







Quality of life and traumatic spinal cord injury: a study using international data sets

Qualidade de vida e lesão medular traumática: um estudo com uso de data sets internacionais

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ABSTRACT

The aim of this quantitative, analytical and cross-sectional study was to assess the quality of life (QOL) of people with a traumatic spinal cord injury (SCI) and its association with the length of time of SCI. Data were collected using two validated instruments (a biological and sociodemographic questionnaire and the QOL Data Set from the International Spinal Cord Society). The sample included 81 participants, 81.5% male, with a mean age of 36 ± 11.9 years. Satisfaction with psychological health had a higher score (7.2), despite 86.4% being dissatisfied or completely dissatisfied with overall QOL. There was no difference when comparing the SCI level to satisfaction with overall life ($p=0.237$). General QOL was associated with the length of time of SCI ($p=0.005$), suggesting that after five years of SCI, people tend to be more satisfied with their lives. This study showed that most participants with SCI are dissatisfied with their quality of life.

Descriptors: Quality of Life; Disabled Persons; Rehabilitation; Spinal Cord Injuries; Nursing.

RESUMO

Avaliar a qualidade de vida (QV) de pessoas com lesão medular traumática (LMT) e sua associação com o tempo de LMT. Estudo quantitativo, analítico e transversal. Os dados foram coletados com dois instrumentos validados (questionário biosociodemográfico e *Data Set* de QV da International Spinal Cord Society). Amostra com 81 participantes, 81,5% do sexo masculino, com média de idade de $36 \pm 11,9$ anos. A satisfação com a saúde psicológica apresentou maior escore (7,2), apesar disso, 86,4% estavam insatisfeitos ou completamente insatisfeitos com a QV geral. Não houve diferença quando comparado o nível da LMT com satisfação com a vida como um todo ($p=0,237$). A QV geral foi associada ao tempo de LMT ($p=0,005$), sugerindo que após cinco anos da LMT, as pessoas tendem a ficar mais satisfeitas com suas vidas. Este estudo mostrou que a maioria dos participantes com LMT apresentam-se insatisfeitos com a qualidade de vida.

Descritores: Qualidade de Vida; Pessoas com Deficiência; Reabilitação; Traumatismos da Medula Espinhal; Enfermagem.

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INTRODUCTION

A traumatic spinal cord injury (SCI) is one of the most debilitating events that can occur in a person's life, and can lead to severe impairment of motor, urinary, intestinal, and sexual functions, among others, impairing an individual's autonomy, level of satisfaction and participation in society^(1,2). As a result of the increase in urban violence, longer life expectancy due to better care, and the increased risk of falling associated with an aging population, the incidence of SCI has increased considerably in the last decade^(3,4). Annually, there are an estimated 40 million new cases of SCI worldwide⁽⁴⁾.

In Brazil, although data on the incidence and prevalence of SCI are vague, inaccurate and relatively old, it is estimated that about 130 thousand individuals have SCI, with approximately 10,000 new cases per year^(5,6). National and international data show that SCI mainly affects young men who are economically active⁽⁶⁻⁸⁾. Within this context, constraints, social isolation, dissatisfaction, and anxiety can develop in the life of the individual with SCI, which may become barriers to treatment and limitations to better QOL^(9,10).

With the aim of enhancing autonomy and maximizing participation in society, as well as promoting the return to activities of daily living and consequently improving QOL after the onset of SCI, it is recommended that individuals with SCI be referred for early rehabilitation^(2,11). In the rehabilitation process, the treatment of individuals with SCI aims to foster the adaptation and social interaction of the individual and their family confronting the sudden changes they have suffered and reduce possible complications, thus guaranteeing QOL of both the person and the family⁽¹⁰⁾.

The concept of QOL is widely used, however, it has a complex meaning due to the subjectivity of each social group or individual⁽¹²⁻¹⁴⁾. According to the World Health Organization (WHO), QOL is the individual's perception of their position in life, in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns⁽¹⁵⁾. Therefore, QOL includes aspects of life related to well-being, happiness, personal fulfillment, expectations, spirituality, and satisfaction, among others. In the area of health, QOL specifically refers to the satisfaction or well-being of an individual in the face of health conditions, illness, treatment, or rehabilitation^(10,14).

The QOL of individuals with SCI can be understood as their ability to do something for themselves and to resume significant roles in the family and society^(14,15). It involves finding the balance between body, mind, and spirit and establishing harmonious relationships within the social, cultural and environmental context^(14,16). As such, despite the magnitude of the concept of QOL and its multidimensional and subjective nature, many studies have been conducted on its assessment and measurement in particular, whether for individuals or groups^(17,18).

