Factors associated with quality of life among spinal cord injury survivors: A cross-sectional survey

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Abstract

Background: Improving the quality of life among patients with spinal cord injury is an imperative goal of treatment. The study’s objectives were to assess the Quality of Life (QOL) and identify the factors of QOL among the patients with spinal cord injury. Methods: Using the total enumeration method, 121 patients of SCI were enrolled in this cross-sectional study. Ethical clearance was taken from Ethics Committee, and consent was taken from patients. World Health Organization Quality of Life-BREF scale (WHOQOL-BREF) was used to assess QOL. Results: The average age of the patients was 47.99±14.70 years. More than half the patients were males. Almost half of the patients (48.0%) reported poor QOL. The psychological and physical domains of QOL were most affected with a mean QOL score of 34.41±11.79 and 38.90±8.55, respectively, out of 100. Significantly poor QOL was reported by patients with higher education (p=0.006), high per capita income (p=0.01), patients who were widow/widower (p=0.03), patient with tetraplegia (p=0.01), depressive symptoms (p<0.03), and patients who were dependent (p<0.03). Conclusions: This study provides evidence that the patient with SCI had poor QOL, where psychological and physical domains were most affected. To boost the holistic well-being of these patients, healthcare providers should incorporate appropriate and individualized rehabilitative services and mind-body interventions. The caregivers should also be involved in the care, both psychological and physical care, as they were with the patient round the clock at home.

Key Words: activity of daily living scale, instrumental activity of daily living, nursing assessment quality of life, spinal cord injury, World Health Organization quality of life-BREF scale

Introduction

Spinal cord injury (SCI) is one of the common causes of disabilities among young adults. The paramount goal of treatment is to improve the quality of life of patients with SCI.1, 2 Identification of various factors determining the quality of life (QOL) of SCI patients would help select appropriate measures to improve it.

The impact of SCI can result in loss of sensation, muscle function, or autonomic function in parts of the body supplied by the spinal cord below the lesion or injury level. Injuries can be classified as complete or incomplete injury according to the level of injury at the spinal cord. People living with SCI have to cope with many health problems such as neurogenic bowel and bladder resulting from the loss of urinary and sphincter control, respiratory symptoms and complications, cardiovascular complications, pressure ulcers, urinary tract infection, autonomic dysreflexia, chronic and neuropathic pain, osteoporosis and fracture.3, 4 These problems alter human beings’ physical and psychological conditions and hamper victim’s sexual and reproductive capacity. The advances in the management of SCI may improve the QOL of the patients, but they often have to cope with altered social roles and psychiatric comorbidities, including mental illnesses like depression and anxiety disorder.2, 4

Global incidence shows a variance from 8 to 246 cases per million of the population in one study, while further research found similar results with 3.3 to 246 per million, so anywhere from 250,000 to 500,000 new spinal cord injuries occurs annually.1, 6 In India, the average annual incidence of SCI is 15,000, with a prevalence of 0.15 million.7

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QOL in persons with SCI is related to mental health, mobility, employment, overall participation of health care workers and family members, accessibility of the external environment, social support, and well-being. The decreased functional ability of an individual after an SCI compromises the patient’s QOL and has an impact on the family. Appropriate training is needed to provide care to disabled family members, assist them in daily living activities, and care for the loved ones.

QOL is the individual perception of their possession in life in the context of culture and values systems in which the individual lives with their goals, standards, expectations, and concerns. There may be various factors that affect these patients’ living style with SCI and hence their QOL. Other than demographical-clinical factors, functional disability, depressive symptoms, etc., also can influence the QOL of patients in SCI. By identifying the QOL and its related factors, nursing personnel and other health care providers may be able to take appropriate measures to improve the QOL of the patients with SCI.

Material and Methods

Study Design: We conducted a cross-sectional study on 121 patients with SCI who are followed up in the outpatient department (OPD) of a tertiary care hospital, North India. Inclusion criteria were patients of SCI for one month to two years and patients willing to participate in the study. We took ethical clearance from the Institute ethical committee, and informed consent was obtained from the patients /their caregivers.

Sampling: Total enumeration method was used to enroll the patients in the study. One hundred and twenty-one patients who met the eligibility criteria and consented to the study were enrolled. A patient information sheet was given to the patients/ caregivers with the objectives of the study.

