



## Quality of life of spinal cord injured patients in Taiwan: a subgroup study

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The major purposes of this study were to assess the quality of life (QOL) of spinal cord injured patients, and to assess the possible factors affecting the QOL. The survey was conducted from 1992–1993 by mailed questionnaires to members of Spinal Cord Injury Association of the Republic of China. There were 347 quality responses with the mean age of  $37.5 \pm 10.2$  years old and the mean duration of illness of  $7.8 \pm 6.8$  years. The questionnaire included five domains, physical mobility, environment-transportation, psychosocial adjustment, education, and economics for a total of 39 items. Each item contained a rating of 'importance' and 'satisfaction'. The quality of life index (QLI) was calculated by multiplying the satisfaction score with the importance score, then dividing by the possible highest score. The major results included: (1) the subjects had mild to moderate dissatisfaction with most items in five domains except psychosocial adjustment; (2) quality of life in those with complete tetraplegia (QLI =  $-0.41$ ) and incomplete tetraplegia (QLI =  $-0.31$ ) was significantly lower than that of those with complete paraplegia (QLI =  $-0.13$ ) and incomplete paraplegia (QLI =  $-0.04$ ); (3) both the severity of injury, and the post-injury working status were the major factors affecting the life quality of spinal cord injured patients in Taiwan.

**Keywords:** quality of life; spinal cord injury; Taiwan

### Introduction

The life expectancy of persons with spinal cord injury (SCI) has dramatically increased in the past 30 years due to the advancement of medical management.<sup>1</sup> As a result, many patients with a SCI are surviving to old age and live with a disability which has possibly some impact on their quality of life (QOL).<sup>2</sup> However, several studies have reported that the perceived quality of life of young and old SCI patients is relatively good.<sup>3–6</sup>

Previous studies have also reported information about factors affecting the quality of life of SCI patients. Siösteen *et al*<sup>6</sup> investigated 56 SCI's who were about 2.8 years post injury and found that their self-perceived life quality was not related to severity of disability. Cushman and Hassett<sup>3</sup> evaluated 43 SCI's who were 10 or 15 years post injury and said that neither the level nor the completeness of the injury significantly affected the perceived quality of life. However, they quantify the quality of life with perceived (subjective) quality of life with only one item rated by visual analog scale.

The quality of life is actually conceptualized in multidimensional terms and it has been hypothesized

to include four large evaluation sectors: behavioral competence, perceived quality of life, objective environment, and psychological well-being<sup>7</sup>. Recently, more researchers<sup>8–11</sup> have taken a broad perspective of life quality in terms of 'importance' and 'satisfaction' to include the following domains: physical functioning, emotional functioning, sexual functioning, education, social activities, recreation and economic status.

The exact number of SCI individuals in Taiwan is not known, because there is no national registry of them at this time. Previous epidemiological studies in Taiwan have shown that the incidence rate of those with traumatic SCI was 14.6 per million population in Taipei City, Taiwan, 1978–1981;<sup>12</sup> and the incidence rate in the Hualien rural-industrial area in Taiwan was 56.1 per million population, 1986–1990.<sup>13</sup> Now, the total population in Taiwan (Formosa Island) is 21 million and the estimated new SCI individuals is probably about 1000 persons/year. The official Spinal Cord Injury Association of the Republic of China (SCIAROC) was founded in 1990. The membership is increasing rapidly and has obtained approximately 1000 SCI's from different areas in Taiwan. This number is currently estimated to be only about 1/20 of the whole SCI population in Taiwan, and may represent some characteristics of SCI's who are interested to get in touch with others.

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The purposes of this study were to assess the overall quality of life in five domains, including physical mobility, environment-transportation, psychosocial adjustment, education and economics, and to analyze the factors affecting the life quality in those with a chronic spinal cord injury who are members of SCIAROC. Furthermore, it is reasonable to assume that great dissatisfaction with important items has a more negative impact on life than great dissatisfaction with unimportant items. Therefore, this study quantifies the quality of life in terms of importance and satisfaction.

## Methods

### Subjects

Subjects with chronic spinal cord injury were randomly selected from the Spinal Cord Injury Association of the Republic of China (SCIAROC), which recruited approximately 1000 members from different areas in Taiwan. The survey was conducted from December 1992 to June 1993 by mailed questionnaires. The criteria of the subjects were: (1) injured at least one year, and (2) at least 20 years old. There were 347 quality responses (e.g., 179 responses from urban areas and 168 responses from rural areas) with a sample size of 528 subjects, and a response rate of 66%. The major reasons for missing correspondences were: (1) changing the address or phone number; (2) being ill and staying in hospital for treatment; (3) not interested in the issue of quality of life; (4) did not know how to answer. The subjects were not followed up in Rehabilitation Clinics regularly, and most of them came to the clinic only for medication. In this study, the SCI subjects were classified as having complete tetraplegia (CT), incomplete tetraplegia (IT), complete paraplegia (CP), and incomplete paraplegia (IP) according to the classification of ASIA.<sup>14</sup>

### Questionnaires

The questionnaires included three parts: (1) basic data, (2) quality of life assessment, and (3) the suggestions. To further understand the characteristics of this subject, the basic data also contained a multiple choice of questions, such as: the most troublesome complication, and the major device for locomotion following spinal cord injury.

