Original Article

Quality of Life after Traumatic Spinal Cord Injury in Rwanda, the Impact of Personal and Contextual Factors: A Follow-Up Exploratory Study

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Abstract

Background
Traumatic spinal cord injury (TSCI) affects quality of life (QoL) depending on the severity and access to rehabilitation. A good QoL is of paramount importance for TSCI survivors all over the world.
Objective
To assess the QoL of TSCI survivors after one year.
Methods
Adults were included who by the time of injury were 18 years or above and registered in a previous epidemiological study. "The International Spinal Cord Injury Quality of Life" standard data set was used to collect data and assess overall QoL (range 0-30) and three domains: satisfaction with life as a whole, physical- and psychological health (range 0-10). A telephone interview was conducted with 58 participants.
Results
The overall mean score of QoL was 13.12 (SD 7.17), satisfaction with life as a whole 3.91 (SD 2.73), psychological health 5.36 (SD 2.95), and physical health 3.84 (SD 2.59). Marital status significantly influenced overall QoL (P = 0.031) and its two domains; satisfaction with life as a whole (P = 0.037) and satisfaction with physical health (P = 0.022). Linear regression analysis showed that being married or widowed predicted poor QoL.
Conclusion
Low scores of overall QoL and its domains implying poor QoL and marital status may play a role, hence it is important to take it into consideration when treating patient with TSCI.
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Keywords: Traumatic injury spinal cord, American Spinal Injury Association classification (ASIA), Quality of Life (QoL) and Rwanda

Background

There are wide disparities in the definition of Quality of Life (QoL); the World Health Organization defines QoL as one's perceived life in the cultural and value contexts in which one lives, from an objective point of view, expectations and standards.[1] The International Spinal Cord Society believes that QoL is a multifaceted variable that should be looked at from different domains; as health-related quality of life (HRQoL), second as well-being, and QoL as a combination of the latter and the former.[2] HRQoL explains problems due to functioning caused by reduced psychological or physical health, while subjective well-being usually manifests in three components: positive and negative experiences, and satisfaction with life.[3]

Spinal cord injury (SCI) compromises one's activity and participation abilities and capacities, consequently, this is likely to affect a person's QoL.[4] It is, therefore, imperative to assess QoL from the victims' perspective of reported point of view. QoL is determined by a number of factors including personal, environmental, injury factors, and community factors. Participation has been associated with better QoL in people with SCI.[5] With increasing survival rates, there is increasing interest among scientists in the aspect of QoL. QoL concept is an elusive phenomenon that is defined by the subjective experience of the person reporting the person living with the disability. The studies reported that between 5.8 and 11% of deaths among SCI survivors were a result of suicide,[6] as study reports a considerably high suicide rate, this suggests difficulty in social engagement post-injury.[7] This is also an indication that the SCI population is not demographically and psychosocially lined with their able-bodied counterpart in terms of life satisfaction. Furthermore suicidal behavior is accompanied by other behavioral problems like drug abuse.[7]

The occurrence of traumatic spinal cord injury (TSCI) globally is between 13.7 and 8.7 per 100,000 persons in low and middle-income countries, and high-income countries respectively.[1] The most reported causes were transport-related and falls, and the male-female ratio in terms of TSCI is estimated to be 3:37.[2]

The incidence data for the region south of Sahara is fragmented as shown by Draulans et al,[3], but in recent years epidemiological surveys of TSCI has been reported; 75.6 per million was reported in South Africa,[8] 38 per million in Tanzania,[9] while 13 per million people reported in Botswana.[10] In Malawi, one hospital registry enrolled 46 new TSC injured survivors.[11]

In high income countries, medical and rehabilitation advances in management allowed longevity following SCI. However low- and middle income countries have not benefited on these advances. In African context, persons discharged from acute care always proceed to private households or family.[12] The effort of a person with SCI, members of his/her family and health professional would be wrongfully scored low if a meaningful quality of life is not regained. There is need to determine the influence of SCI on perceived quality of life in their environment. This study aims at assessing the QoL of TSCI survivors after one year following a TSCI.

Methods

Design

The study used a cross-sectional design to determine QoL using standardized and reliable tool.[13] This study is part of a bigger epidemiological study which registered occurrence of traumatic spinal cord injury in Rwanda from October 2019 to October 2020. TSCI survivors were followed up one year later to assess their quality of life.