Data Collection Tools and Techniques: QOL was assessed using the World Health Organization Quality of Life-BREF Scale (WHOQOL-BREF), Hindi version which is a standardized scale. The score range is from 0-100. It assesses four domains of QOL i.e., physical domain, social relationship domain, psychological domain, and environmental domain. Poor QOL is indicated by numbers pointing to zero, and high quality is characterized by numbers pointing to 100.

Patient Health Questionnaire-9(PHQ-9), A standardized scale contains nine questions was used to assess the level of depression in patients. Its score ranges from zero to 27. The activity of the Daily Living scale (ADLs) was used to assess the dependence level among the patients of SCI. It also includes the Instrumental Activity of Daily Living scale (IADLs) to assess patients’ instrumental activities with SCI. The score ranges from zero to six for ADLs, whereas the total score for IADLs ranges from zero to eight. The time taken of the patient for data collection was 20-25 minutes.

Data Collection: Three nurse researchers who were trained to use the tools did the data collection. We enrolled the patients who met the inclusion criteria after taking informed written consent. The demographic and clinical data were collected from records. The nurse researcher administered the WHO-BREF scale, PHQ-9, ADL scale, and the data collected using self-reports. The researcher had explained the tools to the patients before administering; however, assistance was provided whenever necessary.

Data Analysis: All the analyses were done using Statistical Package for the Social Sciences (SPSS) version 20. Socio-demographic and clinical variables were expressed in mean with standard deviation or frequency with percentage. The correlation coefficient, independent t-test and one-way ANOVA were used to assess various variables’ association with quality of life.

Results

A total of 121 patients were enrolled in the study most of the patients i.e, 44.6% were more than 50 years with a mean age of 47.99±14.69 years. Majority of the patients (53%) were males. More than three fourth of the patients were married. More than one fourth of the patients had education above matriculation and mean of per capita income was 4261.48±4458.2. (Table 1).

Quality of Life, Satisfaction and Depression After SCI

Out of 121 patients, almost three forth of the patients had incomplete paraplegia and 16.5% of the patients had complete paraplegia. Most of the patients (70.2%) had lumbar level spinal injury. Approximately half of the patients had SCI due to heavy weight lifting. (Table 2) 43% reported poor QOL, followed by 28.9% reported very poor QOL. Neither poor nor good QOL was reported by 19.8% of patients. Only 7.4% patients had reported good QOL (Figure 1). Psychological domain of QOL was most affected as the mean score was 34.41±11.79 out of 100. This was followed by domain of physical health where the score was slightly lesser i.e, 38.9±8.55. The environmental and social domains were relatively less affected as the scores were 60.12±14.27 and 64.87±10.79 respectively (Table 2). 54.5% of the patients were dissatisfied of their general health, followed by 23.1% reported very dissatisfied. Neither satisfied nor dissatisfied was reported by 14.0% of patients. Only 8.3% of the patients had reported satisfied general health satisfaction (Figure 2). Approximately half of the patients had mild depression, (41.3%), followed by 31.4% moderate depression, 19% had minimum depression, 7.4% had moderately severe depression and 0.8% had severe depression (Table 3).

Activity of Daily Living and Instrumental Activity of Daily Living Scale

The mean score of ADLs was 2.82±2.30 and majority of the patients i.e. 55.4% were dependent. Mean score of IADLs was 3.74±2.29 and 52.1% were dependent (Table 4).
Association of Socio-demographic and Clinical Variable with QOL Score in Different Domains

QOL score of patients in environmental domain was significantly lower i.e. 52.35±12.60 among graduates as compared to 67.69±13.18 among illiterate (p=0.006). The QOL score in psychological domain was significantly lower i.e. 26.00±11.44 among widow/widower as compared to 35.09±12.00 among married (p=0.03). The QOL score in environmental domain was significantly lower i.e. 53.96±14.81 among patients with high per-capita income as compared to 61.81±13.72 patients with low per-capita income (p=0.01). (Table 6). The QOL score in environmental domain was significantly lower i.e. 53.96±14.81 among patients with high per-capita income as compared to 61.81±13.72 patients with low per-capita income (p=0.01). (Table 6). The QOL score in social relationship domain was significantly lower i.e. 63.00±11.34 among dependent as compared to 67.20±9.66 among independent. It shows that QOL in social relationship domain worsen with poor ADLs (p=0.03). (Table 7)

