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Caregivers of individuals with spinal cord injury: caregiver burden*

CUIDADORES DE INDIVÍDUOS COM LESÃO MEDULAR: SOBRECARGA DO CUIDADO

CUIDADORES DE INDIVIDUOS CON LESIÓN MEDULAR: SOBRECARGA DEL CUIDADO

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ABSTRACT

A sectional study that had as its objectives to assess caregiver burden of for caregivers of individuals with Traumatic Spinal Cord Injury (TSCI) and its association with sociodemographic variables (age and sex), health status (self-reported illnesses) and caregiver characteristics (care time in years and daily hours of care). Data were collected by consultation of patient files and individual interviews at home using the instrument, Caregiver Burden Scale (CBScale). The results showed that most burden occurred in the domains: environment, disappointment and general strain. Presenting health problem (for all domains of the CBScale) and spending more hours per day in care (in the domain disappointment) represented the variables associated with burden. Studies of a more confirmatory nature than exploratory between the variables studied can be used to measure the burden obtained in this population of caregivers of individuals with TSCI.

DESCRIPTORS

Caregivers
Spinal cord injuries
Activities of daily living

RESUMO

Estudo seccional que teve como objetivos avaliar a sobrecarga do cuidado para cuidadores de indivíduos com Lesão Traumática da Medula Espinhal (LTME) e a sua associação com as variáveis sociodemográficas (sexo e idade), estado de saúde (enfermidades autorrelatadas) e características do cuidado (tempo de cuidado em anos e horas diárias de cuidado). Os dados foram coletados por consulta aos prontuários e entrevistas individuais no domicílio utilizando o instrumento Caregiver Burden Scale (CBScale). Os resultados apontaram que a maior sobrecarga ocorreu nos domínios: ambiente, decepção e tensão geral. Apresentar problema de saúde (para todos os domínios do CBScale) e despender mais horas por dia nos cuidados (no domínio decepção) representaram as variáveis associadas à sobrecarga. Estudos de natureza mais confirmatória do que exploratória entre as variáveis estudadas poderão utilizar a medida de sobrecarga obtida nesta população de cuidadores de indivíduos com LTME.

DESCRITORES

Cuidadores
Traumatismos da medula espinal
Atividades cotidianas

RESUMEN

Estudio transversal que tuvo como objetivo evaluar la carga del cuidado de los cuidadores de las personas con Lesión Traumática de Médula Espinal (LTME) y su asociación con variables sociodemográficas (edad y sexo), estado de salud (auto-reporte de enfermedades) y características de la atención (tiempo de atención en los últimos años y las horas de atención). Los datos fueron recogidos por los registros hospitalarios y entrevistas en el hogar utilizando el instrumento Caregiver Burden Scale (CBScale). Los resultados mostraron que la mayor sobrecarga ocurrido en áreas: ambiente, decepción y tensión general. Problema de salud actual (para todas las áreas de CBScale) y pasar más horas por día en la atención (en el campo decepción) representaran las variables asociadas con a sobrecarga. Estudios de una confirmación, más que exploratorio entre variables se pueden utilizar para medir la sobrecarga obtenido en esta población de los cuidadores de los individuos con LTME.

DESCRIPTORES

Cuidadores
Traumatismos de la médula espinal
Actividades cotidianas

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INTRODUCTION

Traumatic spinal cord injury (TSCI) does not exclusively compromise the life of the individual after the incident. Considering the decrease in functional independence and the social and psychological impact on the individual's life after injury(1), his immediate family suffers consequences that require restructuring to meet the needs arising from the health conditions.

While the entire family is affected by the occurrence, it is one of its members, known as the family caregiver, who assumes responsibility for the care of the individual and his needs. In this way, the caregiver divides her/his time and attention between the new demands with the family member who suffered the TSCI and her/his own activities and professional, family, social and marital roles, and may consequently become overwhelmed(2).

