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ORIGINAL REPORT

QUALITY OF LIFE OF TRAUMATIC SPINAL CORD INJURED PATIENTS IN HONG KONG

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***Objective:* To assess the health-related quality of life of patients with traumatic spinal cord injury living in Hong Kong.**

***Design:* A cross-sectional retrospective study.**

***Subjects:* Subjects with paraplegia following traumatic spinal cord injury were recruited from our department, which is one of the 3 main regional spinal cord injury rehabilitation centres in Hong Kong. A total of 120 potential participants were invited to join the study. The final study group comprised 58 patients (25 (43%) men and 33 (57%) women, 30 (50%) of whom were under 40 years of age).**

***Methods:* Health-related quality of life was assessed using the Hong Kong Chinese version of the World Health Organization Quality of Life Measure Abbreviated version (WHOQOL-BREF(HK)). Results were summarized and compared with previous results from healthy and other disease populations in Hong Kong.**

***Results:* There was no significant difference in quality of life between men and women, or between different durations of spinal cord injury, different educational levels or different marital status ($p > 0.05$). However, a significant difference in quality of life was found in different age groups and between people with incomplete and complete paraplegia ($p < 0.05$). Compared with healthy and other disease populations, people with paraplegia had the lowest quality of life in Hong Kong ($p < 0.001$).**

***Conclusion:* People with paraplegia in Hong Kong have a lower quality of life than the general Hong Kong population. More community support is required to meet the needs of these patients in the areas of transportation, medical care and social life, in particular.**

Key words: quality of life, traumatic spinal cord injury, paraplegic, Hong Kong.

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INTRODUCTION

Advances in the medical management of paraplegia have resulted in the saving of lives, a reduction in the severity of the disability, and increased patient longevity (1, 2). With an increased survival rate and life-span (3), people with paraplegia now live with their disability for a much longer period of time. Indicators of results for healthcare interventions, and particularly for rehabilitation of people with paraplegia, have been concerned not only with degree of loss of function, but also with quality of life (QoL) (4, 5). Once the inpatient rehabilitation phase is completed, most people with paraplegia are discharged into the community to resume their social life roles (6). Therefore, based on these facts, the therapeutic focus has shifted more towards living, adjusting to the disability, and improving altered patterns of interpersonal relationships (3); thus it is essential for healthcare professionals to be informed about the QoL of people with paraplegia.

During the last decade, health-related quality of life (HRQoL) has been monitored in many outcome studies of people with spinal cord injury (SCI) in various countries (7–9), yet the exact number of individuals with SCI in Hong Kong is not known, as there is no central registration of patients by diagnosis (3). It has been estimated that there are a few hundred persons with SCI in Hong Kong (3). However, there have been few studies of this type in Hong Kong and there is a lack of information about HRQoL of SCI in Hong Kong.

The physiological and psychological problems of patients with SCI are not generally well understood and little is known about the subjective differences in QoL of SCI patients with different backgrounds, e.g. educational level, age, marital status, and period of time since injury. In addition to these areas, more information is required about the needs of patients resulting from SCI and the QoL of persons with SCI, in comparison with other populations.

The aims of this study were to provide information about the significant problems encountered in daily life by people with paraplegia, and to compare the QoL of people with SCI and other chronic diseases in Hong Kong.

METHODS

Subjects

Participants were recruited from the outpatient clinics for patients with SCI in our department, which is one of the 3 main regional SCI rehabilitation centres in Hong Kong. The current study focuses on the investigation of QoL of patients with paraplegia, while patients with tetraplegia were excluded. The inclusion criteria were: (*i*) patients with paraplegia; (*ii*) injured for at least one year; (*iii*) at least 20 years

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old; (*iv*) no mental health problems in medical history records. The survey was conducted from January 2003 to December 2005. During this period, a total of 120 patients who met the inclusion criteria were recruited at the time they visited the clinic and were given a questionnaire with a stamped addressed envelope for their reply. Involvement in the study was completely voluntary. A total of 76 responses (63%) were received. Any questionnaire with 20% of the answers incomplete, i.e. 6 or more of the total of 28 answers incomplete, was regarded as invalid and was not scored or interpreted (10). In this study, 58 valid responses out of 76 were analysed.

