

Special Article – Spinal Cord Injury Rehabilitation

The Relationship of Participation Restriction with Quality of Life in Individuals with Spinal Cord Injury

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Introduction

Spinal cord injury (SCI) is one of the most serious types of injury, and usually affects all aspects of the individual's life including physiological, psychological and social functions [1]. According to the Taiwan National Health Insurance database, the average incidence of acute SCI in Taiwan was 0.062% per year, and it was similar rate in both genders (male: female =0.99: 1) [2]. The major causes for traumatic SCI in Taiwan include: crushing injuries by heavy objects, falling down from a great height, car accidents, sports injuries, and cut wounds or bullet wounds [3].

Spinal cord injury usually causes permanent impairments and results in tremendous medical sequelae [4]. With the improved health care, the early phase death rate is decreasing and the life expectancy for persons with SCI is obviously increasing [4,5]. As long as the life span increasing, the quality of life (QOL) has gradually become one of the major rehabilitation objectives and important indicators of rehabilitation effectiveness [4,6]. Subjective QOL, such as happiness, psychological well-being, and life satisfaction, in persons with SCI has been reported lower than that of non-SCI group [7]. In addition, based on a meta-analysis research the QOL is fairly consistently correlated with social participation level, but not with the impairment

severity of body function and structures [7]. White neck (2004) also pointed out that the severity of a spinal cord injury is not the best predictor of long-term outcomes [8].

According to National Spinal Cord Injury Statistical Center (NSCISC), 59% of persons with SCI, aged from 16 to 59, were employed when they falling the mishap. Nevertheless, only 29% of them retained their jobs after eight years from accident [9]. The employment rate was low for individuals with SCI [10]. Targett and his colleague believed that in addition to the personal sense of achievement, social identity can also promote life satisfaction for patients with paraplegia [9]. Chou et al.'s article also noted that the employed persons with SCI have better QOL than those non-employed. There was evident positive correlation between job satisfaction and QOL for persons with SCI [11].

Taiwan's Disability Evaluation System (DES) adopts the conceptual framework of the World Health Organization's "International Classification of Functioning, Disability, and Health (ICF)". The medical teams of the authorized hospitals, dated from July eleventh, 2012, started to assess persons with disabilities in two aspects: one was focused on the body function and structure; and the other was on activities and participation. With the reference to WHO

Table 1: Demographic Characteristics of the Study Sample (N=36).

	N or Mean	% or \pm SD
Male gender, n	32	89%
Age, years	40.0	\pm 09.0
Employment status, n		
Employed - employee	9	25%
Employed -self-employee	7	19%
Unemployed-health reason	20	56%
Education, n (%)		
Junior high school	8	22%
Senior high school	15	42%
College/university	12	33%
Graduate program	1	3%
Cause of SCI, n (%)		
Car accidents	23	63%
Heavy object injury	2	6%
Falls	8	22%
Waterslide accidents	1	3%
Gun shots	2	6%
Duration of injury, years	14.2	\pm 8.8
Level of SCI, n (%)		
Thoracic	33	92%
Lumbar	3	8%
Types of mobility devices, n (%)		
Manual wheelchair	26	72%
Electric-powered wheelchair	8	22%
Regular cane	2	6%

Disability Assessment Schedule II (WHODAS 2.0), based on the 36-question version, the ICF team got permission to translated into Chinese and revised it into "The Functioning Scale of the Disability Evaluation System-Adult Version (shortened as FUNDES-Adult) to measure the individual's activity and participation restriction on six domains: Cognition, Mobility, Self-care, Getting along with others, Life activities (household/work or school activities), and Participation [12].

The aims of current research are to investigate the relationships between participation restriction and quality of life in persons with spinal cord injury, and to compare differences of the quality of life and participation restriction between two groups, with or without employment.

Methods

This is a concurrent study and it has been approved with the ethical review done by Institutional Review Boards of two general hospitals. All participants had their written consents before enter this study.

Participants

Thirty-six patients with paraplegia, aged from 18 to 55 years, were invited to participate in this study. The participants were recruited

from a rehabilitation department of an area hospital and a Spinal Cord Injury Association in central Taiwan. All the participants were diagnosed by neurologists as traumatic paraplegia and with disability identifications. The exclusion criteria were: brain injuries, cognitive dysfunction, visual and hearing impairments. Each participant received interview by a qualified interviewer of the Functioning Scale of the Disability Evaluation System and filled out the Quality of Life Questionnaires for Patients with Spinal Cord Injury. Their demographic data were shown in Table 1.

