

ORIGINAL ARTICLES

**QUALITY OF LIFE IN PEOPLE WITH SPINAL CORD
INJURY – EARTHQUAKE SURVIVORS FROM SICHUAN
PROVINCE IN CHINA**

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ABSTRACT

The aims of this study were to assess the quality of life (QOL) in people with spinal cord injury (SCI) following the earthquake in China (2008) and to identify the most important areas of rehabilitation. All study participants (14 people with SCI) completed a closedquestion social questionnaire, Life Satisfaction Questionnaire, and Aims of Rehabilitation Questionnaire. The most satisfying areas of life were partnership relations and contacts with friends and the least satisfying was vocational situation. The most important aim of rehabilitation was: “recovery of independence in everyday functioning”. The least important aim was: “getting a vocational job, which besides regular income guarantees high prestige and offers vocational development”. Overall QOL of SCI-earthquake survivors in China is rather low. There is a demand for patient-education in China on the role of modern rehabilitation and the realistic goals that a person with SCI can achieve in terms of vocational and social inclusion.

INTRODUCTION

Spinal cord injury (SCI) is a significant challenge to one’s quality of life (QOL). The SCI caused by disaster such as an earthquake also result in additional loss of property, family members and close friends. On May 12th 2008, an earthquake with a magnitude of 8.0, occurred in the Sichuan Province in China. More than 87.000 people died, 370.000 were injured and 5 million were displaced. Among them, 50.000 were estimated to be physically impaired and 20.000 suffered from life-long disabilities. Approximately 190 people in the earthquake zone sustained a SCI (1).

Research into QOL in people with SCI, both objective life quality as well as life satisfaction, has been undertaken all over the world for many years, also in China (2, 3). The literature suggests that there are significant differences between people with SCI in countries with developing economy, compared to countries with developed economy. The main factor influencing different levels of QOL is the gap in the standards of rehabilitation (4). The main aim of this study was to assess the QOL in people with SCI 1.5 year after sustaining the injury in the earthquake in China, and to identify the most important areas of rehabilitation, related to the real needs expressed by study participants, in order to precisely plan areas of future intervention.

METHOD

Participants

All wheelchair-dependent SCI-earthquake survivors in Mianzhu County, Sichuan Province in China ($n = 14$) agreed to participate in this study (11 women and 3 men). Their mean age at the time of the study was 51 years ($SD = 16.13$). All participants had paraplegia; 5 people had complete SCI (35.7%) and 9 incomplete injury (64.3%), however all the participants were using wheelchair in everyday life. Twelve people (85.7%) were married or lived with a partner, and 2 participants (14.3%) were widowed.

Measures

Objective QOL was assessed with the questionnaire covering closed questions related to several aspects of life i.e. highest educational achievement, present vocational activity, present income in comparison to average monthly income in rural areas of China i.e. approximately 63 USD per month (1), housing, and time needed to get to the nearest rehabilitation center from participant's place of living.

Life satisfaction was assessed with the Life Satisfaction Questionnaire (LiSat-9), developed by Fugl-Meyer, Bränholm, & Fugl-Meyer (5). The LiSat-9 consists of nine items pertaining to satisfaction with life as a whole and in the specific domains of self-care, leisure, vocation, finances, sexuality, partner relationship, family, and social contact. All nine questions are answered on a six-point scale (1 = very dissatisfied up to 6 = very satisfied). The reliability and utility of the LiSat-9 in SCI populations has been demonstrated in several previous studies

(2, 6, 7, 8). Several of the items of LiSat-9 have been found to show acceptable test–retest reliability, specificity, and sensitivity (9). Convergent evidence of the validity of the LiSat-9 as a measure of life satisfaction based on relations to other variables (10) was obtained in a study where each of the LiSat-9 items were positively associated with one or more other factors conceptually related to life satisfaction, such as employment situation, perceived health, subjective performance ability, and having a partner (11).