Subjects with SCI recruited to this study were classified by a senior orthopaedic specialist as having complete paraplegia (CP) or incomplete paraplegia (IP) according to the 1992 international standars for neurological and functional classification of spinal cord injury made by American Spinal Injury Association (ASIA).

Questionnaire

The questionnaire comprised 3 parts: (*i*) QoL assessment; (*ii*) basic data; and (*iii*) comments or requests.

The questionnaire used was the Hong Kong Chinese version of the World Health Organization Quality of Life Measure Abbreviated version, WHOQOL-BREF(HK), which was translated, modified and validated in 1997 (11, 12). This questionnaire comprises 28 questions, including 2 overall questions and 4 domains: physical health (domain 1), psychological well-being (domain 2), social relationships (domain 3) and environment (domain 4).

The basic data included some personal information, such as age, sex, marital status, educational background and time since the onset of injury.

In addition to the QoL assessment and basic data collection, we invited subjects to describe their individual situations or requirements in the comments or request section. This part included a statement of the most troublesome complication and the greatest problem encountered during their daily lives.

QoL scoring and QoL index (QLI) analysis of questionnaires

Subjects responded to each item on a 5-point scale ranging either from "very important" to "very unimportant" for the importance items, and from "very satisfied" to "very dissatisfied". Score "5" indicated very important or very satisfied, score "4" indicated quite important or quite satisfied, score "3" indicated just feeling fine (i.e. no special preference), score "2" indicated quite unimportant or quite dissatisfied, and score "1" indicated very unimportant or very dissatisfied. The 5 to 1 points were the raw scores of importance and satisfaction.

The QoL was quantified by calculating the QLI, as described by Lin et al. (2). This study used a modified QLI calculation by multiplying the group of QoL scores, and the product was divided by the possible highest score. The formula for calculating QLI was as follows:

$$\text{QLI} = \frac{\text{summation of raw question scores}}{5 \times n \text{ of questions}}$$

In this study, levels of QLI are classified into 4 categories: poor (<50%), barely (50–65%), modest (66–75%) and high (>75%).

Data analysis

The results of the QoL survey were analysed in terms of QoL scores in order to study the factors having a great effect on the life of the subject with paraplegia. Comparisons were carried out between different categories in terms of paraplegic types, gender, age, marital status,

Table I. *Quality of life index (mean (SD)) and comparison (p-value) between different paraplegic subgroups*

	General	Domain 1 (Physical health)	Domain 2 (Psychological)	Domain 3 (Social relationships)	Domain 4 (Environment)
Paraplegia type					
p-value	0.031*	0.263	0.060	0.064	0.036*
IP (*n*=28)	60.0 (13.5)	54.0 (13.5)	61.6 (18.6)	62.0 (19.8)	61.0 (15.2)
CP (*n*=30)	51.4 (11.7)	49.8 (11.1)	51.7 (14.7)	50.8 (14.4)	51.4 (14.4)
Gender					
p-value	0.167	0.548	0.118	0.183	0.197
Male(*n*=25)	52.0 (13.4)	50.5 (13.4)	53.1 (14.2)	51.5 (13.3)	52.4 (16.2)
Female (*n*=33)	57.9 (13)	52.9 (12)	60.9 (15.7)	59.3 (19.9)	58.8 (14.8)
Age (years)					
p-value	0.001*	0.005*	0.004*	0.002*	0.011*
>40 (*n*=30)	61.0 (12.2)	56.4 (11.9)	63.7 (14.7)	63.5 (18.3)	61.4 (13.8)
≤40 (*n*=28)	48.4 (11.2)	46 (10.6)	50.3 (13.3)	46.7 (12.7)	49.7 (15.3)
Education level (years)					
p-value	0.325	0.492	0.135	0.262	0.431
Secondary school or below (*n*=32)	56.6 (10.8)	52.5 (12.8)	57.9 (13.1)	56.9 (21.1)	58.4 (11.1)
Above college level (*n*=26)	61.6 (17.6)	53.9 (15.2)	65.0 (21.4)	62.9 (18.9)	62.2 (20.7)
Marital status					
F-value (ANOVA)	0.740	0.446	0.446	0.657	0.176
p-value(ANOVA)	0.484	0.643	0.643	0.524	0.840
Single (*n*=21)	51.9 (11.3)	48.9 (9.3)	55.2 (14.9)	50.0 (13.6)	52.8 (15.7)
Married/living as married (*n*=18)	55.6 (14)	56.7 (15.3)	57.3 (14.4)	54.4 (22.4)	56.4 (15.8)
Divorced/separated/ widowed (*n*=14)	57.9 (14.5)	51.9 (13.4)	59.2 (20.3)	63.9 (16.2)	58.1(15.8)
Others (*n*=5)					
Years since injury					
F-value (ANOVA)	1.502	0.581	0.436	2.506	0.997
p-value (ANOVA)	0.235	0.564	0.649	0.094	0.377
<5 years (*n*=11)	63.2 (11.4)	56.4 (11.5)	67.5 (13.2)	73.3 (9.4)	58.8 (13)
5–15 years (*n*=21)	58.2 (13.5)	49.0 (12.6)	59.6 (17.6)	65.7 (15.1)	60.7 (16.8)
>15 (*n*=26)	62.1 (11.7)	56.2 (13.1)	66.7 (19.3)	54.4 (27.8)	65.8 (12.8)

