QUALITY OF LIFE IN INDIVIDUALS WITH SPINAL CORD INJURY TREATED IN TERTIARY CARE CENTERS IN NEPAL

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ABSTRACT

Introduction

Traumatic spinal cord injury (SCI) constitutes a significant challenge to the quality of life (QoL). People with SCI perceive the overall QoL at a lower level in comparison to normal individuals.

Objective

This study aims to assess the QoL among individuals with SCI and identify factors affecting the QoL.

Methodology

This prospective cross-sectional study was done in Dhulikhel Hospital, Kathmandu University Hospital (DH, KUH), and Spinal Injury Rehabilitation Center (SIRC), Sanga, Nepal. All the individuals above 18 years with SCI of at least 3 months from trauma seeking treatment in DH, KUH, or SIRC from June 2019 to May 2021 were included. We utilized the WHO quality of life questionnaires (WHOQOL–BREF) for assessing the QoL.

Result

The mean age was 32.95 ± 11.7 years with the majority being males (74.5%). The majority had ASIA Impairment Scale grade A. The social health domain had the highest mean raw and transformed score (13.87 ± 3.13 and 61.7 ± 19.59 respectively). The transformed total QoL score was 50.76±29.76. Only 22 individuals (15.6%) had a transformed total score of > 60 signifying good/ satisfactory QoL.

Conclusion

There is a high rate of poor/ unsatisfactory QoL in individuals with SCI in Nepal. Female gender, married status, loss of relative during trauma, ASIA injury severity (AIS) A or B during admission, and no improvement in AIS grade after treatment are significant predictors of poor / unsatisfactory QoL. Physical health, compared to psychological, social, and environmental health, correlates highest with the transformed total QoL score.

INTRODUCTION

The term "quality of life" (QoL), also known as "well-being," is a general term that refers to how the concerned person judges the "goodness" of different aspects of life.[1] This perceived condition is measured through various instruments, which take into account a person's disposition, sense of life fulfillment and satisfaction, emotional responses to life's events, and satisfaction with one's job and interpersonal relationships.[2] A person who has suffered a traumatic spinal cord injury (SCI) must endure terrible and irreversible health changes.[3] It has been established that SCI constitutes a significant challenge to the quality of life, and people with SCI perceive the health-related and overall quality of life at a lower level in comparison to normal individuals.[4]

There are studies that have evaluated different factors influencing the social well-being of individuals with SCI. Four major biopsychosocial factors, namely intimacy, safety, acceptance, and helplessness are found to associate significantly with normative subjective well-being.[4] Other variables like engagement in leisure activities, positive feeling, and physical activity are reported to have a significant positive impact on subjective well-being; whereas the variables like lower household income, overweight, depression, violent etiology, and injury severity, and being female[6-12] are understood by SCI patients as the cause of more life problems and less life satisfaction. These studies not only point to the greater significance of certain factors of QoL, but also question the significance of the factors identified in the earlier studies.

The number of studies assessing psychological aspects of Nepali patients with SCI exist in a small number. Among these studies, some have evaluated resilience, others have assessed post-traumatic stress disorder, yet others have studied pain experience/ pain management.[13-15] In these studies, however, the issue of social well-being has been overlooked. There is only a single study that has evaluated the QoL among individuals with SCI in Nepal.[16] Therefore, this study aims to access the QoL in four domains namely, physical, psychological, social, and environmental health using the WHOQOL-BREF questionnaire and identify the factors affecting the QoL among the individuals with SCI presenting to a tertiary care hospital and rehabilitation center of Nepal.

METHODOLOGY

This prospective cross-sectional study was done in Dhulikhel Hospital, Kathmandu University Hospital (DH, KUH), and Spinal Injury Rehabilitation Center (SIRC), Sanga, Nepal. DH, KUH is a tertiary care center and a referral center for patients with spinal injuries. SIRC is a non-profit, inpatient rehabilitation center for individuals with spinal injuries. It also provides peer counseling and psychology services as a part of standard care and is the major referral center for spinal rehabilitation in Nepal.