It shows that QOL in environmental domain worsen with higher educational status, higher per-capita income as well as patients with tetraplegia and depressive symptoms.
QOL in psychological domain was reported to be poorer in patients who are widow/widower

Discussion
Spine injuries present in a diverse manner at different levels with varying severity. To enhance the QOL, the patients, after discharge from the hospital, need comprehensive home care strategies, including nutrition, mobility, treatment compliance, and psychological and physical rehabilitation.16-18 This study was conducted to assess the associated factors of QOL among patients of SCI. A total of 121 patients were enrolled in this study. The findings show that the QOL of patients with spinal cord injury is significantly affected, more so in the psychological and physical domains.

The patients’ average age in our study was 47.99±14.67 years, and 53% of the patients were males, whereas a study conducted by Shankar et al. in 2010 showed that patients’ mean age was 32.54±10.75 years and 90.5% of the patients were males. In the present study, SCI’s leading cause is heavy weight lifting and fall; only 14% of the patients had SCI due to road traffic accidents. Whereas more than half of the patients suffered SCI due to road traffic accidents, which explains the patients’ age difference in both the studies.19 Another study conducted by Singh et al. in 2003 shows that SCI’s most common cause was fall from height including roof, trees, electricity pole (44.5%) followed by motor vehicle accidents.20 Similar to the study conducted by Maryam et al., most of the patients were married in our study.21

Above 50% of the patients in our study were dependent on daily living activities and instrumental daily living activities. Approximately 75% of the patients with SCI in our study reported varying degrees of depression. The study conducted by Craig et al. shows that around 30% of patients living with SCI may develop depressive symptoms after discharge.14 The dependency of the patients may lead to depressive symptoms in the patients. They may hesitate to express their requirements to the caregiver, thinking not to burden them.22 More than half of the patients in our study were dependent.

Present study findings showed that the majority, i.e., approximately three-four of the patients, reported poor or very poor QOL, whereas only 7.4% reported good QOL. But another cross-sectional study conducted by Islam et al. in 2016 on 45 patients showed that only 13% of the patients reported very poor QOL, 36% had poor QOL, 31% had neither poor nor good QOL, and only around 20% had good

Table 3: QOL based on WHOQOL-BREF (n=121)

| Domains of QOL                  | Mean±SD (Range) |
|---------------------------------|-----------------|
| Physical health domain          | 38.90±8.55(13-69) |
| Psychological domain            | 34.41±11.79(6-69) |
| Social relationships domain     | 64.87±10.79(44-100) |
| Environment domain              | 60.12±14.27(25-100) |

Table 4: Depression based on Patient Health Questionnaire -9 (n=121)

| Patient Health Questionnaire    | Mean±SD (Range) or f (%) |
|---------------------------------|--------------------------|
| PHQ depression score            | 8.3±4.13(1-21)           |
| Minimal depression              | 23(19.0%)                |
| Mild depression                 | 50(41.3%)                |
| Moderate depression             | 38(31.4%)                |
| Moderately severe depression    | 9(7.4%)                  |
| Severe depression               | 1(0.8%)                  |

Table 5: Activity of daily living and instrumental activity of daily living scale (n=121)

| ADLs and IADLs Variables        | Mean±SD or f (%) |
|---------------------------------|-----------------|
| Activity daily living scale total score | 2.82±2.30       |
| Dependent                       | 67(55.4%)       |
| Independent                     | 54(44.6%)       |
| Instrumental daily living scale total score | 3.74±2.29       |
| Dependent                       | 63(52.1%)       |
| Independent                     | 58(47.9%)       |
This difference may be due to the younger age group of the patients and better rehabilitation services utilized by the patient; as the study was conducted in a rehabilitation centre.

