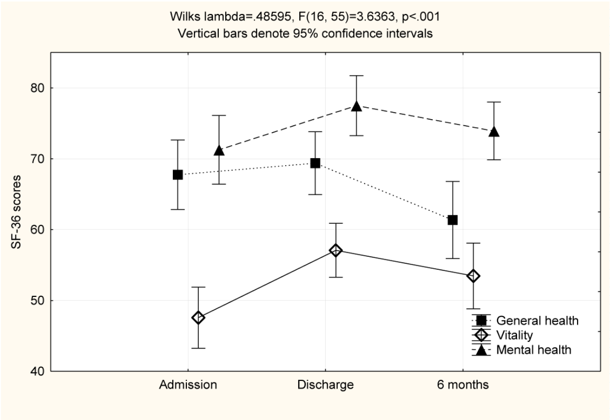

Figure 1: Shows SF-36 domain scores that significantly changed over time (excluding physical function which did not change after discharge).

Discussion

The findings of this research confirmed conclusions made in a number of prior studies that have investigated the QOL of people with SCI [3-5]. SCI imposes a severe personal and social burden on adults who sustain the injury, and this was indicated by the consistently lower QOL scores being found in the SCI sample in comparison to Australian QOL norms for the SF-36 domains, except mental health. Substantially poorer physical functioning and greater physical role limitations scores were found for the SCI sample (Table 2). Given the severe physical impairments associated with SCI, diminished QOL would be expected in physical activities of daily living. It was, however, encouraging that improvement in physical function and reduced physical role limitations (non-significant trend) were found as participants progressed through rehabilitation and into the community. Role limitation due to pain was significantly higher in the SCI sample as shown in Table 2. Pain has a known direct influence on participation and behavior [6,8]. Our finding replicates earlier QOL and SCI studies [3,4], and comes as no surprise as prior studies have established that persons with SCI believe ongoing debilitating chronic pain has severe long-term implications for their health and QOL [6,8,18]. It was concerning that there was a lack of improvement in role limitations due to pain as participants progressed through rehabilitation and into the community. This finding of no change over time suggests SCI pain management strategies employed in rehabilitation and in the community require enhancement and re-thinking [8,18]. For example, it would be beneficial to inject additional resources into improving knowledge about the nature and management of chronic pain in people with SCI during and after rehabilitation, as well as strengthening their self-management skills related to pain interference. These could include cognitive skills such as anti-catastrophization thinking, relaxation skills such as visualization and behavioral skills such as pacing [8,18].

In comparison to community norms, SCI was associated with moderately reduced QOL for SF-36 domains general health, vitality, social functioning and emotional functioning. Diminished QOL in general health, vitality and social function domains is expected given that physical and social disadvantages arising from impairment and social participation restrictions are major problems following SCI [5,26]. It was concerning, however, to find a deterioration in general health after 6 months in the community. Research has found a re-hospitalization rate of almost 60% 10 years after discharge, with the most frequent causes for re-hospitalization including genitourinary (24% of admissions), gastrointestinal (11%), skin related problems (8.9%), musculoskeletal (8.6%), psychiatric disorder (6.8%), cardiovascular (4.8%) and respiratory (4.5%) [27]. These data perhaps help explain why SF-36 general health has begun to deteriorate 6 months after discharge. In the present study, for instance, the participants perceived they were more prone to becoming sick, and that maintaining health was a challenge or not possible. As concluded by prior studies [27], ongoing problems like pressure injuries, urinary tract infections, cardiovascular and respiratory difficulties leading to frequent hospitalization, in combination with chronic fatigue and pain, combine to reduce the person's confidence that he/she can have good quality health. Negative perceptions like these will need addressing with strategies like cognitive behavior therapy approaches [7]. In spite of this, it was encouraging that vitality and social function scores (a non-significant trend) had improved by discharge and after 6 months in the community.

Poor emotional and mental health is a risk for a substantial minority with SCI [7,13-17]. It was therefore expected that the SCI sample would have lowered QOL in the SF-36 mental health domain compared to the general population. However, the SF-36 mental health score for the SCI sample was only marginally lower than the community norm. Prior studies have also not found significant differences between persons with SCI and the general population in the SF-36 mental health domain [4], while others have [3]. Clearly, additional research is required to clarify this issue. It was also encouraging that mental had improved by discharge. Community strategies of maintaining these gains are required, and this should be a future research focus.

It was also expected that the SCI sample would have increased perceived role limitations due to their emotional health. This was the case, though the difference did not reach significance (trend towards significance at p<.07). It was concerning that six months after discharge, role limitations due to emotional problems had increased, resulting in reduced QOL. Emotional distress and elevated anxiety are prevalent in the long-term following SCI, and clinical and community strategies for combating this are required, such as improving access to community participation, and the provision of the development of algorithms that can predict risk of psychological morbidity in the long-term [16]. As found elsewhere, injury and demographic factors such as level of injury, ASIA level, and completeness of the lesion had a limited impact on QOL [5,16]. It was however, surprising that the presence of a partner and pre-morbid psychiatric/ psychological treatment also had no significant impact on QOL, at least up to 6 months post-discharge. Research will need to investigate the influence of these factors on QOL after six months to clarify these findings.

The findings presented in this paper have provided prospective data that confirms the suspected decreased HR-QOL in people with SCI when compared to community norms. The study has also found that improvements in QOL do occur over time, but not in all domains. General health, role limitations due to pain and role restrictions due to emotional problems remain serious concerns. It is therefore, as argued above, critical to establish medical and psychosocial methods of addressing these concerns, such as improved prediction of factors that contribute to adjustment, sensitive assessment methods that can be used to inform treatment, and improved psychosocial treatments. These strategies have been discussed elsewhere in detail [28].

The study had several limitations. Decreasing statistical power occurred over time, especially at the six month follow-up. This was, in part, due to the low incidence of and high complications associated with SCI (about 100 acute injuries occurring in NSW annually), resulting in a challenge to recruit participants into prospective studies. However, sufficient numbers of adults with SCI were recruited providing more than satisfactory statistical power of almost 100%. A further limitation is the limited follow-up of six months after discharge. In response, a follow-up two to three years after discharge is being planned.

In conclusion, the challenges associated with SCI are considerable and require a substantial continued input of resources so as to best assist the person with SCI to make the necessary personal and social adjustments. The results of this study have indicated that many adults with SCI experience substantial reductions in HR-QOL due to the injury, and that while improvements do occur over time, many challenges still remain. Future research will need to focus on addressing these challenges, beginning in the rehabilitation phase and when they settle into their communities following discharge. It is hoped such research will provide real benefits with consequent improved QOL.

Acknowledgments

We acknowledge the financial support of the Lifetime Care Support Authority (NSW, Australia).

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This article was originally published in a special issue, entitled: **"Spinal Cord Injury: Treatment & Rehabilitation",** Edited by Linqiu Zhou, Thomas Jefferson Medical University, USA