All the individuals above 18 years of age with SCI [ASIA injury severity (AIS) A to D] of at least 3 months from trauma who were admitted in DH, KUH or SIRC from June 2019 to May 2021 were included in the study. However, individuals not consenting to the study, individuals with memory loss and cognitive dysfunction, and non-traumatic SCI were excluded.

Ethical clearance was obtained from Institutional Review Committee (IRC) of Kathmandu University School of Medical Sciences (KUSMS) [IRC-KUSMS approval number: 270/2021]. We utilized the semi-structured questionnaires using standard WHO quality of life questionnaires (WHOQOL–BREF) which is a measure, comprising 28 items within four quality of life domains: physical health, psychological well-being, social relationships, and environment.[17] The WHOQOL–BREF has good internal consistency, as well as validity and the measure is argued to be appropriate generic health related quality of life measure.[18-20]

To use the WHOQOL-BREF in the Nepalese context, both forward and backward translation was done. Pre-testing of the WHOQOL-BREF tools was done in the data collected from 10 individuals. Cronbach's alpha coefficient was computed ($\alpha=0.8$, N=27) to determine the reliability of the instruments. Most individuals filled out the questionnaire by themselves, while those needing assistance were interviewed using face to face interview method either by trained physiotherapists or by the treating doctor. A dichotomous variable was created (QoL good/ satisfactory, or poor/ unsatisfactory) using the transformed total QoL score (TTQS) of 0-100 (a score of >60 categorized as good/ satisfactory QoL, and a score of <60 as poor/ unsatisfactory QoL).[21]

The collected data were entered and analyzed using IBM SPSS version 25.0 for Windows (SPSS Inc., Chicago, IL, USA). Normality of continuous variables was checked using the Shapiro- Wilk test. The continuous variables with normal distribution were presented as mean ± SD and non- normal variables were reported as median (interquartile range [IQR]). To identify the significance of association between the outcome (TTQS) and each of independent variables, one way analysis of variance (ANOVA) was done. Pearson correlation coefficient of the different domains of quality of life score was calculated to find out the bi-variate relationship among the domains of QoL.

Hierarchical multiple regression analysis between independent variables and TTQS was done to evaluate the predictors of QoL. Independent variables with $p<0.25$ from one-way ANOVA with TTQS and the variables that were found significant in previous literature were selected for hierarchical regression analysis. After controlling for participants' gender in the first step, the main effect of social factors was tested in the second step. In the third step, the main effect of trauma-related factors was tested. The variance inflation factor (VIF) was calculated to address the issue of multi-collinearity. The VIF of all the included independent variables was less than 2. A value of $P< 0.05$ was considered significant.

RESULTS

Demographics

One hundred and forty-one patients were enrolled in the study. The mean age of the patients was 32.95 ± 11.7 years (49.6% in the age group of 16-30 years) with the majority of the patients being males (74.5%). The majority (56.4%) of individuals were from joint families, and 102 individuals (72.3%) were married. There were 122 (86.5%) Hindus followed by 10 (7.1%) Christians. Regarding the social group, the majority were Janajati (38.3%) followed by Dalits (31.2%) and Brahmins (19.1%). Forty individuals (28.4%) had primary level education followed by 34 (24.1%) receiving secondary level education, and 28 (19.9%) were not formally educated. Only 5% individuals were unemployed before the trauma which increased to 78.7% after trauma.

