

ORIGINAL ARTICLE

The relationship between quality of life and disability across the lifespan for people with spinal cord injury

RN Barker¹, MD Kendall², DI Amsters¹, KJ Pershouse¹, TP Haines³ and P Kuipers⁴

¹The Spinal Outreach Team, Queensland Spinal Cord Injuries Service, Princess Alexandra Hospital, Brisbane, James Cook University, Townsville, Queensland, Australia; ²Transitional Rehabilitation Program, Queensland Spinal Cord Injuries Service, Princess Alexandra Hospital, Brisbane, Queensland, Australia; ³Princess Alexandra Hospital, University of Queensland, Brisbane, Queensland, Australia and ⁴Centre for Remote Health (a joint centre of Flinders University and Charles Darwin University), Alice Springs, Northern Territory, Australia

Study design: Prospective cross-sectional survey.

Objectives: To compare quality of life (QOL) for people with spinal cord injury (SCI) and their able-bodied peers and to investigate the relationship between QOL and disability (impairments, activity limitations and participation restrictions) across the lifespan, for people with SCI.

Setting: A community outreach service for people with SCI in Queensland, Australia.

Methods: A random sample of 270 individuals who sustained SCI during the past 60 years was surveyed using a guided telephone interview format. The sample was drawn from the archival records of a statewide rehabilitation service. QOL was measured using the World Health Organization Quality of Life Assessment Instrument-Brief, impairment was measured according to the American Spinal Injury Association classification and the Secondary Condition Surveillance Instrument, activity limitations using the motor subscale of the Functional Independence Measure and participation restrictions using the Community Integration Measure. Lifespan was considered in terms of age and time since injury. Correlation and regression analyses were employed to determine the relationship between QOL and components of disability across the lifespan.

Results: QOL was significantly poorer for people with SCI compared to the Australian norm. It was found to be associated with secondary impairments, activity limitations and participation restrictions but not with neurological level, age or time since injury. The single most important predictor of QOL was secondary impairments whereas the second most important predictor was participation.

Conclusion: To optimize QOL across the lifespan, rehabilitation services must maintain their focus on functional attainment and minimizing secondary conditions, although at the same time enabling participation.

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Keywords: spinal cord injury; quality of life; disability; ageing; survey

Introduction

Over recent decades, medical advances in the care of people with spinal cord injury (SCI) have led to improved rates of survival and life expectancy.¹ In turn, emphasis has shifted from survival to life-long follow-up and quality of life (QOL).² Despite this change in focus, the degree to which people with SCI experience QOL that is equivalent to their able-bodied peers, and the predictors of that QOL remain underexplored.^{3,4} The aims of this study were to compare QOL for people with SCI and their able-bodied peers, and to investigate the relationship between QOL and the compo-

nents of disability (impairments, activity limitations and participation restrictions) across the lifespan.

Materials and methods

This paper presents, a cross-sectional analysis of data from a prospective and longitudinal study examining outcomes across the lifespan for people with SCI. Data were collected using a pre-arranged and guided telephone interview format in which written questions were provided to participants in advance. This format was chosen to enable participation by a large geographically dispersed sample of people with SCI, for efficiency, ease of administration and to minimize missing data.⁵

Correspondence: KJ Pershouse, Spinal Outreach Team, Queensland Spinal Cord Injuries Service, PO Box 6053, Buranda, Queensland 4102, Australia.
E-mail: kiley_pershouse@health.qld.gov.au
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Participants

A random sample of 270 individuals with traumatic SCI was selected from archival records kept by the Queensland Spinal Cord Injuries Service (QSCIS). Demographic characteristics of the study sample are given in Table 1. Inclusion criteria

Table 1 Demographic characteristics of the study sample at study commencement ($n = 270$)

