

QUALITY OF LIFE OF PERSONS WITH TRAUMATIC SPINAL CORD INJURIES*

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ABSTRACT: This descriptive quantitative study aimed to evaluate the quality of life of persons with traumatic spinal cord injuries attended in a teaching hospital in Manaus, in the Brazilian state of Amazonas, between August and October 2011. A total of 30 paraplegics with traumatic spinal cord injuries participated in the study. The World Health Organization Quality of Life-Bref questionnaire was used for measuring quality of life. This is divided into four domains: physical health, psychological health, social relationships and environment. The results showed a predominance of the male gender, aged between 31 and 45 years old, who had lived with the injury for five to eight years. Of the 30 interviewees, 20% and 36.7% assessed quality of life as 'very good' and 'good' respectively. Among the domains, the psychological, social and environmental stood out, with evaluations of quality of life as good (56.7%), average (43.3%) and average (53.3%). It is concluded that persons with spinal cord injuries perceive themselves as having a satisfactory quality of life in the sets of the psychological and social domains.

DESCRIPTORS: Quality of life; Spinal cord injuries; Personal satisfaction.

QUALIDADE DE VIDA DE PESSOAS COM LESÃO MEDULAR TRAUMÁTICA

RESUMO: Estudo descritivo, quantitativo, cujo objetivo era avaliar a qualidade de vida de pessoas com lesão medular traumática atendidas em um hospital universitário de Manaus, estado do Amazonas, entre agosto a outubro de 2011. Participaram da pesquisa 30 paraplégicos, com lesão medular traumática. Para mensurar a qualidade de vida foi utilizado o questionário *World Health Organization Quality of Life-Bref*, dividido em quatro domínios: físico, psicológico, social e meio ambiente. Os resultados mostram predominância do gênero masculino, com idade entre 31 e 45 anos, com cinco a oito anos de lesão. Dos 30 entrevistados, 20 e 36,7% avaliaram a qualidade de vida como muito boa e boa, respectivamente. Entre os domínios destacaram-se o psicológico, o social e o meio ambiente, com avaliações de qualidade de vida boa (56,7%), média (43,3%) e média (53,3%). Conclui-se que os lesados medulares se percebem com qualidade de vida satisfatória nos conjunto dos domínios psicológico e social.

DESCRIPTORIOS: Qualidade de vida; Traumatismos da medula espinal; Satisfação pessoal.

CUALIDAD DE VIDA DE PERSONAS CON LESIÓN MEDULAR TRAUMÁTICA

RESUMEN: Estudio descriptivo, cuantitativo, cuyo objetivo fue evaluar la cualidad de vida de personas con lesión medular traumática atendidas en un hospital universitario de Manaus, estado de Amazonas, entre agosto y octubre de 2011. Participaron de la investigación 30 paraplégicos, con lesión medular traumática. Para mensurar la cualidad de vida, fue utilizado el cuestionario *World Health Organization Quality of Life-Bref*, organizado en cuatro dominios: físico, psicológico, social y de medio ambiente. Los resultados muestran predominancia del género masculino, con edad entre 31 y 45 años, con cinco a ocho años de lesión. De los 30 entrevistados, 20 y 36,7% evaluaron la cualidad de vida como muy buena y buena, respectivamente. Entre los dominios se destacaron el psicológico, el social y el del medio ambiente, con evaluaciones de cualidad de vida buena (56,7%), media (43,3%) y media (53,3%). Se concluye que las personas con lesión medular se perciben con cualidad de vida satisfactoria en los conjuntos de dominios psicológico y social.

DESCRIPTORIOS: Cualidad de vida; Traumatismos de la médula espinal; Satisfacción personal.

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INTRODUCTION

A traumatic spinal cord injury is a catastrophic problem. In 2011, the worldwide rate of incidence was estimated at 179,312 new cases per year. The epidemiological data show the scale of the problem as number of cases per year (per million people): North America (40), Western Europe (16), Australia (15), Central Asia (25), South Asia (21), the Caribbean (19), Latin and Andean America (19), and Latin and Central America (24)⁽¹⁾.

Injury of the spinal cord compromises the functioning of the motor, sensory, visceral, sexual and trophic functions⁽²⁾; the causes result from urban violence, road traffic accidents and violence involving firearms⁽³⁻⁶⁾; it predominantly affects single men living in urban areas, aged between 18 and 35 years old⁽⁶⁻⁸⁾.