*With statistically significant difference by *t*-test.

IP: incomplete paraplegia; CP: complete paraplegia; SD: standard deviation.

educational level, and years since injury. Student's *t*-test analysis was used to examine whether significant differences occurred between the subgroups in 2 variables of interest, while analysis of variance (ANOVA) with the Tukey test was used to compare subgroups in more than 2 variables of interest. The difference was considered as significant when $p < 0.05$.

In addition, the results from patients with paraplegia were compared with previous surveys from healthy, cardiac, cancer, diabetes, stroke, psychiatric and renal populations within Hong Kong. Data came from the report of the Hong Kong Chinese Version of the World Health Organisation Quality of Life Measure Abbreviated version WHOQOL-BREF(HK), Hong Kong Hospital Authority (10). Comparison was conducted among SCI groups and other populations, including a healthy group of 148 subjects (56 men, mean age 37.43 (standard deviation (SD) 13.48) years and 92 women, mean age 32.07 (SD 10.61) years); a cardiac group of 53 subjects (44 men, mean age 56.84 (SD 12.59) years and 9 women, mean age 60.22 (SD 11.13) years); a cancer group of 57 subjects (16 men, mean age 53.50 (SD 12.69) years and 41 women, mean age 50.46 (SD 11.46) years); a diabetes group of 71 subjects (31 men, mean age 48.42 (SD 15.80) years and 40 women, mean age 55.17 (SD 18.93) years); a stroke group of 86 subjects (59 men, mean age 53.97 (SD 13.45) years and 27 women, mean age 53.30 (SD 15.24) years); a psychiatric group of 135 subjects (82 men, mean age 40.68 (SD 11.48) years and 53 women, mean age 36.77 (SD 10.86) years); and a renal group of 54 subjects (33 men, mean age 40.06 (SD 10.83) years and 21 women, mean age 36.52 (SD 6.30) years).

The multi-group survey was compared by analysis of variance (ANOVA), with a statistical significance level of $p < 0.05$.

RESULTS

Demographic characteristics of the participants

The age range of the participants was 23–89 years, with a mean age of 48 (SD 16.4) years. The time since injury ranged from 1.5 to 49 years, with a mean of 12.5 (SD 8.8) years.

There were 58 participants in the study (25 males and 33 females). Thirty-one participants had functionally CP and 27 had functionally IP. Of the 58 participants, 12.1% ($n = 7$) were at a low level of education (below primary level), 43% ($n = 25$) were at secondary level, 36% ($n = 21$) were at matriculation level, and 8.6% ($n = 5$) were at tertiary college/university level.

For their marital status at survey, 36.2% ($n = 21$) were single, 31% ($n = 18$) were married/living as married, 13.8% ($n = 8$) were divorced/separated, 10.4% ($n = 6$) were widowed, and the remaining 8.6% ($n = 5$) were of unknown marital status.

Importance of needs

Among various different complications mentioned by the participants, urinary problems were rated as the most troublesome (58.6%, $n = 34$), while other complications mentioned were numbness/pain (50%, $n = 29$), spasticity (31.3%, $n = 18$) and pressure sores (12.1%, $n = 7$).

Participants were asked to list the areas in which they experienced greatest difficulty or which were the most demanding areas in their daily lives. In general, people with paraplegia listed the following needs in order of priority: easier transportation or more convenient rehabilitation bus services, health services provided for daily life medical care, and financial support/employment.