The literature provides definitions for the caregiver, distinguishing the primary or informal caregiver, and the secondary or formal caregiver(2). The primary or informal caregiver is the family member who assumes primary responsibility for care. Generally they have no training in health, learning and performing care and attention for another person without necessarily counting on technical and / or emotional preparation(2-3). The secondary or formal caregiver is a person contracted by the family, with preparation compatible with the function, who provides sporadic care(2-3).

Primary caregivers are, for the most part, married women who live with another person and perform other activities in addition to this care. The term *family caregiver* is used more than *informal caregiver*, since the family caregiver is a family member or relative who takes care of a family member, with complicity and commitment in this regard(2).

Caregiver burden is defined as a perception that the individual has in relation to his/her physical health, social life, emotion and status, as a result of caring for a family member, resulting in the concept of burden as the product of a specific, subjective and interpretive process of chronic disease.

Throughout the process, the impact of the activities exercised by the family caregiver can create problems of a biopsychosocial and spiritual nature that influence her life and the quality of care provided(3-4).

After the TSCI, depending on the neurological level, the individual becomes dependent on the caregiver to perform various activities of daily living (ADL), especially in the first year after injury. Studies show that, in carrying out their role, family caregivers go through various situations that can result in caregiver burden(3-4).

Caregiver burden is defined as a perception that the individual has in relation to his/her physical health, social life, emotion and status, as a result of caring for a family member, resulting in the concept of burden as the product of a specific, subjective and interpretive process of chronic disease. It can be seen as a multidimensional concept that encompasses the biopsychosocial sphere and results in the search for a balance between the variables: time available for care, financial resources, and psychological, physical and social conditions, responsibilities, and, distribution of roles(5).

One of the instruments used by researchers in order to measure caregiver burden is the Caregiver Burden Scale (CBScale). This scale was used to assess the burden of caregivers of patients with cerebral vascular accident(6). In Brazil, it was validated with caregivers of patients with rheumatoid arthritis, showing good levels of reliability and validity(3).

The new caregiver activities demand changes in their lifestyle, which can compromise their health, social linkages and economic status. For the exercise of such activities, the caregiver needs to be prepared from the first hospitalization of individuals with TSCI to give continuity of care in the home and minimize the effects of caregiver burden.

The promotion of caregiver well-being and the prevention of burden deserve special attention by health professionals because individuals with TSCI, who are under their responsibility, depend on them to remain in society. The planning, implementation and evaluation of educational interventions for home care caregivers regarding appropriate ways to perform care, guidance on caregiver body posture, and adaptations and accessibility of the environment in which they reside fall under the nurse's responsibility.

For the preparation of the home caregiver it also becomes necessary to offer training courses delivered by skilled health personnel with experience to meet the needs of the dyad, through a systematic process of monitoring and evaluation(7).

An online course for training caregivers of people with disabilities, developed by the Faculty of Medicine of the *Universidade de São Paulo*, with the support of the Secretary of the Rights of Persons with Disabilities, stands out currently in Brazil. It offers a global and human vision of the aspects that involve the daily life of the individual and his caregiver, whether primary or secondary(8). During the period of conducting this study, there were no courses targeted at caregivers, and they reported difficulties related to the lack of guidelines for care of individuals with TSCI at home.

Across the country there are also Independent Living Centers, nonprofit entities formed by teams to provide services and volunteers, with the objective of promoting conditions for independent, productive and quality living, for persons with disabilities, by means of information, support and referrals(9).

In order to contribute to better comprehension and advancement of knowledge about the subject, this study was conducted with the following objectives: to assess caregiver burden of the caregivers of individuals with TSCI and its association with sociodemographic variables (age and sex), health status (self-reported disease) and caregiver characteristics (time of care and hours of care daily).

METHOD

A sectional study conducted with caregivers of individuals with TSCI. For identification of caregivers, patients with TSCI were first located, by reviewing the records of health institutions credentialed by the Unified Health System (SUS) in Ribeirão Preto or within the region (*Departamento Regional de Saúde de Ribeirão Preto* – DRS XIII).