The quality of life questionnaires were constructed according to previous assessment tools, and those questionnaires were modified by the authors to reflect the situations of SCI's in Taiwan. The questionnaires of QOL assessment included five domains: (1) physical mobility, (2) environment-transportation, (3) psychosocial adjustment, (4) education and (5) economics. Totally, thirty-nine items were included in the QOL assessment and each item contained 'importance' and 'satisfaction' evaluation.<sup>9</sup>

The 14 items of physical mobility were listed according to the Modified Barthel Index<sup>15</sup> which was valid and reliable for functional impairment assessment. The 12 items of psychosocial adjustment were listed according to the Psychosocial Adjustment to Illness Scale (PAIS),<sup>16,17</sup> and the suggestions of Trieschmann.<sup>18</sup> The items in environment, education, and economics were listed according to the current social-economic situations in Taiwan. The questionnaires had been tested on 6 subjects prior to this survey to eliminate any improper questions.

### Quality of life index (QLI)

As suggested by Ferrans and Powers<sup>9</sup> this study quantified the life quality by calculating the quality of life index (QLI) which was obtained from multiplying the raw score of importance by the recorded score of satisfaction, and the product was divided by the possible highest score. The range of QLI would be between '+1' and '-1', and '+1' indicated the highest level of life quality. The formula of calculating QLI is shown as follows.

$$QLI = \frac{(\text{Importance Raw Score} \times \text{Satisfaction Recorded Score})}{5 \times 7}$$

The reason to recode the satisfaction score was to distinguish the very satisfied items with low importance from those of the very dissatisfied items with high importance.

Subjects responded to each item on a five-point scale ranging either from 'very important' to 'very unimportant' for the importance items, and from 'very satisfied' to 'very dissatisfied' for the satisfaction items. Score '5' indicated very important or very satisfied; score '4' indicated quite important or quite satisfied; score '3' indicated just feel fine (no special preference); score '2' indicated quite unimportant or quite dissatisfied; and score '1' indicated very unimportant or very dissatisfied. The five to one points were the raw score of importance and satisfaction. It was reasonable to assume that a subject who had great dissatisfaction with important items would get more negative QLI than a subject who had great dissatisfaction with unimportant items. Therefore, the scoring procedures of QLI in each person included: (1) to recode a satisfaction score by centering the score '3' on zero; then adding or subtracting 3.5 to the center score for each item, so that '5', '4', '3', '2', '1' was recorded as '+7', '+3.5', '0', '-3.5', '-7', respectively; (2) to obtain the score of each item by multiplying the raw importance score with the 'recorded satisfaction score', then dividing by 35 (e.g., 5 × 7); (3) to obtain the mean score of each domain (e.g., physical mobility etc.) in each person; (4) to obtain the overall QLI score of each person by summing the mean value of five domains then

dividing by five, so that each domain contributed 20% of the overall QLI (e.g., to eliminate the bias of uneven item numbers in each domain).

*Data analysis*

All the raw and recoded data were constructed in the DBASE IV. The statistical analysis was performed by SAS and SPSS/PC. The demographic data were calculated by Crosstabs to obtain frequency and percentage. The one-way ANOVA and Newman-Keuls test were performed to determine the significance of difference in QLI among tetraplegic and paraplegic individuals. The split-half test of each questionnaire was examined by SPSS for the internal reliability, and the correlation coefficient was 0.6 ( $P < 0.05$ ). The stepwise multiple regression analysis was used to analyze the possible factors affecting the life quality. The statistical significance was set at  $P < 0.05$ .

**Results**

*Basic data*

The descriptive measurements of the subjects which indicated the condition at the time of survey are shown in Tables 1, 2 and 3. The characteristics of the patients at survey time are summarized in Table 1. In this survey, the ratio of complete vs incomplete injury was 2.8, and the ratio of male vs female was 5.9. The mean age of the total sample was  $37.5 \pm 10.2$  (mean  $\pm$  standard deviation) years old (ranges: 20–71 y.o.), and there was no significant difference in age among those with complete tetraplegia ( $38.0 \pm 10.2$  y.o.), incomplete tetraplegia ( $35.3 \pm 9.0$  y.o.), complete paraplegia ( $37.2 \pm 10.1$  y.o.) and incomplete paraplegia ( $39.2 \pm 11.6$  y.o.). The mean duration of illness was  $7.8 \pm 6.8$  years (mean  $\pm$  standard deviation), and there was no significant difference in duration among those with complete tetraplegia ( $7.3 \pm 6.1$  years), incomplete tetraplegia ( $6.2 \pm 7.0$  years), complete paraplegia