Age	Mean, 43 years (range, 20–76 years; s.d. = 11 years)
Age at time of injury	Mean, 28 years (range, 15–55 years; s.d. = 10)
<i>Level and completeness</i>	
Functionally complete quadriplegia	107 (40%)
Functionally complete paraplegia	100 (37%)
Neurological sparing such that ambulation was possible	63 (23%)
<i>Gender</i>	
Male	220 (82%)
Female	50 (18%)
<i>Place of residence</i>	
Metropolitan	136 (50%)
Non-metropolitan	134 (50%)
<i>Marital status</i>	
Married or living as married	137 (51%)
Not living as married	133 (49%)
<i>Living situation</i>	
Living with others	209 (77%)
Living alone	261 (33%)
<i>Employment</i>	
In paid workforce	111 (41%)
Not in paid workforce	159 (59%)

consisted of: (1) SCI of traumatic origin, (2) aged over 15 years and less than 55 years at time of injury, (3) discharged to a community setting after hospitalization and (4) an address within the state of Queensland. Individuals who sustained injuries in childhood or older adulthood were excluded, thus reducing the likelihood of participants displaying either growth-related problems or pre-morbid age-related problems. This yielded a potential sample of 1613 people, which was then stratified into six groups according to time since injury (<5, 5–10, 10–15, 15–20, 20–25 and >25 years). To ensure equivalent representation across strata over the past 60 years, participants were selected randomly from each group and located from QSCIS records and telephone directories, contacted by telephone or by mail and invited to participate. The selection process was repeated until 45 participants were recruited to each group. To achieve the total sample of 270 individuals, 690 names were drawn, of whom 179 could not be located, 64 were found to be deceased, 76 declined to participate, 28 had relocated interstate and 60 were excluded as their motor and sensory function was reported as normal. Those who declined mostly noted insufficient time due to work or family commitments.

As reflected in Table 2, excluding those who were deceased or those with no residual neurological deficit, the final study sample was comparable to the non-participant sample and the QSCIS population on age, age at time of injury, gender and place of residence. However, the study sample contained a greater percentage of people with tetraplegia and with complete injuries than the non-participant sample and the QSCIS archival population.

Measurement

The survey questionnaire consisted of a core of reliable and valid measures of QOL and disability, suited to an SCI population and telephone administration.

Table 2 QSCIS archival record: comparison between the study sample, those selected but who did not participate and the total QSCIS sample

	Study sample ($n = 270$)	Selected but did not participate ($n = 283$) ^a	Total sample QSCIS archival record ($n = 1376$) ^a	Missing data
Mean age (s.d.)	44 (12)	46 (13)	46 (13)	Nil
Mean age at time of injury (s.d.)	28 (10)	30 (11)	29 (10)	Nil
<i>Gender</i>				
Male	220 (82%)	235 (83%)	1144 (83%)	Nil
Female	50 (18%)	48 (17%)	232 (17%)	
<i>Place of residence</i>				
Metropolitan	134 (50%)	127 (45%)	637 (47%)	$n = 10$
Non-metropolitan	136 (50%)	156 (55%)	731 (53%)	
<i>Level of injury</i>				
Tetraplegia	143 (54%)	127 (47%)	637 (49%)	$n = 67$
Paraplegia	122 (46%)	142 (53%)	672 (51%)	
<i>Completeness of injury</i>				
Complete	139 (57%)	86 (33%)	506 (40%)	$n = 110$
Incomplete	105 (43%)	179 (67%)	760 (60%)	

Abbreviation: QSCIS, Queensland Spinal Cord Injuries Service.

^aNote: To ensure consistency between groups, those who were known to be deceased or recorded as Frankel E were removed from those who were selected but did not participate and the entire QSCIS archival record before the comparison was made.

Quality of life

The World Health Organization Quality of Life Assessment Instrument (WHOQOL)-Bref,⁶ a self-report questionnaire used to measure perceived QOL over the past 2 weeks was the key measure selected as its psychometric properties are excellent for a number of disability groups and it is suitable for measurement of QOL in people with SCI.⁷ It profiles QOL across four domains; physical health (seven items), psychological health (six items), social relationships (three items), environment (eight items) and two extra items scoring overall perception of QOL and health. Respondents rate each item on a five-point Likert scale. The summed scores within each of the four domains range from 0 to 100, with a higher score denoting higher QOL. The Analysis was performed at three levels: a basic level using the single item 'how would you rate your quality of life'; an intermediate level using the WHOQOL-8, calculated by summation of eight items contained in the WHOQOL-BREF and a higher level using the four-domain scores (physical, psychological, social relationships and environment).⁸

Disability

Measurement of disability was based on the International Classification of Functioning, Disability and Health framework.⁹ Two impairment measures (primary and secondary), one activity measure and one participation measure were chosen to reflect the three components of disability.