The criteria for selection of potential participants were: suffered the trauma during the period of December 1998 to December 2008, age of 18 years or older at the time of data collection; and, treated in health facilities credentialed by the SUS. Of the 70 individuals identified, 11 reported not having a caregiver to be contacted by the researcher, resulting in a final sample of 59 caregivers. For the selection of caregivers, the proposed inclusion criteria were: family member of the patient, and indicated by the patient as his primary caregiver.

Caregivers were interviewed in their homes. Data were collected about the sociodemographic and clinical characteristics of the patient with TSCI; sociodemographic characteristics and health status (self-reported diseases) of the caregiver and characteristics of care provided (time of performing the caregiver role and number of hours per day spent in the care of the family member with TSCI).

To analyze the perceived caregiver burden, the version of the CBScale instrument(7) adapted for Brazil(3) was used, composed of 22 questions divided into five domains: general strain, isolation, disappointment, emotional involvement and environment. For each question, responses could be attributed from 1 to 4, with 1 = in no way; 2 = rarely 3 = sometimes, and 4 = frequently. The higher the value, the greater the impact/caregiver burden. A global score can be obtained for caregiver burden, or an individual score for each domain. The overall score is obtained by calculating the arithmetic mean of the 22 items, and the score for each domain is obtained through the arithmetic average of the values of each item comprising that domain.

Data analysis was performed by means of exploratory and inferential statistical analysis using the SPSS software (*Statistical Package for the Social Science*), version 15.0.

For caregiver burden, descriptive measures such as mean, median, standard deviation, minimum and maximum values were used, as well as the Cronbach's α coefficient (internal consistency). In the analysis of caregiver burden according to sex and the presence of self-reported diseases (yes/no) the student t-test was used; or the Mann-Whitney rank test was used when the prerequisites for the t-test were not met (normality for small groups, n<30 subjects). The Pearson correlation or a similar non-parametric test in the bivariate analyses was employed to analyze the correlations between measures of burden and the variables, age of caregivers, time providing care, and daily hours spent in care. For the interpretation of the strengths of correlations (*r-values*), we used the classification proposed by Ajzen and Fishbein(10), which considers values up to 0.30 a weak correlation and of little clinical applicability, even when statistically significant; between 0.30 and 0.50, of a moderate magnitude, and values above 0.50 of a strong magnitude. The significance level adopted was 5%.

This study received approval of the Committee on Ethics in Research (process nº 3034/2009). Data were collected after the study was clarified, and consent was obtained from the participants through their signature on the Terms of Free and Informed Consent.

RESULTS

Of the 59 caregivers, 53 (89.8%) were female, with a mean age of 44.8 years (SD=14.7), 44 (74.6%) lived with a partner and 38 (64.4%) had a low level of education. Twenty-three (39%) left their labor activity to take care of the individual with TSCI at home. Of the self-reported diseases, 18 (30.5%) cases of arterial hypertension and six (10%) cases of depression were noted. Regarding the relationship to the individual with TSCI, 22 (37.3%) caregivers were their spouses, 14 (23.7%) were their mothers, and nine (15.3%) were their sisters.

Of the 59 indivíduals with TSCI, 52 (88.2%) were male, with a mean age of 37 years (SD=10.6). The primary causes of trauma were motor vehicle accidents (22; 37.3%) and injury by firearms (17; 22%); 43 (72.8%) were paraplegic and 16 (27.2%) were quadriplegics. Table 1 presents the descriptive statistics of the scores of the CBScale and the internal consistency (Cronbach's α coefficient).

The highest means of the scale were for the environment, disappointment and general strain domains. The value of the Cronbach's α coefficient was lower for the environment domain and higher for the general strain and emotional involvement domains.

In Tables 2, 3 and 4, correlations and comparisons of caregiver burden with some qualitative and quantitative variables of the caregiver of the individual with TSCI are presented.