**Table 1** The characteristics of subjects ( $n = 347$ )

	CT No. (%)	IT No. (%)	CP No. (%)	IP No. (%)	Total No. (%)
Subject	71 (20.5)	41 (11.8)	185 (53.3)	50 (14.4)	347 (100)
Sex					
Male	62 (17.9)	35 (10.1)	157 (45.2)	42 (12.1)	296 (85.3)
Female	9 (2.7)	6 (1.7)	28 (8.1)	8 (2.3)	51 (14.7)
Age (y.o.)					
20–39	42 (12.1)	30 (8.6)	115 (33.1)	27 (7.2)	214 (61.7)
40–59	26 (7.5)	10 (2.9)	66 (19.0)	21 (6.1)	123 (35.4)
60–79	3 (0.9)	1 (0.3)	4 (1.2)	2 (0.6)	10 (2.9)
Duration of Illness (year)					
1.0–5.0	35 (10.1)	26 (7.5)	86 (24.8)	28 (8.1)	175 (50.4)
5.1–10.0	19 (5.5)	10 (2.9)	41 (11.8)	13 (3.7)	83 (23.9)
> 10.0	17 (4.9)	5 (1.4)	58 (16.7)	9 (2.6)	89 (25.7)
Etiology					
MVA	45 (13.0)	25 (7.2)	72 (20.7)	15 (4.3)	157 (45.2)
Fall	7 (2.0)	6 (1.7)	53 (15.3)	9 (2.6)	75 (21.6)
Working injury	4 (1.2)	2 (0.6)	29 (8.4)	10 (2.9)	45 (13.0)
Sports injury	9 (2.6)	2 (0.6)	2 (0.6)	1 (0.3)	14 (4.0)
Others	6 (1.7)	6 (1.7)	29 (8.4)	15 (4.3)	56 (16.2)
Distribution					
City	39 (11.2)	23 (6.6)	84 (24.2)	33 (9.5)	179 (51.6)
Rural area	32 (9.2)	18 (5.2)	101 (29.1)	17 (4.9)	168 (48.4)
Marital Status					
Single	33 (9.5)	16 (4.6)	89 (25.6)	23 (6.6)	161 (46.4)
Married	30 (8.6)	21 (6.1)	81 (23.3)	23 (6.6)	155 (44.7)
Divorced/Widow	8 (2.3)	4 (1.2)	15 (4.3)	4 (1.2)	31 (8.9)
Education Background					
< High school	37 (10.7)	20 (5.8)	80 (23.1)	22 (6.3)	159 (45.8)
High school ~ College	19 (5.5)	12 (3.4)	59 (17.0)	18 (5.2)	108 (31.1)
≥ College	15 (4.3)	9 (2.6)	46 (13.2)	10 (2.9)	80 (23.1)
Employment					
Full-time	3 (0.9)	3 (0.9)	45 (13.0)	16 (4.6)	67 (19.3)
Part-time	2 (0.6)	3 (0.9)	25 (7.2)	6 (1.7)	36 (10.4)
Unemployment	66 (19.0)	35 (10.1)	115 (33.1)	28 (8.1)	244 (70.3)

CT: complete tetraplegia; IT: incomplete tetraplegia; CP: complete paraplegia; IP: incomplete paraplegia; MVA: motor vehicle accident

**Table 2** The occurring frequency of most bothering complication after spinal cord injury ( $n=347$ )

	CT No. (%)	IT No. (%)	CP No. (%)	IP No. (%)	Total No. (%)
Urinary problems	23 (6.8)	10 (2.9)	60 (17.6)	18 (5.3)	111 (32.0)
Spasticity	17 (5.0)	11 (3.2)	35 (10.3)	14 (4.1)	77 (22.2)
Numbness/Pain	11 (3.2)	13 (3.8)	40 (11.8)	13 (3.8)	77 (22.2)
Pressure sores	7 (2.1)	1 (0.3)	27 (7.9)	2 (0.6)	37 (10.7)
Contractures	6 (1.8)	3 (0.9)	9 (2.6)	1 (0.3)	19 (5.5)
Others	7 (2.0)	3 (0.9)	14 (4.0)	2 (0.5)	26 (7.4)

CT: complete tetraplegia; IT: incomplete tetraplegia; CP: complete paraplegia; IP: incomplete paraplegia

**Table 3** Major device for locomotion after spinal cord injury ( $n=347$ )

	CT No. (%)	IT No. (%)	CP No. (%)	IP No. (%)	Total No. (%)
Regular wheelchair	59 (17.0)	26 (7.5)	148 (42.7)	23 (6.6)	256 (73.8)
Electric wheelchair	12 (3.5)	3 (0.9)	3 (0.9)	0 (0.0)	18 (5.2)
Walker	0 (0.0)	2 (0.6)	3 (0.9)	3 (0.9)	8 (2.3)
Crutches	0 (0.0)	9 (2.6)	31 (8.9)	18 (5.2)	58 (16.7)
None	0 (0.0)	1 (0.3)	0 (0.0)	6 (1.7)	7 (2.0)

CT: complete tetraplegia; IT: incomplete tetraplegia; CP: complete paraplegia; IP: incomplete paraplegia

( $8.6 \pm 7.4$  years) and incomplete paraplegia ( $6.6 \pm 5.2$  years). Totally, 45.2% of subjects were injured in a motor vehicle accident (MVA) and 16.2% was due to non-traumatic injuries such as: tumor, spinal cord apoplexy, etc. There were 51.6% subjects who came from 16 urban areas and 48.4% subjects who came from rural areas. The married subjects were 44.7%, and the unemployment rate was 70.3%. Furthermore, 76.9% subjects had an educational background below college level. In Table 2, the most bothering complication was urinary problems, such as: urinary infection, bladder stone, etc. For locomotion, 73.8% SCI chose a regular wheelchair as the major device (Table 3).

#### Importance and satisfaction

By using the 5- to 1-point scale, the raw scores of importance and satisfaction of the subjects (347 questionnaires) are shown in Tables 4–8. The scores of importance were all above 3-point which indicated 'moderate important to very important'. However, the satisfaction scores varied according to the degree of concern and the severity of injury.

