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# Nursing care in the daily rehabilitation of people with spinal injury and their families

**ABSTRACT** | Objective: the objective is to analyze publications on nursing care in the daily rehabilitation of people with spinal cord injury and their families. Method: this is an integrative literature review, in the PubMed, LILACS and SciELO databases, using the descriptors: Nursing, Spinal Cord Injury and Rehabilitation, with inclusion criteria: complete research articles, case reports or experiences, with adults, available in English, Portuguese and Spanish, from 2003 to 2013. Results: 60 articles were selected, which resulted in three categories of analysis: Living with a spinal cord trauma; Nursing care for the person with spinal cord injury in the rehabilitation process; Quality of life of the person with spinal cord injury and his family. Conclusion: it is concluded that in order to care for people with spinal cord injury and their families, it is necessary to seek qualified professional training to promote possibilities of care that improve the living and living of these people.

**Keywords:** Nursing; Spinalcordinjury; Rehabilitation; Family; Activitiesofdaily living.

**RESUMEN** | Objetivo: el objetivo es analizar publicaciones sobre cuidados de enfermería en la rehabilitación diaria de personas con lesión medular y sus familias. Método: se trata de una revisión integradora de la literatura, en las bases de datos PubMed, LILACS y SciELO, utilizando los descriptores: Enfermería, Lesión de la Médula Espinal y Rehabilitación, con criterios de inclusión: artículos completos de investigación, relatos de casos o experiencias, con adultos, disponible en inglés, portugués y español, de 2003 a 2013. Resultados: Se seleccionaron 60 artículos, que dieron como resultado tres categorías de análisis: Viviendo con un trauma medular; Atención de enfermería a la persona con lesión medular en el proceso de rehabilitación; Calidad de vida de la persona con lesión medular y su familia. Conclusión: se concluye que para atender a las personas con lesión medular y sus familias es necesario buscar una formación profesional calificada que promueva posibilidades de atención que mejoren el vivir y vivir de estas personas.

**Palavras claves:** Enfermería;Traumatismos de lamédula espinal; Rehabilitación; Familia;Actividadescotidianas.

**RESUMO** | Objetivo: objetiva-se analisar as publicações sobre o cuidado de Enfermagem no cotidiano da reabilitação de pessoas com lesão medular e suas famílias. Método: trata-se de uma revisão integrativa da literatura, nas bases de dados PubMed, LILACS e SciELO, utilizando os descritores: Enfermagem, Lesão Medular e Reabilitação, sendo critérios de inclusão: artigos completos de pesquisa, de relato de caso ou de experiências, com adultos, disponíveis nos idiomas inglês, português e espanhol, no período de 2003 a 2013. Resultados: foram selecionados 60 artigos, que resultaram em três categorias de análise: O viver e conviver com um trauma raquimedular; O cuidado de Enfermagem à pessoa com lesão medular em processo de reabilitação; Qualidade de vida da pessoa com lesão medular e sua família. Conclusão: conclui-se que para cuidar de pessoas com lesão medular e de suas famílias é preciso buscar formação profissional qualificada para promover possibilidades de cuidados que melhorem o viver e o conviver dessas pessoas.

**Palavras-chaves:** Enfermagem;Traumatismos da medula espinal; Reabilitação; Família;Atividades cotidianas.

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## INTRODUCTION

Spinal cord injury (SCI) is a type of highly disabling injury; not only can it lead to damage or loss of sensation and motor function, but it can also lead to multiple organ dysfunction. <sup>(1)</sup> The etiology of SCI varies between different countries, ethnicities, age and gender, but it is universally associated with psychological, social and economic effects, and it affects not only the individual, but his entire family. <sup>(2)</sup> The main traumatic etiologies in Brazil involve automobile accidents and gunshot wounds as the second most common cause, followed by falls and diving in shallow water. However, SCI can also have non-traumatic causes, such as tumors, infectious, vascular and degenerative diseases. <sup>(3)</sup>

Annually, around 500 thousand peo-

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ple, worldwide, are victims of spinal cord injury.<sup>(4)</sup> The incidence coefficient of traumatic SCI in Brazil is unknown and there are no statistical data on the number of people with SCI, since this condition is not subject to notification, in addition, the scarcity of epidemiological studies with this public is highlighted.<sup>(5)</sup>