In relation to the age of the caregiver, the correlations were positive, that is, the older the caregiver, the greater the caregiver burden; however the correlations were of weak magnitude, without statistical significance. The time spent for care was not statistically significant, and correlations were weak in all domains. The correlations were also positive in relation to hours spent per day on care, (the more hours spent on care, the more burden), although weak. There was statistical significance in the disappointment domain, but the correlation was weak. Time ranged from 30 minutes/day up to the whole day in cases of more recent paraplegia or quadriplegia, demonstrating exclusive dedication of the caregiver.

Table 1 – Measures of position, variability and internal consistency of the domains of the Caregiver Burden Scale (CBScale) applied with the caregivers of patients with TSCI - Ribeirão Preto, 2010

CBScale	χ[a]	DP[b]	Median	Minimum	Maximum	α[c]
Total burden	1.87	0.67	1.68	1.00	3.59	0.92
Domains						
General strain	1.93	0.81	1.75	1.00	3.75	0.88
Isolation	1.64	0.79	1.33	1.00	4.00	0.70
Disappointment	1.94	0.79	1.80	1.00	3.60	0.77
Emotional involvement	1.59	0.84	1.00	1.00	4.00	0.87
Environment	2.14	0.81	2.00	1.00	4.00	0.35

[a] Mean; [b] Standard deviation; [c]Cronbach's α coefficient

Table 2 – Correlation between the measures of caregiver burden and the age of the caregiver, time of care, and hours per day spent providing care - Ribeirão Preto, 2010

CBScale	Age	How long providing care	Hours spent per day providing care
	r	r	r
Total Burden	0.16	-0.03	0.20
Domains			
General strain	0.14	-0.07	0.20
Isolation	0.13	-0.01	0.18
Disappointment	0.18	0.01	0.26*
Emotional involvement	0.11	0.08	0.06
Environment	0.05	-0.13	0.04

*p≤0,05; r=Pearson Correlation.

Table 3 – Comparison of the measures of position and variability of caregiver burden, considering the sex of the caregiver- Ribeirão Preto, 2010

CBScale	Sex of Caregiver				
	Female (n=53)		Male (n=6)		*p
	χ (DP)	Median	χ (DP)	Median	
Total burden	1.89(0.69)	1.68	1.69(0.47)	1.75	0.67
Domains					
General strain	1.64 (0.48)	1.69	1.96 (0.84)	1.75	0.60
Isolation	1.66(0.82)	1.33	1.44(0.40)	1.50	0.84
Disappointment	1.95(0.79)	1.80	1.80(0.73)	1.80	0.74
Emotional involvement	1.61(0.84)	1.33	1.38(0.80)	1.00	0.42
Environment	2.13(0.82)	2.00	2.16(0.69)	2.16	0.82

*Mann-Whitney test

Table 4 – Comparison of the measures of position and variability of caregiver burden, considering the self-reported illnesses of the caregiver - Ribeirão Preto, 2010

CBScale	Self-reported Illnesses				
	NO (n=30)		YES (n=29)		p*
	χ (DP)	Median	χ (DP)	Median	
Total burden	1.57(0.48)	1.52	2.18(0.71)	2.09	<0.001
Domains					
General tension	1.66(0.67)	1.56	2.10(0.87)	2.25	0.01
Isolation	1.33(0.40)	1.33	1.96(0.95)	2.00	<0.001
Disappointment	1.56(0.56)	1.60	2.32(0.79)	2.20	<0.001
Emotional involvement	1.34(0.47)	1.16	1.85(1.04)	1.00	0.02
Environment	1.84(0.75)	1.66	2.44(0.75)	2.66	<0.001

*Student t-test.

The medians of the domains of caregiver burden were higher among the male caregivers, except for the domain of emotional involvement. However, there was no statistical significance for any of the domains when using the Mann-Whitney test.

Caregiver burden was greater when the caregiver reported having some health problem. For all domains on the CBScale and for the total burden score, the difference was statistically significant (p≤0.05).

DISCUSSION

The sociodemographic profile of the caregivers corroborated other studies with caregivers of individuals with TSCI.