In physical mobility, the most important item was 'feeding yourself independently' and the most dissatisfied item was 'up-down stairs with device independently' (see total in Table 4). Generally, the satisfaction of those who were tetraplegic was less regarding physical mobility than that of those who were paraplegic (Table 4). In environment-transportation, the most important item was 'house-equipped with necessities' and the most dissatisfied item was 'bus equipped with necessities' (see total in Table 5). Most of the satisfaction scores in those with

tetraplegia was below '2' which indicated, 'very dissatisfied' (Table 5).

In psychosocial adjustment, the most important item was, 'having respect from your family and others' and the most dissatisfied item was, 'good sexual function' (see total in Table 6). Therefore, most of the satisfaction scores in those who were tetraplegic and paraplegic were above 3, which indicated, 'moderate to very satisfied' (Table 6).

In education, the most important item was, 'having vocational training' and the most dissatisfied item was, 'school providing special education for the disabled', (see total in Table 7). Totally, most of the satisfaction scores was around '2.5', which indicated 'moderate dissatisfied to feel fine' (Table 7).

In economics, the most important item was, 'having enough funding by government for assistive devices', and the most dissatisfied item, was 'having enough funding by government for environment or house remodeling' (see total in Table 8). In summary, most of the satisfaction score in those with tetraplegia and paraplegia was below '3' which indicated 'moderate to very dissatisfied' (Table 8).

#### Quality of life index (QLI)

After recoding the satisfaction score, the QLI was compared among those with complete tetraplegia, incomplete tetraplegia, complete paraplegia, and incomplete paraplegia. As shown in Figure 1, the QLI for complete tetraplegia ( $-0.41 \pm 0.29$ ), incomplete tetraplegia ( $-0.31 \pm 0.29$ ) were significantly ( $P < 0.05$ ) less than that of those with complete paraplegia ( $-0.13 \pm 0.25$ ) and incomplete paraplegia ( $-0.04 \pm 0.29$ ). The negative value of QLI indicated

that their quality of life was below the average (feel fine) level. If comparing the QLI of persons in urban areas ( $-0.18 \pm 0.30$ ,  $n=179$ ) to those in rural areas ( $-0.20 \pm 0.30$ ,  $n=168$ ) by Student t-test, there was no

significant difference. If comparing the QLI of persons with traumatic injury ( $-0.19 \pm 0.30$ ,  $n=291$ ) to those with a nontraumatic injury ( $-0.21 \pm 0.31$ ,  $n=56$ ), there was also no significant difference.

**Table 4** The raw score (mean  $\pm$  standard deviation) of importance (I) and satisfaction (S) in the aspect of physical mobility