Primary impairments were measured according to neurological level and completeness of injury, based on the American Spinal Injury Association (ASIA) classification system,¹⁰ with scores re-ordered so that higher scores reflecting more function. That is, a score of 1 denotes functionally complete tetraplegia (Tetra ASIA ABC), 2 functionally complete paraplegia (Para ASIA ABC) and 3 SCI at any level (all ASIA D) with functional neurological sparing such that ambulation is typically possible.

Secondary impairments were recorded using the Secondary Conditions Surveillance Instrument (SCSI),¹¹ in which participants report their experience and the severity of 40 different problems over the past 12 months on a four-point scale. For each participant, the sum of ratings across all conditions (a measure of overall severity of secondary conditions) was calculated.

Activity limitations were monitored using the motor subscale of the Functional Independence Measure (mFIM), universally recognized for measuring function and previously utilized in SCI and ageing research. It consists of 13 items that assess the degree of independence across self-care, sphincter control, mobility and locomotion. Although not suited to clinical interpretation, it covers functional issues relevant to SCI, and higher scores denote higher levels of function. The validity and reliability of telephone administration of the mFIM with people with SCI has been established.¹²

Participation restrictions were assessed using the community integration measure (CIM), a 10-item, client-centred measure that assesses words of participants with respect to personal attitudes, perceptions and beliefs regarding their

connection with their community. A single summary score (between 10 and 50) is derived. The CIM is a psychometrically sound measure when used with people with SCI.¹³

Procedure

Each telephone interview was arranged and conducted by two physiotherapists with experience in the field of SCI and training in the administration of the interview. Upon receiving verbal consent, an interview time was agreed (daytime or evening) and interview questions, participant information forms and participant consent forms were mailed. Participants were asked to sign and return forms using a reply-paid envelope prior to the first interview. Ethical approval for this project was granted by the Princess Alexandra Hospital Ethical Review Committee, Brisbane, Australia.

Analysis

Data were managed using Microsoft Access Database Management System and analysed using SPSS V13 software. Data quality was high with the frequency of missing item scores less than 10 for the entire sample. Missing data were dealt with using mean substitution for computed variables and pair-wise deletion for single-item variables.

Differences in QOL between people with SCI and the Australian norm were identified using a two-sample *t*-test. Analysis was performed using the QOL single-item score and at the higher level using the four-domain scores. Effect sizes were calculated for the single-item QOL and for all domains by dividing the mean difference in scores by the s.d. of the scores for the Australian norms. To interpret effect size, the suggestions of Cohen¹⁴ were used (0.2–0.5, small; 0.5–0.8, moderate and >0.8, large). Differences between age groups (20s, 30s, 40s, 50s and 60 and over) and time since injury were determined using analysis of variance. The relationship among QOL, the three components of disability (impairments, activity and participation), age and time since injury were examined using univariate linear regression. To determine the relative importance of the components of disability on QOL while taking into account age and time since injury, a multiple linear regression (simultaneous) was utilized for the single-item score, the WHOQOL-8 and each of the four domains of QOL. Measures of QOL were treated as the dependent variable and measures of disability, age and time since injury were treated as the independent variables. Two dummy variables were used to enter neurological status into regression analyses. Significance level was set at <.01 to minimize the probability of making type-1 errors.

Table 3 QOL: comparison between study sample and Australian norm

Measure	SCI sample	Australian norm	P-value	Effect size
Item 1: QOL	3.7 (0.8)	4.3 (0.8)	<0.001	0.75
Physical	63 (19)	80 (17)	<0.001	1.00
Psychological	66 (18)	73 (14)	<0.001	0.50
Social relationships	62 (22)	72 (19)	<0.001	0.53
Environment	70 (15)	75 (14)	<0.001	0.36

Abbreviations: QOL, quality of life; SCI, spinal cord injury.

Results

On average, participants in this study were found to have significantly lower QOL than the Australian norm for the single-item QOL and for all domains^{15,16} (Table 3). The differences in the physical domain (1.00) reflected a large effect size whereas the single-item QOL (0.75) and the social relationships domain (0.53) showed moderate effect sizes, the psychological domain (0.50) had a small-moderate effect size and there was only a small effect size within the environment domain (0.36). When compared for each age group, the difference was significant for all domains, with the exception of the 60s and over group that differed significantly for the physical domain only (Figure 1; Table 4). When QOL was compared between people with SCI of different ages and time since injury, no significant differences were detected.