The predominance of female caregivers refers to gender, because care for the disabled person is usually assigned to women as a result of their traditional role as caretakers for the home and family(2,4,11).

With regard to the sociodemographic characteristics of individuals with TSCI, these were highlighted by other studies reporting that the population most affected by TSCI is that of young adults, aged 18 to 35 years, and overwhelmingly of the male gender(1,11-13).

In relation to the causes that led to the injury, we observed a higher frequency of motor vehicle accidents, followed by injury with a firearm. These results, as well as other studies, confirm that urban violence, traffic accidents and work have contributed to the high rate of people with physical disabilities in Brazil, especially in cities of medium and large size(11-13).

Faced with the new attributions and responsibilities inherent in the care of the individual with TSCI in the home, the caregiver presents demands relating to material resources, equipment and an adapted environment that fosters and promotes the care of the health needs for the affected family member.

The National Policy for the Integration of Persons with Disabilities provides principles, directives, objectives and instruments that deal with governmental action and the responsibilities of each sector and they determine full access to the resources for health, education, habilitation and vocational rehabilitation, work, culture, tourism and leisure. Despite the advances in the sphere of the legislative force, such initiatives are not in fact ensuring that individuals with disabilities are protected. Other elements that interfere with the allocation of public resources for health care, the role of the market economy and the insufficiency of the State budget, can interfere and need to be analyzed(14).

In November of 2011, the federal government established the National Plan on the Rights of Persons with Disabilities - Living without Limit, for the purpose of *promoting, through the means of integration and articulation of policies, programs and actions, the full and equal enjoyment of the rights of people with disabilities*. Article 3 of the Directives, section VI, states: *expansion and qualification of the network of health care for the disabled person, in particular the services of habilitation and rehabilitation*(15).

In this study, during the interviews, many individuals with TSCI and their caregivers complained about the difficulty in acquiring necessary resources for assistance in the home, as well as the lack of guidance and referrals to specialized rehabilitation services. It was evident that few municipalities belonging to the region of the DRS-XVIII offered resources that the individual needed, such as, for example, wheelchairs, uretheral catheter for bladder catheterization, dressing materials for pressure ulcers, among others.

Due to the high level of functional impairment, the care needs of individuals with TSCI are many. Depending on the neurological level of injury, these individuals need assistance for the total or partial performance of ADLs, such as dressing, putting on shoes, bathing, and eating. The higher the neurological level of spinal cord injury, as in the case of quadriplegic patients, the greater the time spent in care(1,11,16), because individuals with TSCI, especially quadriplegics, are dependent on long-term care and the lack of, or failure in, the planning of care can lead to caregiver burden.

In this study, family caregivers of quadriplegic or paraplegic individuals with a short period of time since the TSCI reported spending considerable amounts of time on care activities, both throughout the day, for the performance of ADLs, and during the night, with activities such as repositioning, intermittent bladder catheterization, among others. It was also found that the caregivers providing care to patients from the initial moment of TSCI, accompanied them during hospitalization and after discharge care at home. For paraplegic individuals with more time since the injury and greater functional independence, caregivers reported spending fewer hours of care per day.

In a qualitative study conducted in the southern and southeastern regions of Brazil, through semi-structured interviews with individuals with spinal cord injury and their parental caregivers, the authors noted that the presence of the family caregiver was essential for the aid in ADL and in self care of those with high spinal cord injury. The feeling of fear of losing their parents or caregivers or that they will become sick and would be unable to care for or meet their needs was a concern displayed by all quadriplegic individuals interviewed, who reported having hopes to achieve some functional gain to acquire more independence and not rely so much on the caregivers to supply their needs(16).

The results concerning caregiver burden were similar to a study conducted in the city of São Paulo with paraplegic patients and their caregivers, in which caregiver burden, assessed by means of the instrument CBScale, showed higher values in relation to the domains of environment (x=2.44), disappointment (x=1.74), and general strain (x=1.59)(11).