Instruments

The functioning scale of the disability evaluation system-adult version: The Functioning Disability Evaluation Scale - Adult version (FUNDES-Adult) was developed based on the 36-item version of WHODAS 2.0, the trial version for functional assessment, the activity and participation (d code) and environmental factors (e code) components of the ICF coding system [13-15] and has shown acceptable validity and reliability [12,16]. The FUNDES-Adult has 8 domains [13]. This study focused on the first 6 domains for measuring participation restriction in order to measure the individuals' activity and participation restriction in daily life in the past 30 days in: (1) Cognition (six items) related to communication and thinking activities including concentrating, remembering, problem solving, learning and communicating; (2) Mobility (five items) related to activities such as standing, moving around inside the home, getting out of the home and walking a long distance; (3) Self-care (four items) related to hygiene, dressing, eating and staying alone activities; (4) Getting along with others (five items) related to interaction activities with other persons; (5) Life activities (household and school/work, eight items) related to take responsibilities of domestic activities, work or school activities; and (6) Participation (eight items) related to community activities, barriers and hindrances for affecting dignity. Each item is 5-point Likert score from 0 to 4: no difficulty (0), mild difficulty (1), moderate difficulty (2), severe difficulty (3), and extreme difficulty (4) [12,16,17]. All domains address the performance and capability dimensions in this study. The difficulty levels based on performance dimensions were judged with the presence or aid of existed assistive devices and personal assistances, and that of the capability dimensions were without the aid of devices and personal assistances. The Domain score were calculated according to the scoring algorithm of the WHODAS 2.0 [17] where we converted the original scores to 0 to 100 for each domain and to total summary scores that higher scores indicate greater levels of participation restriction. Based on the norm data of the WHODAS 2.0, we defined that summary scores between 50 to 70 mean mild restrictions, those scores between 70 to 90 indicate moderate restrictions, and scores above 90 mean severe restrictions [18].

Quality of life questionnaire for persons with spinal cord injury: 'Quality of Life Questionnaire for Persons with Spinal Cord Injury' was developed based on 'World Health Organization's Quality of Life Questionnaires-Taiwan Version' and some items has been added to measure the quality of life for individuals with SCI appropriately [19]. It was a self-administered questionnaire, and contained 32 items in total, including four domains: Q3 physiological health (8 items), Q4 psychology (7 items), Q5 social relationship (5 items), and Q6 environment (10 items). Each item is 5-point Likert score from 1 to 5, 1 indicating very dissatisfied and 5 indicating

Table 2: Mean Domain Scores of the Functioning Scale of the Disability Evaluation System-Adult Version (FUNDES-Adult) and Quality of Life Questionnaires for Individuals with Spinal Cord Injury (N=36).

		Mean	±SD
FUNDES-Adult	Dimensions		
Do1 Cognition	Performance ^a	5.3	±7.2
	Capability	11.1	±17.4
Do2 Mobility	Performance ^a	49.0	±16.3
	Capability	97.4	±10.0
Do3 Self-care	Performance ^a	12.2	±12.0
	Capability	51.2	±15.8
Do4 Getting along	Performance ^a	11.7	±10.9
	Capability	39.0	±35.4
Do5-1 Household	Performance ^a	45.0	±28.5
	Capability	95.1	±15.1
Do5-2Workactivities	Performance ^a	60.9	±45.1
	Capability	97.9	±9.2
Do6Participation	Performance ^a	44.4	±20.1
	Capability	77.3	±16.4
Quality of Life Questionnaires			
Q1 Overall Quality of Life		3.0	±0.9
Q2 Overall Health		2.6	±0.9
Q3 Physiological Health		12.2	±2.4
Q4 Psychology		12.3	±2.7
Q5 Social Relationship		12.6	±1.9
Q6 Environment		12.9	±2.1

^aPerformance scores > Capability scores of the FUNDES-Adult, $P < 0.05$ by paired t test.

very satisfied. Domain scores were calculated by adding all the item scores of the same domain and transfer it with a formula, and ranged from 4 to 20. Score 4 means very dissatisfied, score 12 means neither satisfied nor dissatisfied, and score 20 very satisfied. Higher score means better quality of life. In addition, there are two independent items: Q1 overall quality of life (1 item, score range 1-5, score 1 means very poor, score 3 neither poor nor good, score 5 very good) and Q2 overall health (1 item, 1-5, score 1 means very dissatisfied, score 3 neither satisfied nor dissatisfied, score 5 very satisfied) to describe the general subjective experience of the individuals. The participants answered the questionnaires based on their perception in the past two weeks [4].

