

Individuals with Spinal Cord Injury in Rehabilitation: Quality of Life Study

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Abstract

Among the various types of disability that can affect humans, spinal cord injury (SCI) is undoubtedly one of the most devastating. This type of injury is a disruptive incident in the individual's life, entails significant changes and requires a biopsychosocial adaptation. The following research aims to contribute to the study about the quality of life in individuals with SCI. The sample was composed of 36 individuals with SCI, inpatients of the Portuguese Central Region Center of Rehabilitation Medicine-Rovisco Pais, aged between 20 and 82 years old ($M = 53.56$, $SD = 18.27$). Participants completed a sociodemographic and clinical information questionnaire and measures of functioning independence and quality of life. The results indicate that individuals with SCI present a good perception of quality of life, which is promising of psychological adaptation. The results highlight the need for health professionals and family/caregivers to acquire knowledge which facilitates the process of adaptation to the clinical condition consequently contributing to the health and well-being of individuals with SCI.

Keywords

Spinal Cord Injury, Quality of Life, Rehabilitation

1. Introduction

Spinal cord injury (SCI) is a devastating clinical condition with several incapacitating and permanent manifestations resulting in a loss of partial or total functionality of the spinal cord [1]. A worldwide incidence study of traumatic SCI carried out in 2011 estimated an overall incidence rate of 23 cases per million, that is, 179.312 new cases per year. Several incidence rates from Western European countries were reported in this study, with the median calculated being 16 cases per million [2]. In another study, an incidence rate of traumatic SCI in Portugal was reported in the order of 57.8 individuals per million [3]. However,

most studies on the incidence of SCI are retrospective or based on a hospital population, and do not provide a generalized view of their true incidence in the general population [4].

The emergence of SCI leads to a significant change in the individual's life, leading to a series of biopsychosocial consequences [5] [6] [7]. Such consequences can impact and impair people's lives at a personal (e.g., physical, emotional, sexual), economic/professional (e.g., lose their jobs, etc.) and social levels (e.g., family and couple relationship, friends, social stigma, etc.). Specific consequences such as sensorimotor changes, sexual dysfunction, pain, muscle spasms, fatigue, pressure ulcers, osteoporosis, bowel/bladder problems may also occur [5] [6] [8] [9]. However, the type of injury translates into different consequences, levels of autonomy, and physical, psychological and social functioning [5].

SCI can be classified according to a functional level and the extension of the injury. Regarding the functional level, this type of injuries is divided into paraplegia and tetraplegia. Paraplegia refers to the decrease or loss of motor and/or sensory function in the thoracic, lumbar or sacred segments of the spinal cord, which may compromise the trunk, pelvic organs, and lower limbs, depending on the level of the injury. Tetraplegia refers to the decrease or loss of motor and/or sensory function in the cervical segments of the spinal cord, compromising the trunk, pelvic organs, upper and lower limbs. Regarding the extension of the injury, a SCI is complete when there is an absence of motor and sensory function below the injury area and incomplete when there is some preservation of motor and/or sensory function [10]. Etiologically, these types of injuries can be divided into traumatic and non-traumatic injuries. Traumatic injuries are the most frequent and result from events where there is a high-velocity impact (e.g., road accidents, falls, diving accidents, gunshot wounds). In contrast, non-traumatic injuries are a consequence of a pathology, such as vascular dysfunctions, degenerative joint disease, neurological diseases, neoplasia among others [4].

After a SCI is installed, institutionalization in a center of rehabilitation medicine might be required in order to provide a standardized support which familiarizes the individual with SCI with his/her acquired disability [11]. The rehabilitation process aims the reintegration of the individual with SCI in the community. This is generally achieved by promoting the individual's and his/her family's adjustment to the new clinical condition, his/her personal autonomy, and psychological adaptation. The later includes helping the individual with SCI to define individual adaptive responses to the condition, changing the behavior, thinking and circumstances in relation to the factors associated with injury and disability. The rehabilitation program should, therefore, take into account the resources of the individual, the nature of their difficulties and the medical-functional prognosis, as well as the capacity to acquire new skills and knowledge, in order to boost their available levels of activity. At the end of the process, it is expected that patients and their families/caregivers make the most of the opportunities, thus improving patients' quality of life and satisfaction with life [12] [13].

Literature has proved that quality of life is a variable that can positively influence psychological adaptation, making it more effective [9] [14]. In addition, it is still mentioned by other authors that quality of life is a moderating variable of psychological adaptation [7] [15]. According to World Health Organization (WHO), quality of life is defined as the individual perception of their position in life, in cultural system context and values which people live and are related to, their goals, expectations, standards and concerns. It is a broad concept that is influenced by physical health, psychological condition, level of independence, social relationships, personal beliefs and their correlation to the important aspects of the environment [16].

The consequences of a SCI are a present reality in the life of individuals with this type of injury and can interfere with their quality of life [11] [17]. Several investigations have consensually shown the reduction of the quality of life in this population, despite indicating satisfactory subjective well-being indexes [18]. Although the disability is irreversible and has implications for quality of life, there are several personal and social factors that can influence positively or negatively the life of these individuals. Thus, it is possible to live with a chronic health condition and maintain life satisfaction [6] [19] [20].

