

## ORIGINAL ARTICLE

# The relationship between and predictors of quality of life after spinal cord injury at 3 and 15 months after discharge

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**Study design:** Longitudinal study.

**Objectives:** To examine the relationship between and predictors of quality of life (QOL) at 3 and 15 months post-rehabilitation discharge using the Disability Creation Process model as an explanatory framework.

**Setting:** Vancouver, Canada.

**Methods:** A consecutive sample of individuals with spinal cord injury (SCI) was enrolled in the study. Data were collected using the Quality of Life Index (QLI) and a variety of personal, participation and environmental instruments. On admission, 197 subjects were recruited, but dropouts and missing values led to the final inclusion of 93 cases in multiple regression models used to identify predictors of QOL at 3 and 15 months post-rehabilitation discharge.

**Results:** Mean QLI group scores did not differ between 3 and 15 months ( $P=0.85$ ). Regression models accounted for 64% of variance in QLI total scores at 3 months and 70% of variance at 15 months. The main predictors of QOL at 3 months were health competence and mood state. The main predictors of QOL at 15 months were QOL level at 3 months, health competence and family support. At both time points, personal factors explained most of the variance, whereas participation and environmental factors were less significant.

**Conclusion:** Given that health competence, mood state and some environmental factors may be amenable to modification, this study suggests interventions to mediate these variables might improve subjective QOL after SCI.

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**Keywords:** Disability Creation Process; quality of life; participation; environmental factors

## Introduction

Limited knowledge exists regarding how well-being changes and what factors influence it after spinal cord injury (SCI). Although a number of studies have explored how personal factors are associated with subjective quality of life (QOL), few have included environmental and personal factors in the same analysis and even fewer have been longitudinal in nature. As a systematic model of human development, the Disability Creation Process (DCP)<sup>1</sup> represents a good holistic approach to frame predictors of QOL after SCI. According to the DCP, participation, which encompasses an individual's life habits, results from and contributes to a dynamic interaction between intrinsic personal characteristics (that

include organ systems and physical and cognitive capabilities) and environmental attributes.

As suggested by this model a variety of personal, participation and environmental factors separately demonstrate significant associations with subjective measures of QOL. Although personal factors such as current age, age at injury, time since injury, and lesion level demonstrate only weak correlations,<sup>2</sup> other personal factors such as self-assessed health,<sup>3</sup> perceived control<sup>3</sup> and functional ability<sup>2</sup> demonstrate more moderate associations. Variables such as mobility, income, marital status, pain and presence of secondary complications demonstrate significant correlations with QOL.<sup>3</sup> General self-efficacy has also been identified as an important predictor of QOL.<sup>4</sup> Dijkers' meta-analysis found mild to moderate correlations between participation limitation and subjective well-being depending on the social role/domain.<sup>2</sup> Environmental variables—including social support, place of residence and

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accessibility—have also been correlated with subjective well-being.<sup>3</sup>

Whiteneck *et al.*<sup>5</sup> explored the combined impact of personal, participation and environmental factors. This cross-sectional study found that environmental factors accounted for 10% and participation factors accounted for 15% of the variation in life satisfaction scores when considered individually. When all variables were analyzed together, including those related to demographics and health, 26% of the variation in QOL scores was accounted for and participation and environmental factors appeared to make a significant contribution.

Our study was undertaken to address both the lack of longitudinal studies of predictors of QOL in individuals with SCI and the limited research exploring the combined impact of personal, participation and environmental factors. Using the DCP as an explanatory framework this project was intended to:

- (1) Examine the relationship between QOL scores at 3 and 15 months post-rehabilitation discharge, and
- (2) Identify the predictors of QOL at 3 and 15 months post-rehabilitation discharge.

We hypothesized that variables from the personal and environmental and participation domains of the DCP would be significant predictors of QOL scores at both time points.