Cases of traumatic spinal cord injury are increasing and becoming a public health problem due to the rising number of occurrences of urban violence. In Brazil, updated or consolidated data do not exist; however, around 7000 cases of persons diagnosed with traumatic spinal cord injury are reported per year⁽⁹⁾.

The inclusion of persons with spinal cord injury in rehabilitation programs means – besides the possibility of regression of the neurological deficit – the reduction of their degree of dependency, the improvement of ability to socialise and the reduction of clinical comorbidities⁽⁵⁾, due to the fact that sequelae resulting from the trauma can interfere in peoples' quality of life⁽³⁾.

Quality of life is a multidimensional concept that addresses health, lifestyle, social functioning and health conditions, and is expressed in the way that the person perceives herself and positions herself in life in relation to the cultural context and the system of values in which she lives, and in relation to her objectives, expectations, standards and concerns⁽¹⁰⁾.

This study's objective was to assess the quality of life of persons with traumatic spinal cord injury attended in a teaching hospital in Manaus, in the Brazilian state of Amazonas (AM).

METHODS

This is a descriptive study with a quantitative approach, undertaken in August – October 2011, with 30 patients diagnosed with traumatic spinal cord injury, undergoing inpatient treatment in the Getúlio Vargas Teaching Hospital (HUGV) in

Manaus (AM). Its inclusion criteria were: people receiving inpatient treatment in the period 2000 – 2010, diagnosed with traumatic spinal cord injury, aged 18 years old or over, and whose address was stated as being in the city of Manaus, in the state of Amazonas.

The initial sample of patients with spinal cord injury was 381; for 194 of these, the complete records were found in the medical records. After triage, 45 subjects were considered eligible to participate in the study. Fifteen of these, however, declined to participate in the study when they did not sign the terms of free and informed consent. The final number of participants in the study was 30.

The instrument used for measuring quality of life was the Brazilian version⁽¹¹⁾ of the World Health Organization Quality of Life-Bref (WHOQOL-Bref) questionnaire, with 26 questions, of which 24 were distributed in four domains: physical health, psychological health, social relationships and environment. These domains are represented by facets and their questions are represented on a Likert-type scale of intensity (none-extremely), capacity (none-completely), frequency (never – always) and evaluation (very dissatisfied-very satisfied; very bad-very good). In the responses, one corresponds to negativity and five to positivity, it being the case that the lower the evaluation percentiles, the lower or inferior the levels of quality of life. Besides the four domains, the study also worked on the question relating to the perception of quality of life: "How satisfied are you with your health?", for which the responses varied between very satisfied and very dissatisfied⁽²⁾.

In order to ascertain the correlation between quality of life and the variables (age, functional independence, gender, income, the time the person has had the injury and sequelae), the Spearman correlation coefficient was used, with a level of significance of 5% ($p < 0.05$).

The data analysis was undertaken using the Statistical Package for the Social Sciences (SPSS) program, version 16.0. The statistical analyses included descriptive analyses of measurement of central tendency (mean), measurement of position (minimum and maximum value) and measurement of dispersion (standard deviation).

This article was extracted from the Master's degree dissertation entitled: "Study of the quality of life of the person with a spinal cord injury", 2011. The project was approved by the Research

RESULTS

Among the 30 subjects with traumatic spinal cord injury, there was a predominance of men (83.3%); aged between 31 and 45 years old (56.7%); who had had the spinal cord injury for five to eight years (40%), with sequelae of paraplegia (50%), with an income of up to two minimum salaries (60%) and with complete/altered dependence (53.3%). Regarding the causes of the spinal cord injury, the main one was falls (47%), followed by road traffic accidents (20%) and firearms (13%), the remaining causes totaling 20%.

Of the 30 interviewees, 20% assessed general quality of life as 'very good' (6), 36.7% as 'good' (11), and 3.3% as 'bad' (1). Of the participants, 40% stated that they had an average quality of life.

When the domains were analyzed, in the physical domain, the subjects assessed quality of life as 'bad' (30%), 'average' (30%), 'good' (30%) and 'very good' (10%). The highest means stood out in the facets of: energy and fatigue (3.6), disposition regarding pain (3.5), sleep and rest (3.3), activities of daily living (3.2) and mobility (3.1). In contrast, the facets in which the subjects presented the greatest dissatisfaction were: dependence on medication or treatment and capacity to work, with a mean of 2.9 for each facet.

