Health-Related Quality of Life Among Caregivers of Individuals With Spinal Cord Injury

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ABSTRACT

The consequences of spinal cord injury (SCI) not only affect patients' health-related quality of life (HRQoL) but also extend to the entire family. The health condition the injury imposes requires the participation of a family caregiver, who will be responsible for taking care of the individual in a disabling condition. This is an observational, exploratory study using a cross-sectional design that aimed to study the association between HRQoL and gender, age, presence of comorbidities, and characteristics of the care among caregivers of individuals with SCI with the purpose of identifying potential factors that are associated with HRQoL in this population. Participants were 59 caregivers of individuals with traumatic SCI. The data were collected by consulting the patient histories and applying questionnaires. To assess the caregivers' HRQoL, the Short Form-36 was used. For analysis, exploratory and inferential statistics were used. Most of the caregivers of the individuals with SCI were female, with a mean age of 44.8 years. The domains that most contributed to a worse HRQoL were physical aspects, pain, vitality, and emotional aspects. No statistically significant associations were found between HRQoL and the variables gender, hours per day spent on care, and length of activity as caregiver. The associations between HRQoL and self-reported diseases and age were statistically significant. The results support the planning of nursing interventions from the perspective of aspects of the care demands, which can affect the caregiver's HRQoL. **Relevance to clinical practice:** Interventions to prepare the individuals with SCI and their caregivers are a strategy aimed at improving the HRQoL of both.

Keywords: activities of daily living, caregiver, family caregiver, nursing, quality of life, rehabilitation, spinal cord injury

The spinal cord injury (SCI) creates a chronic health condition, causing severe and disabling consequences for a series of vital functions, such as locomotion, sensitivity, sexuality, urinary and intestinal elimination, and the autonomous nervous system (Angel, Kirkevold, & Pedersen, 2011; Livecchi, 2011; Lucke, Martinez, Mendez, & Arévalo-Flechas, 2013; Rabeh & Caliri, 2010; Stahel, VanderHeiden, & Finn, 2012). Studies show that the main cause of SCIs is trauma and that most of the population affected is younger than 40 years. Hence, severe psychobiological, psychosocial, and economic repercussions are observed because of SCI, influencing a healthy, young, and active population (Nogueira, Caliri, & Haas, 2006; Rabeh & Caliri, 2010; Stahel et al., 2012).

The consequences of SCI affect the quality of life (QoL) of the individuals who are victims of this injury as well as the entire family involved in the new health condition (Chen & Boore, 2009; Livecchi, 2011; Lucke et al., 2013). Depending on the neurological level of the injury, the individual needs hours of care each day. Mainly patients with cervical and upper thoracic injury become dependent for the accomplishment of activities of daily living, such as grooming, clothing, eating, transfers, and elimination (Lucke et al., 2013; Paralyzed Veterans of America, 1999; Rabeh, 2007). Therefore, in view of the reduced functional independence of individuals with SCI and the psychological and social impact, some needs to impose demands that

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require the presence of a caregiver, responsible for care delivery to individuals in disabling conditions.

The caregivers' activities cause changes in their lifestyle, which can compromise their health, social bonds, and economic status. Thus, the impact of the care burden can manifest itself in the caregiver through physical and psychological problems (Chen & Boore, 2009; Paker, Bugdayci, Dere, & Altuncu, 2011; Yeung, Lui, Ross, & Murrells, 2007) that influence the care delivered to the individual with SCI and the health-related QoL (HRQoL) of both (Nogueira, Rabeh, Caliri, Dantas, & Haas, 2012).

To respond to the care demands of individuals with SCI, the caregivers need to be prepared from the patient's first hospitalization to continue the care at home and, thus, to minimize the effects of the care burden, to avoid affecting their own HRQoL. The adoption of educative interventions in the preparation of caregivers and the promotion of their well-being deserve special attention from health professionals. Nurses have a fundamental role to play in planning, implementing, and assessing the educative interventions in nursing activities aimed at home caregivers, considering appropriate forms of delivering care, besides orientation on the adaptations and accessibility of the environment they live in.