		CT	IT	CP	IP	Total
1. Feeding yourself	(I)	4.76 $\pm$ 0.57	4.54 $\pm$ 0.71	4.61 $\pm$ 0.81	4.64 $\pm$ 0.80	4.64 $\pm$ 0.75
	(S)	2.28 $\pm$ 1.38	3.02 $\pm$ 1.33	4.33 $\pm$ 1.02	4.51 $\pm$ 0.82	3.78 $\pm$ 1.42
2. Wearing shirt by yourself	(I)	4.58 $\pm$ 0.65	4.32 $\pm$ 0.99	4.52 $\pm$ 0.93	4.60 $\pm$ 0.90	4.52 $\pm$ 0.88
	(S)	1.61 $\pm$ 1.03	2.71 $\pm$ 1.49	4.24 $\pm$ 1.12	4.54 $\pm$ 0.80	3.56 $\pm$ 1.57
3. Wearing pants by yourself	(I)	4.59 $\pm$ 0.67	4.34 $\pm$ 0.96	4.51 $\pm$ 0.92	4.60 $\pm$ 0.96	4.52 $\pm$ 0.88
	(S)	1.45 $\pm$ 0.84	2.54 $\pm$ 1.50	3.85 $\pm$ 1.36	4.11 $\pm$ 1.16	3.23 $\pm$ 1.62
4. Bathing yourself	(I)	4.51 $\pm$ 0.79	4.33 $\pm$ 0.97	4.43 $\pm$ 0.96	4.65 $\pm$ 0.75	4.48 $\pm$ 0.90
	(S)	1.41 $\pm$ 0.84	2.43 $\pm$ 1.48	3.61 $\pm$ 1.35	3.83 $\pm$ 1.21	3.04 $\pm$ 1.56
5. Normal urinary control	(I)	4.72 $\pm$ 0.61	4.49 $\pm$ 0.89	4.54 $\pm$ 0.94	4.52 $\pm$ 0.93	4.57 $\pm$ 0.87
	(S)	1.54 $\pm$ 0.84	2.42 $\pm$ 1.09	2.44 $\pm$ 1.29	2.92 $\pm$ 1.35	2.32 $\pm$ 1.27
6. Normal bowel control	(I)	4.68 $\pm$ 0.65	4.41 $\pm$ 0.87	4.52 $\pm$ 0.95	4.55 $\pm$ 0.82	4.54 $\pm$ 0.87
	(S)	1.49 $\pm$ 0.81	2.45 $\pm$ 1.22	2.53 $\pm$ 1.32	3.00 $\pm$ 1.25	2.37 $\pm$ 1.30
7. Rolling independently	(I)	4.55 $\pm$ 0.89	4.21 $\pm$ 0.81	4.52 $\pm$ 0.79	4.42 $\pm$ 1.09	4.48 $\pm$ 0.87
	(S)	1.83 $\pm$ 1.24	2.98 $\pm$ 1.25	3.91 $\pm$ 1.22	4.16 $\pm$ 0.96	3.41 $\pm$ 1.47
8. Transfer independently	(I)	4.54 $\pm$ 0.83	4.11 $\pm$ 1.13	4.54 $\pm$ 0.77	4.59 $\pm$ 0.93	4.50 $\pm$ 0.86
	(S)	1.52 $\pm$ 0.95	2.71 $\pm$ 1.41	3.74 $\pm$ 1.35	4.13 $\pm$ 1.00	3.22 $\pm$ 1.55
9. Wheelchair activity independently	(I)	4.62 $\pm$ 0.74	4.24 $\pm$ 1.14	4.52 $\pm$ 0.82	4.34 $\pm$ 1.06	4.40 $\pm$ 0.88
	(S)	1.91 $\pm$ 1.12	2.61 $\pm$ 1.37	3.79 $\pm$ 1.25	4.12 $\pm$ 0.93	3.32 $\pm$ 1.45
10. Ambulation with device (indoors)	(I)	4.46 $\pm$ 1.04	4.54 $\pm$ 0.74	4.23 $\pm$ 1.12	4.71 $\pm$ 0.65	4.38 $\pm$ 1.02
	(S)	1.33 $\pm$ 0.81	1.95 $\pm$ 1.21	2.40 $\pm$ 1.45	3.46 $\pm$ 1.22	2.29 $\pm$ 1.43
11. Ambulation with device (outdoors)	(I)	4.41 $\pm$ 1.05	4.36 $\pm$ 0.93	4.17 $\pm$ 1.20	4.59 $\pm$ 0.72	4.30 $\pm$ 1.09
	(S)	1.36 $\pm$ 0.77	1.84 $\pm$ 1.13	2.03 $\pm$ 1.33	3.15 $\pm$ 1.20	2.03 $\pm$ 1.30
12. Up-down stairs with device independently	(I)	4.28 $\pm$ 1.14	4.16 $\pm$ 1.12	3.94 $\pm$ 1.41	4.12 $\pm$ 0.82	4.12 $\pm$ 1.27
	(S)	1.29 $\pm$ 0.75	1.79 $\pm$ 1.10	1.51 $\pm$ 1.02	2.82 $\pm$ 1.38	1.70 $\pm$ 1.15
13. No complications (such as: spasticity)	(I)	4.54 $\pm$ 0.83	4.34 $\pm$ 0.79	4.32 $\pm$ 1.08	4.52 $\pm$ 0.97	4.40 $\pm$ 0.99
	(S)	1.76 $\pm$ 0.92	1.80 $\pm$ 0.88	2.28 $\pm$ 1.06	2.40 $\pm$ 1.36	2.13 $\pm$ 1.09
14. Good home care	(I)	4.43 $\pm$ 0.87	3.92 $\pm$ 1.18	3.60 $\pm$ 1.34	3.80 $\pm$ 1.32	3.80 $\pm$ 1.32
	(S)	2.28 $\pm$ 1.24	2.32 $\pm$ 1.20	2.49 $\pm$ 1.18	2.50 $\pm$ 1.13	2.43 $\pm$ 1.19

CT: complete tetraplegia; IT: incomplete tetraplegia; CP: complete paraplegia; IP: incomplete paraplegia. Rating the score by 5-point scale: 5—very important or very satisfied; 4—moderate important or moderate satisfied; 3—just feel fine (no preference); 2—moderate unimportant or moderate dissatisfied; 1—very unimportant or very dissatisfied

**Table 5** The raw score (mean  $\pm$  standard deviation) of importance (I) and satisfaction (S) in the aspect of environment—transportation

		CT	IT	CP	IP	Total
1. House equipped with necessities	(I)	4.72 $\pm$ 0.74	4.58 $\pm$ 0.68	4.54 $\pm$ 0.86	4.67 $\pm$ 0.03	4.60 $\pm$ 0.79
	(S)	2.34 $\pm$ 1.36	2.44 $\pm$ 1.21	2.63 $\pm$ 1.30	3.13 $\pm$ 1.29	2.61 $\pm$ 1.32
2. Buildings designed for the disabled	(I)	4.63 $\pm$ 0.83	4.56 $\pm$ 0.71	4.44 $\pm$ 1.02	4.66 $\pm$ 0.72	4.53 $\pm$ 0.91
	(S)	1.96 $\pm$ 1.11	1.90 $\pm$ 0.93	2.13 $\pm$ 1.15	2.21 $\pm$ 1.19	2.08 $\pm$ 1.12
3. Road with smooth ground	(I)	4.71 $\pm$ 0.73	4.59 $\pm$ 0.77	4.51 $\pm$ 0.89	4.66 $\pm$ 0.63	4.58 $\pm$ 0.82
	(S)	2.03 $\pm$ 1.04	1.95 $\pm$ 1.04	2.15 $\pm$ 1.18	2.26 $\pm$ 1.03	2.12 $\pm$ 1.11
4. Bus equipped with necessities	(I)	4.67 $\pm$ 0.78	4.50 $\pm$ 0.93	4.52 $\pm$ 0.95	4.73 $\pm$ 0.73	4.58 $\pm$ 0.89
	(S)	1.81 $\pm$ 1.02	1.75 $\pm$ 0.84	1.82 $\pm$ 1.03	2.00 $\pm$ 1.27	1.84 $\pm$ 1.05
5. Enough parking lot for the disabled	(I)	4.49 $\pm$ 0.93	4.48 $\pm$ 0.96	4.48 $\pm$ 0.91	4.66 $\pm$ 0.87	4.50 $\pm$ 0.91
	(S)	1.97 $\pm$ 0.98	1.76 $\pm$ 0.80	2.07 $\pm$ 1.09	1.79 $\pm$ 0.83	1.98 $\pm$ 1.01
6. Having adaptable devices for outdoors	(I)	4.48 $\pm$ 0.94	4.53 $\pm$ 0.92	4.49 $\pm$ 0.96	4.61 $\pm$ 0.91	4.51 $\pm$ 0.94
	(S)	1.80 $\pm$ 1.08	1.74 $\pm$ 1.02	2.54 $\pm$ 1.42	2.88 $\pm$ 1.44	2.35 $\pm$ 1.38