Due to its incapacitating nature, people who have suffered a spinal cord injury need to participate in a rehabilitation process that helps them reach their best physical, psychological and social, vocational and educational potential, compatible with their physiological, anatomical deficit, environmental limitations, desires and life plans. Rehabilitation is a concept that must involve the entire health system and actively integrate or reintegrate into society the person whose capacity is impaired.<sup>(2)</sup>

Spinal cord injury and its sequelae have become more incident and prevalent, especially traumatic injuries caused by urban violence. The person's chance of survival after spinal cord injury has increased with advances in the medical field and technological resources. However, there is no effective therapy to prevent possible complications, the person who suffered the injury may live with physical changes that reduce their quality of life. Therefore, rehabilitation should begin as soon as the diagnosis of spinal cord injury is made and extends to other levels of health care as recommended by Ordinance 793/2012.<sup>(5, 6)</sup>

In this thinking, it is salutary that health professionals, specifically nursing professionals, as they spend most of the time with people with spinal cord injury and their families, seek to improve knowledge, aiming at specialized care in rehabilitation.

Nursing, in turn, plays an important role in the rehabilitation process, having as one of its main activities, the educational and assistance role, focused on the skills of the daily activities of people with disabilities and their families, seeking to strengthen their powers and building care

possibilities that improve the living and coexistence of these people and families, especially establishing important bonds and partnerships in the process of rehabilitating these people.

Thus, in view of the relevance of the aforementioned theme, the present study aims to: analyze publications on nursing care in the daily rehabilitation of people with spinal cord injuries and their families.

#### METHOD

It is an integrative review of the literature about specialized nursing care, in the rehabilitation of people with spinal cord injury. The integrative review aims to gather and analyze results of relevant research, enabling the synthesis of the state of knowledge of a given subject, in addition to pointing out gaps in knowledge that need to be filled with the realization of new studies.<sup>(7-8)</sup>

The guiding question for the construction of this review was "What has been published in the area of Nursing, focusing on specialized care in the Rehabilitation of people with spinal cord injuries and their families, from 2003 to 2013. The research was carried out in May 2013 in the databases PubMed (International Literature in Health Sciences/Medical Literature Analysis and Retrieval System On-line), LILACS (Latin American and Caribbean Literature in Health Sciences) and SciELO (Scientific Electronic Library Online- line), using the keywords: "spinal cord injury" OR "spinalcord" OR "spinal cord injury" OR "spinalcordinjury, AND" Nursing "OR" nursing "OR" nurses "in the SciELO, LILACS Database, and the MeSH Terms "spinalcord" OR "spinalcord injuries" AND "nursing" OR "nursing", at PubMed.

To establish the study sample, inclusion criteria were created, namely: to be complete articles, involving research, case reports or reports of experiences, available in English, Portuguese and Spanish, from 2003 to 2013, dealing with thematic with adults, from the age of 18 years old onwards, the results of the elec-

tronic searches were evaluated and selected with the purpose of retrieving articles considered relevant in the specialized care in rehabilitation nursing for people with spinal cord injury, and excluding those who did not meet the scope of the research. As a result of the search, 307 articles were found, of these, 210 in the PubMed database, 65 in the LILACS e32 database in the SciELO database.

Considering that there were some articles that were present in more than one database and that did not correspond to the inclusion criteria previously defined, they were considered relevant for nursing care in rehabilitation with people with spinal cord injury, 60 articles, of these, were 30 (PubMed), 17 (LILACS) and 13 (SciELO) were selected.

In this perspective, the analysis of the studies found was systematized, following the steps of bibliographic research (7), contemplating: the preliminary bibliographic survey in the aforementioned databases; the exploratory reading of the studies, verifying the feasibility of the studies found for the literature review; selective reading, analyzing, in a specific way, the relevance of the studies; analytical reading, summarizing the information found critically; interpretative reading, articulating the knowledge versed in all analyzed studies; and the elaboration of the final text that summarizes the results of the literature search.

