



# Quality of Life in Patients with Spinal Cord Injury: A Prospective Longitudinal Study

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## Abstract

**Introduction** Spinal cord injury (SCI) is one field of neurotrauma where fierce research has been going on to achieve a cure for the dreaded disease. Complete cure of this condition still remains elusive. Although focus is mainly on reversing the physical disability, not much importance is given to other factors which have an immense bearing on quality of life (QOL) of the victim. These factors include social health, psychological health, and environmental factors. The Indian Armed Forces offers the unique advantage of following up a patient from the time of injury till rehabilitation. This prospective longitudinal study is the first of its kind in India, undertaken to assess the QOL of the SCI patient from the time of trauma till end of 1 year. We have attempted to measure QOL of the SCI patients in four main domains (physical health, psychological health, social health, and environmental factors) and further tried to highlight the predictors which play a major role in improving QOL. It is proposed that identifying these important predictors and correcting them with appropriate targeted interventions can play a major role in improving the QOL in SCI patients.

**Materials and Methods** This prospective longitudinal study was carried out in a single tertiary care hospital from May 2017 to October 2019. All patients with SCI were treated and followed up for at least 1 year posttrauma using the World Health Organization Quality of Life-BREF questionnaire. A total of 68 patients were treated and studied. Results were analyzed and conclusions drawn.

**Observations and Results** Physical health was the most important domain to have an impact on QOL while environmental health had the least. Maximum improvement occurred in all domains during the first 6 months after which the improvement in scores was unimpressive. The degree of improvement correlated directly to the severity of initial motor deficits. Strong caregivers' support and structured care in a rehabilitation center played important role in improving the QOL of SCI patients.

**Conclusion** Our study goes on to prove that in order to improve QOL of SCI patients an assessment needs to be undertaken going beyond physical domain. Factors playing a major role in deciding QOL should be identified and then subsequently be corrected with targeted interventions.

## Keywords

- ▶ spinal cord injury
- ▶ World Health Organization Quality of Life Questionnaire
- ▶ predictors of QOL

## Introduction

Spinal cord injury (SCI) is one of the most disruptive traumatic events in any human's life. SCI may cause quadriplegia or paraplegia depending on the level of injury affecting the functioning of limbs, trunk, pelvic organs, bladder, and bowel, as well as sexual function. This loss of function leads to significant changes in life of the affected individual making routine vocational, social, sexual, and recreational activities impossible. Shortly after the injury, all attention is put into stabilizing the patient. Following the acute phase of definitive management, individual is left to cope with challenges thrown to him at physical, social, environmental, and psychological levels.

Limited knowledge exists as on date regarding analysis of factors influencing quality of life (QOL) in SCI on long term. Number of studies has explored how personal factors are associated with subjective QOL. Few studies have included environmental and personal factors in their same analysis, and yet even fewer have been longitudinal in nature. No prospective studies have been conducted in India so far to assess the QOL of patients with SCI on a long-term basis. This study is an attempt to measure the QOL of the SCI patients, and further tries to highlight the predictors which could play a major role in improving the QOL in these patients with appropriate interventions.

## Materials and Methods

This was a prospective longitudinal study in which each patient with SCI reporting to a single tertiary care hospital in southern India were treated and followed up for 2 years. The World Health Organization Quality of Life (WHO QOL-BREF) questionnaire was given to them at time of presentation to treatment facility (within 48 hours of trauma). The same questionnaire was given to them at 6th month and then at end of 1 year following trauma. Results were analyzed and conclusions drawn. Any patient above the age of 18 years was included in the study. Patients with concomitant head injury or history of psychiatric illness were excluded from this study. A total of 72 patients were enrolled in this study after taking ethical clearance from the hospital ethical committee. By the end of 2 years 68 patients completed this study, which was conducted from May 2017 to October 2019. This action was in line with WHO QOL-BREF recommendations. According to the same recommendations, participants were oriented to answer the questionnaire based on the previous responses.