As for the reliability, the internal consistency of the questionnaires (Cronbach α) showed that, the physical health domain was 0.79; the psychological domain was 0.80; the social relationship domain was 0.64; and the environment domain was 0.79. The test-retest reliability for each domain also reached more than 0.75. Overall, this instrument demonstrated acceptable psychometric properties.

Data analysis

The computer statistics software SPSS 17.0 of Microsoft was used to analyzing the data. A descriptive statistics was adopted to illustrate the distribution of the participants' demographic information. The researchers used the Pearson's product-moment correlation

coefficient (γ) to examine the correlation between the participation restriction and the quality of life for patients with SCI, the paired t test to compare the performance and capability scores of the FUNDES-Adult, the repeated ANOVA to examine the differences among capability scores of 6 domains of the FUNDES-Adult and the independent t test to examine the differences between employed and unemployed groups.

Results

Participation of individuals with spinal cord injury

Table 2 indicates that the mean domains scores of the FUNDES-Adult in performance dimension were all lower than those in capability dimension ($P < 0.05$, by paired t test). The results explicated the participants encountered significantly less restriction with the aids of assistive devices or others. When we looked at the mean performance scores, the highest participation restriction was the Do 5-2 Work activities (60.9±45.1) that indicating a mild restriction. The performance score of other domains were all less than 50, means didn't reach the mild disability scores. The performance score of Do1 Cognition (5.3±7.2) was the least which meant the learning and communication participation restriction was neglectable.

In the capability dimension, there were significant differences among the 6 domains. The three domain scores (Do 2 Mobility, Do 5-1 Household and Do 5-2 Work activities) were significantly higher than the others ($P < 0.05$). Followed by the mean score of Do 6 Participation, Do 3 Self-care, Do 4 Getting along, Do1 Cognition sequentially ($P < 0.05$, by repeated ANOVA). As performance dimension, Do 1 Cognition capability was the least restricted domain compared to the others.

QoL of individuals with spinal cord injury

Table 2 showed mean scores in the 6 domains of QoL were all near the neutral, neither satisfied nor dissatisfied. However, when we carefully examined the data, the percentage of poor (score less than 3), neither satisfied nor dissatisfied (score 3) and good (above 3) in the Q1 Overall Quality of Life were 25%, 42% and 33% respectively which indicating that there were still 25% of the participants expressing very poor or poor in their overall QoL. In addition, there was half of the participant indicating very dissatisfied or dissatisfied in Q2, as well as more than one third in all other four domains (44% in Q3, 36% in Q4, 33% in Q5, and 33% in Q6 respectively).

Relationship of participation restriction with QoL

Table 3 showed the correlation coefficients between domain scores of the FUNDES-Adult and the QoL. More performance scores of the FUNDES-Adult were significantly correlated with the QoL than the capability scores. Most domains of performance dimension of FUNDES-Adult displayed significantly low to medium negative correlation with QoL except Do1 Cognition. The capability score of Do1 Cognition, not the performance score, had significant correlation with QoL Domain 1 and 4-6. Among 6 domains of performance dimension of the FUNDES-Adult, Do6 Participation performance restriction and Do4 Getting along with others were more associated with QoL. Do6 performance scores significantly correlated to all domains of QoL while Do4 was also significantly correlated to 4 domains of QoL.

Table 3: Correlation Coefficients between Domain Scores of the FUNDES-Adult and Quality of Life for Persons with Spinal Cord Injury (QoL) (N=36).

