

Assessment of the quality of life of spinal cord injury patients in Peshawar

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Abstract

Objective: To assess the quality of life of spinal cord injury patients.

Methods: This cross-sectional study was conducted at Paraplegic Centre Hayatabad, Peshawar, Pakistan, from November 2015 to January 2016, and comprised spinal cord injury patients. A 26-item World Health Organisation quality of life questionnaire was used. Some of the patients were recruited from the paraplegic centre while others participated by filling an online questionnaire. SPSS 20 was used for data analysis.

Results: Of the 54 participants, 35(64.8%) were male and 19(35.2%) were female. Besides, 50(92.6%) participants were paraplegic while 4(7.4%) were tetraplegic. The overall mean score for the physical health domain was 54.79 ± 18.39 , psychological health domain 52.33 ± 19.37 , social relationship 58.79 ± 20.69 and environmental domain 54.11 ± 17.25 .

Conclusion: Patients with spinal cord injuries had moderate level of quality of life.

Keywords: Quality of life, Spinal cord injury, Cross-sectional survey, Satisfied, Dissatisfied, WHO-BREF, Health. (JPMA 67: 434; 2017)

Introduction

Spinal cord injury (SCI) badly affects the mental, physical, social and psychological aspects of life of the victims.¹ Worldwide approximately 90 million people are suffering from SCI. In developed countries, SCI incidence ranges from one to five persons per 100,000. Its most common causes are motor vehicle accidents (50%), fall (22%), gunshot (11%) and recreational sports activities (11%).² Post-SCI life expectancy of the patient has improved as a result of advancement in medical care and establishment of specialised units. Increased life expectancy with the disability exposed these individual to physical, social, psychological and environmental problems.³

The most common complication of spinal cord injury are mobility limitation, bowel and bladder dysfunction, sexual dysfunction, pressure ulcers and chronic pain which results in disruption to their lives along with negative effects on psychosocial functioning.^{1,4} In acute as well as chronic SCI patients, physical, psychological and social consequences are quite evident that result into problems while integrating into the community.⁴ The secondary complications of SCI include negative effect on long-term health, employment, social participation, mobility, dignity and independence. Also, SCI patients

score lower in physical, mental, social health and other essential domains of quality of life (QOL) as compared to non-SCI patients.⁵

QOL is the true indicator rather than loss of function of the result of health care intervention, particularly rehabilitation.⁶ QOL is the best representation in order to evaluate the health-related outcome of rehabilitation in disabilities, particularly those with spinal cord injury.⁷ A study reported that despite QOL being the essential element of rehabilitation, each author has his own definition.⁸ Another study defines quality of life as the ability to work with a paid job, having high degree of autonomy, minimal changes in social relationship along with the partner relationship, ability to drive and to have a satisfactory love life.⁹ The QOL is an objective and effective way to evaluate the effectiveness in rehabilitation units.¹⁰

Although QOL is frequently used, it is still an ill-understood concept in medicine. The majority (72%) of British health care professionals consider it as happiness while other understood QOL as social (26%), physical (25%), mental (18%) health or functioning.¹¹ The World Health Organisation (WHO) defines QOL as "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".⁷ Literature review supports three approaches to measure and operationalise QOL, health-related quality of life (HRQOL), well-being and QOL as superordinate construct.¹⁰

The various generic QOL tools used by different studies

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are sickness impact profile, the quality of well-being scale, the medical outcomes study 36-item short-form health survey, World Health Organisation's quality of life (WHOQOL-100) assessment scale and its short version (WHOQOL-BREF), Nottingham health profile and the European quality of life scale. Although various measurement tools have been used by investigators according to the specific condition, they cannot be compared with general population and cross-cultural applicability was not available.¹²

Subjective QOL assesses the individual satisfaction of their health, employment, friendship, sexual life, family relation, finance as well as leisure times.⁴ Subjective well-being or QOL is the major goal and outcome in physical medicine and rehabilitation as its achievement is dependent on improving the health and functional levels of the individuals. Various research studies relate QOL and subjective well-being with richness and high quality of social contacts of individual. Other studies relate it to community functioning and social interaction instead of injury level and independent functional level.¹³ Some people feel compelled to commit suicide due to depression and prolonged self neglect. However, in developed countries SCI patients are satisfied with their QOL as they have enough facilities of medical care, adaptive equipment, getting enough economic and social support and living in cities and towns with accessible housing, public spaces and buildings and transport facilities.¹⁴