**Measures and instruments used:** The WHO QOL-BREF questionnaire was the primary tool to collect information on QOL of SCI patients. All 26 items in the WHO QOL-BREF are based on a five-point Likert scale. Among these items, 24 items are grouped under four domains of QOL: physical health (7 items), psychological well-being (6 items), social relationships (3 items), and environment (8 items). The 24 items in the domains are as follows:

1. Physical health activities of daily living:
  - Dependence on medicinal substances and medical aids.
  - Energy and fatigue.
  - Mobility.
  - Pain and discomfort.
  - Sleep and rest.
  - Work capacity.
2. Psychological bodily image and appearance:
  - Negative feelings.
  - Positive feelings.
  - Self-esteem.
  - Spirituality/religion/personal beliefs.
  - Thinking, learning, memory, and concentration.
3. Social relationships:
  - Personal relationships.
  - Social support.
  - Sexual activity.
4. Environment:
  - Financial resources.
  - Freedom, physical safety, and security.
  - Health and social care: accessibility and quality.
  - Home environment.
  - Opportunities for acquiring new information and skills.
  - Participation in and opportunities for recreation/leisure activities.
  - Physical environment (pollution/noise/traffic/climate).
  - Transport.

**Scoring in WHO QOL-BREF:** The four domain scores denote an individual's perception of QOL in each particular domain. Domain scores are scaled in a positive direction (i.e., higher scores denote higher QOL). The mean score of items within each domain is used to calculate the domain score. The WHO QOL-BREF questionnaire was scored after its administration to the study subjects and the raw scores were converted to transformed scores. The first transformation converts scores to a range of 4 to 20 and the second transformation converts domain scores to a 0 to 100 scale. Higher scores reflect a better QOL.

## Observation

**Physical health:** WHO QOL was assessed for each patient using WHO QOL questionnaire. At onset of injury, total physical health score mean was 64.66. For the cervical subgroup it was 60.69, for thoracic 63.5, for lumbar 67.96, and for sacral 77. At 6 months postinjury the mean score was 72.49, for the cervical subgroup it was 71.76, for thoracic 70.29, for lumbar 73.2, and for sacral 82. At 1 year postinjury the mean score was 78.94, for the cervical subgroup it was 78.76, for thoracic 78, for lumbar 78.92, and for sacral 84.67 (► **Figs. 1–2**).

The factors which played major role in first month were pain and discomfort. At the end of 6 months, the pain factor regressed in order of importance while factors like pressure sore, dysreflexia, urinary tract infection, and spasticity were the major factors. At the end of 1 year, mobility and work capacity were the major determinants of physical health domain QOL.

**Psychological health:** At onset of injury, total psychological health score mean was 66.81. For the cervical subgroup it

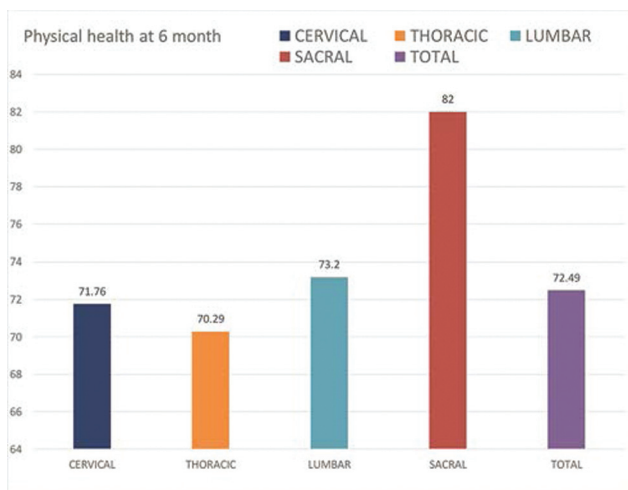


Fig. 1 Bar chart showing physical health domain score at 6 months.