The questions on the CBScale instrument that most contributed to the *environment* domain obtaining a higher mean were: *does the home environment make it difficult for you to care for your relative?* and *is there something in the neighborhood where your relative lives, for example, difficulty in getting transport, difficult access to the pharmacy and/or medical services, problem with the neighbors - which hinders you in caring for him?*

This fact can be explained by the mobility deficit of the individual and the need to use a wheelchair and/or bathing, which often makes movement at home difficult, as there is a need for adjustments and readaptations, such as door width, physical space of the house, presence of ramps, which can not always be done immediately. Environmental factors can act as barriers or facilitators for performing ADLs and the social inclusion of the individuals with TSCI.

The Brazilian Standard for Accessibility NBR9050 ABNT (Brazilian Association of Technical Standards), of 2004, provided for the conditions of accessibility in the urban environment. It established criteria and technical parameters to be observed for construction, installation and adaptation of buildings, furniture, urban spaces and equipment to the conditions of accessibility (inclusion), indicating specifications that aimed to provide the safe use of the environment or equipment for the largest possible quantity of persons, regardless of age, height or mobility limitation(17). However, in many municipalities there is a lack or insufficient numbers of adapted public transport, and lack of adequate sidewalks with ramps for access.

A study conducted in Londrina, PR, evaluated the wheelchair user access to the physical space of movement and sports training at the Center for Physical Education and Sport in a state university. The researchers measured 32 points using measuring tape metrics, and recorded digital images. Of the 32 points assessed, 21 (65.6%) were not in accordance with the accessibility standards of NBR9050, and only 11 (34.4%) were adequate(18).

Another study conducted with individuals with spinal cord injury and their families in Maringa, PR, identified that one of the difficulties encountered by individuals was the lack of physical structure of the city, which included lack of transportation, employment, physical activity and also prejudice. The difficulties referred to the inadequate structure of health services, which included everything from transport difficulties to deficiencies in physical infrastructure, lack of ramps, waiting lines and shortages of care by specialized professionals(19).

In a study conducted in Ribeirão Preto, the obstacles faced by individuals with TSCI and their caregivers on returning home after hospital discharge were related to the architectural structure of the residence, mobility difficulties due to the size of the wheelchair, and also to the fact that the houses were not constructed to harbor a disabled person. Architectural barriers did not allow free access of individuals with TSCI to the rooms of the house, to the entrance and exit. Many managed to overcome these barriers, while others, due to lack of financial resources, depended on other family members to overcome the obstacles, such as stairs or even getting in and out of the house itself(20).

The disappointment and general strain domains had the second and third highest mean in the CBScale. Caregivers of the individuals with TSCI were mostly women who needed to divide their time among activities required by the caregiver role and those remaining: home, children, professional activities. Questions in the disappointment domain that had high scores were, for example: *Do you think life has been unfair to you?*, *Did you expect that life, at your age, would be different than it is today?*. In the general strain dimension, the questions were: *Do you think that you are assuming too much responsibility for the well-being of your relative?* and, *Do you sometimes feel the urge to flee this whole situation in which you find yourself?*

Studies show that the majority of caregivers of individuals with TSCI are wives or mothers. The results indicate that many have to divide time between care provided and other activities, leaving little or no time for leisure activities and rest(2,11).

There are many risk factors considered in the literature for the development of anxiety, depression and other health problems in caregivers. These factors relate not only to the patient himself (level of functional and/or cognitive disability, behavioral problems, disease duration) but also to the caregivers themselves (age, sex, degree of relationship, quality of relationship with the patient, comorbidities)(2,4).

In a study conducted in the community of Fiji, South Pacific, the instrument, the Caregiver Burden Inventory, was administered to 30 primary caregivers of individuals with spinal cord injury. Among other results, it was observed that the caregivers spent an average of 6.1 hours per day (SD=2.19) in providing care. The burden was significantly related to the number of hours spent in care ($r=0.35$, $p<0.05$) and the age of caregiver, with the oldest presenting higher caregiver burden ($r=0.46$, $p<0.01$). The researcher concluded that being the primary caregiver of an individual with spinal cord injury contributed to caregiver burden and the results indicated that the contributions of these people should be recognized and interventions tailored not only to meet the needs of care recipients, but also of the caregivers(21).