The national studies about this subject are little, so it's clear the pertinence and relevance of this research that intends to contribute to a deeper understanding of the perception of quality of life in individuals with SCI, in inpatient at a Portuguese rehabilitation medicine center. Specifically, we intend to investigate possible differences in sociodemographic and clinical data regarding the perception of quality of life.

2. Method

2.1. Participants

The present investigation had as a sample a clinical population of 36 individuals diagnosed with SCI, hospitalized at the Central Region Center of Rehabilitation Medicine-Rovisco Pais (CMRRC-RP).

The exclusion criteria used were aged under 18 years old and cognitive alterations which could bias comprehension and response capabilities to the applied psychological assessment instrument. These criteria were in line with those of the experts in the area [21] [22].

In terms of the sample, 23 participants were male (63.9%) and 13 were female (36.1%). The participants were aged between 20 and 82 years, with a mean of 53.56 years (SD = 18.27) [*We are aware of this variability and what is inherent in it. However, we find the integration of all individuals to be of great utility*].

Regarding the marital status, 22 of the individuals were married/non-marital partnership (61.1%), eight were single (22.2%), five were widowers (13.9%) and one was divorced/separated (2.8%).

With regard to literacy, 12 individuals (33.3%) completed elementary education, 15 (41.6%) had primary education, three (8.3%) had secondary education and six (16.7%) had higher education.

The clinical characterization of the sample regarding the functional level, extension, and etiology of the injury is presented in **Table 1**.

The participants' ages at the time of injury were between 13 and 80 years, with a mean of 50.25 years (SD = 19.87). Total rehabilitation time ranged from 1 to 432 weeks, with a mean duration of 54.78 weeks. While the rehabilitation time in the CMRRC-RP ranged from 1 to 96 weeks, with an average duration of 18.47 weeks.

The Functional Independence Measure (FIM) applied to the sample ranges from 48 to 123 points, with the mean being 82.33 points (SD = 21.33) [*Interpret these data according to the parameters of the Functional Independence Measure (FIM)*]. Of the total sample, 17 participants (47.2%) went to their homes at the weekend.

2.2. Instruments

Sociodemographic and Clinical Questionnaire: Collects information on sociodemographic variables such as gender, age, marital status, and literacy. The questionnaire also covers the injury functional level, extension and etiology, the age of the individual at the time of injury, the total rehabilitation time, the rehabilitation time at the CMRRC-RP, the functional independence of the participant at the beginning of hospitalization and the number of times individuals goes to their homes at the weekend.

Functional Independence Measure (FIM): FIM is the Portuguese version of the Adult Functional Independence Measure, Guide for the Uniform Data System for Medical Rehabilitation [23] [24]. This assessment tool is a basic indicator of the disability severity and focuses on performing daily life activities independently. It was developed for the monitoring of individuals who are in the rehabilitation process, evaluating their performance in 18 tasks. Each of the 18 items (tasks) are ranked on a scale of 1 (*total dependence*) to 7 (*total independence*) points, which represent levels of dependency. The total value can vary

Table 1. Clinical characterization of the sample regarding injury' functional level, extension and etiology.

	Frequency	Percentage (%)
Injury Functional Level		
Paraplegia	24	66.7
Tetraplegia	12	33.3
Injury Extension		
Incomplete	26	72.2
Complete	10	27.8
Injury Etiology		
Non-Traumatic	19	52.8
Traumatic	17	47.2
Total	36	100.0

between 18 and 126 points; the lower the score, the higher the level of dependency and so forth. The FIM presents the following subscales: self-care, sphincter control, mobility/transfers, locomotion, communication and social cognition [10] [24]. There are several validation and reliability studies of the FIM with good statistical power, having the studies that evaluated its psychometric properties presented good properties. Despite being an instrument widely used in the clinical context, no adaptation studies were found regarding the Portuguese population [25]. FIM value and other clinical information related to the injury were obtained through consultation of the clinical processes, after the consent of participants.

World Health Organization Quality of Life-Bref (WHOQOL-BREF): The World Health Organization Quality of Life Assessment (reduced version) was translated and validated for the Portuguese population, in 2006, by Vaz Serra *et al.* [26]. This questionnaire is composed of 26 items on a Likert scale (1 to 5). This instrument evaluates four domains (physical, psychological, social relationships and environmental) and includes two items that assess the general quality of life (general facet). The score may be presented as a percentage and the individual's quality of life is higher the higher the score. For the Portuguese version, the psychometric studies demonstrated that the WHOQOL-BREF presents good internal consistency characteristics (*Cronbach's alpha* of .92), discriminant validity, content validity and test-retest stability, making it a good instrument to evaluate the quality of life in Portugal [26].

2.3. Procedure

With the respective authorizations of the Board of Directors and the Ethics Committee for Health of the CMRRC-RP, data collection was carried out after all participants were informed of the objectives of the research, having given their consent for the participation in the research, ensuring anonymity, confidentiality of the collected data and access to results. The data were collected between May and June of 2016. The protocol was carried out through structured interviews, in order to allow a standard application to all the participants, despite of dexterity limitations that they could or not present.