In the present study psychological domain of QOL (34.41±11.79) and physical domain (38.90±8.55) were most affected. The QOL in the environmental domain and social relationship domain was relatively better. Similar findings were also reported by Alishah et al., in which the overall mean score for the psychological health domain was 52.33±19.37, physical health domain 54.79±18.39, environmental domain 54.11±17.25, and social relationship domain 58.79±20.69. Similar findings are reported by Gurcay et al. in 2010. It shows the need for an appropriate support system in physical assistance and counseling for the patients surviving with SCI.

In our study, QOL under the environmental domain in SCI patients, decreased with an increase in per capita income; this may be explained by their limited income due to injury, limitations in social interactions, inability to avail themselves the opportunities to acquire new skills or knowledge. While another study conducted by Khazaiepour et al. showed that there was no significant relationship between QOL and per capita income.

As per the present study, poor QOL was reported by patients with tetraplegia and dependant patients, which was similar to the findings of Chang et al. Another study conducted by Saadat et al. showed a significant relationship between QOL and impairment level.

The following table presents the association of socio-demographic variable with QOL score in different domains.

Table 6: Association of socio-demographic variable with QOL score in different domains

| Demographic variables | Psychological | QOL Domain | Environmental | t or F or r value (p value) |
|-----------------------|--------------|------------|--------------|----------------------------|
|                       | Mean ± SD    | t or F or r value (p value) | Mean ± SD    | t or F or r value (p value) |
| Age                   | 0.04 (0.68)  | 0.11 (0.24) |              |                           |
| Gender                | Male         | 35.67±12.09 | 1.25         | 61.20±14.01               |
|                       | Female       | 33.00±11.40 | (0.21)       | 58.91±14.58               |
| Education             | Illiterate   | 35.96±13.03 | 0.59 (0.67)  | 67.69±13.18               | 3.78 (0.006*) |
|                       | Primary      | 35.00±11.06 |              | 61.74±13.50               |
|                       | Metric       | 32.13±12.97 |              | 58.07±14.51               |
|                       | Senior secondary | 36.62±12.02 |              | 57.76±13.57               |
|                       | Primary      | 35.00±11.06 |              | 52.35±12.60               |
|                       | Metric       | 32.13±12.97 |              |                           |
|                       | Senior secondary | 36.62±12.02 |              |                           |
|                       | Graduation and above | 34.53±7.84 |              |                           |
| Marital status        | Married      | 35.09±12.00 | 2.02 (0.03*) | 60.38±13.88               | 0.53 (0.59) |
|                       | Unmarried    | 33.50±8.62  |              | 56.41±17.08               |
|                       | Widow/widower| 26.00±11.44 |              | 62.71±16.20               |
| Occupation            | Professional | 31.62±4.87  | 0.954 (0.43) | 52.08±10.76 65.00±14.17   | 1.75 (0.14) |
|                       | Farmer       | 33.29±13.34 |              | 58.94±16.17               |
|                       | Self-employed| 38.52±12.92 |              | 61.12±14.75               |
|                       | Unemployed   | 37.00±8.53  |              | 61.06±13.10               |
|                       | Housewife    | 33.89±11.88 |              |                           |
| Per capita income     | Upto 5000    | 35.32±12.03 | 2.46 (0.10)  | 61.81±13.72               | 0.49 (0.01*) |
|                       | Above 5000   | 31.07±10.41 |              | 53.96±14.81               |

QOL. This difference may be due to the younger age group of the patients and better rehabilitation services utilized by the patient; as the study was conducted in a rehabilitation centre.

In the present study psychological domain of QOL (34.41±11.79) and physical domain (38.90±8.55) were most affected. The QOL in the environmental domain and social relationship domain was relatively better. Similar findings were also reported by Alishah et al., in which the overall mean score for the psychological health domain was 52.33±19.37, physical health domain 54.79±18.39, environmental domain 54.11±17.25, and social relationship domain 58.79±20.69. Similar findings are reported by Gurcay et al. in 2010. It shows the need for an appropriate support system in physical assistance and counseling for the patients surviving with SCI.

In the present study, QOL was lower in highly educated patients because of their higher expectations in life and the adverse impact the injury had on the social interactions and relationship. Similarly, another study conducted by Moghimian et al. showed a significant relationship between QOL and educational level. QOL was lower among widows/widower, probably because of less family support during disease in meeting the needs and therapeutic compliance, including follow-up and rehabilitation. A significant relationship between QOL and the patients’ marital status is previously reported in the literature.