Background

According to the World Health Organization, QoL is the individual's perception regarding his or her position in life, in the cultural context and the value system attributed, in view of his or her objectives, expectations, standards, and concerns. This definition includes six main domains: physical health, psychological condition, independence levels, social relationship, environmental characteristics, and spiritual patterns (The WHOQOL Group, 1995). Other definitions are more focused, specific, and restricted to health. In that sense, many researchers are interested in those aspects of QoL related to alterations in the individuals' health. In these cases, the expression HRQoL has been more used to distinguish it from QoL in its broadest sense (Fayers & Machin, 2007).

Measuring the HRQoL of caregivers of individuals with SCI is relevant when considering that this condition causes changes in the social, psychological, and emotional aspects, besides the physical/functional aspect in these individuals' lives. Special attention to the caregivers can contribute to improving their QoL as well as that of the patients with SCI and the entire family. Nevertheless, a large part of the population of family caregivers still has not received the support needed for this activity (Chen & Boore, 2009; Lucke et al., 2013), representing a risk factor to maintain the QoL and HRQoL.

In view of the above, the aims of this research were to assess the HRQoL of family caregivers of individuals with traumatic SCI and to investigate its association with the sociodemographic variables (gender and age), health condition (self-reported diseases), and care characteristics (length of activity as caregivers and daily care hours).

Methods

Design

This is an observational, exploratory study using a cross-sectional design.

Data Collection

The study was carried out in two phases. In the first phase, a survey was undertaken in health institutions accredited in the Unified Health System (SUS), located in Ribeirao Preto, Brazil, to identify the histories of adult and elderly patient victims of traumatic SCI attended between December 1998 and December 2008. In this phase, 102 patients were identified.

In the second phase, the researchers attempted to locate the patients, but 13 had died, and 19 were not located at the address and telephone number listed in the history, resulting in 70 individuals with traumatic SCI. Eleven of them were independent for the accomplishment of activities of daily living and referred that they did not have a caregiver. Therefore, they were not considered for this study.

Departing from the 59 individuals with SCI who were identified, interviews were held with their respective caregivers, who self-reported their relationship with the patient. The inclusion criteria determined that the caregivers should be relatives of the patients and indicated by them as their primary caregivers.

Data were collected through home interviews. From the individuals with traumatic SCI, data were collected regarding the sociodemographic and clinical characteristics. From the family caregivers, data were collected regarding the sociodemographic characteristics, health condition (self-reported diseases), and care characteristics (length of time as caregiver, number of daily hours spent on care for relative with traumatic SCI).

The Medical Outcomes Study Short Form 36-Item Health Status Survey (SF-36) was used to measure HRQoL (Ware & Sherbourne, 1992). We used a Portuguese version of SF-36, which was culturally adapted to Brazil (Ciconelli, Ferraz, Santos, Meinão, & Quaresma, 1999). It consists of 36 multiple-choice questions in eight domains: physical functioning, role physical, bodily pain, general health status, vitality, social functioning, role emotional, and mental health. Scores for each domain range from 0 to 100, where 0 is the worst and 100 is the best possible health status (Ware & Sherbourne, 1992).

Data Analysis

Data were analyzed using the Statistical Package for Social Sciences, Version 15.0 (SPSS, Inc., Chicago, IL). A descriptive analysis was performed for all variables. Differences in the mean score of the SF-36 domains according to gender and self-reported comorbidities (yes/no) were tested using a Mann–Whitney test. Pearson's linear correlation between the scores of the SF-36 domains and the age, time in the role of caregiver (in years), and time spent on care per day (in hours), considered the following levels: less than 0.30, weak correlations and little clinical applicability, even when statistically significant; between 0.30 and 0.50, moderate correlations; and above 0.50, strong correlations (Ajzen & Fishbein, 1980). The significance level of the statistical tests was .05. Because this study was exploratory and we were looking for potential associations, we did not make any corrections for multiple comparisons.