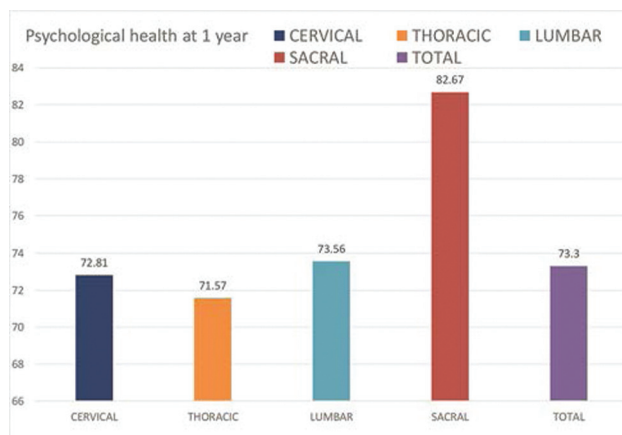


Fig. 4 Bar chart showing psychological health score at 1 year.

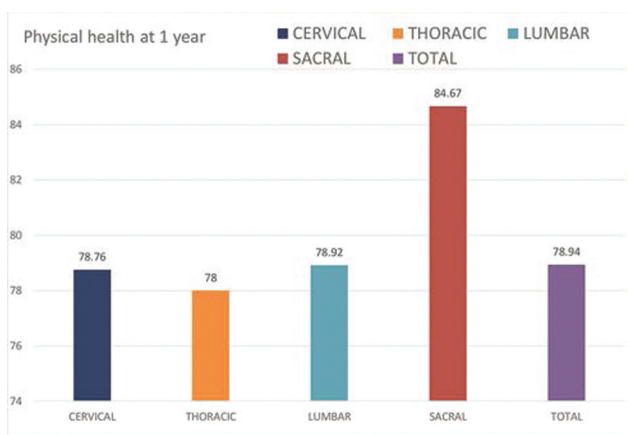


Fig. 2 Bar chart showing physical health domain score at 1 year.

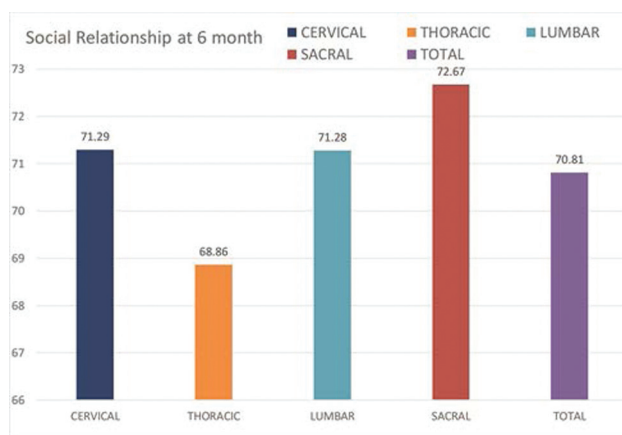


Fig. 5 Bar chart showing social relationship score at 6 month.

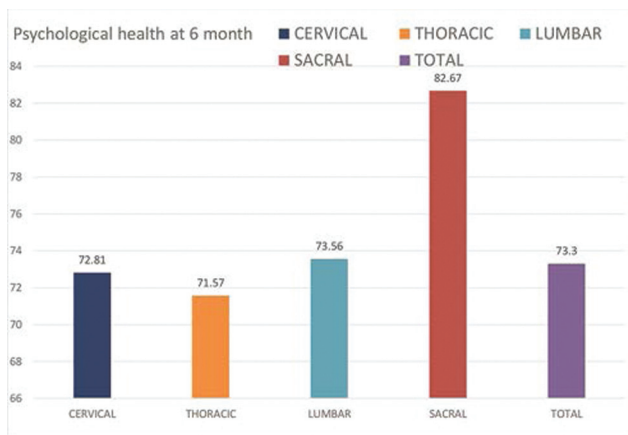


Fig. 3 Bar chart showing psychological health score at 6 month.

was 63.85, for thoracic 66.86, for lumbar 68.88, and for sacral 75. At 6 months postinjury, the mean score was 73.3, for the cervical subgroup it was 72.81, for thoracic 71.57, for lumbar 73.56, and for sacral 82.67. At 1 year postinjury, the mean score was 78.03, for the cervical subgroup it was 78.9, for thoracic 77.16, for lumbar 78.92, and for sacral 84.67 (→Figs. 3–4).