Research Setting

The current study was carried out in Rwanda, among the smallest countries in east and central African region on. According to the recent national census of 2022, the population is estimated at 13,246,394 people an area of 26,340 km.[14] In Rwanda the only available housing arrangement is a family household therefore all participants were spread all over the country in their respective households in towns and rural areas.

Study population and sampling

The study population included all participants with a TSCI included in the forementioned epidemiological study. Therefore, the study population included 58 individuals and an inclusive sampling strategy was used as in Figure 1.

The inclusion criteria were: 1) all participants who consented for follow up upon admission to one of the four hospitals Butare and Kigali teaching hospitals, Rwanda military hospital and King Faisal hospital Kigali; 2) consenting at the time of collecting follow up data; 3) traceable during follow up through retained telephone contacts; and 4) a resident of Rwanda during the study period.

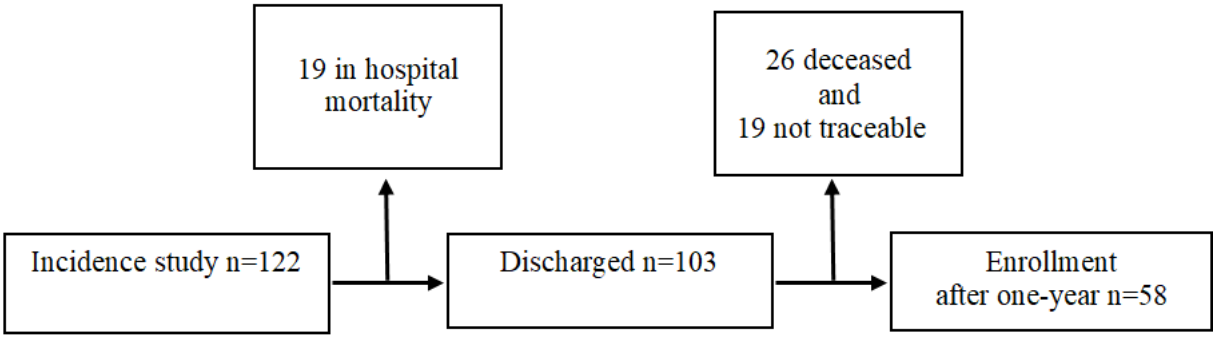

Figure 1. Participant enrollment post one-year follow up in the community

Instrumentation and data collection procedure

Data were collected via a telephone interview from May 2021 till October 2021 with two questionnaires; 1) Socio-demographic and Injury information tool and international quality of life data set for SCI (version 1.0). Sociodemographic and injury information questionnaire consisted of five items intended to collect demographic and injury characteristics like age, gender, marital status, injury level and cause of injury. International SCI QoL Basic Data Set (QoL-BDS) questionnaire, is a spinal cord specific measure of QoL.[15] The three domains measured by the QoL-BDS tool include satisfaction with life as a whole, satisfaction with physical health, and satisfaction with psychological health. All questions refer to a period of the last four weeks and a 0–10 numerical rating scale. The total score of QoL-BDS can be 0 as the lowest through to 30 as the highest while the domain scores range 0-10, higher scores means better quality of life.[16] Questions asked under this tool are;(1) "thinking of your own life and personal circumstances, how satisfied are you with your life as a whole in the past four weeks"? (2) "how satisfied are you with your physical health in the past four weeks"? and (3) "how satisfied are you with your physical health, emotions and mood in the past four weeks"?. This tool measures subjective not objective QoL as defined by Das et al.[17] QoL-BDS has undergone psychometric study to assess its reproducibility among community-dwelling adults living with SCI or disease, and it was found to have good reliability and validity.[18] The tool was pretested on five people with SCI; two female and 3 male. A participant is required to reflect and determine his or her own QoL from a personal point of view, and use his or her own internal measurement and assessment to do this. In such a case, people may select all factors that they think contribute to their QoL.

DataAnalysis

All collected data were entered and analysed using IBM SPSS Statistics for Windows version 26.0 (IBM Corp, Armonk, NY, USA). Descriptive information is displayed using frequency tables in the form of numbers, percentages, means and standard deviation. A normality check resulted into a normal distribution. Test for equality of variance (homogeneity) was carried out; and Brown-Forsythe test for robustness of data.