Ethical Approval

The research project was analyzed and received approval from the research ethics committee at the University of São Paulo at Ribeirão Preto Medical School Hospital das Clínicas (process 3034/2009). The data were collected after the participants had received clarifications about the research and had given their consent by signing the free and informed consent form.

Results

Among the 59 individuals with traumatic SCI, 52 (88.2%) were male, with a mean age of 37 years (*SD* = 10.6 years). The main trauma causes were accidents with motor vehicles (22, 37.3%) and firearm injuries (FAIs; 17, 22%). As regards the level of the injury, 30 (50.8%) had a thoracic injury, 26 (44.1%) had a cervical injury, and 3 (5.1%) had a lumbar injury; 43 (72.8%) became paraplegic, and 16 (27.2%) became tetraplegic.

Concerning these individuals' caregivers, 53 (89.8%) were female, with a mean age of 44.8 years (*SD* = 14.7 years); 44 (74.6%) were married, and 38 (64.4%) presented a low educational level. As regards the degree of parenthood with the individual with traumatic SCI, 22 (37.3%) caregivers were wives, 14 (23.7%) were mothers, and nine (15.3%) were sisters. Twenty-three (39%) gave up their job to take care of the individual with traumatic SCI at home, and 29 (49.2%) referred some kind of health problem, particularly arterial hypertension (18, 30.5%) and depression (6, 10%).

In Table 1, the HRQoL scores and the internal consistency coefficients (Cronbach's α) are displayed.

The lowest mean scores were found for these domains: role physical, bodily pain, vitality, and role emotional—indicating that the caregiver's HRQoL was more compromised in these domains (worse HRQoL). Cronbach's α ranged between .45 and .92 and was superior to .70 in seven domains.

In Tables 2, 3, and 4, correlations and comparisons are displayed between HRQoL and some qualitative and quantitative variables of caregivers to individuals with traumatic SCI.

Concerning age, negative correlations were identified in all domains of the SF-36. This means that the older the caregiver, the worse his or her HRQoL. This result was similar for the number of daily hours spent on care, but in relation to age, moderate and statistically significant correlations were found, whereas the correlation with the number of daily care hours were all weak and not statistically significant.

As regards the length of the relative's experience as caregiver, most correlations were positive, that is, the longer the length of care, the higher the score on the SF-36, but the correlations were weak and without statistical significance.

The medians reveal that, among female caregivers, the HRQoL was worse in the following domains: role physical and role emotional. Among male caregivers, the HRQoL was worse in the domains physical functioning, bodily pain, general health status, and social aspects. When comparing the HRQoL between men and women, however, no statistically significant differences were found. It is highlighted that considerably more caregivers were women.

When the caregiver of the individual with traumatic SCI referred some disease, the mean scores indicated that his or her HRQoL was worse across the domains, with statistically significant differences in six of eight domains.

Discussion

The sociodemographic and clinical profiles of the study participants are in line with other studies in which men in their productive age and predominantly injured at the thoracic level were identified as the most frequent victims of traumatic SCI (Blanes, Carmagnani, & Ferreira, 2009; Ljungberg, Kroll, Libin, & Gordon, 2011; Nogueira et al., 2006; Paker et al., 2011; Rabeh & Caliri, 2010).

As regards the causes that lead to the trauma, higher frequencies of accidents with motor vehicles were found, followed by FAIs. This trend has been observed in Brazil and around the world because of increased violence (Blanes et al., 2009; Ljungberg et al., 2011; Nogueira et al., 2006; Paker et al., 2011).