In the immediate postinjury status till the end of first month 60% of them required psychological counseling and medication in the form of anxiolytics and antidepressants. The number of sessions with psychiatrists was found to be directly proportional to the severity of motor impairment in the immediate posttrauma period. Thinking, learning, memory, and concentration were the main factors which improved at the end of 6 months and 1 year.

*Social relationship:* At onset of injury, total social relationship score mean was 63.47. For the cervical subgroup it was 60.62, for thoracic 63.86, for lumbar 66, and for sacral 65.33. At 6 months postinjury, the mean score was 70.81, for the cervical subgroup it was 71.29, for thoracic 68.86, for lumbar 71.28, and for sacral 72.67. At 1 year postinjury, the mean score was 76.3, for the cervical subgroup it was 78, for thoracic 74.14, for lumbar 76.12, and for sacral 76 (→Figs. 5–6).

Personal relationships and social support were the main factors which were a major determinant up to 6 months. Patients with close relatives as caregivers did better as compared to others. The attitude of the caregivers was found to be playing a significant role in improving the social relationship. Younger patients with strong social support were found to give lesser credence to sexual activity.

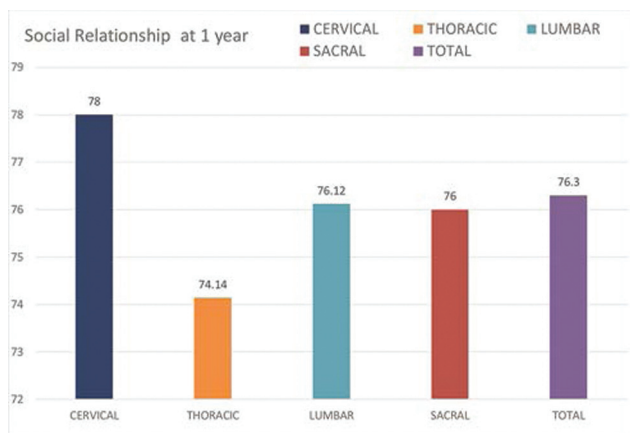


Fig. 6 Bar chart showing social relationship score at 1 year.

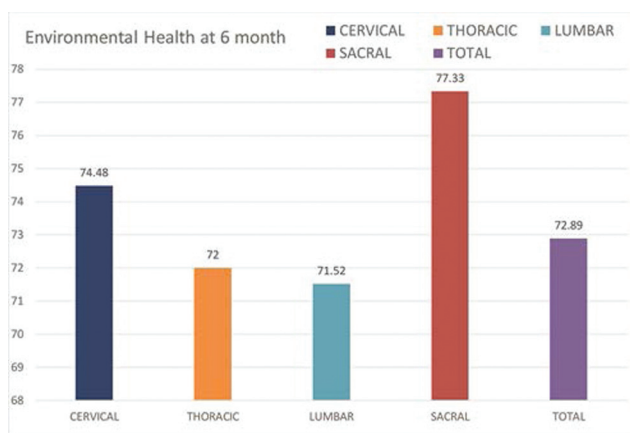


Fig. 7 Bar chart showing environmental health score at 6 month.

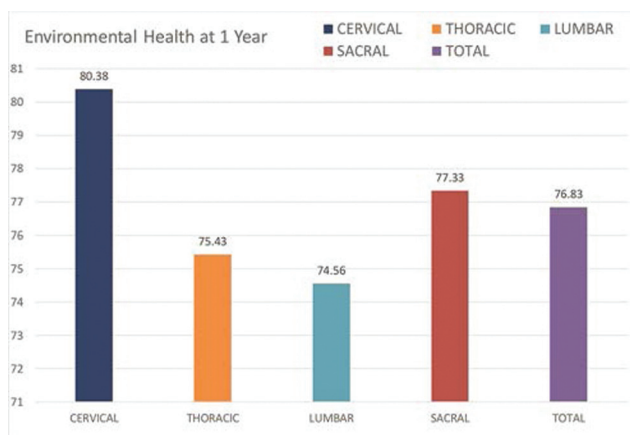


Fig. 8 Bar chart showing environmental health score at 1 year.