## Materials and methods

As part of a larger study on rehabilitation outcomes, a consecutive sample of individuals with SCI was assessed at 3 and at 15 months post-rehabilitation discharge on various parameters (for example, secondary impairments, physical and mental capabilities, participation, perceived influence of the environment, subjective QOL). Individuals were eligible for inclusion if they had sustained a traumatic SCI, but were excluded from the study if they had a concomitant diagnosis of traumatic brain injury or a psychiatric disorder. The sample included individuals who sustained a traumatic SCI between September 1999 and June 2003, were admitted into one of two SCI rehabilitation centers and who consented to participate to the research. Overall, a sample of 197 participants was recruited. Only 15.6% of potential participants admitted to rehabilitation did not consent to participate. At the first and second follow-ups, 27 (13.7%) and 50 (25%) participants were lost to follow-up for various reasons including transportation or health-related issues, return to previous occupation, refusal and death.

### Measures

The independent variables selected for the study are presented according to the components of the DCP model. These measures were selected based on their conceptual coverage and robust psychometric properties. For all these measures, higher values indicate greater amounts of the construct being measured (for example, better mood, more pain and so on).

### Personal factors

*Medical and demographic information.* Demographic information included sex, age, marital status, income (in \$5000 increments) and education (years). Medical information included type of paralysis, presence of secondary complications and American Spinal Injury Association (ASIA) impairment scale scores.<sup>6</sup>

*Mood.* Mood was measured using the Profile of Mood States (POMS), a 65-item scale that measures mood in seven negative affective states (for example, depression–dejection, tension–anxiety and so on). Test–retest Pearson's correlation coefficients range from 0.68 to 0.83 across mood states and its domains demonstrate concurrent validity with measures of similar constructs.<sup>7</sup>

*Pain.* To measure pain, two subscales of the Multidimensional Pain Inventory (MPI) were used: pain interference and severity. Test–retest scores on these subscales range from 0.86 to 0.82 and its domains are correlated as hypothesized with related measures.<sup>8</sup>

*Functional ability.* Functional independence was measured using the Function Independence Measure (FIM) that covers two domains of motor and cognitive functions, confirmed with factor analyses from data from over 90 000 patients from 20 impairment groups.<sup>9</sup> A meta-analysis of FIM reliability studies found a median interrater reliability of 0.95 and a median test–retest reliability of 0.95.<sup>10</sup>

*Self-efficacy.* General self-efficacy, a measure of belief in ability to cope with life events, was measured using the 10-item General Self-Efficacy scale, which demonstrates high internal consistency ( $\alpha=0.86$ ) unidimensionality and construct validity.<sup>11</sup>

*Health competence.* The Perceived Health Competence scale was used to measure subjective health behavior competence. The 1-week test–retest reliability is 0.82 and it demonstrates construct validity as it is moderately correlated with measures of self-rated health, pain and psychological distress.<sup>12</sup> Examples of questions include 'It is difficult for me to find effective solutions to the health problems that come my way,' and 'I'm generally able to accomplish my goals with respect to my health.'

*Optimism.* Personal optimism was measured using the 8-item Life Orientation Test. Test–retest reliability is 0.79 and construct validity is indicated by its inverse correlation with perceived symptom severity.<sup>13</sup>

### Participation

Participation was assessed using the Assessment of Life Habits (LIFE-H 3.0). This measure evaluates 69 life habits from 12 domains: nutrition, fitness, personal care, communication, housing, mobility, responsibilities, interpersonal relationships, community life, education, employment and recreation. Test–retest reliability of  $r=0.95$  has been

reported<sup>14</sup> and it demonstrates concurrent and discriminant validity.<sup>15</sup> Following standard scoring algorithms for this measure, scores for the first and last six domains were averaged to create a daily activity score, and a social role score, respectively.

#### *Environmental factors*

*Quality of the environment.* Environmental barriers and facilitators were measured using the Measure of the Quality of the Environment (MQE) comprising 109 items covering 23 domains. Concordance tests from two studies found that 87 and 85% of items had 60% or greater concordance between Time 1 and Time 2.<sup>16</sup> To determine its domain structure we performed principal component analysis on the 3-month MQE results. A four-factor solution was the best fit for the data. Using varimax rotation and retaining variables with loadings  $>0.434$ , we identified four domains: (1) physical and social barriers (accessibility, traffic, social rules and so on); (2) physical facilitators (climate, accessibility, assistive technology and so on); (3) community social facilitators (public services, social organization and so on) and (4) personal social facilitators (social networks, attitudes of others and so on).