The Brown-Forsythe test results indicated that variances are not significantly different (W=1.77, P = 0.18) among the groups, Hence, we did not reject the null hypothesis that group variances are equal. As the group variances are not different, the Homogeneity of variance assumption for the one-way ANOVA test is valid. The overall QoL, environmental factors, and injury information was assessed by comparing means and standard deviations in one-way ANOVA. One-way analysis of variance with post-hoc analysis was carried out to determine the relationship between independent variables and dependent variables (overall quality of life and the three domains of quality of life). Independent variables that were significantly influencing QoL while comparing variables with two groups, collinearity was assessed. Dummy tables were created for all categorical independent variables and linear regression model was used to predict independent variables that influence QoL.

Ethical considerations

The study protocol was approved by the Institutional Review Board of the College of Medicine and Health Sciences at the University of Rwanda (Approval No. 308/CMHS IRB/2019). We certify that we complied with the principles in the Helsinki Declaration in its amendments to date and the Ministry of Health, the Republic of Rwanda guidelines on human research participants, before, during, and after data collection. All participants provided written informed consent.

Results

Participants' characteristics

This study managed to trace 58 participants in the community. All of them consented to take part in the study. Slightly more than 75% (77.6%, n=45) were male and more than half (56.9%, n=33) were categorized as paraplegia. Most of the participants were in the youthful age bracket 18-33 years (32.8%, n=19). The leading cause of TSCI was falling (74.1%, n=43) followed by road traffic accidents (15.5%, n=9) as seen in Table 1.

Table 1. General characteristics of study sample (n=58)

Variables		Frequency (n)	Percent (%)
Age category	18-33	19	32.8
	34-49	18	31.0
	50-65	17	29.3
	66 and above	4	6.9
Gender	Male	45	77.6
	Female	13	22.4
Marital status	Married	29	50.0
	Unmarried	21	36.2
	Widowed	8	13.8
Cause of injury	Sports	1	1.7
	Assault	2	3.4
	Transport	9	15.5
	Fall	43	74.1
	Other traumatic causes	3	5.2
Level of injury	Paraplegia	33	56.9
	Tetraplegia	25	43.1
Severity of injury	Complete lesion	18	31.0
	Incomplete lesion	40	69.0

Quality of life

The QoL and its domains mean scores and SD were: overall QoL of 13.12 (7.17); satisfaction with life as a whole 3.91 (2.73), with physical health 3.84 (2.59) and psychological health 5.36 (2.95) as seen in Table 2. The international QoL measure ranges from a score of 0–30, a low score means a poor QoL, and vice versa. Results show a low overall QoL score implying poor QoL of the sample.

Contextual factors and injury variables were assessed by comparing means and standard deviations by one-way ANOVA, the results of which are summarised in Table 3. Among personal factors, it was seen that marital status was significantly associated with overall QoL, high mean scores of physical health and life as a whole domain of QoL among TSCI persons living in Rwanda community P = 0.031, 0.037 and 0.022 respectively. Injury parameters that were analysed for this sample were injury level and completeness of injury; it was found that both parameters were not significantly affecting QoL of the sample.

Table 2. Quality of Life (QoL) and its domains mean scores and standard deviations

QoL domain	Mean	Std. Deviation
Overall QoL	13.12	7.17
Satisfaction with life as a whole	3.91	2.73
Satisfaction with your physical health	3.84	2.59
Satisfaction with your psychological health	5.36	2.95

Table 3. Results of the bivariate one-way ANOVA analysis of overall the quality of life (QoL), and the domain scores, life as a whole, physical health and psychological health