In relation to the psychological domain, the subjects assessed quality of life as 'good' (56.7%), 20% assessed it as 'average', 13.3% as 'very good' and 10% as 'bad'. In general, for this domain, the participants showed averages above 3.2 in all the facets (positive feelings; personal beliefs; concentration; acceptance of bodily appearance; self-esteem and absence of negative feelings).

In the social domain, made up of the facets of personal relationships, sexual activity and social support, the subjects (43.3%) assessed quality of life as average, that is, they did not consider themselves to be satisfied but did not mention dissatisfaction. In spite of this result, it was ascertained that the highest means were found in the facets of personal relationships (3.5) and social support (3.3), and the lowest means in the facet of sex life (2.8).

In relation to the domain of the environment, related to physical safety and protection, the home environment, financial resources, the availability and quality of health and social care,

opportunities for acquiring new information and skills and opportunities for recreation and leisure, in addition to physical environment and transport, in the evaluation of the subjects, quality of life was considered as 'average' for 53.3%, while 30% evaluated it as 'bad'. In relation to the items of the domain of environment, the lowest means were observed in the variables of: financial resources (2.1); leisure activity (2.1); access to the health services (2.2) and means of transport (1.9). On the other hand, the highest means were for issues referent to opportunity for new information (3.7); physical safety (3.2); physical environment (3.2) and housing conditions (3.1).

When the subject's satisfaction was ascertained in relation to his or her health, 40% of the interviewees responded that they were neither satisfied nor dissatisfied with their health, showing a mean of 3.1 in their responses.

Of the social variables studied (age, functional independence, gender, income, time the person had had the injury and sequelae), all were significant; age is highlighted as it is considered a highly significant variable, when related to quality of life (Table 1).

Table 1 - Correlation coefficient between quality of life and the variables. Manaus, AM, Brazil, 2011

Correlation between quality of life and variables		
Age	Correlation coefficient	-0.461
	Significance	0.010
Functional independence	Correlation coefficient	0.008
	Significance	0.968
Gender	Correlation coefficient	0.047
	Significance	0.807
Income (in Minimum Salaries)	Correlation coefficient	-0.069
	Significance	0.718
Time of Injury (in years)	Correlation coefficient	-0.311
	Significance	0.094
Sequelae	Correlation coefficient	0.208
	Significance	0.269

DISCUSSION

Quality of life is a multifaceted construction which encompasses the individual's behavioral and cognitive capacities, emotional well-being, and skills which require performing domestic, professional and social roles; it is, therefore, a dynamic concept which incorporates not only the physical, psychological and social domains,

but also the individual perceptions and values⁽¹²⁾.

In this context, in relation to the subjects with traumatic spinal cord injury, the sequelae resulting from the trauma and the social difficulties can negatively influence the levels of quality of life, entailing compromising of the social and physical aspects⁽¹³⁻¹⁴⁾. The literature mentions that the person with a spinal cord injury can experience, in her day-to-day, both physical and organic problems, such as pressure ulcers, urinary infections, spasticity and deformities; conditions which can, in the majority of cases, cause difficulty or incapacity for undertaking movements, situations which are perceived negatively by this type of patient, to the extent that it affects their mental health⁽¹⁵⁻¹⁶⁾. Hence, it is inferred that these may be some of the reasons for the subjects' dissatisfaction regarding the facets of capacity to work and dependence on medication or treatments.

In relation to the psychological domain, the majority of the subjects assessed quality of life as positive, a result similar to that found in another study⁽³⁾. In general, for this domain, the participants showed themselves to be satisfied in all the facets (positive feelings; thought, learning, memory and concentration; self-esteem; appearance and body image; absence of negative feelings; spirituality, religion and personal beliefs).

In the social domain, the demonstration of satisfaction (in the facets of personal relationships and social support) was similar to a separate study on quality of life, undertaken with Chinese people diagnosed with spinal cord injury, which showed that social and professional inclusion are relevant aspects for quality of life⁽¹⁷⁾. Other studies^(15,18) have shown there to be difficulties in relation to the social domain, when they mentioned the existence of dissatisfaction with sex life, indicating, among the causes: absence of sexual relations, and sexual dysfunction, such as non-ejaculation and lack of pleasure⁽¹⁵⁾. Other studies⁽¹⁹⁻²⁰⁾ have indicated results similar to those of the present study.

In relation to the domain of the environment, the evaluation of quality of life as average corroborated the results found in a separate study on patients with spinal cord injury⁽³⁾. In this respect, it was perceived that the facets evaluated as positive were the activities which the individual can undertake at home, such as turning on the television, accessing the Internet, listening to the radio or reading a magazine. On the other hand, the facets evaluated as negative

were those whose activities occur outside the home, such as: accessing the health services, practicing leisure activities and transport. This is because these depend on other factors in order to be undertaken satisfactorily.