Clinical characteristics

The most common SCI etiology was fall (72.4%) followed by road traffic accidents (23.3%). Among the patients, four (2.8%) reported having lost their relatives during the traumatic incident. The majority of the patients were ASIA Impairment Scale (AIS) A (65.2%) followed by AIS C (15.6%). Using International Standard for Neurological Classification of Spinal Cord Injury (ISNCSCI), it was found that majority (70.2%) of the patients had T1-S4/5 injury with AIS A, B or C followed by equal number of patients (11.3%) with C1-C4, and C5-C8 injury with AIS A, B or C. Almost 25% individuals were tetraplegic. More than 90% of the SCI individuals had undergone operative management. Almost one fourth of the total SCI individuals had at least one AIS grade improvement among whom 3.5% individuals had an improvement by two AIS grade. The participants' demographic and clinical characteristics along with their mean TTQS scores are presented in table 1.

Table 1: Demographic and clinical characteristics of individuals with SCI

Variables		Percentage	(n)	Transformed total QoL score (TTQS)	SD	P value*
Gender	Male	74.5	105	51.70	7.80	0.02
	Female	25.5	36	47.90	10.00	
Age (Years)	16-30	49.6	70	51.17	8.47	0.94
	31-45	35.5	50	50.58	9.23	
	46-60	13.5	19	49.83	7.71	
	61-75	1.4	2	50.07	7.14	
Family type	Nuclear	42.9	60	50.77	8.40	0.99
	Joint	56.4	79	50.97	8.70	
	Single	0.7	1	50.40		
Marital status	Married	72.3	102	49.70	8.40	0.06
	Unmarried	27.0	38	53.50	8.70	
	Divorced	0.7	1	54.70		
Income	No regular income	92.2	130	50.69	8.40	0.12
	<15000	3.5	5	57.41	5.87	
	16000-30000	2.1	3	50.69	16.55	
	31000-45000	2.1	3	42.50	5.65	
Religion	Hindu	86.5	122	50.50	8.76	0.67
	Christian	7.1	10	53.67	8.26	
	Buddhist	4.3	6	52.12	6.44	
	Muslim	1.4	2	45.76	1.05	
	Kirat	0.7	1	55.40		
Education	Uneducated	19.9	28	49.20	7.89	0.63
	Primary	28.4	40	49.32	7.53	
	Secondary	24.1	34	52.36	8.65	
	Higher Secondary	19.1	27	52.18	9.89	
	Bachelors	6.4	9	52.02	11.44	
	Masters	0.7	1	52.79		
	Informally Educated	1.4	2	48.54	3.08	
Ethnicity	Brahmin	19.1	27	52.99	8.99	0.11
	Janajati	38.3	54	51.28	7.77	
	Chhetri	31.2	44	49.17	9.06	
	Dalit	7.1	10	46.46	5.31	
	Other	4.3	6	54.90	11.36	
Etiology	Fall Injury	63.8	90	50.07	8.89	0.43
	Road Traffic Accidents	31.9	45	52.07	8.28	
	Others	4.3	6	51.68	4.44	
Relative loss	No	97.2	137	51.04	8.43	0.02
	Yes	2.8	4	41.08	8.67	
Disability card	No	82.9	116	51.15	8.81	0.26
	Yes	17.1	24	48.99	7.42	
Surgery	No	6.4	9	47.31	9.51	0.22
	Yes	93.6	131	50.96	8.51	
AIS grade at admission	AIS A	65.2	92	49.11	7.47	0.00
	AIS B	12.8	18	54.62	9.73	
	AIS C	15.6	22	51.62	9.09	
	AIS D	6.4	9	57.88	10.44	
Improvement	No improvement	76.6	108	49.58	8.17	0.00
	Improvement by 1 grade	19.9	28	52.69	7.59	
	Improvement by 2 grade	3.5	5	65.45	8.09	
Tetra/paraplegic	Tetraplegia	24.3	34	51.25	9.96	0.69
	Paraplegia	75.7	106	50.59	8.16	

*One way ANOVA

Quality of life scores

The mean raw score and transformed score in the four domains are given in table 2. The social health domain had the highest mean raw and transformed score (13.87 ± 3.13 and 61.7 ± 19.59 respectively). The TTQS was 50.76±29.76. Only 22 individuals (15.6%) had the TTQS of more than 60 signifying good/ satisfactory QoL. The remaining 84.4% of individuals had poor/ unsatisfactory QoL.