Relationship between QOL and disability across the lifespan

All measures of QOL were associated with SCSi ($\beta = -0.28$ to -0.68) and CIM ($\beta = 0.29-0.45$) but only the physical ($\beta = 0.30$) and environment domains ($\beta = 0.21$) were associated with mFIM. No measures of QOL were associated with age, duration of injury and neurological status (Table 5).

The two factors that accounted for the variance in QOL, when taking into account age and time since injury, were secondary impairments and community integration. In Table 5, regression coefficients, semi-partial correlations and percentage of unique variance are presented. On the basis of the WHOQOL-8, secondary impairments demonstrated the highest semi-partial correlation (sr) among all of the variables (sr=0.51, $P < 0.001$) and were responsible for more than 32% of the unique variance in QOL (WHOQOL-8)

and the single largest independent predictor of QOL, irrespective of the contributions of other factors that influence QOL. The CIM also demonstrated a significant

Table 4 QOL across age groups for SCI compared to the Australian norm

	Australian norm		SCI in Queensland		P-value
	n	Mean (s.d.)	n	Mean (s.d.)	
<i>Physical domain</i>					
20s	47	85.4 (10.9)	41	64.3 (17.9)	<0.001
30s	87	82 (13.5)	66	62.4 (19.7)	<0.001
40s	88	77.8 (19.8)	95	64 (17.8)	<0.001
50s	66	80.3 (16.9)	52	61.1 (20.4)	<0.001
60s	188	72.3 (17.8)	16	60.3 (13.6)	<0.01
<i>Psychological domain</i>					
20s	47	71.4 (17.5)	41	67.1 (19.9)	NS
30s	87	73.5 (14)	66	62.6 (21.5)	<0.001
40s	88	71.5 (14.4)	95	66 (16.3)	<0.01
50s	66	73.8 (12.6)	52	67 (16.2)	<0.01
60s	188	69.9 (15)	16	68 (13.2)	NS
<i>Social relationships domain</i>					
20s	47	72.9 (18.8)	41	64.8 (22.5)	NS
30s	87	73.7 (19.4)	66	61.6 (22.1)	<0.001
40s	88	72.1 (17.7)	95	61.1 (20.9)	<0.001
50s	66	73.1 (18.2)	52	60.9 (21.9)	<0.01
60s	188	69.9 (18.7)	16	62.5 (20.2)	NS
<i>Environment domain</i>					
20s	47	74.3 (14)	41	68.2 (13.9)	<0.05
30s	87	73.2 (12.5)	66	68.2 (16.7)	<0.05
40s	88	72.3 (12.9)	95	69.5 (14.9)	NS
50s	66	77 (13.3)	52	72.2 (14.8)	NS
60s	188	76.1 (12.6)	16	69.7 (12.9)	NS

Abbreviations: NS, not significant; SCI, spinal cord injury.