*Perceived social support.* Perceived emotional social support was measured using the 20-item Perceived Social Support (PSS) scales (Family (Fa) and Friend (Fr)). Internal consistency ranged from 0.88 to 0.91 for the PSS-Fa and 0.84 to 0.90 for the PSS-Fr and construct validity is demonstrated given its correlations with psychological distress and social competence.<sup>17</sup>

The dependent outcome variable, subjective QOL, was measured using QOL Index (QLI). The QLI has 32 items that cover four domains: health and functioning, socioeconomic, psychological and spiritual, and family. Satisfaction scores are multiplied by importance scores for each item, and these products are summed and divided by the total number of items to create a total score for the test. Test-retest reliability scores for each domain range from  $r=0.81$  to  $0.87$ .<sup>18</sup> Factor analysis confirmed the four-domain structure of the measure,<sup>19</sup> and concurrent validity has been shown by strong correlations between the QLI and other life satisfaction assessments.<sup>18,19</sup> Although a SCI-specific version of the tool now exists,<sup>20</sup> it was unavailable when this longitudinal study commenced. The total score was used for analysis in this study.

#### *Protocol*

Supervised by a research coordinator, therapists were formally trained to administer the tools according to a standardized protocol. The research protocol was approved by the research ethics committee of the rehabilitation centers participating in the study.

#### *Analyses*

Summary statistics were calculated for all variables so that we could describe the sample. Income was treated as a continuous variable for analytic purposes as there were 13

categories. To assess objective one, a paired sample *t*-test was conducted to identify any statistical change in QOL between 3 and 15 months after discharge. To better understand change in QOL at 3 and 15 months, we organized participants into three groups: improved ( $\geq 3$  point increase in QLI scores), stable (change in scores between  $\pm 3$ ) or deteriorated ( $\geq 3$  point decrease in QLI scores). A three-point difference was selected to make this categorization as this exceeded by 1 the standard error of measurement of 2.00 we calculated for the QLI, based on published reliability data<sup>18</sup> and QLI scores from our study. Multivariable multiple regression analyses were conducted to address the second objective. Here we evaluated whether personal, environmental and participation factors independently predicted QOL at 3 and 15 months. Given the large number of variables it was decided *a priori* to only include predictor variables that had a bivariable statistical relationship with the dependent variable (QLI) for the regression modeling of the personal factors and environmental factors domains of the DCP. The daily activity and social roles subscales were selected *a priori* to represent the participation domain of the DCP. For categorical variables, independent sample *t*-tests and analyses of variance were used to determine any statistically significant ( $P<0.05$ ) differences between these variables and QOL. For continuous variables, Pearson's correlations were calculated to identify any associations of interest. Only correlations with  $r>0.25$  between the independent and dependent variables were included in the regression models. As intercorrelation of  $>0.75$  between the independent variables suggests the presence of collinearity, which destabilizes regression models,<sup>21</sup> we only included the collinear variable with the strongest first-order correlation in the modeling.

A hierarchical regression approach was used to enable us to examine the separate contribution of the DCP factors. Variables within each DCP factor (participation, environmental and personal factors) were entered as blocks. This order was chosen *a priori* to highlight the contribution of the first two DCP domains to QOL scores, before adding personal factors. At 15 months, QOL at 3 months was entered as the last block in the regression model so that changes in other domains could be better stood over time, as the models included the same variables until that point. Outliers who had negative residuals that were more than three standard deviations from the mean were not included. Missing cases were excluded list-wise and the same individuals were compared at both time points. We compared subjects included in the regression analyses and those who we excluded to identify differences in the samples. SPSS 15 (Chicago, IL, USA) was used for all statistical analyses.

## Results

There were 93 subjects with complete data at both times on variables used in the regression analysis and results for this sample only were included in the analyses. Most participants were men (89%) and common causes of injury were car accident (44%), falls (43%), violence (4%) and sports injury

(9%). ASIA scores, place of residence and number of participants living alone are described in Table 1. No differences in means were identified between these categorical demographic variables and the QOL scores at either 3 or 15 months.