The Aims of Rehabilitation (AOR) were identified with the measure developed for this study by the first author, on the basis of previous extensive research into cultural differences completed by Hofstede (12). The objective of this measure is to find out which aims of rehabilitation are more important to people with SCI. The AOR consists of eight statements 5 (4 typical for individualistic countries and 4 typical for collectivistic countries) related to four areas of rehabilitation: 1) medical i.e. ability to become physically independent versus receive help from relatives, 2) community-based i.e. ability to undertake individual hobbies versus tasks for members of own social group, 3) social i.e. ability to have family with equal roles for both parents or unequal roles where fathers provide for materially and mothers for spiritually, 4) vocational i.e. ability to have job which besides regular income guarantees/or not high prestige and requires/or not vocational development. Participants were asked to put them in order giving numbers from 1 (the most important) to 8 (the least important). Descriptive statistics were used for the presentation of the results: median (M), mean (\bar{x}), standard deviation (SD), percent (%). Statistical analysis was performed using SPSS 14.0.

Procedure

All wheelchair-dependent SCI-earthquake survivors in Mianzhu County, Sichuan Province in China ($n = 14$) were asked to participate in the study and all agreed to complete the survey (filled in the consent form). All three measures were translated from English to Chinese by sworn translators (back-translation). The data for this study was gathered within face-to-face interviews due to lack of reading literacy amongst some study participants. This report is part of the “Multicultural Quality of Life Study in People with Spinal Cord Injuries living in Asian and African Countries” (project official website: <http://dimensions.spss.pl/qol.htm>). The study was approved by the Asian Spinal Cord Network which holds the honorary patronage of this project.

RESULTS

Objective QOL

With respect to residential wheelchair accommodation, 21.4% of participants reported that they lived in housing that was fully adapted, 50% had partially accessible accommodation, and 28.6% lived in houses not adapted at all to their needs. 64.3% indicated that they had obtained primary education, and 35.7% had no formal education; 76.8% noted that they were unemployed and 21.4% reported that they were homemakers/parents. The majority of participants (85.7%) stated that their income was lower than average monthly income in rural areas of China, 7.1% had similar income, and 7.1% had no income at all. In order to get to the nearest rehabilitation center, study participants had to travel on average 1 hour ($SD=.36$) from their place of living.

Subjective QOL

Life as a whole was assessed between “rather satisfying” and “rather dissatisfying” ($M=3.50$, $SD = 1.60$). The most satisfying area of life was partnership relations ($M = 5.50$) and the least satisfying areas were: vocational situation ($M = 2.00$), and sexual life ($M = 2.00$), however 9 people (64.2%) refused to give answer to question regarding their sexual life (Table 1).

Table 1. Life satisfaction in people with SCI – earthquake survivors in Sichuan Province, China

LiSat-9	<i>M</i>	<i>SD</i>
Life as a whole	3.50	1.60
Self-care ability	5.00	1.60
Leisure situation	4.50	1.88
Vocational situation	2.00	1.38
Financial situation	3.00	1.37

Sexual life	2.00	1.64
Partnership relations	5.00	1.33
Family life	4.50	1.39
Contacts with friends	5.00	1.23

Aims of rehabilitation

The most important aims of rehabilitation expressed by study participants were: “recovery of independence in everyday functioning” and “getting care and aid from the nearest family members in everyday functioning”. The least important aim was “getting a vocational job which besides regular income guarantees high prestige and offers vocational development”. The ranking list of aims of rehabilitation is presented in Table 2.

Table 2. Ranking of aims of rehabilitation in people with SCI – earthquake survivors in Sichuan Province, China

Rank	Aims of rehabilitation	<i>M</i>	<i>SD</i>
1	Recovery of independence in everyday functioning ¹⁾	1.00	2.02
2	Getting care and aid from the nearest family members in everyday functioning ²⁾	2.00	2.25
3	Striving to return to / start up my own family in which both parents provide for materially and spiritually ¹⁾	3.50	1.70
4	Ability to realize individual interests and hobbies ¹⁾	3.50	1.94
5	Getting a vocational job which besides regular income does not put high requirements nor need for vocational development ²⁾	6.00	1.74

6	Striving to return to / start up my own family in which fathers provide for materially and mothers for spiritually ^C)	6.00	1.74
7	Ability to realize essential tasks for members of my own social group ^C)	6.50	2.07
8	Getting a vocational job which besides regular income guarantees high prestige and offers vocational development ^I)	7.50	2.25