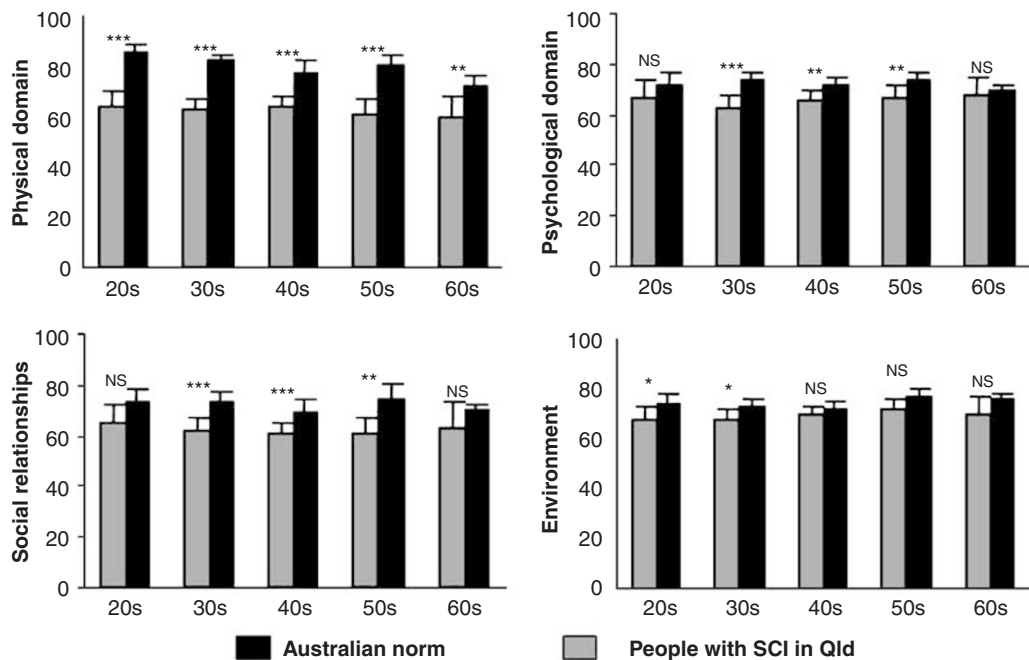


Figure 1 Quality of life (QOL): comparison between spinal cord injury (SCI) and population norms across age groups. *Significant at <0.05, **significant at <0.01, ***significant at <0.001.

Table 5 Bivariate and multivariate relationships between disability and QOL across the lifespan

	Bivariate		Multivariate			
	β	P-value	R ²	sr	% var	P-value
<i>Item 1: QOL</i>						
			0.24			
Neuro 1	0.06	0.36				
Neuro 2	-0.05	0.40				
SCSI	-0.40	<0.001		-0.34	13	<0.001
mFIM	0.01	0.82				
CIM	0.29	<0.001		0.22	6	<0.01
Age	-0.06	0.33				
Time since injury	0.09	0.13				
<i>WHOQOL-8</i>						
			0.48			
Neuro 1	0.07	0.23				
Neuro 2	-0.02	0.74				
SCSI	-0.60	<0.001		-0.51	32	<0.001
mFIM	0.14	0.02				
CIM	0.45	<0.001		0.31	11	<0.001
Age	0.00	0.99				
Time since injury		0.18				
<i>Physical</i>						
			0.52			
Neuro 1	0.13	0.04				
Neuro 2	0.06	0.32				
SCSI	-0.68	<0.001		-0.60	39	<0.001
mFIM	0.30	<0.001				
CIM	0.34	<0.001		0.17	6	<0.001
Age	-0.07	0.24				
Time since injury	0.04	0.53				
<i>Psychological</i>						
			0.37			
Neuro 1	0.08	0.21				
Neuro 2	-0.08	0.21				
SCSI	-0.47	<0.001		-0.38	19	<0.001
mFIM	0.08	0.18				
CIM	0.45	<0.001		0.35	16	<0.001
Age	0.01	0.94				
Time since injury	0.09	0.13				
<i>Social relationships</i>						
			0.23			
Neuro 1	0.04	0.56				
Neuro 2	0.02	0.78				
SCSI	-0.28	<0.001		-0.20	5	<0.001
mFIM	0.02	0.77		-0.16	3	<0.01
CIM	0.41	<0.001		0.37	15	<0.001
Age	-0.06	0.32				
Time since injury	-0.01	0.88				
<i>Environment</i>						
			0.38			
Neuro 1	0.10	0.09				
Neuro 2	0.03	0.59				
SCSI	-0.50	<0.001		-0.40	20	<0.001
mFIM	0.21	<0.01				
CIM	0.45	<0.001		0.32	15	<0.001
Age	0.05	0.41				
Time since injury	0.05	0.41				

Abbreviations: CIM, Community Integration Measure; mFIM, motor subscale of the Functional Independence Measure; QOL, quality of life; SCS, spinal cord injury; SCS, Secondary Conditions Surveillance Instrument.

semi-partial correlation ($sr=0.31$, <0.001) and was responsible for 11% of the variance indicating that it is also a strong predictor for QOL. Figure 2 illustrates the comparative importance of each factor entered into the regression equation expressed using β -weights that represent the change in QOL (WHOQOL-8) associated with a one unit