Table 2 Raw and transformed QoL score in different domains of SCI individuals

Domains	Raw Score				Transformed score			
	Mean	SD	Min	Max	Mean	SD	Min	Max
Physical Health	12.49	2.75	4.57	20.00	53.09	17.16	3.57	100.00
Psychological Health	12.09	2.84	5.33	18.67	50.56	17.76	8.33	91.67
Social Health	13.87	3.13	5.33	20.00	61.70	19.59	8.33	100.00
Environmental Health	12.30	2.25	6.00	18.50	51.91	14.07	12.50	90.63
Overall Quality of life					50.76	8.57	29.76	77.17

Pearson correlation was done between the scores of all the four domains and TTQS. The domain with the highest correlation to the TTQS was physical health (R value= 0.827). All four domains, however, showed a strong positive correlation with the TTQS (R value >0.7) (Table 3)

Table 3: Pearson correlation between the quality of life score and its domain

	Physical health	Psychological health	Social health	Environmental health
Physical health	1			
Psychological health	.640	1		
Social health	.422	.293	1	
Environmental health	.563	.531	.436	1
Transformed total QoL score (TTQS)	.827	.758	.742	.790

The hierarchical multiple regression analysis revealed that at step one, gender contributed significantly to the regression model (Male gender predicting higher TTQS), F (1, 138) = 6.2, p< 0.01) and accounted for 4.3% of the variation in TTQS (Table 4). Introducing the social factors (marital status, income, and social group) explained an additional 8.3% of the variation in TTQS (Male gender, higher social group, and unmarried individuals predicting higher TTQS) and this change in R² was significant, F (3, 135) = 8.1, p < 0.01 (Table 4). Male gender and unmarried individuals were the most predicting variables (p< 0.01). Adding trauma-related factors (Relative loss during trauma, AIS at admission, treatment modality, and improvement in AIS) to the regression model explained an additional 14.5% of the variation in TTQS and this change in R² was highly significant, F (4,131) = 7.55, p<0.001 (Table 4). Individuals who lost their relatives during trauma and individuals who had no improvement in AIS grade following treatment/ rehabilitation had significantly lower TTQS (p<0.05).

					Change Statistics			
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.207a	.043	.036	8.43143	.043	6.197	1	138	.014
2	.355b	.126	.100	8.14750	.083	4.262	3	135	.007
3	.521c	.271	.226	7.55279	.145	6.524	4	131	.000

Table4: Model summary of hierarchical multiple regression analysis

a. Predictors: (Constant), Gender
b. Predictors: (Constant), Gender, Social group, Income, Marital status
c. Predictors: (Constant), Gender, Social group, Income, Marital status, Loss of relatives during trauma, AIS during admission, Treatment modality (Conservative vs surgery), Improvement in AIS.

DISCUSSION

More than 80% of the individuals had the TTQS of <60 signifying a very high rate of poor/ unsatisfactory QoL in the individuals with SCI in Nepal. Female gender, married status, loss of relative during trauma, AIS A or B during admission (Motor complete individuals), and no improvement in AIS grade after treatment were the significant predictors of poor/ unsatisfactory QoL in the individuals with SCI in Nepal. However, age, family type, income, religion, education level, social group, injury etiology, mode of treatment (surgery vs conservative), and tetraplegic/ paraplegic status were not the significant predictors of QoL.

