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## Quality of life of primary caregivers of spinal cord injury survivors

*Qualidade de vida de cuidadores familiares de pessoas com lesão da medula espinal*

*Calidad de vida de cuidadores familiares de personas con lesión de medula espinal*

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### ABSTRACT

The aim of this study was to analyze quality of life of caregivers who are relatives of patients with spine cord injury (SCI). Fourteen women (seven caregivers and seven controls) were evaluated by the Medical Outcomes Study 36 - Item Short-Form Health Survey (SF-36) and the Caregiver Burden Scale (CBS) Questionnaires. The data from both questionnaires were compared using the Mann-Whitney U testing procedure for differences between caregivers and controls ( $p < 0.05$ ). The results from SF-36 were not statistically significant between groups, however, for the CBS data, there were significant differences between groups ( $p > 0.05$ ), characterized by the percentage difference of 62%, 66.7%, 55%, 50%, 57% and 63% for tension, isolation, disappointment, emotional involvement, environment and overall score, respectively. The CBS questionnaire was more adequate for verifying quality of life of caregivers of SCI patients, and caregiving may have a negative impact on their quality of life.

**Key words:** Spinal Cord Injuries; Caregivers; Quality of Life.

### RESUMO

Este estudo objetivou avaliar a qualidade de vida de cuidadores familiares de pacientes com Lesão da medula espinal (LM). Quatorze mulheres (sete cuidadoras familiares e sete controles) foram submetidas à avaliação pelo questionário Medical Outcomes Study 36 – Item Short-Form Health Survey (SF-36) e pelo questionário Caregiver Burden Scale (CBS). Utilizou-se o Teste de Mann-Whitney ( $p < 0,05$ ) para comparação entre os grupos acerca dos escores obtidos para os dois questionários. Para o primeiro questionário (SF-36) não houve diferença significativa entre os grupos, porém para o segundo questionário (CBS) os resultados apresentaram diferença estatisticamente significativa ( $p > 0,05$ ), caracterizada pela diferença percentual de 62%, 66,7%, 55%, 50%, 57% e 63%, para tensão geral, isolamento, decepção, envolvimento emocional, ambiente e escore global, respectivamente. O questionário CBS mostrou-se adequado para verificar a qualidade de vida dos cuidadores de pessoas com LM e o ato de cuidar produz um impacto negativo sobre a qualidade de vida destes.

**Descritores:** Traumatismos da Medula Espinal; Cuidadores; Qualidade de Vida.

### RESUMEN

Este estudio objetivó evaluar la calidad de vida de los cuidadores familiares de pacientes con Lesión de Médula Espinal (LM). Catorce mujeres (siete cuidadores familiares y 7 controles) se sometieron a la evaluación del cuestionario SF-36 y el cuestionario CBS. Para la comparación entre los grupos acerca de los cuestionarios se utilizó el test de Mann-whitney ( $p < 0,05$ ). Para el SF-36 no hubo diferencia significativa entre los grupos, pero para el CBS los resultados fueron estadísticamente significativos ( $p > 0,05$ ), por la diferencia de porcentaje del 62 %, 66,7 %, 55 %, 50 %, 57 % y 63 %, para una tensión general, aislamiento, decepción, implicación emocional, el medio ambiente y puntuación global, respectivamente. El cuestionario CBS ha demostrado ser apropiado para comprobar la calidad de vida de los cuidadores de personas con LM y el ato de cuidar produce un impacto negativo sobre la calidad de vida de estos.

**Palabras clave:** Lesiones de la Médula Espinal; Cuidadores; Calidad de Vida.

## INTRODUCTION

According to the American Spinal Injury Association<sup>(1)</sup>, spinal cord injury (SCI) is a reduction or loss of motor and/or sensory and/or autonomic function below the level of injury due to trauma of neuronal elements of the spinal canal. It may be partial or total, which in turn can lead to complications and changes in respiratory, thermal, circulatory and neuromotor function, spasticity and pain<sup>(2)</sup>.

In this sense, people with SCI need assistance from others to perform daily living, leisure and professional activities, usually provided by relatives or caregivers, who become responsible for providing a broad and complex range of services and tasks, to assist recovery, promote independence and improve quality of life of these people<sup>(3)</sup>.