CT: complete tetraplegia; IT: incomplete tetraplegia; CP: complete paraplegia; IP: incomplete paraplegia. Rating the score by 5-point scale: 5—very important or very satisfied; 4—moderate important or moderate satisfied; 3—just feel fine (no preference); 2—moderate unimportant or moderate dissatisfied; 1—very unimportant or very dissatisfied

**Table 6** The raw score (mean±standard deviation) of importance (I) and satisfaction (S) in the aspect of psychosocial adjustment

		CT	IT	CP	IP	Total
1. You can accept the fact of injury	(I)	4.44±0.91	4.32±0.99	4.33±0.90	4.48±0.88	4.37±0.91
	(S)	3.24±1.34	2.93±1.10	3.36±1.12	3.49±1.10	3.30±1.17
2. You won't get angry easily	(I)	4.37±0.88	4.12±0.93	4.14±0.96	4.39±1.01	4.22±0.95
	(S)	2.91±1.17	3.10±1.07	3.38±0.92	3.53±1.02	3.27±1.02
3. Usually you are not in depression	(I)	4.34±0.94	4.17±0.86	4.14±0.89	4.28±0.99	4.20±0.91
	(S)	3.14±1.11	3.00±0.96	3.31±0.98	3.31±1.03	3.24±1.02
4. You won't mind curious inquiry	(I)	4.31±1.04	4.15±0.92	4.12±1.02	4.12±1.15	4.17±1.03
	(S)	3.04±1.25	3.05±1.12	3.28±1.13	3.48±1.13	3.23±1.16
5. You are not alcoholic or drug abused	(I)	4.43±1.04	4.20±1.07	4.15±1.16	4.23±1.29	4.22±1.14
	(S)	3.62±1.46	3.73±1.13	3.79±1.17	3.85±1.09	3.76±1.22
6. Having respect from your family and others	(I)	4.69±0.60	4.57±0.63	4.39±0.86	4.40±0.86	4.47±0.80
	(S)	3.49±1.32	3.85±0.94	3.84±1.02	3.71±1.06	3.75±1.09
7. Having good care from your family and others	(I)	4.68±0.68	4.37±0.86	4.27±0.93	4.46±0.77	4.39±0.87
	(S)	3.45±1.37	3.63±1.10	3.73±1.00	3.58±1.09	3.64±1.16
8. You are enthusiastic in public services	(I)	4.11±1.09	4.20±0.81	4.10±1.00	4.35±0.86	4.15±0.98
	(S)	2.82±1.25	2.90±1.16	3.16±1.09	3.29±1.10	3.08±1.14
9. Encouraging and helping others	(I)	4.54±0.73	4.47±0.73	4.30±0.84	4.52±0.74	4.40±0.80
	(S)	3.04±1.29	3.15±1.15	3.40±1.01	3.40±1.01	3.30±1.10
10. Having recreational activities	(I)	3.94±1.30	3.88±1.05	3.83±1.16	4.04±1.21	3.89±1.18
	(S)	2.32±1.24	2.68±1.16	2.88±1.17	2.78±1.23	2.73±1.21
11. Good relationship with others	(I)	4.31±1.12	4.15±1.15	4.35±0.92	4.39±0.95	4.32±0.99
	(S)	3.10±1.48	3.13±1.10	3.33±1.18	3.34±1.24	3.22±1.24
12. Good sexual function	(I)	3.82±1.26	3.92±1.24	3.74±1.30	3.92±1.35	3.80±1.29
	(S)	2.30±1.17	2.58±1.08	2.34±1.13	2.32±1.14	2.36±1.13

CT: complete tetraplegia; IT: incomplete tetraplegia; CP: complete paraplegia; IP: incomplete paraplegia. Rating the score by 5-point scale: 5—very important or very satisfied; 4—moderate important or moderate satisfied; 3—just feel fine (no preference); 2—moderate unimportant or moderate dissatisfied; 1—very unimportant or very dissatisfied