#### RESULTS

The time dimension of publications varied from 2003 to 2013, with the highest incidence of publications occurring in the years 2011 and 2012 (n=09) in each year, however there was an increasing increase in publications, starting in 2006. It is suggested that this fact may be related to the recent publications of health policies for people with physical disabilities, as well as to the increase in urban violence, such as traffic accidents, work accidents, assault by firearms and their implications for society.

As for the journal that obtained the largest number of publications regarding nursing care, in the rehabilitation of people with spinal cord injury was the Revista de Escola de Enfermagem of the University of São Paulo (EEUSP), with the publication of eight articles, followed by RehabilNurs, Spinal Cord, J Spinal Cord Med, with four

items in each.

Comparing the number of articles produced by Institution, the Federal University of Ceará stands out with ten articles, followed by the Nursing School of the University of São Paulo (EEUSP), with four articles, the State University of Maringá and the Center of Rehabilitation Hoens-

broek, in the Netherlands, with three studies each.

It is also noted that of the 30 articles in the PubMed Database, 43.33% (n = 13) are from the USA, followed by the Netherlands, with 04 articles. In the LILA-CS and SciELO databases, it can be seen that of the 30 articles found, 96.66% (n =

**Chart 1: Characterization of the selected studies regarding the title of the article, journal and year of publication (2003-2013).**

Seleção artigos	Citação no texto	Título	Periódico	Ano
01	09	Cuidador (d)eficiente: as representações sociais de familiares acerca do processo de cuidar.	Rev Latino-Am Enfermagem	2006
02	10	Encontrar um novo sentido da vida: um estudo explicativo da adaptação após lesão medular.	Rev Esc Enferm USP	2008
03	11	Interpretando as experiências da hospitalização de pacientes com lesão medular.	Rev Bras Enferm	2009
04	12	Conhecendo a história e as condições de vida de indivíduos com lesão medular.	Rev GaúchaEnferm	2006
05	13	Percepção das pessoas com lesão medular sobre a sua condição.	Rev GaúchaEnferm	2012
06	14	A escala de Waterlow aplicada em pessoas com lesão medular.	Av Enferm	2011
07	15	Fenômenos de Enfermagem em portadores de lesão medular e o desenvolvimento de úlceras por pressão.	Rev Enferm - UERJ	2005
08	16	Disreflexia autonômica e intervenções de Enfermagem para pacientes com lesão medular.	Rev Esc Enferm USP [online]	2013
09	17	Avaliação funcional de pessoas com lesão medular: utilização da escala de independência funcional – MIF.	Texto-ContextoEnferm	2012
10	18	Qualidade de vida em pacientes com lesão medular.	Rev GaúchaEnferm	2013
11	19	Estudo da qualidade de vida em pessoas com lesão medular traumática.	Arq Neuro-Psiquiatr. [online]	2006
12	20	Sobrecarga del cuidado e impacto en la calidad de vida relacionada a la salud de los cuidadores de individuos con lesión medular.	Rev Latino-Am	2012
13	22	Towards personalized care for persons with spinal cord injury: a study on patients' perceptions.	J Spinal Cord Med	2011
14	23	The power of hope: patient's experiences of hope a year after acute spinal cord injury.	Journal of Clinical Nursing	2006
15	24	Back to life again—patient's experiences of hope three to four years after a spinal cord injury-a longitudinal study.	Can J NeurosciNurs	2009
16	25	Adaptation to spinal cord injury for families post-injury.	NursSci Q	2009
17	26	Using peer mentoring for people with spinal cord injury to enhance self-efficacy beliefs and prevent medical complications.	J ClinNurs	2011
18	27	Alterações e expectativas vivenciadas pelos indivíduos com lesão raquimedular e suas famílias.	Rev Esc Enferm USP [online]	2007
19	28	Pacientes com lesão raquimedular: experiência de ensino-aprendizagem do cuidado para suas famílias.	Esc. Anna Nery [online]	2006
20	29	Burden of support for partners of persons with spinal cord injuries.	Spinal Cord	2005
21	30	Úlceras por presión en personas con lesión medular: conocimiento de familiares y cuidadores.	Rev Enferm	2010