	Do 1		Do2		Do3		Do4		Do5-1		Do5-2		Do6	
	P	C	P	C	P	C	P	C	P	C	P	C	P	C
Q1	-0.04	-0.39*	-0.36*	-0.14	-0.16	-0.10	-0.30	-0.21	-0.18	-0.20	-0.32	-0.25	-0.39*	-0.31
Q2	-0.10	-0.32	-0.26	0.17	-0.14	0.06	-0.32	-0.27	-0.17	-0.11	-0.24	-0.02	-0.38*	-0.21
Q3	-0.14	-0.20	-0.37*	0.12	-0.42**	-0.007	-0.44**	-0.14	-0.32	-0.16	-0.39*	-0.08	-0.52**	-0.19
Q4	-0.27	-0.47**	-0.23	0.04	-0.19	0.02	-0.54**	-0.19	-0.22	-0.24	-0.35*	-0.04	-0.42*	-0.28
Q5	-0.22	-0.37*	-0.16	0.001	-0.15	-0.03	-0.50**	-0.19	-0.41*	-0.34*	-0.32	-0.20	-0.57**	-0.37*
Q6	-0.16	-0.35*	-0.43**	-0.56	-0.17	-0.23	-0.35*	-0.14	-0.46**	-0.32	-0.47**	-0.32	-0.54**	-0.36*

Abbreviation: FUNDES-Adult: The Functioning Scale of the Disability Evaluation System-Adult Version; P: Performance Dimension; C: Capability Dimension of FUNDES-Adult; Do1: Cognition; Do2: Mobility; Do3: Self-care; Do4: Getting along; Do5-1: Household; Do5-2: Work Activities; Do6: Participation; Q1: Overall Quality of Life of the QoL; Q2: Overall Health; Q3: Physiological Health; Q4: Psychology; Q5: Social Relationship; Q6: Environment. * $P < 0.05$, ** $P < 0.01$, by Pearson's product-moment correlation test.

Differences of participation and QoL between persons of SCI with and without employment

Table 4 presents the mean domain scores FUNDES-adult and QoL of persons SCI with and without work. Generally speaking, the employed persons had better quality of life. For QoL, the significant difference were found in the Physical Health Domain ($P=0.015$) and the Environment Domain ($p=0.006$) between the two groups. For FUNDES-Adult, the employed group demonstrated lower scores in all domains of performance dimension and most domains of capacity dimension (less restriction). The significant differences were found in the Do5-1 Household performance ($P=0.003$) and Do5-2 Work activities performance ($P < 0.001$).

Discussion

The individuals with SCI demonstrated more participation restriction in the Do2 Mobility, Do5-1 Household, and Do 5-2 Work, and less restriction in the Do1 Cognition, Do3 Self-care, and Do4 Getting alone. It might be due to all participants in this study were paraplegia. With the aid of assistive devices and personal assistances, they had no obvious difficulty in some self-care activities, such as taking bath, putting on clothes, and eating. The participants also showed lower participation restriction in all domains of performance dimension than those in capability dimension. The environmental facilitators (assistive devices and personal assistances) played a significant role on their daily participation. In this study, all participants could move around independently with mobility devices (72% with manual wheelchairs, 22% electric-powered wheelchairs, and 6% regular canes). Those devices not only enhanced their mobility, but also provided their opportunities to learn new things, to live independently, to talk to others, to go to work, and to participate in various social activities. For persons with SCI integration into the community, such as involving self-care and productive activities, could maintain or enhance their health [5]. However, some participants in this study still mentioned that existed environmental barriers affected their willingness to move around and participate actively in a lot of social activities.

In this study, the participants expressed 'neither poor nor good' in their overall quality of life, but they were not so satisfied with their overall health. The other four domain scores of QoL were ranging from 12.2 to 12.9, which indicating their satisfactions were between 'neither dissatisfied nor satisfied' to 'satisfied'. The results were similar

Table 4: The Differences of Domain Scores of the Quality of Life Questionnaires and the FUNDES-Adult Between Persons of SCI With and Without Employment.

QoL	Employed (N=16)		Unemployed (N=20)		P Value
	Mean	±SD	Mean	±SD	
Q1 Overall Quality of Life	3.3	±0.7	2.8	±1.0	0.07
Q2 Overall Health	2.8	±0.8	2.4	±1.0	0.19
Q3 Physiological Health	13.3	±2.2	11.4	±1.0	0.02*
Q4 Psychology	13.1	±2.4	11.5	±2.3	0.07
Q5 Social Relationship	13.2	±1.9	12.1	±2.7	0.09
Q6 Environment	14.0	±1.9	12.0	±1.8	0.006*
FUNDES-Adult					
Do1 Cognition Performance	4.2	±4.8	6.3	±8.7	0.40
Capability	8.6	±15.0	13.1	±19.2	0.45
Do2 Mobility Performance	45.6	±16.3	51.8	±16.2	0.27
Capability	97.2	±11.3	97.5	±9.1	0.93
Do3 Self-care Performance	9.4	±11.4	14.4	±12.4	0.22
Capability	50.8	±16.1	51.6	±16.0	0.89
Do4 Getting along Performance	10.3	±10.9	12.8	±11.1	0.51
Capability	48.7	±36.7	31.3	±33.2	0.15
Do5-1 Household Performance	29.7	±22.1	57.2	±27.5	0.003*
Capability	93.8	±19.4	96.3	±11.0	0.63
Do5-2 Work Performance	12.1	±13.2	100	±0	0.00*
Capability	95.3	±13.6	100	±0	0.13
Do6 Participation Performance	39.3	±19.6	48.4	±20.1	0.18
Capability	78.7	±19.5	76.3	±13.9	0.66