**Table 7** The raw score (mean±standard deviation) of importance (I) and satisfaction (S) in the aspect of education

		CT	IT	CP	IP	Total
1. Attending workshop for basic medical knowledge	(I)	4.55±0.81	4.45±0.90	4.44±0.76	4.56±0.84	4.48±0.80
	(S)	2.29±1.12	2.20±1.02	2.49±1.09	2.53±1.18	2.42±1.10
2. School providing special education for the disabled	(I)	4.46±0.88	4.20±1.02	4.40±0.85	4.55±0.87	4.41±0.88
	(S)	1.83±0.96	2.11±1.03	2.27±1.05	2.36±1.14	2.17±1.06
3. Having vocational training	(I)	4.67±0.68	4.40±0.96	4.53±0.76	4.64±0.72	4.56±0.76
	(S)	2.06±1.16	2.13±1.04	2.57±1.06	2.37±1.04	2.39±1.09

CT: complete tetraplegia; IT: incomplete tetraplegia; CP: complete paraplegia; IP: incomplete paraplegia. Rating the score by 5-point scale: 5—very important or very satisfied; 4—moderate important or moderate satisfied; 3—just feel fine (no preference); 2—moderate unimportant or moderate dissatisfied; 1—very unimportant or very dissatisfied

*Factors affecting quality of life*

The possible factors affecting the quality of life were listed as sex, age, location (urban/rural areas), duration of illness, severity of injury, marital status, educational background, post-injury working status and urinary complications. The underlying assumptions of regression analysis were checked and no meaningful violations were apparent. The nonparametric data with three or more groups were assigned with a dummy or a reference group. In post-injury working status, the group without work was set as reference and coded as '0'. The group with part-time work or full-time work was coded as '1' during stepwise analysis. In severity of injury, the complete tetraplegics was set as the reference and coded as '0'. Those who had

incomplete tetraplegia or complete paraplegia, or incomplete paraplegia was coded as '1' during stepwise analysis. As shown in Table 9, post-injury working status and severity of injury were the major factors affecting the quality of life, and location and sex did not affect the quality of life significantly, and the contributions from other factors were trivial.

**Discussion**

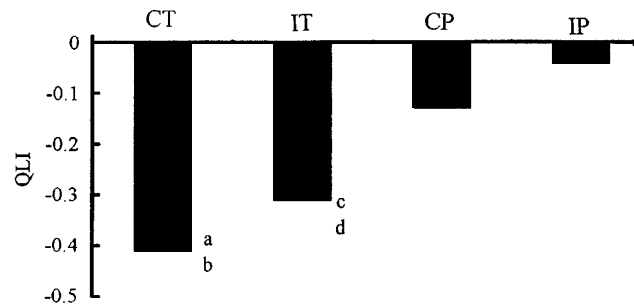
The results of this study indicate: (1) spinal cord injured patients had mild to moderate dissatisfaction with most items in four domains (e.g., physical mobility, environment-transportation, education, and economics) except psychosocial adjustment; (2) the

quality of life of those who were tetraplegic was significantly lower than was that of those who were paraplegic; (3) both the level of injury and post-injury working status were the major factors influencing the quality of life. However, previous reports mentioned that the quality of life of SCI's was relatively good and was not related to the level of injury.<sup>3-6</sup> This variance in results might be due to the different method of assessment and/or cultural background.

In our method of assessment, the major differences of this study included: (1) to measure the quality of life in five domains (physical mobility, environment-transportation, psychosocial adjustment, education, and economics) which were supposed to reflect the overall scope of life quality; (2) to quantify the life quality by quality of life index which could carefully identify the difference of importance and satisfaction in each domain. However, previous studies focused on the assessment of perceived well-being, with only one item qualifying as subjective quality of life.<sup>3-6</sup>

If examining the score of psychosocial adjustment of this study, all the subjects showed 'moderate to very' satisfied in most items (Table 6). Therefore, this

result seemed not contradictory to previous reports on the issue of the subjective assessment of perceived well-being in SCI.<sup>3-6,17-18</sup> Furthermore, examining the score of physical mobility of this study, all the subjects showed 'moderate to very' dissatisfied in most items



**Figure 1** The comparison of quality of life index (QLI) among those who have complete tetraplegia (CT), incomplete tetraplegia (IT), complete paraplegia (CP), and incomplete paraplegia (IP). a: CT < CP at  $p < 0.05$ ; b: CT < IP at  $p < 0.05$ ; c: IT < CP at  $p < 0.05$ ; d: IT < IP at  $p < 0.05$

**Table 8** The raw score (mean  $\pm$  standard deviation) of importance (I) and satisfaction (S) in the aspect of economics

		CT	IT	CP	IP	Total
1. Having stable job and income	(I)	4.55 $\pm$ 0.91	4.32 $\pm$ 1.13	4.53 $\pm$ 0.87	4.57 $\pm$ 1.00	4.51 $\pm$ 0.93
	(S)	1.71 $\pm$ 1.08	1.93 $\pm$ 1.21	2.22 $\pm$ 1.23	2.65 $\pm$ 1.23	2.14 $\pm$ 1.23
2. Having enough money for basic living	(I)	4.51 $\pm$ 0.86	4.41 $\pm$ 1.05	4.48 $\pm$ 0.96	4.56 $\pm$ 0.91	4.49 $\pm$ 0.94
	(S)	1.87 $\pm$ 1.08	1.90 $\pm$ 1.15	2.23 $\pm$ 1.19	2.79 $\pm$ 1.29	2.20 $\pm$ 1.21
3. Having enough funding by government for assistive devices	(I)	4.62 $\pm$ 0.74	4.45 $\pm$ 1.01	4.64 $\pm$ 0.71	4.79 $\pm$ 0.46	4.64 $\pm$ 0.73
	(S)	2.41 $\pm$ 1.11	2.23 $\pm$ 0.99	2.68 $\pm$ 1.14	2.77 $\pm$ 1.05	2.58 $\pm$ 1.11
4. Having enough funding by government for environment or house remodeling	(I)	4.60 $\pm$ 0.79	4.45 $\pm$ 1.01	4.58 $\pm$ 0.78	4.81 $\pm$ 0.50	4.59 $\pm$ 0.83
	(S)	1.93 $\pm$ 1.14	1.73 $\pm$ 0.91	2.04 $\pm$ 1.03	2.22 $\pm$ 1.13	2.01 $\pm$ 1.05