22	31	Psychological impact and the burden of caregiving for persons with spinal cord injury (SCI) living in the community in Fiji.	Spinal Cord	2011
23	32	(In)dependência funcional na dependente relação de homens tetraplégicos com seus (in)substituíveis pais/cuidadores.	Rev Esc Enferm. USP [online]	2010
24	36	Vivência da sexualidade por pessoas com lesão medular.	René	2008
25	38	Sexuality and spinal cord injury.	NursClin North Am	2007
26	39	O cuidar do enfermeiro especialista em reabilitação físico-motora.	Rev. esc. enferm. USP [online]	2005
27	40	Comparison of two Dutch follow-up care models for spinal cord-injured patients and their impact on health problems, re-admissions and quality of care.	ClinRehabil	2007
28	41	Post-discharge nursing problems of spinal cord injured patients: on which fields can nurses contribute to rehabilitation?	ClinRehabil	2003
29	42	Improving the continuing care for individuals with spinal cord injuries.	Br J Nurs.	2005
30	43	Consumer-directed teaching of health care professionals involved in the care of people with spinal cord injury: the Consumer-Professional Partnership Program.	J ContinEducNurs	2008
31	46	O processo de reabilitação de pessoas portadoras de lesão medular baseado nas teorias de enfermagem de Wanda Horta, Dorothea Orem e Callista Roy: um estudo teórico.	CogitareEnferm	2005
32	47	A secondary analysis of the meaning of living with spinal cord injury using Roy's adaptation model.	NursSci Q	2006
33	48	A model for assessing learning readiness for self-direction of care in individuals with spinal cord injuries: a qualitative study.	SCI Nurs	2004
34	49	Diagnósticos de enfermagem de maior ocorrência em pessoas com lesão medular no contexto do atendimento ambulatorial mediante abordagem baseada no modelo de Orem.	Rev EletrEnf [online]	2008
35	50	Autocatereterismo vesical intermitente na lesão medular.	Rev Esc Enferm - USP [online]	2011
36	51	Patient's perceptions of their roles in goal setting in a spinal cord injury regional rehabilitation program.	Can J NeurosciNurs	2012
37	52	Establishing a super-link system: spinal cord injury rehabilitation nursing.	J AdvNurs	2007
38	53	Evaluation of super-link system theory for spinal cord injury patients using participatory action research in a rehabilitation hospital.	RehabilNurs	2012
39	54	Diagnósticos de Enfermagem e proposta de intervenções para pacientes com lesão medular.	Acta Paul Enferm	2005
40	55	SCI. Rehab Project series: the supplemental nursing taxonomy.	J Spinal Cord Med	2009
41	56	Combined application of the international classification of functioning, disability and sealth and the NANDA-International Taxonomy II.	J AdvNurs	2010
42	57	The SCIREhab project: treatment time spent in SCI rehabilitation. Nursing bedside education and care management time during inpatient spinal cord injury rehabilitation.	J Spinal Cord Med	2011
43	58	Relationship of nursing education and care management inpatient rehabilitation interventions and patient characteristics to outcomes following spinal cord injury: the SCIREhab project.	J Spinal Cord Med	2012
44	59	Care needs of persons with long-term spinal cord injury living at home in the Netherlands.	Spinal Cord	2010
45	60	Aspectos fisiopatológicos e assistenciais de enfermagem na reabilitação da pessoa com lesão medular.	Rev Esc Enferm USP	2004