	Overall QoL		Life as a whole		Physical health Mean		Psychological health	
Variables	**Mean (SD)**	**P-value**	**Mean (SD)**	**P-value**	**(SD)**	**P-value**	**Mean (SD)**	***P* Value**
Age category								
18-33	11.21(6.8)	0.163	3.42 (2.4)	0.372	2.89 (2.6)	0.053	2.89 (3.0)	0.352
34-49	12.33 (7.4)		3.44 (3.0)		3.78 (2.6)		5.11 (2.9)	
50-65	16.35 (6.8)		4.76 (2.8)		5.18 (2.3)		6.41 (3.0)	
66 and above	12.00 (7.1)		4.75 (2.6)		3.00 (2.2)		4.25 (2.8)	
Gender								
Male	13.00 (6.8)	0.678	3.98 (2.5)	0.743	3.80 (2.5)	0.809	5.56 (2.8)	0.358
Female	12.38 (8.7)		3.69 (3.4)		4.00 (3.1)		4.69 (3.4)	
Marital status								
Married	12.97 (7.6)	**0.031**	3.76 (3.1)	**0.037**	4.17 (2.5)	**0.022**	5.03 (3.0)	0.150
Unmarried	11.14 (6.5)		3.29 (2.3)		2.76 (2.5)		5.10 (3.1)	
Widowed	18.88 (4.6)		6.13 (0.8)		5.50 (2.2)		7.25 (2.1)	
Severity of injury								
Complete lesion	13.67 (6.9)	0.701	4.39 (2.6)	0.379	3.61 (2.5)	0.649	5.67 (2.9)	0.603
Incomplete lesion	12.88 (7.3)		3.70 (2.8)		3.95 (2.7)		5.23 (3.0)	
Level of injury								
Paraplegia	12.97 (7.0)	0.856	3.88 (2.8)	0.912	3.67 (2.6)	0.649	5.42 (2.9)	0.856
Tetraplegia	13.32 (7.5)		3.96 (2.7)		4.08 (2.6)		5.28 (3.0)	

Significant personal and contextual factors affecting QoL

A post-hoc multiple comparison for overall quality of life, satisfaction with physical health and satisfaction with life as a whole domain, and marital status. This was done to better understand the predictors of quality of life of Rwandans living with TSCI. A regression model using bidirectional elimination (two step) was built using personal factor marital status that was found to significantly influence QoL from the bivariate analysis. Significant variables in the bivariate analysis were assessed for collinearity, the findings showed that the variance inflation factor (VIF) ranged from 2.313 to 7.480, and the tolerance ranged from 0.432 to 0.192. The outcome of the multiple regression analyses is shown in Table 4.

The pattern for sum of QoL scores indicated 51.4% of the variance, $P < 0.05$. Across the marital status spectrum being married and widowed are likely to significantly influence overall QoL and its two domains:satisfaction with physical health and life as a whole ($P < 0.05$) as indicated in Table 4. Marital status, being married and loss of a partner/ widowed predicts low quality of life as indicated by negative coefficients for both overall QoL and its two domains, satisfaction with physical health and life as a whole. Overall QoL (married -5.909, $P = 0.035$ and widowed -7.732, $P = 0.009$). Satisfaction with physical health domain is significantly influenced by being widowed only (married -1.328, $P = 0.182$, widowed -2.738, $P = 0.010$) and satisfaction with life as a whole is significantly influenced by having a spouse and loss of a spouse (married -2.366, $P = 0.027$ and widowed -2.839 $P = 0.012$).

There was no influence of marital status on the psychological health domain, ($P > 0.15$). Even when the difference in psychological health domain was not statistically significant, widowed along with unmarried SCI participants reported the highest scores, while married had slightly lower score among the three groups.

Table 4. The multivariable regression model for the overall score of quality of life (QoL), satisfaction with physical health and satisfaction with life as a whole domain of QoL

Categories	Coefficient	Standard error	Standardised coefficient (β)	P Value
Overall QoL				
Unmarried (Constant)	18.875	2.423		**<0.001**
Married	-5.909	2.736	-0.416	**0.035**
Widowed	-7.732	2.847	-0.523	**0.009**
Satisfaction with your physical health				
Unmarried (Constant)	5.500	.869		**<0.001**
Married	-1.328	.981	-.259	0.182
Widowed	-2.738	1.021	-.513	**0.01**
Satisfaction with life as a whole				
Unmarried (Constant)	6.125	.925		**<0.001**
Married	-2.366	1.045	-.437	**0.027**
Widowed	-2.839	1.087	-.504	**0.012**