Table II. *Table for transforming raw domain scores for the WHOQOL-BREF(HK)*

Domain 1 (Physical health)		Domain 2 (Psychological)		Domain 3 (Social relationships)		Domain 4 (Environment)	
Raw score	TF score (4–20)	Raw score	TF score (4–20)	Raw score	TF score (4–20)	Raw score	TF score (4–20)
7	4	8	4	3	4	8	4
8	5	9	5	4	5	9	5
9	5	10	5	5	7	10	5
10	6	11	6	6	8	11	6
11	6	12	6	7	9	12	6
12	7	13	7	8	11	13	7
13	7	14	7	9	12	14	7
14	8	15	8	10	13	15	8
15	9	16	8	11	15	16	8
16	9	17	9	12	16	17	9
17	10	18	9	13	17	18	9
18	10	19	10	14	19	19	10
19	11	20	10	15	20	20	10
20	11	21	11			21	11
21	12	22	11			22	11
22	13	23	12			23	12
23	13	24	12			24	12
24	14	25	13			25	13
25	14	26	13			26	13
26	15	27	14			27	14
27	15	28	14			28	14
28	16	29	15			29	15
29	17	30	15			30	15
30	17	31	16			31	16
31	18	32	16			32	16
32	18	33	17			33	17
33	19	34	17			34	17
34	19	35	18			35	18
35	20	36	18			36	18
		37	19			37	19
		38	19			38	19
		39	20			39	20
		40	20			40	20

TF: transformed.

Cross-sectional comparison

Table I shows the summarized QLI results of the patients with paraplegia. Among different domains, physical health (domain 1) showed the least satisfaction, while the other 3 domains were of similar QLI. Of the total of 58 people with paraplegia evaluated, 16 (27.6%) had a poor QLI (< 50%), 25 (43.1%) a barely QLI (50–65%), 14 (24.1%) a modest QLI (65–75%), and only 3 (5.2%) a high QLI (> 75%).

The QoL results were compared with each other between different levels of socio-demographic and medical variables (Table II). There was no significant difference between subgroups in terms of gender, years since injury, educational level and marital status. However, significant differences were found in the general and domain 4 QoL scores between patients with IP and CP. As indicated in Table II, all the results from the 4 domains and the general scores showed significant differences between the 2 age subgroups (≤ 40 years old, > 40 years old).

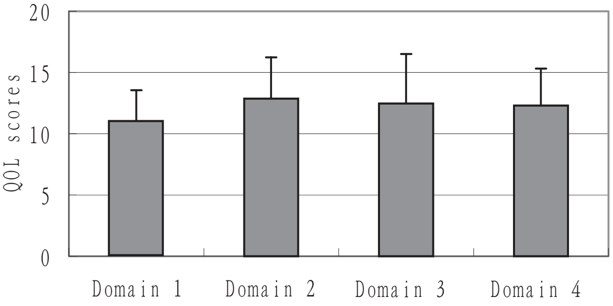

Fig. 1. Quality of life (QoL) scores of patients with paraplegia in different domains. Domain 1: physical health; domain 2: psychological well-being; domain 3: social relationships; domain 4: environment. SCI: spinal cord injury.

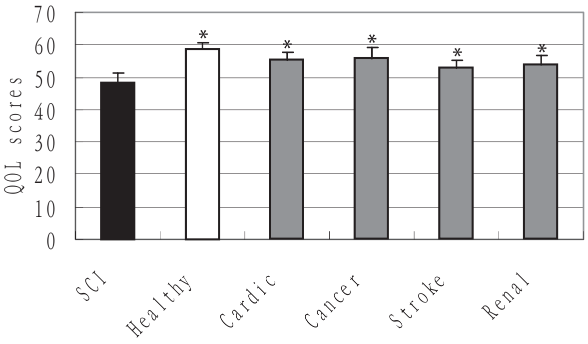

Fig. 2. Comparison of total quality of life (QoL) scores among different disease and healthy populations. SCI: spinal cord injury.