There is a diversity of instruments used to measure the QOL of individuals with SCI, however, there was a need for instruments that would enable international data comparison^(14,19). In this regard, based on the demand for common metrics to evaluate the health care of people with SCI, worldwide, a group of researchers from different areas associated with the American Spinal Injury Association (ASIA) and the Spinal Cord International Society (ISCoS), developed the International SCI Basic Data Set^(20,21).

The data sets were developed to assess bodily functions and structures (Intestinal Function, Lower Urinary Tract, and Metabolism, among others), activity and participation, in addition to a set of data for personal characterization and data for assessing QOL⁽²⁰⁾. These instruments are in the public domain, available for download on the ISCoS website, aiming at collaborative and comparative studies between different cultures, assisting in the therapeutic evolution of SCI based on scientific evidence⁽³⁾. The perspective is that studies like this will enable Brazil's participation in international comparative studies on spinal cord injury.

In this context, the QOL data set is considered an essential assessment for the rehabilitation process of people with SCI, as it helps and contributes to the improvement of rehabilitation as well as collaborating in improved knowledge on the characteristics and adequate treatment of this population⁽¹⁴⁾.

Nevertheless, in the literature consulted, Brazilian studies on the quality of life of people with SCI using ISCoS data sets were not found. Therefore, aiming at international comparative studies to improve the rehabilitation of people with SCI and, consequently, their quality of life, this study aimed to assess the QOL of people with traumatic spinal cord injury and the influence of the length of time of SCI.

METHODS

This is a quantitative, analytical and cross-sectional study, carried out in two rehabilitation centers located in Ribeirão Preto (SP) and Florianópolis (SC), which are referral centers for patients with SCI in the interior of the state of São Paulo, the south of the state of Minas Gerais and the state of Santa Catarina.

For the convenience sample, all patients diagnosed with traumatic SCI aged 18 years or older, participating in the rehabilitation programs at either of the two study sites, from December 2015 to September 2016, were invited to participate in the study. Patients who were unable to finish the interview were excluded from the study.

The interviewers were four nurses, two from each rehabilitation center, with a minimum experience of five years as a rehabilitation nurse. During two face-to-face meetings of four hours each, in addition to virtual meetings, the interviewers were trained to apply the data collection instruments, using the ISCoS manual guidelines for the

collection of each variable, with practical clinical examples developed specifically for training interviewers.

A questionnaire was used to collect data on the sociodemographic characterization of the participants based on the population surveys applied by the Brazilian Institute of Geography and Statistics (IBGE), including the categories of age, sex, city/state of origin, education, profession/occupation and family income⁽²²⁾. For the data related to SCI, a questionnaire was used, based on the ISCoS Core Data Set^(20,21), containing data on the date of the injury, etiology, and neurological, sensory and motor levels, in addition to the date of hospital discharge. To evaluate the QOL, the International Spinal Cord Injury Quality of Life Basic Data Set⁽²⁰⁾ was used. The data set was translated and validated for Brazilian Portuguese according to the methodology recommended by ISCoS⁽²¹⁾. Data sets are instruments used to collect public domain data and QOL data sets aim to assess QOL from the perspective of the participant. It consists of three domains: satisfaction with overall quality of life, satisfaction with physical health, and satisfaction with psychological health. The data set is composed of three questions, one from each domain, with the possibility of answering on a numerical scale from zero to 10, ranging from “completely dissatisfied” to “completely satisfied”. The data set is not a measurement instrument and does not have scores; the objective is the clinical follow-up of patients with traumatic SCI in different international contexts.

This study was approved by the Research Committees of the participating rehabilitation centers and approved by the Research Ethics Committee of the Ribeirão Preto School of Nursing of the University of São Paulo, protocol no. 46817115.5.0000.5393 and approval no. 1.267.532. After accepting and signing the Consent Form, data were collected through face-to-face interviews, or via telephone if the participant was not available to answer the survey at that time. The interviews were conducted in a reserved location only in the presence of the interviewer, thereby guaranteeing the participant’s privacy.

For statistical analysis, data were entered into the Survey Monkey® platform and imported into the Statistical Package for the Social Sciences (SPSS) application, version 22.0, and R, version 3.3.0. Descriptive statistical analysis was performed using absolute and relative frequencies of qualitative variables and central tendency (mean, median, standard deviation) and variability (minimum, maximum and standard deviation) for quantitative variables. For the statistical tests, aiming at the association between the domains of quality of life and the other variables, the Mann-Whitney test was used for two independent samples, and the Kruskal-Wallis test for more than two independent samples in the case of ordinal or continuous variables. The level of significance adopted for the study was 5% ($p \leq 0.05$).