**Table 1** Categorical variables at 3 and 15 months after discharge

Variables	3 months			15 months		
	N	N per category	%	N	N per category	%
<i>Categorical personal factors</i>						
Married/Common-law vs living alone	93	50	53.8	93	48	51.6
<i>ASIA Score</i>						
ASIA A	93	28	30.1	93	28	30.1
ASIA B	93	11	11.8	93	11	11.8
ASIA C	93	11	11.8	93	9	9.7
ASIA D	93	43	46.2	93	44	47.3
ASIA E	93	0	0.0	93	1	1.1
<i>Place of residence</i>						
House	93	55	59.1	93	64	69.6
Cooperative	93	1	1.1	93	1	1.1
Apartment	93	19	20.4	93	19	20.7
Condominium	93	2	2.2	93	2	2.2
Long-term care center	93	3	3.2	93	2	2.2
Other	93	13	14.0	93	4	4.3

Abbreviation: ASIA, American Spinal Injury Association.

On average, participants were 39 years of age at 3 months post-discharge, had 11 years of education and earned between Can\$25 000 and Can\$29 999 as noted in Table 2. Subjects included in the regression models were similar to those excluded on most study variables, but did have significantly higher FIM motor scores, less secondary complications and lower POMS scores.

For objective one, no significant difference was noted when average QOL scores were compared at 3 and 15 months ( $t = -0.19, P = 0.85$ ). Among changes in QOL for individuals, 15 (16.1%) of participants improved (>3 point improvement), 80 (67.7%) remained stable (-3 to +3 points) and 15 (16.1%) regressed (>3 point decline).

Correlations between continuous variables and QOL at 3 and 15 months are presented in Table 3. Overall, the magnitude of correlations between QOL and participation and environmental variables tended to be lower than for psychological personal factors. The strength of the correlations between QOL and some environmental dimensions changed substantially between these two time points. For example, correlations between QOL and family support increased from  $r = 0.274$  to  $r = 0.513$ .

Collinearity between several variables was evident and restricted those that could be included in the regression models. Because of high intercorrelations between the POMS domains, only the POMS total score was used. Moreover, because of high collinearity between FIM motor scores and

**Table 2** Continuous variables at 3 and 15 months after discharge

Continuous variables	3 months					15 months				
	N	Mean	s.d.	Min	Max	N	Mean	s.d.	Min	Max
<i>Personal factors</i>										
Income	87	6.05	3.53	1.00	14.00	89	5.83	3.44	1.00	14.00
Age	93	39.53	14.78	18.00	78.00	93	40.61	14.77	19.00	79.00
Education	93	11.38	3.11	2.00	18.00	93	11.26	3.30	2.00	18.00
Secondary impairment	93	0.37	0.64	0.00	3.00	93	0.40	0.78	0.00	3.00
FIM motor	85	75.88	15.78	13.00	91.00	86	75.98	16.67	18.00	91.00
Optimism	93	17.92	3.79	9.00	24.00	93	17.75	3.60	7.00	24.00
Health competence	93	3.75	0.74	1.25	5.00	93	3.69	0.76	1.10	5.00
Self-efficacy	93	33.02	5.36	10.00	40.00	93	33.81	4.70	17.00	40.00
POMS (total)	93	17.27	40.46	-29.00	171.00	93	14.03	32.97	-32.00	139.00
MPI interference	93	2.45	1.71	0.00	5.88	93	2.34	1.77	0.00	6.00
MPI severity	93	2.62	1.57	0.00	6.00	93	2.67	1.71	0.00	6.00
<i>Participation factors</i>										
Daily activities	93	7.71	1.29	3.60	10.00	93	7.98	1.23	4.77	10.00
Social roles	93	7.72	1.34	3.61	10.00	93	8.10	1.39	3.08	10.00
<i>Environmental factors</i>										
PSS (friend)	93	41.69	12.98	0.00	60.00	93	42.54	13.07	0.00	60.00
PSS (family)	93	45.49	12.04	6.00	60.00	93	45.62	12.02	0.00	60.00
<i>MQE</i>										
Physical barriers	93	8.75	5.64	0.00	21.00	93	10.54	5.73	0.00	34.00
Physical facilitators	93	7.65	6.11	0.00	24.00	93	9.08	7.31	0.00	30.00
Community social facilitators	93	4.87	3.62	0.00	15.00	93	5.34	3.33	0.00	13.00
Personal social facilitators	93	6.63	3.80	-3.00	14.00	93	6.05	4.18	-7.00	14.00
<i>Quality of Life</i>										
Total QLI	93	19.62	4.35	8.15	28.55	93	19.69	4.59	8.78	30.00