**Environmental health:** At onset of injury, total environmental health score mean was 67.25. For the cervical subgroup it was 66.35, for thoracic 68.29, for lumbar 67.32, and for sacral 69.67. At 6 months postinjury, the mean score was 72.89, for the cervical subgroup it was 74.48, for thoracic 72, for lumbar 71.52, and for sacral 77.33. At 1 year postinjury, the mean score was 76.83, for the cervical subgroup it was 80.38, for thoracic 75.43, for lumbar 74.56, and for sacral 77.33 (► Figs. 7–8).

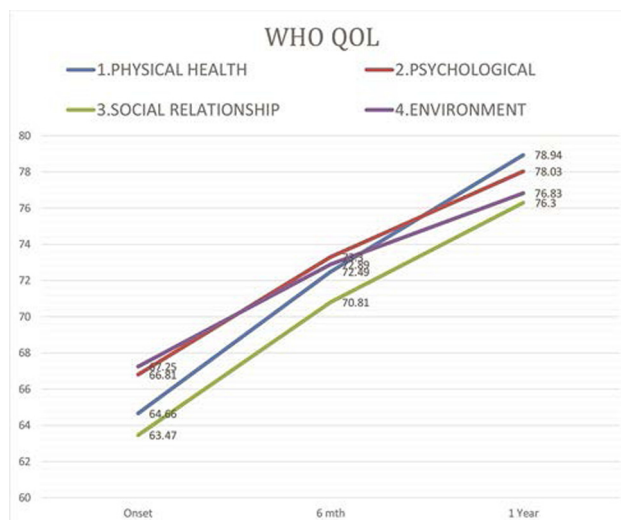


Fig. 9 Chart showing overall World Health Organization Quality of Life (WHO QOL) score traced for 1 year.

Compared to the other three domains environmental factor scores showed the least improvement. Patients undergoing management in rehabilitation centers with facility of motorized mobility assisting devices and occupation therapy facilities scored better at the end of 1 year.

The overall WHO QOL score when traced for 1 year showed that the maximum improvement in all four domains was in the first 6 months. At the end of 1 year maximum improvement was seen in the physical health domain (► Fig. 9).

## Result

Our study showed that spinal injury mainly affects males (82.4%) in the age groups of 30 to 50 years (41.2%). Most common observed mechanism was fall from height (42.6%) followed by RTA (19.1%). Patients having cervical injury were more prone to develop neurogenic bladder (76.92%). We found incomplete injuries (76.47%) more than the complete injuries (23.52%), cervical spine injuries being the most common (38.2%). The overall mortality rate following spinal injury in our study was 7.35%. Majority of patients underwent surgical intervention (54.41%). We observed a gradual neurological, clinical, and QOL domain improvement over a follow-up period of 1 year. The improvement being maximum in the initial 6 months followed by a relative plateau over further course of time. Our study showed the following results which can be summarized as follows:

1. Four domains studied included physical health, psychological health, social relationship, and environmental health factors. Of this, physical health was a major determinant of QOL till the end of 1 year.
2. Pain and degree of motor impairment was a major predictor of QOL influencing all domains.
3. Quadriplegics as compared to paraplegics and complete injury and compared to incomplete injury were found to have a lower score in the initial 6 months.