RESULTS

The sample consisted of 81 participants, 25 (30.9%) from Ribeirão Preto (SP) and 56 (69.1%) from Florianópolis (SC). Regarding gender, 66 (81.5%) were male and 15 (18.5%) female, with a mean age of 36.4 ± 11.9 years, a minimum age of 18.0 and a maximum of 77.0. In terms of level of education, 34 (42.0%) of the participants had no education or had only incomplete elementary education. Most were on sick leave or retired due to disability (72.8%), and 48.2% had an income of one to three minimum wages (minimum wage of Brazil, reference value: R\$ 880.00).

In relation to the cause of traumatic SCI, the primary cause was traffic accidents (43.2%), followed by falls (21.0%), and accidents with weapons (18.5%). The age of the participants at the time of the SCI ranged from 15.4 to 77.0, with a mean age of 31.7 ± 8.8 years. After hospital discharge, 70.0% of participants returned to their homes, and 30.0% were admitted to specialized rehabilitation centers to continue treatment.

The participants’ mean SCI time was 4.7 ± 5.3 years. The majority of participants (43.2%) had less than two years of SCI, followed by participants with SCI for more than five years (32.1%), and the minority (24.7%) between two and five years of SCI. The most frequent SCI levels were thoracic (53.1%) and cervical (35.8%); 11.1% had a lumbar level injury and none of the participants had a sacral level injury. Considering the classification of the participants by the level of paraplegia (thoracic, lumbar, or sacral SCI) and tetraplegia (cervical SCI), the majority (64.2%) had paraplegia.

Regarding the assessment of QOL, Table 1 describes the questions of the three domains with the respective means and standard deviations of each item evaluated.

Table 1. Quality of life means obtained from the quality of life assessment data set ($n=81$). Ribeirão Preto (SP) and Florianópolis (SC). Brazil, 2015–2016.

Issue / domain	Mean	SD(±)
Domain: Satisfaction with overall quality of life		
When thinking about your own life and personal circumstances, how satisfied have you been with your overall quality of life in the past 4 weeks?	6.53	2.70
Domain: Satisfaction with physical health		
How satisfied have you been with your physical health in the past 4 weeks?	6.88	2.42
Domain: Satisfaction with psychological health		
How satisfied have you been with your psychological health, emotions, and mood in the past 4 weeks?	7.20	2.86

SD: standard deviation from mean.

Most participants (70-86.4%) had some dissatisfaction or were completely dissatisfied in the domain “satisfaction with overall quality of life” and 11 (13.6%) were completely satisfied with their life in general. For “satisfaction with physical health”, 69 participants (85.5%) were dissatisfied with some point of their physical health, while 12 (14.8%) considered themselves completely satisfied. Of the participants, 62 (76.5%) had some dissatisfaction or were completely dissatisfied with their psychological health, emotions, and mood; and 19 (23.5%) assessed themselves as completely satisfied with their psychological health.

In assessing satisfaction with overall quality of life, participants with less than two years of SCI had a lower mean (5.34) than participants who had an SCI for more than five years (7.54). Thus, when comparing the length of time of the SCI to satisfaction with overall quality of life, a statistically significant difference was found between the means, the longer time of SCI being associated with a higher level of satisfaction with overall quality of life ($p=0.005$, Kruskal-Wallis test). For this analysis, these time intervals after the SCI were considered, since the majority had up to five years of injury, a period in which patients are in rehabilitation and still considered a critical period of the chronic phase⁽⁴⁾.

Regarding satisfaction with physical health and with emotional and/or psychological health, there was no statistically significant difference in relation to the length of time of SCI ($p=0.396$ and $p=0.923$ respectively, Kruskal-Wallis test). There was also no statistically significant difference when comparing the SCI level with satisfaction with overall quality of life ($p=0.237$, Mann-Whitney test), satisfaction with physical health ($p=0.807$, Mann-Whitney test), and satisfaction with psychological health, emotions, and mood ($p=0.477$, Mann-Whitney test).

DISCUSSION

From the findings, the age group at the time of the traumatic SCI (young people) and the prevalence of males (81.0%), reflect the global reality, since national and international studies report that traumatic SCI primarily affects young men^(6,8,11,23). The literature attributes these findings to male behavior that tends to be more daring, making them more easily exposed to risky activities, especially in youth⁽¹³⁾. This study showed a large number of people with SCI at an economically active age who stop contributing taxes, generating significant loss in GDP and, as a consequence, they use more public resources, in addition to the fact that the SCI has already increased the individual's use of health services, besides increasing social security costs^(11,23).

Among the main causes of traumatic SCI, those related to transportation, such as car or motorcycle accidents and events related to falls, stood out, followed by factors

related to violence such as robberies. These findings are in line with other Brazilian and international epidemiological studies that indicate traffic accidents as the main cause of SCI, and an increasing tendency in accidents related to falls, which is causally related to aging of the general population⁽¹¹⁾. In this context, it is increasingly necessary for authorities to implement awareness campaigns on the severity of SCI, aimed at the young male population, and to intensify surveillance to ensure compliance with traffic laws in order to reduce traffic accidents and, consequently, SCI.