QoL comparison among patients with paraplegia and other populations

The QoL results for patients with paraplegia were compared with those from healthy, cardiac, cancer, stroke and renal populations in the same city. Previous QoL scores for other population groups were collected from the Hong Kong Project Team on the Development of the Hong Kong Version WHOQOL (2, 10). In order to be comparable with the QoL scores of previous reports, the raw QoL scores in this survey were converted into transformed domain scores with a range of 4–20. A table for converting raw to transformed domain scores is shown in Table II. Fig. 1 shows the transformed QoL score of the patients with paraplegia. Similar to the results shown in Table I, QoL scores for domain 1 were significantly lower than for any other domain. Fig. 2 shows the comparison of QoL among different populations. SCI patients had significantly lower QoL than any other populations, either healthy or diseased ($F = 87.047$, $p < 0.0001$ by the ANOVA comparison). Fig. 3 shows the comparison of transformed domain QoL scores among different disease and healthy populations. Patients with SCI had a significant difference from healthy subjects in all domain QoL, while other disease populations had a significant difference only in total score ($F = 87.05$, $p < 0.001$ by ANOVA) and domain 1 score ($F = 23.698$, $p < 0.001$, by ANOVA).

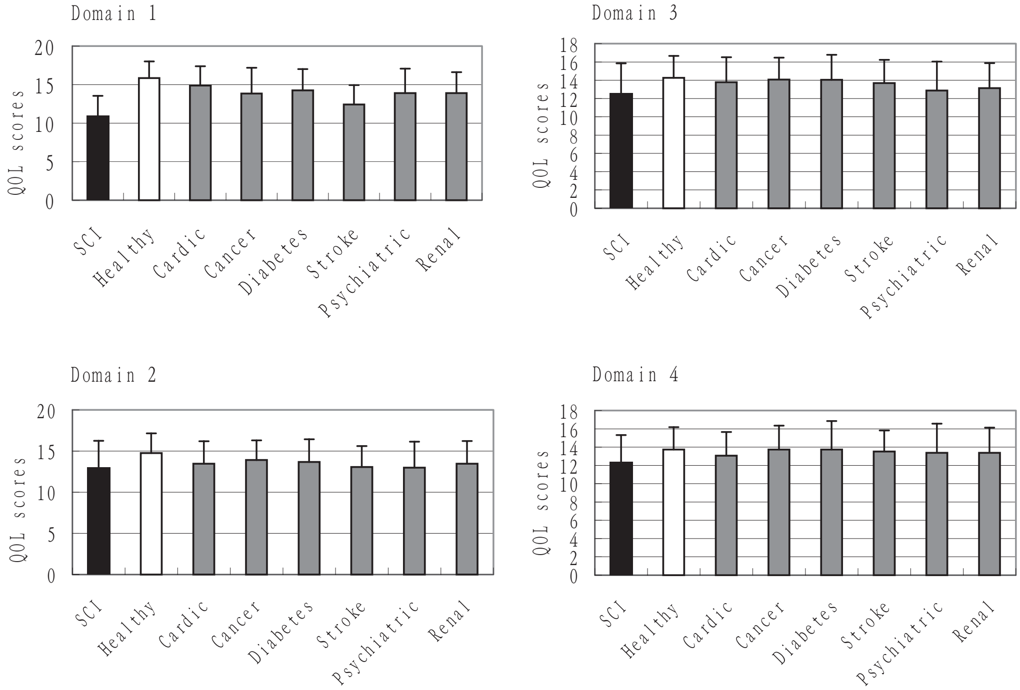

Fig. 3. Comparison of quality of life (QoL) transformed domain scores among different disease and healthy populations. Domain 1: physical health; domain 2: psychological well-being; domain 3: social relationships; domain 4: environment. SCI: spinal cord injury.

DISCUSSION

This cross-sectional study aimed to explore the profile of QoL in SCI in Hong Kong. It is difficult for investigators to obtain accurate figures for SCI, since there is no central registration of patients with paraplegia in Hong Kong. Hence, a focus group study was administered to patients with traumatic SCI from one of the 3 major regional SCI centres that provides rehabilitation services to patients with SCI in the whole Hong Kong Island region.

Conflicting results exist concerning the influence of the degree of disability and impairments on QoL in patients with SCI (2, 7, 9). A comparison of QoL between IP and CP in this study showed significant differences only in the general and environment domains of QoL scores, but no significant difference in the other 3 domains (Table I). Even though physical function, independence and physical well-being affected the QoL of complete patients with paraplegia to a greater extent, it was not surprising that the subjective QoL in other domains was similar between IP and CP, because both groups experienced similar issues of limited mobility. The QoL difference between patients with CP and IP living in Hong Kong is due mainly to environmental issues. These findings could be attributed to the preponderance of high-rise buildings and homes with limited space, and/or that patients with CP had more requirements within the environment domain. Public transport, housing facilities and recreation areas may partially support patients with IP, but are not sufficient for patients with CP.