The attention, support for activities of daily living, assistance with functional difficulties in self-care (personal hygiene, eating, ambulation) and emotional support<sup>(3-4)</sup>, may reflect on the quality of life of caregivers, since the higher the difficulty and burden experienced by the caregiver, the greater the physical, emotional and social impact<sup>(2,4-7)</sup>.

Qualitative studies have discussed the experiences of caregivers of persons with disabilities<sup>(2-3,7-9)</sup>. There is a strong correlation between depression in caregivers and the level of assistance and the amount of hours per day devoted to the care of these people<sup>(7)</sup>; it has been also reported high levels of physical and emotional stress, exhaustion, fatigue, anger, resentment and depression, interfering directly in their quality of life<sup>(10)</sup>.

However, investigations to date have limitations on the methodological aspects, few had control groups, and application of general questionnaires on quality of life, such as the Medical Outcomes Study 36 - Item Short-Form Health Survey (SF-36)<sup>(11)</sup>, which often cannot measure with depth the effects and consequences that caring can have on the life of family caregivers of people with SCI.

The Caregiver Burden Scale (CBS)<sup>(12)</sup> is an instrument used to specifically measure the subjective impact of chronic diseases in the lives of caregivers. The questionnaire consists of 22 questions, grouped into five areas: general strain, isolation, disappointment, emotional involvement and environment, therefore covering important areas for caregivers, including health, mental well-being, personal relationships, physical overload, social support, finance and environment. Each question has four types of responses (in any way, rarely, sometimes or often), with scores ranging from one to four. The score of each dimension is calculated using the arithmetic mean of each item comprising the dimension, to then obtain the overall score, by calculating the arithmetic mean of the scores assigned to the 22 items. The value of the overall score can range from one to four, and the higher the score, the greater impact of the disease on the caregiver's life<sup>(10)</sup>. In Brazil, the CBS has been translated and validated for caregivers of rheumatic patients and showed applicability and reliability and was also applied to a population of caregivers of SCI patients in São Paulo<sup>(12-13)</sup>.

The aim of this study was to evaluate the quality of life of family caregivers of patients with SCI, through a general questionnaire (SF-36) and another questionnaire specific for caregivers (CBS).

## MATERIALS AND METHODS

It was executed a cross-sectional series of cases and controls, where the sample consisted of family caregivers, having as initial inclusion criteria: age greater than or equal to 18 years and to be caregivers of people with SCI for at least a year, and control participants with similar age and gender to the caregivers, who did not perform any caring activity for people with disability. Participants who sought medical attention for any reason, in the last three months, who suffered of chronic or severe disorders such as chronic injuries, orthopedic and rheumatic disorders, severe or chronic cardiorespiratory disease since before or after the onset of the caregiving activity, or showing any cognitive deficit were excluded from the study. Participants were selected from the list of family caregivers of SCI patients treated at the Adult Neurofunctional Physical Therapy Clinic, University Hospital of Londrina State University, and the controls living in the city of Londrina.

The study began after approval by the Ethics Committee of the University Hospital of Londrina State University, according to the norms of the Resolution 196/96 of the National Health Council on research involving humans, protocol No. 049/10.

Thus, seven family caregivers met the criteria for inclusion, forming the case group, and the control group consisted of seven healthy subjects, non-caregivers, matched by sex and age. After receiving information about the study purpose and the procedures they would be submitted, all participants signed a consent form.

Data collection was conducted through interviews at the Adult Neurofunctional Physical Therapy Clinic, University Hospital of Londrina State University, between August and October of 2010, and the interviews were scheduled according to the possibilities of the participants.

The assessment of quality of life was made with an initial application of the SF-36 questionnaire<sup>(11)</sup>, through personal interview, followed by the CBS questionnaire<sup>(12)</sup>.

The variables were summarized by the median and interquartile range, with the exception of the general characteristics of the groups, which were expressed as mean and standard deviation.

To verify possible differences between the groups on scores produced by both questionnaires, the Mann-Whitney test was applied. To compare information on the general characteristics of the groups, the Student's *t* test for independent samples was used. For data processing, we used SPSS version 13.0, adopting a significance level of  $P < 0.05$ .