In a retrospective study, Nogueira et al. (2006) reviewed the histories of victims of traumatic SCI, hospitalized at a teaching hospital in a city in the State of São Paulo, Brazil, and identified that the main

TABLE 1. Position Measures, Variability, and Internal Consistency of SF-36 Domains Applied to the Caregivers of Individuals With Traumatic SCI

SF-36 Domains	Mean	*SD*	Median	Minimum	Maximum	α
Physical functioning	69.40	27.15	80.00	5.00	100.00	.92
Role physical	52.12	41.33	50.00	0.00	100.00	.84
Bodily pain	58.17	24.59	61.00	10.00	100.00	.78
General health status	65.15	22.02	67.00	20.00	100.00	.45
Vitality	59.49	25.81	55.00	10.00	100.00	.79
Social functioning	72.03	29.93	87.50	0.00	100.00	.74
Role emotional	60.45	43.97	66.66	0.00	100.00	.87
Mental health	66.51	22.67	68.00	16.00	100.00	.81

Note. SF-36 = Short Form-36; SCI = spinal cord injury.

cause of trauma were FAI (44.7%), followed by vehicle collision/rollover (23.4%). At the same hospital, Rabeh and Caliri (2010) conducted a prospective study of individual victims of SCI and identified accidents with motor vehicles and falls as the main trauma causes. Ljungberg et al. (2011) identified that the main causes of SCI were FAI (47%), followed by falls (16%) and automobile accidents (16%), whereas 5% were because of robberies in Bethesda, Maryland. In another study in Aarhus, Denmark, the authors identified accidents with motor vehicles (50%), followed by occupational accidents and falls (Angel et al., 2011), as the main causes of traumatic SCI.

TABLE 2. Correlation Between HRQoL and Caregiver's Age, Length of Time as Caregiver, and Daily Hours Spent on Care

	r		
SF-36 Domains	**Age**	**Length of Care**	**Daily Hours Spent on Care**
Physical functioning	−.44**	.09	−.16
Role physical	−.20	.12	−.13
Bodily pain	−.31*	.05	−.20
General health status	−.34**	.09	−.08
Vitality	−.32*	.02	−.08
Social functioning	−.27*	.11	−.20
Role emotional	−.16	−.08	−.06
Mental health	−.30**	.03	−.05

Note. HRQoL = health-related quality of life; SF-36 = Short Form-36; *r* = Pearson's correlation.
$^*p \le .05$. $^{**}p \le .01$.

These results underline that urban violence, traffic, and occupational accidents are important disabling agents around the world, especially in medium and large urban centers.

The caregivers' sociodemographic and clinical characteristics are also in accordance with other studies, in which the predominance of female, married caregivers with a low educational level stood out, who gave up their paid job to assume home care for their family member (Blanes, Carmagnani, & Ferreira, 2007; Chen & Boore, 2009; Lucke et al., 2013; Paker et al., 2011; Rabeh, 2007).

As regards the health conditions, 29 (41.4%) caregivers reported some diseases and referred being under treatment. Among these, arterial hypertension and depression stood out. Depression is one of the main pathologies caregivers develop because of yearlong care (Chen & Boore, 2006; Paker et al., 2011). Many factors have been considered in the literature and risks for the development of anxiety and depression in caregivers. These are related not only to patients' conditions but also to other factors, such as age, gender, degree of parenthood, quality of the relation with the patient, and caregivers' comorbidities (Chen & Boore, 2006; Paker et al., 2011).

Blanes et al. (2007) undertook a study in the city of São Paulo, Brazil, involving caregivers of paraplegic patients and identified that 38.3% of the caregivers experienced a chronic condition. Oliveira, Carvalho, Stella, Higa, and D'Elboux (2011) investigated caregivers of elderly people in the South of Brazil, and the identified self-reported illnesses were similar to those found in our study: depression (23.8%) and arterial hypertension (35.7%).

TABLE 3. Comparison of Position and Variability Measures of HRQoL Domain Scores in View of Caregivers' Gender

	Gender of Caregivers				
	Female (*n* = 53)		Male (*n* = 6)		
Domain	**Mean (*SD*)**	**Median**	**Mean (*SD*)**	**Median**	***p***
Physical functioning	71.41 (25.53)	80.00	51.66 (36.69)	55.00	.18
Role physical	51.41 (41.72)	50.00	58.33 (40.82)	62.50	.71
Bodily pain	57.83 (23.99)	61.00	61.16 (31.95)	51.50	.91
General health status	66.02 (21.89)	67.00	57.50 (23.69)	52.00	.35
Vitality	59.71 (26.30)	55.00	57.50 (22.96)	55.00	.74
Social functioning	72.87 (29.59)	87.50	64.58 (34.83)	62.50	.59
Role emotional	57.86 (43.92)	66.66	83.33 (40.82)	100	.14
Mental health	65.96 (23.04)	68.00	71.33 (20.30)	68.00	.61

Note. Mann–Whitney test. HRQoL = health-related quality of life.