I) Individualism; C) Collectivism

DISCUSSION

A number of studies demonstrate a significant decrease of QOL in people with SCI and usually this effect is mediated by country of residence (2). In a study of perceptions of QOL for Chinese adults with SCI, Hampton and Qin-Hilliard found that economic well-being which included financial security, material satisfaction and being able to contribute to society, is one of the most important components of QOL (4). The present study found that 76.8% of the study participants were unemployed and 85.7% stated that their income was lower than the average monthly income in rural areas of China (1). Low employment rates, leading to rather poor financial situation, undoubtedly constitute an important factor affecting lives of people with SCI. Additionally, to the Chinese, having a job also meant that they could support their parents financially (4).

The results of this study suggest that the Chinese people with SCI tended to assess their overall life satisfaction as rather low. The results of our study are consistent with those of Songhuai et al. (2) who studied a group of 22 Chinese patients with SCI. Remarkable differences were observed in the assessment of self-care ability which, according to Songhuai respondents, was one of the least satisfying aspects of life (2.0). In the current study group it was one of the most satisfying categories (5.0). A possible explanation of different results is that both study groups were demographically diversified. In the Songhuai study 19 of the 22 participants were men, all of whom had tetraplegia. This study group consisted of 11 women and 3 men and all of them had paraplegia. Apart from obvious different potential

achievements in self care-abilities between people with paraplegia and tetraplegia there may also be gender differences in this aspect of life satisfaction. Chinese males with SCI seemed to have higher expectations from their self-care abilities than females. Traditionally, men have been viewed as financial providers, whereas women have been viewed as caretakers. This finding is consistent with previous research. Hampton and Marshall reported that Chinese males with SCI had lower life satisfaction scores than Chinese females (3).

The final outcome of the rehabilitation process following SCI is the improvement of the person's QOL, and as such it is necessary to recognise the most important aims of rehabilitation. Such aims could also be influenced by country of residence and life values preferred by people living in particular parts of the world. In this study the most important aim of rehabilitation expressed by study participants was: "recovery of independence in everyday functioning" and "getting care and aid from the nearest family members in everyday functioning". The first statement is typical for individualistic countries but the second for collectivistic countries (12). These two aims seem to be contradictory, however in Chinese reality it could be explained by difficult living environment, especially in the post-earthquake zone. On the one hand people with SCI would like to become independent, but on the other hand they probably realise that everyday life without aid from family members is impossible. What is interesting, despite being the least satisfactory aspect of life, vocation is only ranked at number 5 and 8 in the list of quoted aims of rehabilitation. These findings could be interpreted in the context of limited understanding of modern rehabilitation and knowledge of the possible functional recovery following a SCI. Thus the possibilities of vocational activity following a SCI is seldom promoted. It could be suggested that there is a limited sense of empowerment and self-belief in the studied population.

There are undoubtedly a number of limitations related to this study which need to be discussed. Firstly, the AOR scale is a newly developed measure, and therefore future research should examine its psychometric properties. Second important limitation of the present findings involves the nature of the study group which consisted of 11 women and 3 men, mean age over 50 years. This unusual epidemiology for the people with SCI may be explained by the time of the earthquake: 14.28.01 pm. – a time when many older people and women were at home resting. A small number of study participants ($n = 14$) limited this report to a descriptive analysis. Due to a lack of control group and small sample size, it is not possible to determine

whether the study results are characteristic for SCI-earthquake survivors in Sichuan Province as a whole or whether they reflect the general condition of people with SCI in China. Finally, due to lack of reading literacy of 35.7% participants with SCI the data for this study was gathered within interviews which could have influenced the answers, especially in the case of “sensitive questions” (9 people refused to give answer to question regarding their sexual life). Due to the above limitations this study should be considered as a case report only.

CONCLUSION

There is a definite need for more information and awareness on what rehabilitation can bring for people with SCI after natural disasters and how long term follow-up, vocation and social inclusion, should be an important planning feature in case of emergency support for SCI11 earthquake survivors. Also the analysis on females with SCI in China should be further investigated in terms of gender issues and expectations after SCI accidents.

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