## RESULTS

Participants were seven women family caregivers, four wives and three mothers, and seven women completed the control group. The general characteristics of the groups are shown in Table 1. There was no difference between groups for age, since the control subjects were selected based on similarity to gender and age.

**Table 1** - General characteristics of the caregivers (n = 7) and control (n = 7) groups.

Variables	Caregivers Group (N = 7)	Control Group (N = 7)	p
Age (years)	51.29 ± 4.21	51.29 ± 4.21	1.0
Total time as a caregiver (years)	7:43 ± 3:02	0	0.03
Time spent as a caregiver daily (hours)	18:29 ± 3.71	0	0.003

\*  $P < 0.05$ .

Table 2 shows the results of the comparison between the groups on the scores obtained by the SF-36 questionnaire<sup>(11)</sup>. There was no significant difference between the groups ( $p > 0.05$ ).

**Table 2** - Comparison between caregivers (n = 7) and control group (n = 7) for the scores of the SF-36 questionnaire.

SF-36 Domains	Caregivers Group (N = 7)	Control Group (N = 7)	p
Functional capacity	75 (70-90)	95 (75-95)	0.13
Physical Appearance	75 (50-100)	100 (75-100)	0.14
Pain	41 (22-51)	34 (22-61)	0.89
Overall health	52 (32-92)	87 (75-92)	0.40
Vitality	50 (35-55)	50 (45-60)	0.69
Social aspect	50 (25-100)	87.5 (75-87.5)	0.32
Emotional aspect	66.7 (0-100)	100 (33.33-100)	0.35
Mental health	52 (40-60)	56 (52-60)	0.56

\*  $P < 0.05$ .

Table 3, in turn, presents the results of both groups on the CBS questionnaire<sup>(12)</sup>. There were statistically significant differences for all domains ( $p < 0.05$ ).

**Table 3** - Comparison between caregivers (n = 7) and control group (n = 7) for the scores of the CBS questionnaire.

CBS domains	Caregivers Group (N = 7)	Control Group (N = 7)	p
General strain	2.62 (1.87-3.37)	1 (1.1)	0.001
Isolation	3 (2-3.33)	1 (1.1)	0.003
Disappointment	2.20 (2.20-3)	1 (1.1)	0.001
Emotional involvement	2 (1-2.33)	1 (1.1)	0.009
Environment	2.33 (2-2.66)	1 (1.1)	0.001
Overall score	2.72 (1.95-2.86)	1 (1.1)	0.001

\*  $P < 0.05$ .

## DISCUSSION

According to the results on general characteristics, it was found that, although we did not stipulate the female gender as one of the initial inclusion criteria for participation in the study, all participants in the caregivers group were women, which corroborates the information in the literature that suggests women with the social role of caregiver<sup>(8,14-18)</sup>. Another important aspect concerns the degree of kinship, since that in the present study, of the seven caregivers, four were wives and three were mothers of patients with SCI. These data agrees with the information that the role of caregiver is usually assigned to women<sup>(8)</sup>, what is seen as something natural, since, socially, a woman, in her role as mother or wife, assumes these tasks as one more function relevant to the domestic sphere<sup>(19)</sup>.

When analyzing the literature for information about the gender of people with SCI, it seems that most individuals are male<sup>(20-24)</sup>, which is aligned with the characteristics of the individuals in this study.

With respect to the total time as a caregiver and time (in hours per day) spent in the care of patients, statistically significant differences between groups were found, which was expected, since women without caring activity for people with disabilities were selected for the control group, so we could check the impact of this activity in family caregivers.

Regarding the SF-36 questionnaire<sup>(11)</sup>, there was no statistically significant difference between caregivers and control group for any of the areas included in the questionnaire. This suggests that this questionnaire might not be an adequate tool to identify possible differences between caregivers of patients with SCI and their respective controls.

It is noteworthy that the number of seven women may be a small representation of this population, and also the fact that they have been caregivers for years and are not at the early stage of SCI when the difficulties are greater<sup>(25-26)</sup>, may have influenced the results. Unlike the results of this study, Ünalán et al.<sup>(4)</sup> when comparing the quality of life of 50 caregivers of people with SCI (with time of injury ranging from 0 to 49 months) to 40 healthy people (control group), by applying the SF-36 questionnaire<sup>(11)</sup>, caregivers had lower scores in their domains, which was statistically significant in all but the pain domain.