In this research, the daily hours spent on care to the individual with traumatic SCI ranged from half an hour to the entire day, and some caregivers reported spending their entire time, day and night, on care, for more recent cases, involving paraplegia or tetraplegia, which indicated exclusive dedication to the relative. It should be highlighted that the caregivers followed the individuals with traumatic SCI since the first hospitalization and at home during the postdischarge period. For paraplegic individuals who had been injured longer and had a higher level of functional independence, the caregivers indicated less hours per day spent on care.

According to the guidelines of the Paralyzed Veterans of America (1999), depending on the neurological level of the injury, the individual demands a different number of care hours spent per day: in case of high complete injuries (C1–C4), which required ventilator assistance for breathing, between 12 and 24 hours per day are spent on care (mean = 24 hours); level C5, between 10 and 24 hours (mean = 23 hours); level C6, 8–24 hours (mean = 17 hours); level C7 and C8, between 2 and 24 hours (mean = 12 hours); level T1–T9, between 0 and 15 hours (mean = 3 hours); level T10–L1, between 0 and 8 hours (mean = 2 hours); and level L2–S5, between 0 and 2 hours (mean = 0 hour).

In a study undertaken in an interior city in the State of São Paulo, Brazil, involving individuals with SCI and their respective caregivers, Rabeh (2007) identified that the total time the caregivers spent on care for the family member with SCI ranged from 4 to 15 hours, with a mean of 8.5 hours (*SD* = 3 hours).

TABLE 4. Comparison of Position and Variability Measures of HRQoL Domain Scores in View of Self-Reported Diseases

	Self-Reported Diseases				
	No (*n* = 30)		Yes (*n* = 29)		
SF-36 Domains	**Mean (*SD*)**	**Median**	**Mean (*SD*)**	**Median**	***p***
Physical functioning	80.33 (24.87)	90.00	58.10 (25.01)	60.00	<.01
Role physical	57.50 (40.01)	62.50	46.55 (42.64)	25.00	.31
Bodily pain	67.66 (22.72)	67.00	48.34 (22.85)	51.00	<.01
General health status	73.83 (18.07)	76.00	56.17 (22.39)	52.00	<.01
Vitality	73.50 (17.91)	70.00	45.00 (24.89)	40.00	<.01
Social functioning	80.83 (24.94)	87.50	62.93 (32.30)	62.50	.02
Role emotional	63.33 (43.19)	83.33	57.47 (45.33)	66.66	.61
Mental health	77.20 (17.80)	78.00	55.44 (22.08)	56.00	<.01

Note. Student's *t* test. HRQoL = health-related quality of life; SF-36 = Short Form-36.

For individuals with cervical SCI, the caregivers spent more hours, mean of 10 (*SD* = 3.4) hours, against 8 hours for individuals with thoracic SCI (*SD* = 2.8 hours) and 4 hours for those with lumbar SCI.

Individuals with traumatic SCI, mainly those with superior neurological injuries, are care dependent in the long term. The lack of, or errors in, planning for discharge and in the preparation of the dyad (patient–caregiver) can affect their HRQoL.

As regards the results found for the caregivers' HRQoL, the lowest means were found in the following domains: role physical (52.12), bodily pain (58.17), vitality (59.49), and role emotional (60.45). In other words, in these domains, the caregivers' HRQoL was more compromised (worse HRQoL).