Abbreviations: FIM, Functional Independence Measure; MPI, Multidimensional Pain Inventory; MQE, Measurement of the Quality of Environment; POMS, Profile of Mood State; PSS, Perceived Social Support; QLI, Quality of Life Index.

LIFE-H daily activities, the former variable was not included in the regression modeling because it had lower first-order correlations. Likewise, pain interference was selected rather than pain severity in both regression models.

The results from the regression models at 3 and 15 months are presented in Tables 4 and 5. At 3 months, the inclusion of

**Table 3** Pearson's correlations between personal, participation and environmental factors and total QLI scores at 3 and 15 months after discharge

	QOL 3 months		QOL 15 months	
	R	P-value	r	P-value
<i>Personal factors</i>				
Age	0.080	0.444	0.025	0.809
Income	0.212	0.048	0.053	0.621
Education	0.136	0.194	0.024	0.818
Number of secondary impairments	-0.088	0.402	-0.141	0.179
FIM motor	0.154	0.160	0.201	0.063
Optimism	0.654	0.000	0.559	0.000
Health competence	0.729	0.000	0.626	0.000
Self-efficacy	0.618	0.000	0.465	0.000
POMS (total)	-0.734	0.000	-0.635	0.000
MPI interference	-0.440	0.000	-0.425	0.000
MPI severity	-0.272	0.008	-0.217	0.036
<i>Participation factors</i>				
Daily activities	0.266	0.010	0.288	0.005
Social roles	0.307	0.003	0.363	0.000
<i>Environmental factors</i>				
PSS (friend)	0.464	0.000	0.328	0.001
PSS (family)	0.274	0.008	0.513	0.000
<i>MQE</i>				
Physical barriers	-0.235	0.023	-0.237	0.022
Physical facilitators	-0.059	0.575	0.022	0.831
Community social facilitators	-0.008	0.936	-0.045	0.671
Personal social facilitators	0.133	0.202	0.226	0.029

Abbreviations: FIM, Functional Independence Measure; MPI, Multidimensional Pain Inventory; MQE, Measurement of the Quality of Environment; POMS, Profile of Mood State; PSS, Perceived Social Support; QLI, Quality of Life Index; *r*, Pearson's correlation coefficient.

participation and environmental factors resulted in a modest amount of explained variance, but the adjusted  $r^2$  increased dramatically in the third step with the addition of personal factors. Although the variables entered at each step produced a significant change in  $r^2$  ( $P \leq 0.05$ ), ultimately health competence and mood state were the only significant predictors of QOL at 3 months in the final model (third step).

The variance explained at 15 months was greater than that explained at 3 months ( $r^2 = 0.70$  and  $0.64$ , respectively). Although the relative contribution of the DCP factors was similar at 15 months (that is, the variance explained was greatest for personal factors), the contribution of environmental factors seemed more important at this time point as family support was a significant independent predictor in the final regression model. Variables entered at each step produced a significant change in  $r^2$  ( $P \leq 0.05$ ).

### Discussion

This research is the only known published longitudinal study that examined the impact of personal, participation and environmental factors on QOL in individuals with SCI early after discharge from rehabilitation. Mean QLI scores were similar to those obtained for a sample of individuals with SCI with an average time since injury of 15.5 years, using the SCI version of the QLI<sup>20</sup> (21.01 (s.d. = 4.27) compared with 19.62 (s.d. = 4.35) in our study).