CT: complete tetraplegia; IT: incomplete tetraplegia; CP: complete paraplegia; IP: incomplete paraplegia. Rating the score by 5-point scale: 5-very important or very satisfied; 4-moderate important or moderate satisfied; 3-just feel fine (no preference); 2-moderate unimportant or moderate dissatisfied; 1-very unimportant or very dissatisfied

**Table 9** Multiple regression analysis for possible factors affecting quality of life

Variable	Beta	Standard error	Partial R <sup>2</sup>	Model R <sup>2</sup>	P-value
(Intercept)	-2.63	0.03			
Post-injury work					
Without work	reference				
Part-time	0.72	0.20	0.013	0.013	0.02*
Full-time	0.54	0.24	0.061	0.074	0.01*
Severity of injury					
Complete tetraplegics	references				
Incomplete tetraplegics	0.44	0.26	0.006	0.080	0.09
Complete paraplegics	1.20	0.19	0.044	0.124	0.01*
Incomplete paraplegics	1.65	0.25	0.100	0.224	0.01*
Location	0.19	0.15	0.004	0.228	0.22
Sex	0.23	0.20	0.003	0.231	0.27

\*Indicates highly significant. Partial R<sup>2</sup>: the correlation of quality of life in each variable. Model R<sup>2</sup>: the accumulated value from partial R<sup>2</sup> to show the predictive accuracy of quality of life

and the scores were related to the level of injury (Table 4). This result was similar to the report of Siösteen *et al* on the objective assessment of Modified Barthel Index (self-care and mobility index) of spinal cord injured patients.<sup>6</sup> Therefore, it is better to interpret the results with the explanation of our evaluation methods.

In terms of the cultural background, a difference between oriental (Taiwan) and western countries exists. In Taiwan, the economic and social support systems for the disabled person are mainly from the family and/or relatives, while the community rehabilitation and nursing home care systems are not well established. The living stipend for the disabled offered by the government is around the minimum living standard in Taiwan. Also, there are some limitations in funding for necessities. Therefore, the satisfaction for family support was around 3.7 (see psychosocial adjustment in Table 6), but the satisfaction for government funding was around 2.1 (see economics in Table 8). Furthermore, it was noticed that the rating for the sexual importance was not as high as the other aspects of life in this study (see psychosocial adjustment in Table 6). The study of White *et al*<sup>11</sup> in Texas also showed that 79 SCI's rated the importance of sexual life in the lowest rank as compared to others of life, such as family relationship, and recreational activities. The cultural or religious influence on this issue might require further investigation. However, decrease of sexual drive in spinal cord injured patients has been reported.<sup>18</sup>

The major factors affecting the quality of life are severity of injury and the postinjury work status (Table 9), and those two factors can explain 22.4% of the life quality. The next possible factors, such as location and sex, can explain only about 0.7% more of the life quality. For future study, the influence of estate on life quality may have to be taken into consideration. This study indicated that the working opportunity for the disabled is highly limited. However, the relationship between postinjury work status and quality of life may not be the true cause-effect phenomenon, because the reverse is equally possible. Therefore, a comparison of the life quality before and after injury is suggested for future studies.

The satisfaction on environment-transportation was low in this survey (see environment-transportation in Table 5). At the time of survey, most of the new buildings or buses have the set-up for disabled persons, but the older buildings or buses do not incorporate these features. In this survey, the major suggestions from the spinal cord injured persons were: (1) to provide enough funding or loans for persons who want to develop his/her own career; (2) to simplify the procedures and reduce limitations for application of assistive devices or house remodeling; (3) to establish the proper welfare system for the disabled.

The major limitations of this survey are that the response rate was low and the validity of the

questionnaire was not well-established. The low response rate may be due to the complexity of the questions compounded by the ignorance of this type of issue by some people. However, the validity is shown indirectly in this survey by having all of the items perceived by our staff to be important to the patients. The other limitation in this study is that this study only solicited the members of the SCI association, and may over estimate the life quality of the spinal cord injured patients in Taiwan, because the members are more active in the participation of the meetings, workshops, and legislation for the disabled to promote their life quality. However, this study may still be helpful for the clinicians and the officials in planning future programs for improving the quality of life of the spinal cord injured patients.

After this survey, the results were reported to the Department of Health, Executive Yuan, Republic of China. Since then, the government and the private enterprises have made several modified interventions to improve the life quality of spinal cord injured patients, such as establishing a computer training program and a practising factory for paraplegic and tetraplegic individuals, in 1995.

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