Abbreviation: QoL: Quality of Life Questionnaire for Persons with Spinal Cord Injury; FUNDES-Adult: Functioning Disability. Evaluation Scale - Adult version; * $P < 0.05$ by Independent t test.

to Dijkers's research; he found that persons with SCI tend to report lower subjective well-being than non-disabled people [7].

Our results indicated that there were significant correlations between participation restriction and quality of life, especially the participation performance restriction. Our result is similar to the Dijkers's work, she also found the QOL is more correlated with social participation, and less correlated with the impairments of body function and structures [7]. Wang also found that participation

frequency affect the quality of life for persons with SCI. Persons with SCI participated activities more frequently, they possessed higher QOL [20]. Putzke stated the factors associated with lower self-reported life satisfaction at persons with SCI included being male and unemployed, with poor perceived health, decreased mobility, and decreased social integration [21]. Therefore, how to increase the participation of persons with SCI should be the focus of the rehabilitation [21]. The International Classification of Function and Disability (ICF) proposed a paradigm that considers the environmental supports, including assistive devices and personal assistance, are able to facilitate the social participation of individuals [22].

One of the important factors that contribute to socialization of SCI patients is returning to work. In various studies regarding employment status after SCI, the rate of returning to work was between 11.5-74% [23]. As we know, assistive technology is important for the employment success of individuals with SCI [24]. However, with the aids of devices and personal assistances, only 44% of participants in this study were employed or self-employed. During the interviews, most of the participants complained about their physiological problems such as pain, insomnia, incontinence, bedsore, poor energy and stamina, preventing them get employed or affecting their job performance. The physiological problems seem to be a barrier for persons with SCI returning to work. Kurtaran et al. also indicated successful bladder-emptying program is a significant factor in returning to work for individuals with SCI [23].

The employed participants expressed they have better quality of life in the Physiological health and the Environment domain than those unemployed. Chuang in her research also observed that employed paraplegia patients' mean scores in the domains of the physiological health, psychology domain, social relationship and the environment were higher than the unemployed ones. The result of this research was similar to her research [25]. With relatively similar participation restriction of all the domains in capability between employed and unemployed persons with SCI, the employed persons with SCI have lower participation restriction in Do5-1 and Do5-2 in performance dimension. How to facilitate persons with SCI returning to work, assistive technology devices do play a significant role. The wheelchair is the most important mobility device for persons with SCI, but the one is also that the users most commonly cited barrier [26]. People complain the hardware structures of the wheelchair were usually too heavy and space-taken to limit their participation in social activities, especially going to work [26]. Under the American Disability Act, businesses must provide reasonable accommodations to protect the rights of individuals with disabilities in all aspects of employment. Effective workplace accommodations, such as accessible workstation, accessible parking for a person who does drive, and flexible work schedule for persons with disabilities should be provided by employers to facilitate participation in work [27].

Study Limitation

This research was based on purposive sampling. The thirty-six participants were all traumatic lower limbs paraplegic. Other cervical vertebra and non-traumatic paraplegia patients were not including in this research. Since most samples were members from the regional spinal cord injury association, with the limited research samples

unable to infer the result to the whole spinal cord injury community, this research result was unrepresentative. The follow up research should include other cervical vertebra and non-traumatic paraplegia patients, or non-members of the spinal cord injury association to make the research data more complete and comprehensive.

Conclusions

The participation performance (Domain 6) of the FUNDES-Adult was significantly correlated with all domains of Quality of Life Questionnaire. Therefore, enhancing participation in the living context can promote their quality of life effectively for individuals with paraplegia. Besides, the employed individuals had better quality of life and better societal participation. Therefore, in order to promote the social participation and the employment status of each individual with SCI, the rehabilitation services should focus on the needed environmental supports.

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