46	61	A reabilitação da pessoa com lesão medular: tendências da investigação no Brasil.	Enferm Global	2003
47	62	Perfil de pacientes com lesão traumática da medula espinhal e ocorrência de úlcera de pressão em um hospital universitário.	Rev Latino-am Enferm	2006
48	63	Spinal cord injury and pressure ulcers. Enfermagem.	Clin North Am	2005
49	64	Comparing and contrasting knowledge of pressure ulcer assessment, prevention and management in people with spinal cord injury among nursing staff working in two metropolitan spinal units and rehabilitation medicine training specialists in a three-way comparison.	Spinal Cord	2012
50	65	Preventive Skin Care Beliefs of People with Spinal Cord Injury	RehabilNurs	2008
51	66	Tecnologia de Enfermagem na prevenção da úlcera por pressão em pessoas com lesão medular.	Rev Bras Enferm. [online]	2011
52	67	Estratégias para aplicação da escala de waterlow à pessoa com lesão medular: relato de experiência.	Rev Rene	2010
53	68	Comparative study of pressure distribution at the user-cushion interface with different cushions in a population with spinal cord injury.	ClinBiomech	2009
54	69	Intermittent catheterization in the rehabilitation setting: a comparison of clean and sterile technique.	ClinRehabil	2006
55	70	Internet education for spinal cord injury patients: focus on urinary management.	RehabilNurs	2007
56	71	Qualidade de vida de adultos com lesão medular: um estudo com WHO-QOL-bref.	Rev Esc Enferm - USP [online]	2011
57	72	Characteristics of neurogenic bowel in spinal cord injury and perceived quality of life.	RehabilNurs	2012
58	75	Vivencia de discapacidad por traumatismo de la médula espinal y el proceso de rehabilitación.	CienEnferm	2011
59	76	Considerações sobre o paciente com lesão raquimedular ou vítima de trauma: um estudo qualitativo.	Nursing (São Paulo)	2010
60	77	O des-cuidar do lesado medular na Atenção Básica: desafios bioéticos para as políticas de saúde.	Rev Bras Enferm	2012

Fonte: Bases de dados da BVS: LILACS, PubMed e SciELO, 2013.

29) are from Brazil, with emphasis on the Southeast (n = 09) and Northeast (n = 12), followed by Portugal and Chile, with 01 article each.

No quadro 01 são apresentadas as informações relativas aos estudos quanto à sua identificação, periódico e ano de publicação.

## DISCUSSION

The results emerged three categories of analysis: Living with a spinal cord trauma; Nursing care for the person with spinal cord injury in the rehabilitation process; Quality of life of the person with spinal cord injury and his family.

### Living with a spinal cord trauma

When analyzing scientific productions in their entirety, different meanings of living with spinal cord injury are observed. Spinal cord injury, in addition to the emotional impact<sup>(10-11)</sup>, it generates a series of difficulties resulting from the transformation that the body undergoes, with implications, not only physical, but in several aspects of human life: psychological, socioeconomic, spiritual and family.

Spinal cord injury affects people in the economically active age group, who generally participate in the management of the home and family, contributing to the aggravation of disorders of daily life.

The selected studies<sup>(12-20)</sup> corroborate with what refers to the predominance of people with spinal cord injury, young adult (18 to 45 years old), with little education, traumatic etiology, American Spinal Injury Association ASIA (A), cervical and thoracic level. However, in females, spinal cord injury is more frequent after 29 years old.<sup>(12)</sup> The age at which the injury occurs is an important point in the coping process, showing that adults who suffered spinal cord injury in childhood have less problems with adaptation than people who acquired the injury during adulthood; because while the child adapts to his body and the external environment, already with the physical limita-

tions present; the adult needs to develop new mechanisms to carry out activities previously done without difficulties.<sup>(21)</sup>

Regarding the marital status of the person who suffered the trauma, studies<sup>(12-13)</sup> affirm, in a similar way with national and international statistics that, although at the time of the accident people were married, at the time of the survey, at least half were already separated, revealing yet another problem experienced by these people, especially women, that they often find themselves abandoned by their spouses, becoming dependent on caregivers belonging to the family of origin.

Certainly, the adaptation of people to the new condition of life will depend on several factors, intrinsic and extrinsic, of living and living with spinal cord injury, ranging from the type and extent of the injury, to the prognosis, as well as to the personality type, level educational, social and cultural.

The Rehabilitation Program<sup>(10,12)</sup> it also influences the subjects' mobilization to seek strategies that enable a better adaptation to the injury situation, which, in turn, leads to the recognition of the relevance of the performance of health professionals in this path, and of nurses, more specifically. In a study in Italy<sup>(22)</sup>, it appears that, the greater the link with the health team, the greater the adaptability of people with spinal cord injury, for the freedom to explicitly expose the prognosis to them.