In terms of study objective one, there was no significant difference in QOL over time, as over two-thirds of subjects had change scores of between -3 and +3. The lack of difference in QOL between 3 and 15 months contributes to the ongoing discussion in this area. The findings are similar to those of Kennedy and Rogers,<sup>22</sup> who found no significant difference between QOL scores at 1 month and 6 months after discharge with a similar sample of individuals with SCI. The findings could indicate that either a response shift has already occurred for some participants, in that they

**Table 4** Regression models of predictors of total QLI scores at 3 months post-discharge (N = 93)

Steps	1 (Participation factors)					2 (Environmental factors)					3 (Personal factors)				
	$\beta$	s.e.	S $\beta$	LB	UB	$\beta$	s.e.	S $\beta$	LB	UB	$\beta$	s.e.	S $\beta$	LB	UB
(Constant)	<b>10.706</b>	<b>2.855</b>		<b>5.033</b>	<b>16.378</b>	<b>5.831</b>	<b>2.873</b>		<b>0.122</b>	<b>11.540</b>	3.031	3.473		-3.875	9.938
Daily activities	0.402	0.432	0.120	-0.456	1.261	0.595	0.393	0.177	-0.187	1.376	0.495	0.278	0.147	-0.059	1.049
Social roles	0.753	0.418	0.232	-0.077	1.583	0.127	0.400	0.039	-0.668	0.923	0.065	0.281	0.020	-0.494	0.624
PSS (friend)						<b>0.130</b>	<b>0.032</b>	<b>0.387</b>	<b>0.066</b>	<b>0.194</b>	0.009	0.027	0.026	-0.045	0.062
PSS (family)						0.062	0.034	0.172	-0.006	0.129	0.025	0.024	0.069	-0.024	0.073
Optimism											0.205	0.112	0.179	-0.018	0.428
Health competence											<b>1.546</b>	<b>0.632</b>	<b>0.265</b>	<b>0.289</b>	<b>2.804</b>
Self-efficacy											0.062	0.075	0.077	-0.087	0.211
POMS (total)											<b>-0.034</b>	<b>0.012</b>	<b>-0.316</b>	<b>-0.057</b>	<b>-0.011</b>
MPI interference											-0.066	0.195	-0.026	-0.453	0.321
Cumulative Adj $r^2$			0.08					0.25					0.64		
Adj $r^2$ change per step			0.08					0.17					0.39		

Abbreviations: LB, lower 95% confidence interval for  $\beta$ ; MPI, Multidimensional Pain Inventory; MQE, Measurement of the Quality of Environment; POMS, Profile of Mood State; PSS, Perceived Social Support; QLI, Quality of Life Index; S $\beta$ , standardized  $\beta$ ; s.e., standard error; UB, upper 95% confidence interval for  $\beta$ . Boldface signifies values at  $P \leq 0.05$ .



include facilitating social support, treating mood issues and improving health competence. Based on the findings of the study, it might be suggested these interventions would have a positive impact on the self-perceived QOL of individuals with SCI.

#### Strengths and limitations

Longitudinal collection of personal, participation and environmental data represents one of the primary strengths of this study. Loss of subjects over time is a limitation. As those included in the regression analyses were more functionally independent, had less secondary complications and had fewer mood issues, the predictors identified in this sample may not be the same for those that we excluded. Although this study found that participation and environmental factors had less effect on QOL than personal factors, this may be an artifact of the imperfect tools used to measure these constructs.<sup>2,5</sup> Finally, without normative data for the QLI, it is impossible to determine if participants were already at normal values for their QLI scores, which would create a ceiling effect for these scores.

#### Conclusion

This longitudinal study, which was informed by the DCP, has identified personal, environmental and participation variables that predict QOL in individuals with SCI at 3 and 15 months after discharge. The results provide some validation for the DCP, although the participation, measured in terms of performance, was only a moderate predictor of QOL. This study identified a variety of factors affecting QOL that may be amenable to intervention on a clinical or societal level. As part of an ongoing study, additional data points have already been collected; these will be compared with the current findings to explore the stability of these models over time.

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