On the other hand, accessibility is fundamental if a person in a wheelchair, or with difficulty in getting around the city, is to travel autonomously and undertake activities related to health or to leisure. Lack of access has implications for quality of life, as it restricts opportunities which are pleasurable and important for survival. Researchers⁽¹⁵⁾ have identified some difficulties of persons with spinal cord injuries for accessing the health services, such as: transport difficulties, lack of accessibility to places, waiting lines for attendance and weaknesses in specialized attendance. Therefore, alterations in the environments are necessary in order to make them more inclusive and accessible, as in the example of access to public buildings and public transport, such that the rights of people in situations of physical and motor vulnerability may be ensured and their needs met⁽²¹⁻²²⁾.

In the evaluation of the domain of the environment, it was observed that the subjects showed themselves to be satisfied in relation to security, to the physical environment (climate, noise, pollution and environments capable of providing distractions) and to the availability of information; however, they showed themselves to be dissatisfied in relation to financial resources, opportunities for practicing leisure activities and access to health services and means of transport, given that these are situations in which the person with a spinal cord injury depends on other factors in order to be satisfactorily undertaken. Hence, the relationship with the environment is another factor which can affect the quality of life of the person with a spinal cord injury.

The present study's results evidenced that the variables of functional independence, gender, income, time the person had had the injury and injury sequelae did not present a direct relationship with the quality of life of the subjects with spinal cord injury, strengthening the concept that quality-of-life is subjective and, consequently, individual.

Perception is a mental process of the perceived world. In this perspective, of abstraction of the context experienced, to analyze a subject with a spinal cord injury who does not present functional independence, but who does not perceive this as something negative or as something which affects

his quality of life, and another subject in the same condition, but who has a negative perception of functional independence for her life, can affirm that quality-of-life is not related to the condition of functional dependence, but rather to how the environment is perceived. As a result, perception of quality of life is more related to the phases of overcoming the trauma than to the conditions of functionality, gender, income or time the person has had the injury. Through this prism, quality-of-life can be perceived in different ways and by different people in identical scenarios, at one and the same time, as it is a response which arises from human subjectivity.

The subjects' positive or negative perception of quality-of-life is related to age, given that the younger patients present better quality of life and, as a consequence, better social insertion⁽⁷⁾, a condition which is linked to the reduction of the physiological reserve, to the reduction of vitality and to the aging of the body⁽¹⁴⁾.

In comparing the level of quality of life of the persons with spinal cord injury in this study with those of other studies⁽²³⁻²⁵⁾, it was evidenced that in relation to the physical and environmental domains, the results of the present study were more negative. In the psychological domain, the results were better in relation to victims of trauma, patients with panic disorder and patients with diabetes mellitus and associated arterial hypertension. In the domain of social relationships, the result was superior for the patients with colorectal cancer, this being due to the fact that the person with a spinal cord injury experiences physical and organic problems such as: the presence of pressure ulcers, urinary infections, spasticity and deformities⁽¹⁵⁾; in addition to this, they have difficulties or incapacity for undertaking physical movements, which may be perceived negatively in relation to possible potentials or alternatives and in relation to meeting their needs and concerns⁽²⁶⁾. It is emphasized that quality-of-life among persons with spinal cord injury is related to mobility, social integration and occupation, which are significant social roles.

CONCLUSION

Persons with spinal cord injuries perceive themselves as having good quality-of-life and satisfactory health. In the evaluation of the set of the domains of physical health, psychological health, social relationships and environment, the results evidenced that the persons with spinal

cord injuries evaluated the psychological and social domains as 'satisfactory', demonstrating dissatisfaction with the environmental conditions (the domain of the environment).

The domain of the environment was presented as a barrier to full satisfaction regarding quality-of-life. In contrast, the participants defined the physical domain as neither satisfactory nor dissatisfactory. The present study's results suggest that age directly influences the quality of life of the person with a spinal cord injury.

It is concluded that although the number of interviewees is a limitation of this study, it is hoped that its results may contribute to public health policies geared towards the creation of programs which reintegrate subjects with spinal cord injuries to the social condition and work condition, allowing their social and professional independence.

Further studies are necessary to better assess how people with traumatic spinal cord injury experience the changes which take place in their lives over time.

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