In a qualitative study<sup>(10)</sup>, made up of nine people who suffered spinal cord injury and with a successful adaptation path, it was observed that the spiritual dimension proved to be the engine of the person willing to manage the consequences of their injury, maintaining goals in life. One year after the injury, a descriptive, longitudinal study, with a phenomenological-hermeneutic approach, based on Ricoeur's philosophy<sup>(23)</sup> notes that hope was important for all participants, providing energy and power for the struggle process, being necessary for progress and personal development in this period. In another complementary study<sup>(24)</sup>, três a

quatro anos depois da lesão, os participantes concentraram seus objetivos mais na vida presente do que na esperança do devir, pela experimentação adaptativa da nova condição de vida.<sup>(25)</sup> Still, regarding the search for support<sup>(10)</sup>, social support, contact with people already adapted, peer tutoring<sup>(26)</sup>, in a rehabilitation environment, they encourage an encouragement of health behavior, implying the search for the meaning of life that, progressively, creates space for the awareness of the situation, making it possible to organize own resources. Similarly, in another study<sup>(13)</sup>, it was evidenced that the overcoming of the new condition of life comes from the recognition of their condition and construction of small goals, daily.

Another point to be highlighted in living and living with spinal cord injury, which Rehabilitation Nursing brings, is the importance of the family, a role most frequently assumed by the woman, followed by parents, brothers, aunt, niece and friends, within an age range that ranged from 20 to 50 years, with the majority of caregivers, with educational level, between elementary school and complete and incomplete high school.<sup>(9,12,20,27-30)</sup>

Studies<sup>(9,27-29,31)</sup> point out that the daily life of families is difficult, charged with suffering and pain, permeated by the ambiguity of feelings, which determines many emotional conflicts, marked by exhausting socioeconomic changes and lack of technical and institutional support, for a practice that presupposes so many specificities. The suffering that permeates the care process is influenced by the perception of the other's suffering, for which dependence, a strong mark of disability, by making him unable to take on his own life, generates feelings of aggression and revolt. Significant predictors of family burden<sup>(29)</sup> were (in order of importance): the amount of support given, the patient's psychological problems, age, sex between partners and time<sup>(32)</sup> available for care. A substantial proportion of partners of people with spinal cord injuries suffer from the severe burden of support. Thus, the prevention of

burnout (state of emotional tension and chronic stress caused by stressful physical and psychological work conditions) for the family, needs to be part of the arsenal of care and/or guidance throughout the life of people with spinal trauma. However, in a study<sup>(32)</sup> performed at the home of 08 people with spinal cord injury, living in the South and Southeast of Brazil, the shortage of guidance to families by health professionals at home is revealed.

Considering that the involvement of the family in the rehabilitation program is essential for a continuous rehabilitation at home, it is necessary to know, care for, support and instrumentalize the family, which will, in most cases, be the main support network for people with injuries spinal cord, especially to identify situations<sup>(33)</sup> where she needs to be better advised. For this<sup>(28)</sup>, families need adequate training, teaching them by demonstrating nursing care<sup>(28,34)</sup>, considering that maintaining the health of these individuals<sup>(27)</sup> requires knowledge about the changes resulting from spinal cord injury, and, especially, the complications, leaving the person who suffered the injury more confident<sup>(28)</sup>, regarding the continuity of care at home, correctly, although the person with spinal cord injury points out a discontent<sup>(12,27)</sup>, by the situation of dependence on the other.

The expression of sexuality is another very important dimension of living and living with spinal cord injury. Physical disability does not neutralize sexuality<sup>(35)</sup>, sexual function is an integral part of a person's life and its exercise rejuvenates the ego. However, it is common to have an unbalanced relationship after serious disorders, especially those that generate sexual disorders, such as spinal cord injury.

Studies carried out by rehabilitation nursing<sup>(36)</sup>, with regard to sexual changes in spinal cord injury, they consolidate what already exists in the current literature. In a study<sup>(37)</sup> with 40 paraplegic people, aged between 18 and 50 years, it was found that most (n=33) have an erection (reflex or psychogenic), but do not have

ejaculation (n=30), and that half of them have orgasm (n=7), pointing out that, in many cases, the erection is not enough for coitus to be complete and that impotence seems to be more impacting for men. The most widespread method among respondents<sup>(36)</sup> for the acquisition of a satisfactory erection, it was the use of oral or injectable medications for men, and the use of lubricants during sexual intercourse and caresses, for women. However, even with the knowledge of some methods, some people do not use them due to the difficulty of access and the high cost.