2.4. Data Analysis

Statistical analysis of the collected data was performed using *Statistical Package for the Social Sciences* (IBM SPSS, Version 20.0 for the *Windows* operating system) software. Descriptive statistics were used to characterize the sample and the applied psychological assessment instrument. After studying the normality of the sample, it was found that it differs significantly from the normal distribution. Given this, we chose non-parametric statistics, where the *Mann-Whitney* test was applied to independent samples.

3. Results

The results showed a higher average score for the environmental domain ($M =$

66.72, SD = 9.44), followed by the psychological domain (M = 66.64, SD = 14.97) and social relationships domain (M = 62.47, SD = 13.44), physical domain (M = 60.94, SD = 15.05) and the general facet mean (M = 60.36, SD = 20.52) evidenced lower average scores.

Table 2 shows the values obtained in the WHOQOL-BREF, in the present study, and in the Portuguese validation study.

Regarding the perception of the quality of the environment, it was higher in individuals with a non-traumatic injury (Mdn = 72.00, SD = 9.69) than in individuals with a traumatic injury (Mdn = 63.00, SD = 7.95). A *Mann-Whitney* test for independent samples showed that the difference between conditions was statistically significant ($U = 96.50$, $Z = -2.07$, $p = .038$, $r = -0.35$).

Regarding social relationships, these were perceived as better by individuals diagnosed with tetraplegia (Mdn = 67.00, SD = 8.77) than by individuals diagnosed with paraplegia (Mdn = 58.00, SD = 14.40). Statistically significant differences were found between conditions ($U = 83.50$, $Z = -2.09$, $p = .041$, $r = -0.35$).

The social relationships were also perceived as better by the individuals who suffered the injury at younger ages (Mdn = 67.00, SD = 14.40) than by the individuals who suffered the injury at more advanced ages (Mdn = 58.00, SD = 12.19). Statistically significant differences between conditions ($U = 93.50$, $Z = -2.11$, $p = .039$, $r = -0.35$) were found.

4. Discussion

Literature has shown that variables such as quality of life can positively influence psychological adaptation, making it more effective [9] [14]. The present study investigated the psychological variable in a sample of individuals with a SCI.

The studied sample had inferior results in the general facet and in three domains of quality of life (physical, social relationships and psychological), compared to the sample of the validation study, being the physical domain one of the domains with lower scores, which corroborates with previous investigations [18] [27] [28] [29] [30] [31].

Table 2. Comparison of the values obtained in the WHOQOL-BREF, between the sample of patients with a SCI, in the internment regime, in the present study and the Portuguese sample of the validation study.

WHOQOL-BREF	Sample of the present study	Sample of the validation study
	Mean (SD)	Mean (SD)
General	60.36 (20.52)	71.51 (13.30)
Physical	60.94 (15.05)	77.49 (12.27)
Psychological	66.64 (14.97)	72.38 (13.50)
Social Relationships	62.47 (13.44)	70.42 (14.54)
Environmental	66.72 (9.44)	64.89 (12.24)

The sample values of the present investigation were higher than those of the sample of the validation study in the environmental domain, and this can be explained by the fact that the CMRRC-RP facilities are adapted to the needs of the individuals with a SCI. It was also evidenced in one study [11], a great satisfaction with the environment, by individuals who suffered a SCI. Possibly, the environmental domain score may be reduced when individuals diagnosed with SCI are discharged from hospital and returned to their environmental contexts. Thus, it is necessary to emphasize the process of change experienced by these individuals in order to minimize the negative impact felt, as well as to provide a continuity of adaptation to the clinical situation in a non-hospital environment.

Several authors report that younger individuals have higher levels of quality of life and broader social networks, which maximizes new social experiences and is associated with positive outcomes [32]. The results of the present study are in agreement with previous studies since the individuals who suffered the injury at younger ages, perceived better social relationships. Some studies show that individuals diagnosed with SCI can perceive a good quality of life [6] [19] [22] [30], which may be a possible justification for the results found in our study.

We can mention that the individuals of the present study present a good perception of quality of life, which is promising of psychological adaptation. However, it is important to stress here that the adequate and high quality of the psychological monitoring that is carried out in the CMRRC-RP may have contributed to some of the positive results presented here.

Notwithstanding the conclusions found in our study, it is necessary to take into account some limitations inherent to this type of study, namely: social desirability, sample size and representativeness, the scarcity of recent literature in the national context concerning individuals with SCI and the absence of validated instruments for the population of individuals with this type of injuries, in contrast to other clinical populations.

For future research, it is necessary to study other psychological variables as well as the inclusion of larger samples, to construct and validate psychological assessment instruments for the population of individuals with SCI. In addition to the need to replicate the present study, it is also important that studies of a longitudinal nature can be carried out in order to investigate the quality of life throughout the life stages of these individuals.

5. Conclusion

In conclusion, the results highlight the need for health professionals and family/caregivers to acquire knowledge that can facilitate the adaptation process to clinical condition, thus contributing to health and well-being of individuals with SCI.

Conflict of Interest

The authors declare that they have no conflicts of interest.

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