Another study conducted in the Netherlands described the perceived caregiver burden by caregivers of individuals with spinal cord injury and examined the predictors of burden. The number of hours spent on the performance of ADLs was found to be one of the strongest determinants for caregiver burden (35% of the variation in perceived caregiver burden). Other significant determinants were the number of psychosocial problems of the individual with the spinal cord injury, the age of the caregiver (older caregivers reported increased burden) and time, that is, the more time in years of care, the lower the burden(22).

The initial moments after TSCI are the most difficult to tackle, because this is when the patient-caregiver dyad is faced with the disabilities resulting from the injury. It is a phase of adjustment and adaptation to the new condition. Thus, during hospitalization, the care of the patient with TSCI should focus on discharge preparation, by inserting the family into this process through active participation in care.

In order to give continuity to patient care after discharge, beyond the family, there must be a sufficient and complete social support network to address the needs generated by the high complexity care required by a patient with TSCI. The institution of measures for ensuring early rehabilitation and continuity of patient care through compliance with the guidelines for professionals, family or caregiver is also a necessity.

The nurse should make home visits, pre- and post-discharge, to perform preventive interventions aimed at the quality of long-term care, to guide the adjustments and adaptations in the environment, in order to promote and facilitate the implementation of care(23) and to evaluate accessibility issues. The rehabilitation process itself should be initiated as soon as the individual with TSCI attains an appropriate clinical condition and the caregiver should be an active participant in the entire process.

The rehabilitation program for individuals with TSCI is understood to be a set of activities performed by specialized professionals, with objectives established for the treatment of the individual with physical disabilities(1,23).

Nursing is an integral part of the rehabilitation team and its actions should be systematized and interrelated, aiming at comprehensive care for human beings in order to ensure the best quality of care. The role of nursing is not only apparent in the process of rehabilitation of the patient, but also in the social responsibility of inclusion of the family, as a caregiver, considering the social and environmental context, favoring the dyad, improving their quality of life and reducing caregiver burden(23).

By means of the Nursing Care Systematization, rehabilitation nurses can develop and implement a plan of care designed to facilitate the rehabilitation, restore and maintain healthy levels of life and avoid complications secondary to the injury.

When there is interaction among health professionals, individuals with TSCI, and their caregivers, there is a greater possibility of active participation in a process which requires that the dyad is informed, motivated, prepared and has the skills to manage care at home, allowing greater capacity for resolution of care. However, it is important to integrate health management policies and systems of information, to strengthen partnerships, organize services and prepare the health team.

CONCLUSION

The results of this study demonstrated a predominance of females, mean age of 44.8 years and a low level of education, amongst the 59 family caregivers of individuals with TSCI. Caregiver burden was higher for the environment, disappointment, and general strain domains. There were no statistically significant associations between the caregiver burden and sociodemographic variables (gender and age) of the caregivers, as well as the variable related to the length of time over which they provided the care. Caregivers presented higher burden associated with the fact of spending more hours per day on care (for the disappointment domain) and self-reported disease (for all domains of the CBScale).

The results presented should be analyzed considering the limitations of the study, which refer to the fact that it was conducted with a small sample, attended only by public health services, which can bring restrictions to the generalization of findings.

The results of this study pointed to the need to design and implement programs for interventions and support that are effective for the management of care and reduction of burden.

Individuals with TSCI demand care from the simple to the most complex, depending on the neurological level of spinal cord injury. It is necessary and extremely important to conduct further research studies on the theme, which may endorse initiatives to mitigate and prevent the impact of burden in the life of family caregivers. Actions performed with caregivers with the intention of reducing caregiver burden may become, effectively, a solution within the task of caring.

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