Discussion

We aimed at assessing QoL of TSCI survivors after one-year follow-up of a TSCI. Recalling that higher scores represent better QoL and low scores poor QoL, this sample generally reported poor QoL. The results show that being married and widowed predicts poor QoL. However other demographic variables, such as age gender and injury characteristics were not predictors of QoL. This is comparable with studies carried out elsewhere.[16,19] The findings of this study also follows a trend of affairs which show that demographic profile variables are widely considered as both determinants and proxies used to assess social well-being; itself a measure of subjective/perceived QoL, it has been reported that these demographic variables account for small influence on social wellbeing.[3]

The difference might be due to environmental factors like societal resources. In the Rwandan context following TSCI and any other long term illness, the victim is left to themselves, or to the family with limited resources. This means that when he/she is no longer earning income due to SCI yet he/she has family to cater for, it becomes stressful. This might explain the negative relationship between married and widowed, and QoL reported in the regression model in our study. Comparatively in some countries there is possibility of government policy providing some of the basic needed resources, like accommodation and food through social grants.[16,20] Marital status and gender, and QoL has been studied in Korea and results show that for married men they negatively affect quality of life.[21] The current study did not compare marital status and gender however the difference might be explained in terms of gender,role and division of labor in different contexts. The same study in Korea showed that married people regardless of their gender scored high on the measurement scale of wellbeing which is a measure of subjective QoL which is in line with the results of this study.

Psychosocial factors has been associated with poor QoL outcome and single people (including widowed).[19,22] A large study DHS reported that married, separated and widowed participants scored high on Euro Quality of life visual analogue scales (Q-VAS), the findings of this study concur with the results of this study, the difference in subgroups might be due to the methodological approaches like difference in the measurements used.[23] Rehabilitation services have been seen to be predictors of better QoL.[16]

In Rwanda, specialized rehabilitation services that a TSCI person might need are limited in terms of availability and access. [24] This is likely to contribute to poor QoL of TSCI community dwellers seen in this study. However, on the other hand, the familial responsibility might act as predictor of better QoL by providing societal environment/support. It is widely accepted that a healthy social life is essential for a better QoL.[16] The results of this study are comparable with results of other groups of people in the community with different disabilities like the elderly. A large cohort study of older adults on the US-Mexico border showed that widowed and divorced reported better quality of life while married senior citizens report the highest quality of life in social relationships domain.[25] The differences in scores of QoL among the matched groups might be due to contextual differences and the roles and responsibilities that societies attach to people due to their gender, age and marital status.

Strengths and Limitations

The importance of this study is based on the value of attributes of the meaning of quality of life and how and the extent to which it can be easily affected when the community factors do not ensure its existence. Therefore, it is important to consider that in a society like that of Rwanda with a history of social violence, such as that of 1994 Rwanda genocide against Tutsi, marital status could be considered a "protective/affective strategy" for general QoL satisfaction and in particular physical health satisfaction following TSCI.

Limitation of this study was the sample, for future research it is recommended that, the sample size be sufficiently large, and the study incorporate qualitative investigation as well. Large sample size will ensure representativeness while qualitative designed studies will allow in-depth understanding of QoL. The results of this study might be affected by unequal distribution of resources among Rwandans which is likely to affect every aspect of life in the society like access to rehabilitation services, basic needs and vocational training. This is one of the right step towards disseminating the possible influence of sociodemographic and environmental factors, on quality of life of people with SCI in in Rwanda.

Conclusion

This study evaluated the possible influence of personal and contextual factors on quality of life. Out of the highlighted factors, it was found that marital status significantly affected overall quality of life and its two domains: satisfaction with physical health and life as a whole of people with SCI. Along the marital status, the married status predicted poor overall quality of life and satisfaction with life as a whole domain, while widowed predicted poor overall QoL, satisfaction with physical and life as a whole domain. Our study results show generally low scores of overall QoL and its associated domains implying poor QoL. This calls for integrated and holistic rehabilitation approach. There is need for community reintegration readiness assessment before discharge. Our study participants were living in the mainstream community for one year and above, community rehabilitation programs need to be strengthened. The results of the this study are particularly relevant for Rwanda community following genocide in which quality of life is likely to be jeopardized. The study data showed that most of the injuries happened in cervical region predicting the disability burden among TSCI survivors.

Conflict of interest

There are no conflict of interest to declare.

Authors' contribution

All authors have played a significant role in the conception, design, data analysis and interpretation, and writing of the manuscript.

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