The QOL assessment is important for health team in order to take new decisions regarding health care and make new policies.⁷ The most important factors that predict and correlate with QOL of people with SCI are access to the community, social support, employment, marriage and community integration.¹⁵ The various factors that correlate with QOL are employment, relationships and autonomy and mobility circumstances. Manns and Chad in their study found no association between subjective perception of QOL and the level of injury.¹⁶

The QOL is of valuable attention as it reflects how the individual cope with new situation of life. It is an evidence-based fact that the health-related quality of life is not merely based on physical condition, but other factors like social factors, economic condition, culture and living condition also contribute to it.¹ Westgren and Levi in their study identified no difference in QOL of complete and incomplete paraplegic and tetraplegic patients, respectively. They have also identified high score of QOL in old patients as compared to newly injured patients.¹⁷ Dijkers in his study identified strong relationship between the level of injury and QOL and no relationship between

QOL and completeness of injury.¹⁸ Yong Hu et al. reported low QOL in SCI patients than normal population.⁶

Blanes et al. recorded low quality of life in a sample of 60 SCI patients using 36 items of short form scale (SF-36).¹⁹ QOL of SCI patients revealed low quality of life scores nationally and internationally and researchers have acknowledged the need for further studies to evaluate the QOL of SCI patients.⁷ In contrast, some studies claim there are no such medical or psychosocial problems in the lives of people with SCI.⁴ The QOL assessment is important for health team in order to take new decision regarding health care and make new policies.⁷ The current study was planned to assess the QOL of people who had suffered spinal cord injury.

Materials and Methods

This qualitative, cross-sectional survey was conducted at Paraplegic Centre Hayatabad (PCH), Peshawar, Pakistan, from November 2015 to January 2016, and comprised SCI patients. WHOQOL-BREF questionnaire was used.²⁰ Ethical approval for the study was obtained from the head of the department concerned, i.e. chief executive officer (CEO) of the Paraplegic Centre Hayatabad. Convenient sampling method was adopted. Some of the participants were recruited from PCH, while others filled an online questioner using a survey software in which the questionnaire was presented in written form with check boxes. Informed consent was obtained from all participants. Researchers themselves filled the questionnaires for participants who were unable to fill them. Questionnaires were distributed by self-approach. WHOQOL-BREF questionnaire is a very complex and time-taking questionnaire. It was first explained to the patients and the purpose and meaning of each question were made clear. Enough time was given to patients to answer the question. SPSS 20 was used for data analysis. Percentages and frequencies were calculated for age and gender. Questions were analysed descriptively using frequencies and percentages and bar charts were applied showing percentage of people attempting the questions.

Results

Of the 54 participants, 35(64.8%) were male and

Table-1: Patient characteristics.

S. No	Gender	Frequency	Percent	Valid Percent
1	Male	35	64.8	64.8
1.1	Female	19	35.2	35.2
2	Level of Injury	Frequency	Percent	Valid Percent
2.1	Paraplegic	50	92.6	92.6
2.2	Tetraplegic	4	7.4	7.4

Table-2: Mean domain scores.

S. No	Domains Score	Mean score	Minimum	Maximum	Std. Deviation
3	Physical health	54.79	19.00	94.00	18.39478
3.1	Psychological health	52.33	19.00	81.00	19.36774
3.2	Social relationship	58.79	19.00	100.00	20.69249
3.3	Environment	54.11	13.00	94.00	17.24606

Std: Standard.

19(35.2%) were female. Age of 33(61.1%) participants ranged from 15-30 years, 14(25.9%) participants ranged from 31-45 years, 6(11.1%) from 46-60 years and 1(1.9%) from 61-75 years. Moreover, 50(92.6%) participants were paraplegic while 4(7.4%) were tetraplegic (Table-1).

The mean domain score was 54.79 ± 18.39 for physical health, 52.33 ± 19.37 for psychological health, 58.79 ± 20.69 for social relationship and 54.11 ± 17.25 for environment (Table-2).