In a study undertaken in the city of São Paulo, Brazil, involving 60 caregivers to paraplegic patients, Blanes et al. (2007) used the SF-36 to assess their HRQoL and found that the lowest mean scores were attributed to the same domains as in this study, but in a different order and with different scores: bodily pain (65.02), vitality (65.58), role emotional (68.18), and role physical (69.17). This means that, in both studies, the HRQoL of the caregivers to individuals with SCI was more compromised in the physical domain, to the detriment of the mental domain.

In another study, carried out in Pennsylvania, Lucke, Coccia, Goode, and Lucke (2004) described and assessed the factors that affected the HRQoL of caregivers to 10 individuals with SCI during the first 6 months after discharge from the rehabilitation hospital. For this purpose, they used the SF-36 and found that vitality and role physical were the domains that most affected the HRQoL.

In another study in the city of São Paulo, Brazil, involving caregivers to elderly people experiencing Alzheimer, Pinto et al. (2009) used the SF-36 to assess their HRQoL, and among other findings, the researchers found that more hours of care per week, living with the patient, and being female negatively influenced the caregivers' HRQoL.

In the South of Brazil, Oliveira et al. (2011) identified that caregivers to elderly people, mostly aged 60 years or older, obtained lower mean scores for the following SF-36 domains: physical functioning, role emotional, and vitality.

Studies about the HRQoL of individuals with functional dependence, associated with sociodemographic, clinical, and care variables, are important to support the caregivers.

The SCI leads the patients to chronic health conditions, including risks of secondary complications and recurrent care demands. In this perspective, family caregivers play a fundamental role in the process and need preparation for this activity.

In a study carried out in Texas, involving family caregivers to Latino/Hispanic patients with SCI, Lucke et al. (2013) identified that most caregivers felt alone and abandoned after the relative with SCI returned home. The lack of resources and equipment, such as a wheelchair, bathing chair, and ramps, the language and economic factors were the main barriers that strongly influenced the QoL and health of the family caregivers. They felt unprepared to modify their homes and deliver the care, mainly when the relative presented some kind of complication or pain.

In the same study, the family caregivers indicated feeling physically and emotionally exhausted and that they did not know how to deal with their own emotions. They experienced conflicts between offering the best care to their family members with SCI and satisfying their own or other family members' needs. Many family caregivers had to stop working because of the time and demands their new role required (Lucke et al., 2013).

Programs to prevent the burden and negative emotional impact can positively affect the health and HRQoL of dependent individuals and their caregivers. In the care context, nurses are responsible for care planning, keeping in mind each patient's and family caregiver's individual needs, especially in the preparation of the dyad through educative interventions, aiming for the continuity of care.

Access to rehabilitation centers and other specialized health services in care delivery to individuals with SCI and their caregivers is needed to continue the monitoring process of the chronic conditions and to grant the dyad a better QoL.

The integration of healthcare services and the interaction between the multiprofessional team and the patient–caregiver dyad is a strategy that can enhance the problem-solving ability of care. This process favors the patient's and caregiver's active participation, who need to be prepared, informed, and motivated to manage the chronic conditions at home. The importance of integration of health management policies and information systems is highlighted as well as the strengthening of partnerships, the organization of services, and the equipment/training of health professionals to support self-management and prevention of complications, thus furthering these individuals' HRQoL (World Health Organization, 2002).

Conclusion and Relevance to Clinical Practice

These study results evidence that, among the 59 caregivers of individuals with traumatic SCI, most were female, with a mean age of 44.8 years and low educational level. The HRQoL was worse for the domains role physical, bodily pain, vitality, and role emotional. No statistically significant associations were observed between the HRQoL and the variables gender, daily hours spent on care, and length of activity as caregiver. The caregivers displayed a worse HRQoL, associated with self-reported diseases (for six of eight SF-36 domains) and with age, that is, the older the caregiver, the worse the HRQoL (in six of eight SF-36 domains).

Many studies exist about the impact of SCI in patients' lives as well as about their QoL/HRQoL after the injury. Nevertheless, little attention has been paid to the needs of these individuals' family caregivers.

Studies about the theme can contribute to propose nursing interventions aimed at improving the HRQoL of family caregivers to individuals with SCI.

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