The participants' length of time of SCI had a mean of 4.7 years, and most participants had up to five years of injury, still considered a critical period of the chronic phase⁽⁴⁾. One of the priorities of this phase is the restoration of the psychological state, due to the number of people who suffer from some type of psychological disorder related to the sudden trauma^(4,8). The sooner these individuals are included in rehabilitation programs, the greater their chances of overcoming difficulties, emphasizing the role of the interdisciplinary team and family support in recovering an individual's biopsychosocial functions after SCI^(14,16). However, it was observed that only 30.0% of participants were admitted to hospitals or rehabilitation centers immediately after hospital discharge. This reality has already been previously described by another Brazilian study with data showing some participants who took up to 12 years to look for a rehabilitation center after SCI⁽⁶⁾. Another prospective study carried out in South Africa, with 147 people, also found a low number of people who access rehabilitation centers immediately after traumatic SCI⁽²³⁾. Early rehabilitation favors both the return and inclusion of the individual with SCI in the job market, acquiring functional independence and improving family income.

Regarding the participants' QOL, the data showed that a small number of participants considered themselves completely satisfied with overall quality of life, with their physical health, and with their psychological health, mood and emotions. In this regard, national and international literature has shown, from quantitative and qualitative self-report studies, a complexity of biological and sociocultural factors that affect the QOL of people after trauma and how they consider themselves dissatisfied with their new condition and quality of life⁽¹²⁻¹⁴⁾.

In this context, the role of the interdisciplinary team and family support in the rehabilitation of the biopsychosocial functions of people affected by an SCI is emphasized. The rehabilitation process is dynamic and involves the entire team in meeting the main needs of the individual and the family, looking for functional solutions to the challenges of living with SCI. Thus, this process aims to develop the physical potential to the maximum, restore autonomy, and enable the resumption of occupational and social activities, promoting a better QOL⁽¹⁶⁾.

As demonstrated, a higher mean QOL was observed in the domain of satisfaction with psychological health.

Previous studies^(14,16) corroborate this data and suggest that satisfaction in the psychological domain involves aspects of well-being, self-esteem, personal beliefs, but also negative feelings, such as despair, anxiety, and depression. The rehabilitation of individuals with SCI must encompass the entire context in which the individual is inserted, in a holistic way, considering the individual as the protagonist of this process.

In this study, the association between satisfaction with overall quality of life and length of time of SCI was statistically significant, suggesting that as time passes after the SCI, people tend to adapt and become more satisfied with their lives. General satisfaction with life can include assessment of the life circumstances within their context of culture and values, and the subjective feeling of physical well-being that encompasses psychological, social, and spiritual dimensions⁽¹⁴⁾. It is understood that the individual faces adversity by striving to achieve the proposed rehabilitation goals, which leads to a cycle of recovery of skills initially lost, reducing dependence on others for personal care, resuming work activities, increasing participation, and, consequently, improving QOL⁽⁴⁾.

In view of the results, it is suggested that it may be profitable for the government to develop social policies that support the rehabilitation and return to society and work, instead of maintaining dependency on social security. In addition to the social and economic issue, scholars emphasize the role of work in people's lives, and how this activity is fundamental for personal fulfillment, the development of self-esteem, and feelings of capacity and autonomy, in addition to promoting social participation^(13,16). In addition, more investment is needed to create rehabilitation centers and finance studies that lead to the integration of databases in the Brazilian health system, leading to continuity in the flow of treatment and monitoring of people with SCI^(13,14).

This study highlights important data on the QOL of individuals with traumatic SCI, however, due to regional characteristics and sample size, generalization of the data should be avoided. Longitudinal studies with a larger sample size, national coverage and a probabilistic sample, should be carried out to obtain a better understanding of the impact of injury time on the QOL of people with SCI.

CONCLUSIONS

This study showed that most participants with traumatic SCI are dissatisfied with their quality of life, regardless of the domain (satisfaction with overall quality of life, physical health, and psychological health). Satisfaction with psychological health was the domain with the best mean among respondents. There was an association between satisfaction with overall quality of life and the length of time of SCI, suggesting that after five years of SCI, people tend to adapt and become more satisfied with their lives.

Furthermore, the results showed that it can be profitable for the government to develop social policies that support the rehabilitation and return to society and work, instead of maintaining dependency on social security. In addition, more investment is needed to create rehabilitation centers and finance studies that lead to the integration of databases in the Brazilian health system, leading to continuity of treatment in the network and monitoring of people with SCI until their complete reintegration into society, which would reflect positively on their quality of life.

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