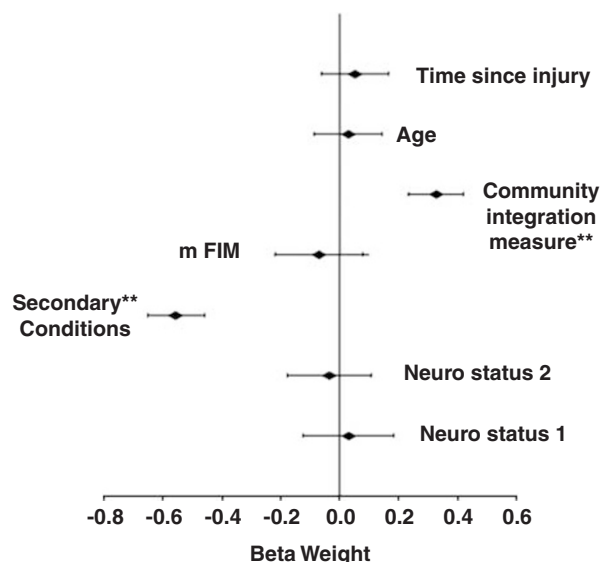


Figure 2 Relationships between quality of life (QOL) (World Health Organization Quality of Life Assessment Instrument, WHOQOL-8) and disability: comparative importance of regression analysis factors expressed using β -weights. **Significant at <0.01 .

change in the individual component of disability with all other factors held constant.

Discussion

Consistent with previous reports, QOL for people with SCI in Queensland was significantly lower than the Australian norm.^{2,17} QOL was significantly associated with all components of disability with the exception of primary impairments (level and completeness of injury). The single most important predictor of QOL was the presence of secondary conditions whereas the second most important predictor was the extent of societal participation.

Some methodological limitations of the current study must be noted. First, restricting inclusion to people who could be contacted and who had access to the telephone may have led to some selection bias. In addition, some potential participants may have lacked the time to participate due to work or family responsibilities. For some, age-related changes may have occurred that were expected and so were not viewed negatively. Changes in perceived QOL may have resulted from 'response shift' or a re-framing of expectations or adapting to life events hypothesized to impact on QOL.¹⁸ It is also likely that those potential participants who had died would have had a very different ageing experience from the study participants.¹⁰ Finally, it is important to acknowledge that these results cannot be generalized to the SCI population as the study sample was drawn from incomplete archival records of people from only one geographical area. In addition, the sample consisted of a greater percentage of people with a higher level of neurological impairment when compared to those who chose not to participate and to the overall sample from which they were drawn. Further

investigations with a number of samples from different geographical areas in Australia will be required before generalizations to the SCI population can be made.

Consistent with other studies,^{2,17,19} findings indicate that QOL for the average person with SCI is lower than the general population norm, irrespective of age or time since injury. Although the differences in QOL were statistically significant, interpreting the clinical significance of these findings is perhaps more challenging and inherently subjective.²⁰ Effect sizes may be taken to reflect the clinical significance of differences across domains. The largest effect size is for the physical domain, which is not surprising given the physical nature of SCI. Moderate effect sizes evident for the social relationships and psychological domains highlight that these domains of QOL remain important to consider in the rehabilitation context. The smallest effect size for the environment domain suggests that individuals may have made significant environmental modifications to address potential difficulties in this area, although this proposition requires further investigation. The findings highlight the central importance of QOL following SCI, as both a goal and outcome of rehabilitation, and support the need to identify how hospital and community rehabilitation services can best address QOL issues.²¹

Findings with respect to the relationship between QOL and disability were also consistent with previous studies,^{4,22} providing confirmation that the experience of SCI in Australia is comparable to other Western nations. QOL was related to impairments (secondary but not primary), activity limitations and participation restrictions, irrespective of an individual's age or time since injury.

Secondary impairments (for example neuropathic pain, urinary tract infection) were found to have the greatest impact on QOL, in keeping with previous studies.^{22,23} Although significant attention has been given to the prevention and management of secondary conditions to prevent hospital re-admission,²⁴ these findings underline the need for continued efforts to reduce both the incidence and the impact of these conditions on QOL.

Societal participation was also a significant predictor for QOL, as has been previously reported.²⁵ Of concern, however, is that many rehabilitation services continue to focus their day-to-day service delivery on impairments and activity limitations with less emphasis on participation.²¹ These findings prompt the need for both hospital and community rehabilitation services to place greater emphasis on assessment and intervention related to social participation, particularly on enhancing factors that facilitate participation and overcoming barriers that impede participation.

Conclusion

QOL for people with SCI was found to be lower than for their able-bodied peers, confirming the need to more effectively address QOL as a goal for hospital and community rehabilitation services. Rehabilitation services must employ improved methods to address the most common and most disabling secondary conditions while at the same time

maintaining the focus on functional attainment and providing greater attention to enabling participation. Research is required to identify and investigate the individual factors that influence each of these dimensions of disability.

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