As per the present study, poor QOL was reported by patients with tetraplegia and dependant patients, which was similar to the findings of Chang et al. Another study conducted by Saadat et al. showed a significant relationship between QOL and impairment level.
by the study participants. The dependent patients require assistance in meeting their personal needs, ADL and treatment strategies, and rehabilitation needs. The present study also highlights the relationship between poor QOL and depressive symptoms in patients of SCI. Similarly, another study conducted by Mousavi et al. showed that there was a significant and direct relationship between depressed mood and QOL. This emphasizes that QOL in SCI patients decreases with the increase in a depressed mood, and we should ensure adequate utilization of psychological guidance and counseling services by these patients.

The impact of the type of surgical intervention on the outcome of spinal disorders need not be overemphasized. We did not analyze this aspect, as the focus was on overall care.

The majority of the patients with SCI had reported poor QOL with a higher impact on psychological and physical domains. Significantly poor QOL was reported by patients with higher education and per capita income, among widows/widowers, among patients with tetraplegia, dependency, and depressive symptoms. Hence, health care providers have to take appropriate interventions to improve the QOL of patients with SCI, especially in psychological and physical domains. Like any other neurological illness, nurses should also focus on the patients’ holistic well-being surviving with SCI. Patients and caregivers should be trained and informed about various options and facilities for their psychological and physical well-being. Hence, nurses play a vital role in improving the QOL of patients with SCI. Rehabilitation services are poorly known to and utilized by the patients, explicitly rural sectors in India. Though they are advised for home-based or institute-based rehabilitation after discharge, many patients do not avail the rehabilitation effectively due to financial constraints and inconveniences. Hence, counseling and guidance facilities regarding rehabilitative services, e.g., physiotherapy, occupational therapy, devices such as walkers and crutches, must be made available to these patients by policymakers to enhance the holistic well-being of these patients. Nurses led services also may be developed and tested as quick services can be made available to the patients, especially in resource-constrained countries like India.

### Conclusions

This study provides evidence that the patient with SCI had poor QOL, where psychological and physical domains were most affected. Significantly poor QOL was reported by patients with higher education and per capita income, widows/widowers, patients with tetraplegia, dependency, and depressive symptoms. To improve the holistic well-being of these patients, healthcare providers should incorporate appropriate and individualized rehabilitative services and mind-body interventions. The caregivers should also be involved in the care, both psychological and physical care, as they were with the patient round the clock at home.

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**Table 7: Association of clinical variables with QOL score in different domains**

| Clinical variables | Psychological Mean ± SD | t or F or r value (p value) | Environmental Mean ± SD | t or F or r value (p value) |
|--------------------|-------------------------|-----------------------------|--------------------------|-----------------------------|
| Type of impairment |                         |                             |                          |                             |
| Tetraplegia        | 32.33±10.76             | 0.24 (0.79)                 | 51.16±16.51              | 4.39 (0.01*)                |
| Complete paraplegia| 35.80±11.03             |                             | 67.60±9.93               |                             |
| Incomplete paraplegia | 34.25±12.09             |                             | 59.11±14.41              |                             |
| Duration since spinal cord injury | | | | |
| 1-6months          | 35.62±12.20             | 1.37 (0.26)                 | 60.61±13.90              | 0.07 (0.92)                 |
| 7-12months         | 31.25±9.70              |                             | 59.61±15.68              |                             |
| > upto 2 years     | 34.79±12.55             |                             | 59.55±14.15              |                             |
| Patient health questionnaire score | 0.09 (0.30) |                             | 0.19 (0.03*)              |                             |
| Activity of daily living scale | | | | |
| Dependent          | 32.92±12.83             | 1.55 (0.12)                 | 61.64±12.98              | 1.30 (0.19)                 |
| Independent        | 36.25±10.19             |                             | 58.24±15.64              |                             |
| Instrumental activity of daily living scale | | | | |
| Dependent          | 35.11±12.15             | 0.67 (0.50)                 | 61.49±13.03              | 1.10 (0.27)                 |
| Independent        | 33.65±11.45             |                             | 58.63±15.48              |                             |
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