Another study<sup>(16)</sup> that analyzed the quality of life of nine informal caregivers of patients with neurological sequelae (stroke and SCI), using the SF-36 questionnaire<sup>(11)</sup> and comparing the scores with the results of the control group (n = 11), found higher values for the scores of all domains of the SF-36<sup>(11)</sup> for the control group ( $p < 0.05$ ) except for the general state of health domain.

Conversely, the CBS questionnaire<sup>(12)</sup> provided very interesting information in this study, since, when scores on this questionnaire were compared, all domain values for the caregivers group were higher when compared to the control group ( $p < 0.05$ ), which in percentage terms would be 62%, 66.7%, 55%, 50%, 57% and 63% for general strain, isolation, disappointment, emotional involvement, environment and the overall score, respectively, which indicates that SCI may have a negative impact on the quality of life of family caregivers.

In a study of 60 female caregivers, authors<sup>(13)</sup> also used the SF-36<sup>(11)</sup> and CBS<sup>(12)</sup> and found that, regarding the domains of the SF-36<sup>(11)</sup>, results showed a greater impact on the physical component than on the mental component, pain and vitality were the most affected and for the CBS questionnaire<sup>(12)</sup>, the environment domain showed the highest score, followed by the disappointment domain. However, because this study did not use a control group, it was not possible to quantify differences in percentage terms, which makes inferences about the larger impact of the act of providing assistance in the lives of caregivers difficult.

In the present investigation we verified that the family caregivers provided assistance for a period ranging from two to 24 hours a day, for a total time of one to 19 years, which agrees with the information pointed out by authors<sup>(8)</sup> that reported that the time (in hours per day) directed to the care of patients dependent on others usually ranges from 3 to 24 h.

The significant difference in the strain domain might be due to experiencing the new responsibility of caring for a person who is dependent not only on the physical aspect, but also on the emotional one, which corroborates the information of authors<sup>(9)</sup> that showed that the most common reports of caregivers relate to the fear of not providing adequate care. In addition, these caregivers cope with feelings of powerlessness in the face of a distressing future and feelings of incompetence for the specific and stressful tasks of care<sup>(27)</sup>.

In the same study<sup>(9)</sup> it was showed that the profile of the possible physical complications resulting from SCI outlines another profile of equivalent problems depicted by social isolation and alienation because of embarrassment, rejection and self-degradation. However, this isolation affects the person with SCI and their families, which is confirmed by data from this study, since the isolation domain also showed significant difference.

As a result, the family caregiver, when undertaking the arduous task of caring for a person with physical dependence, abdicates the activities which are generally performed in their daily life (leisure, professional), moving away from contact with other people.

Caring for someone with SCI at home is a complex task because, besides taking into account the characteristics of the inability of the person being cared for, the care often requires the use of resources to support the work of the caregiver<sup>(25)</sup>. Furthermore, studies show that SCI is a major public health problem, and this is due to the difficulty and complexity of caring for these people at home thus requiring new hospitalizations<sup>(27-29)</sup>.

In this sense, on the environment domain, it is important to discuss the matter of wheelchair accessibility in the bathroom, which is necessary for the person with SCI to be able to perform activities of personal hygiene and movement. For this, the transfers require physical effort, and that overloads the caregivers, which could lead to a deterioration in their quality of life.

Thus, the level of difficulty and complexity of home care for a physically disabled person will generally be related to their degree of incapacity for self-care and/or activities of daily living, coupled with the availability of material resources to perform such task<sup>(25,30)</sup>.

## CONCLUSION

The results of this study showed that the CBS questionnaire was more appropriate for evaluating the quality of life of family caregivers of people with SCI and suggest that caring for a person with neuromotor disabilities can have a negative impact on the quality of life of family caregivers.

Consideration should be given to the fact that due to the number of study participants, errors type I and II may be present, which suggests the continuation of the study or other controlled studies with a more appropriate number of participants and follow up to validate the results, since the greatest difficulties are encountered in the initial phase of spinal cord injury.

Through the results, we conclude that family caregivers of people with SCI have a significant reduction in the quality of life compared to the control group, justifying the need to monitor not only the person with SCI, but also of their caregivers, in order to meet their needs and minimize potential losses in their welfare.

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