The percentage of individuals with poor/ unsatisfactory QoL is staggeringly high in the individuals with SCI in Nepal. The years post-injury (YPI) could be a factor affecting QoL and there are studies suggesting that QoL in SCI would be increased with YPI[22,23] because increased YPI could help patients with SCI to adapt to both internal (illness-related) and external circumstances.[24] In our study, the injury to interview duration is relatively short with the YPI less than 1 year (patients were interviewed between 3 months to 1 year of injury) compared to other studies. Because of a short YPI, individuals in our study might not have got enough time for adapting with the SCI related aftermath and complications leading to a lower QoL score. Furthermore, most of the individuals in the study have low-income and low-education. There are studies showing low-income and low educational status related to lower QoL.[16] Additionally, the cross-cultural comparative studies of WHOQOL-BREF showed that under the same background, higher life satisfaction scores were found in Western countries.[25] The lower QOL scores from the Nepalese background cannot exclude the effect of cultural differences.

Our study showed no relationship between the age group and QoL. A similar finding is seen in the study by Barker et.al.[26] Contrastingly, in the study by Yong et al, a significantly higher QoL was found in an elderly group.[27] However, in the study by Wang et al., the finding was opposite with individuals with traumatic SCI at younger age having better QoL score.[28] Due to a varying reports in different studies, the exact relationship between age and QoL is still indeterminate. Evaluating the gender, our study showed females with lesser QoL scores which is similar to the finding by Krause JS.[12] However, in the study by McColl et al., both the genders rated their QoL equally.[23] Similarly, loss of the close ones/ relatives during trauma (exclusively road traffic accidents) was another predictor of poor QoL in our study population with the individuals who lost their relatives during trauma scoring significantly less (41.08 ±8.43) compared to other individuals (51.04 ± 8.43). Individuals who lost their relatives during trauma are more prone to develop posttraumatic stress disorder, depression, and other mental health related issues which can play a role in diminished QoL score.

In our study, the QoL of individuals who had AIS A or B (Motor complete) was significantly worse compared to individuals with AIS C or D (Motor incomplete). Similarly, individuals with improvement in AIS grade after treatment had significantly higher QoL scores. This finding is similar to other studies.[29,30] Functional independence is one of the major predictors of a good QoL among individuals with SCI with individuals with motor incomplete status having better functional independence. Literature suggests improving mobility or the ability to get around in an energy-efficient manner may improve QoL in SCI.[30]

Marital status was a significant predictor of QoL among SCI individuals in our study. Married individuals had a significantly low QoL score compared to unmarried individuals (49.70 ±8.4 vs 53.50 ± 8.7). This finding is similar to the study by Shin et al.[29] Getting married adds more financial and social responsibilities to an individual. Therefore, if a married individual sustains SCI, he/she will definitely experience the pressure of not being able to fulfill their familial responsibilities, further leading to a sense of lesser life satisfaction, and a lower QoL score.

Pearson correlation showed physical health showing the highest positive correlation to the transformed overall QoL score. This is in contrast with the study done by Gautam et. al., where they have shown the highest positive correlation with psychological health.[16] Our study showed a high correlation of all four domains with the TTQS (R>0.7). However, in the study by Gautam et al., all the domains had a lower correlation (R<0.7).[16] Therefore, though all the

domains are important for the overall score, our study showed that physical health is the most important domain among individuals with SCI in Nepal.

CONCLUSION

There is a very high rate of poor/ unsatisfactory QoL in individuals with SCI in Nepal. Female gender, married status, loss of relative during trauma, AIS A or B during admission, and no improvement in AIS grade after treatment are significant predictors of poor/ unsatisfactory QoL. Physical health is the most important domain of QoL. The findings of this study can be implemented for formulating policies for the overall improvement of QoL in individuals with SCI in Nepal.

LIMITATIONS OF THE STUDY

A detailed assessment of psychosocial and other social support factors, that may influence QoL in SCI, was not done in our study. Furthermore, the participation of females and minorities was relatively small; hence, factors specific to these populations may not have been accounted for in our analysis. Similarly, there is a probability of occurrence of observer bias and/or interviewer bias in those individuals who were interviewed either by trained physiotherapists or by the treating doctor. This study being a cross-sectional study, it may also be difficult to derive a causal relationship between SCI and QoL due to only a one-time measurement of the WHOQOL-BREF score.

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