In physical health domain, 8(14.8%) participants were having physical pain that extremely affects their activity of daily life (ADL). Similarly, 5(9.3%) participants were having extreme need of medicine for management of their physical pain. Among all, 4(7.4%) participants were not having energy for daily life activities, 13(24.1%) were having very less opportunity to get around, 3(5.6%) were very dissatisfied with their sleep and 18(33.3%) were dissatisfied with their capacity of work. In psychological domain, 16(29.6%) participants were unable to enjoy their life while 8(14.8%) participants rated their life to be meaningless. Similarly, 6(11.1%) participants were having concentration problems, 2(3.7%) were dissatisfied with themselves and 21(38.9%) reported seldom mood problem, anxiety and depression. In social domain, 5(9.3%) participants were dissatisfied with their personal relationships, 12(22.2%) were extremely dissatisfied with their sex life and 2(3.7%) were not satisfied with the support they get from their friends. In environmental domain, 8(14.8%) participants reported extreme risk of fall in daily life and 9(16.7%) participants were facing problems in their physical environment. Besides, 4(7.4%) participants had no money to meet daily life needs, while 9(16.7%) reported non-availability of information in their daily lives. Among all, 4(7.4%) participants were dissatisfied with their access to healthcare services. Also, 5(9.3%) participants were dissatisfied with the transport facilities.

Discussion

Rehabilitation intervention outcomes are mostly judged in the form of functional outcomes. For instance, has the patient's range of motion (ROM) improved? Can he brush his teeth independently? Is his gait steady? Can the

individual walk without assistance? Of course these questions are valuable to judgment of rehabilitation intervention. Another valuable question to be asked is: can independent brush, gait stability, increase in ROM and independent ambulation increase QOL? The participants of this study were largely male. Also, the number of paraplegic patients was higher than tetraplegic patients.

Among all the four domains, the lowest score was found in psychological health domain (52.33%) which means that patients were not enjoying their life and their life was less meaningful. It also implied that they were not satisfied with their self and they also did not accept their injury.

One-third of the participants rated their quality of life as good. Similarly, nearly half of the patients were satisfied with their health status. A study reported that QOL of post-SCI patients was positively affected by the availability of resources like adequate income, attendant care and transportation facilities, while negatively affected by factors like rehospitalisation for secondary health problem post-SCI, pain, spasticity, low income, reduced social relationship, reduced mobility and feeling of loss of control over personal life.⁸

In physical health domain, 14.8% of the participants were facing problems in their ADLs due to severe pain. About 9.3% of the participants were taking medicine for their pain management.

Among all, 33.3% of the participant reported low capacity of work, 24.1% were unable to get around, some of the participants were having sleep difficulty while another 7.4% reported decreased energy level of body. Decker and Schulz identified in their study that most of the SCI patients withdraw from leisure activity due to fatigue, limited physical access stress and social devaluation.¹³ In psychological domain, findings of the current study showed that 38.9% participants had mood problem, anxiety and depression, 29.6% were unable to enjoy their life and 14.8% believed their life was meaningless. Some of the patients were unable to concentrate while some others were dissatisfied with themselves. Stensman in his study identified that one-fourth of the subjects reported some type of anxiety and depression 2-4 years after SCI.²¹

In social domain, 22.2% participants of the current study were dissatisfied of their sexual relationship, 9.3% reported decline in their social relationship while others believed their friends and family did not support them. Regarding satisfaction with partner relationship, a study revealed that one-third of the patients were dissatisfied, half were satisfied while one-fifth did not reply about their sexual relationship with their partner.⁹ A study reported that post-SCI both acute and chronic stage patients face physical, psychological and social problems that bring negatives effects on people social interaction with community.⁴ In environmental domain, 16% of the patients had extreme chances of fall, 9.3% had financial problems and availability of limited health resources as well as transport facilities in their community.

Some of the most prominent problems faced by SCI patients were inconvenient transport facilities, reduced health facilities for daily medical problems and unemployment.⁶ A study conducted by MR Hill et al. pointed out that physical domain was affected the most, followed by psychological domain, social domain and environmental domain.²² Another study found that the domain of physical function and physical role had suffered the most. Comparatively, physical domain score was lower in paraplegic patients than tetraplegic ones; however, the level and severity of injury role was unclear.²³

The limitations of the current study were small sample size, convenient sampling, online questionnaire filling and the inclusion of only one centre of spinal cord injury.

Conclusion

People with SCI had moderate level of quality of life in relation to physical health, psychological health and social relationship dimensions. The lowest score was found in psychological health domain which means that the patients were not enjoying their life and their life was less meaningful to them. They were not satisfied with themselves and they also did not accept their injury. Moreover, WHOQOL-BREF questionnaire was found to be the standard tool to measure quality of life of people with spinal cord injuries.

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