In this study, gender seemed not to affect the QoL of patient with SCI, which supported the findings of previous studies (2, 9, 13), but differed from some other reports (8, 14). The difference from some previous studies (8, 14) may be due to different QoL tools or ethnicity. Chinese culture is generally less sexually expressive and has been described as "asexual" compared with that observed in America (15). A manifestation of this is the Chinese cultural belief that intimacy between close partners is more independent of sexual relations than in the West (15). This cultural belief is noted as concealing the gender differences in QoL of Hong Kong patients with paraplegia, as was supported by a study of SCI in Taiwan (2), which has a similar cultural background.

The years post-injury (YPI) could be a factor affecting QoL. It was assumed that QoL in SCI would be increased with YPI (9, 13, 16, 17). However, it is difficult to obtain a consistent pattern of correlation between YPI and SCI QOL (18), because increased YPI could help patients with SCI to adapt to both internal (illness-related) and external circumstances (19) but may also induce worsening urinary changes, functional declines, decreased social role performance, increased costs, and improvements in community integration. In accordance with the results of Kennedy & Rogers (20) and Leduc & Lepage (14), our study showed no observable difference in QoL between the YPI. In contrast, a significantly higher QoL was found in an elderly group than those in a younger group, which agrees with the results of previous studies, showing that increased age is associated with improved life satisfaction (14, 18, 21).

Considering educational background as a factor in QoL in SCI, persons with a higher level of education may obtain employment more easily, have a higher income, and obtain more information about rehabilitation in order to adopt a new life. However, the results of this study did not show significant difference in QoL between patients with different educational levels. This could be explained by the fact that patients with paraplegia with a higher educational level may have higher expectations in their daily life, which may lead to disappointment in their actual situation.

A study in Canadian subjects with SCI (22) found that married elderly couples were expected to have higher incomes, morale, life satisfaction, mental and physical health, and lower rates of institutionalization and high-risk health behaviours. However, probably due to the cultural difference between Western and Chinese people, the results of this study did not show a significant difference in QoL between different marital statuses. In this study, participants usually received support from their family, which was in similar nature to the support from their spouse. Therefore, marital status was not a critical factor in paraplegic QoL in Hong Kong.

In this study, the lowest QoL among patients with paraplegia in comparison with other disease populations in Hong Kong is alarming. Our results showed that patients with paraplegia had lower QoL in the physical domain compared with other populations, suggesting that physical problems are a key factor affecting the general QoL of patients with paraplegia. In agreement with previous studies (2, 14, 23), the QoL score for physical domain in this study was the lowest of the 4 different domains, as was the QLI of domain 1 (Fig. 1). This finding suggests that SCI has a greater impact on physical health than on mental health.

The physical activities of patients with paraplegia are particularly limited by the environmental situation in Hong Kong, which is one of the most crowded cities in the world. Thus the mobility of patients with paraplegia is currently a big problem. Previous researchers have identified links between QoL and mobility (6, 24–27). The participants in this study raised similar problems in accessing transportation or community facilities, and they enquired about having mobility and technical equipment, followed by more adequate financial support and medical supplies.

The relatively small sample size is a limitation of this study, which weakens its power and generalizability, i.e. limited representativity. However, the present study suited its purposes by serving an exploratory role to identify the key problems of patients with paraplegia in their daily lives and to provide comparative information between the QoL of patients with SCI and other disease populations in Hong Kong.

In Hong Kong, people with paraplegia have a lower QoL than other healthy and disease populations. Moreover, in terms of physical health, psychological well-being, social relationships, and the environment, people with paraplegia were shown to have the lowest score for in physical health, indicating a significant demand for improvement in their physical ability. For their subjective requirements, mobility was the top demand; in fact, it is achievable by providing more support for transport for people with paraplegia. To this end, there should be more community support to provide transportation, medical care and social lives for these patients.

These results provide information that should assist healthcare, rehabilitation professionals, social workers and the government take the appropriate steps to enable people with paraplegia to improve the quality of their lives.

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