**Table 1** Study comparison with similar studies worldwide

Study done so far	Time as an important predictor of QOL	Important physical factors determining QOL	Important psychological factors	Important environmental predictors	Important social factors	Depression	Marital status	Importance of physical factor in determining long-term QOL	Important take away
Lude et al, 2014 (n = 292)	Yes	Pain Lesion level (tetraplegia versus paraplegia) Lesion type (complete versus incomplete)	Appraisals Coping strategies	Level of mobility	Social support	Important factor	Inconclusive	Not clear relationship	Psychological health showed maximum increase from 6 to 12 months. Physical health showed maximum increase in first 6 months
Shin et al, 2012 (n = 106)	Yes	Motor ability. Not studied motor deficits in detail	Mood Coping strategies	Level of mobility	Social support Interpersonal relation	Majority of SCI suffer from depression	Unmarried fare better	Not significant in long term	Depression, maximum in first 6 months
Middleton et al, 2007 (n = 106)	Inconclusive	More on lesion level Inconclusive on lesion type	Coping strategies	Mobility level	Inconclusive on social support	Depression and poor QOL linked to self-efficacy targeted toward SCI	Inconclusive on marital status	Inconclusive	Self-efficacy is an important factor determining QOL
Our study, 2018 (n = 68)	Yes	Neuropathic pain Lesion level Lesion type	Coping strategies	Mobility level	Inconclusive	Strong factor	All patients studied were married	Chronic pain was the only significant physical factor	All domains show maximum improvement in first 6 month thereafter it plateaus

Abbreviations: QOL, quality of life; SCI, spinal cord injury.

- Degree of motor impairment in the first month directly correlated with psychiatric intervention requiring counseling and pharmacotherapy.
- Strong moral and social support by patients' caregiver had a significant impact in improving the QOL score in all domains.
- Maximum improvement in all domains occur in the first 6 months.
- Patients in rehabilitation centers along with a strong supportive caregiver fare better in long term as compared to patient undergoing the same in nonspecialized centers.

Literature so far published regarding QOL analysis in SCI patients support most of the findings which have emerged from our study.<sup>1-3</sup> All the comparative studies show that there is a definite improvement in QOL with passage of time. Maximum improvement is seen in the initial 6 months to 1 year. The level of SCI takes precedence over completeness of SCI (► **Table 1**).

## Discussion

The WHO Mental Health Division's Quality of Life Group considers QOL as the individual's perception about his position in life in the context of the culture and value systems he lives in, considering his objectives, expectations, standards, and concerns.<sup>4</sup> This Group elaborated the WHO Quality of Life - 100 and its short version, called the WHO QOL-BREF, in which a cross-cultural approach is adopted, as well as three aspects regarding the QOL concept: subjectivity (individual perception of his life), multidimensionality (understanding

about the different dimensions of life), and both positive and negative assessment elements.

SCI patients are vulnerable to the injury and its sequel occurring from the phase of rehabilitation to the community reinsertion phase. Physical problems that can affect these patients include pressure ulcers and urinary tract infection, which affects at least 35% of patients. Pressure ulcers can result in severe medical and psychosocial complications. These factors increase morbidity, health care costs, and have a direct bearing on individuals' QOL.<sup>5</sup> Other problems associated with SCI are depression, affecting 25% of men and 47% of women, transient amenorrhea, affecting 60% of women, and neuropathic pain, occurring in 34 to 94% of victims. In patients suffering injuries at T6 or above this level develop autonomic dysreflexia, characterized by a dangerous increase in blood pressure, orthostatic hypotension, thermo dysregulation, and vasomotor abnormalities.<sup>6,7</sup> With advancement in the understanding of SCI and incorporation of bioengineering technology, physical recovery has been the main focus but complete cure continues to remain elusive. Our longitudinal prospective study shows that there is a lot of scope for intervention in social, psychological, and environmental factors to improve QOL. Appropriate targeted intervention in improving these factors has a definite role in improving the QOL of these unfortunate victims.

## Conclusion

All patients with SCI show improvement with time. Although physical domain is the main predictor of QOL at time of injury, the other domains play an important role in the later

stages. Improved functional status, alleviation of pain, good social skills, and high self-efficacy are some of the factors which play an important role in improving overall QOL. Unfortunately, these factors seem to be undermined in developing countries. Further longitudinal research is suggested to clarify the mutual adjustment process of people with SCI and their close persons. Our study shows that the SCI victim requires intervention in physical, mental, psychological, and social domains so that we can integrate them back to their social milieu with high morale and self-esteem.

#### Conflict of Interest

None declared.

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