Within this meander, studies (36-37) indicate for the importance that people with injury medulartentham knowledge about these possibilities and access to the use of techniques. Therefore, the need for sexual counseling in a rehabilitation program is emphasized. However, it is an area that, normally, the professional himself is not prepared to address this issue.<sup>(12)</sup> The nurse is in an important position to promote health<sup>(36,38)</sup>, requiring specific preparation and spontaneity to address positive attitudes towards the new reality of life of the person with spinal cord injury and their partners.

Considering that the nurse is present in each of the phases of the rehabilitation experience in the community, in the hospital and in the rehabilitation center, it can be said that the nurse is fundamental for the construction and strengthening of the support networks in rehabilitation programs<sup>(39-40)</sup> and in the community, with a high degree<sup>(41)</sup> of resolution.

Some Nursing practices in the care of people with spinal cord injury stand out, namely: In Holland (40), transmural care, care provided by the nurse who "articulates" between former patients who live in the community with primary care professionals and the rehabilitation team. In the United Kingdom<sup>(42)</sup>, the led nurse clinic was created to review, evaluate, advise and help people with spinal cord injuries to develop problem-solving strategies that allow them to maintain their level of independence in the community, avoid unnecessary hospi-

talizations and minimize the development of complications more severe that arise as a result of aging with a spinal cord injury. Still in the UK<sup>(43)</sup>, the Consumer-Professional Partnership Program (CPPP) was developed, with the purpose of increasing the participation of people with spinal cord injuries in the training of nurses and other health professionals. Its objective is to inform nurses about disability and health problems, from the perspective of people with spinal cord injury.

### **Nursing care for the person with spinal cord injury in the rehabilitation process**

The diagnosis of a spinal cord injury is a devastating experience, surrounded by limitations and dependencies that disrupt the living and coexistence of people in their process of being healthy. However, with the development of a rehabilitation program, feelings and reactions begin to be reworked, with the possibility of redefining life, with the help of self-care practices.

In this thinking, rehabilitating health professionals, specifically, the Nurse, whose care model is essentially educational, have an important role with regard to the elaboration of a care plan that favors changes from a state of dependence to a state of independence in activities of daily living, contributing to the re-signification of the living and coexistence of people with spinal cord injury and their families.

In this contemporaneity, in the practice of Nursing, there is a trend, with regard to the application of scientific methodologies that lead to individualized, planned, qualified and scientific assistance.<sup>(44)</sup> The applicability of a Nursing theory allows to explain the purposes, contexts, variables, theoretical explanations, empirical evidence and the use of new approaches in Nursing practice that determine the nature of its descriptive elements.<sup>(45)</sup>

In a given survey<sup>(46)</sup>, it appears that the theories of Wanda Horta, Callista Roy, Dorothea Orem, apply to the rehabilitation process in all its stages. Wanda Horta emphasizes the first part of this process: basic needs and, both Callista Roycom and Do-

rothea Orem use perception in their conceptual structures, for establishing a connection between the four major concepts of Nursing Theories: the human being, health, the environment and Nursing. Besides, Roy<sup>(25,47)</sup>, Orem<sup>(48-49)</sup>, and Horta<sup>(50)</sup> address holistic thinking, essential to the practice of nursing in rehabilitation. In another study<sup>(51)</sup>, Imogene King's theory was successfully used to achieve rehabilitation goals in 13 people with spinal cord injury.

The Super-Link System Theory was also applied to rehabilitation nursing practices, aiming to identify the needs of people with spinal cord injuries and their families during the rehabilitation process, and the strategies used by rehabilitation nurses to assist such needs.<sup>(52-53)</sup>

Thus, the practice of Nursing supported by a theory, helps and guides the path to be taken, serving as a basis for the implementation of the Nursing Care Systematization (Sistematização da Assistência de Enfermagem - SAE), aiming at a better quality and continuity in Nursing care, to people in rehabilitation process. It is observed, through the selected studies, that the applicability of Nursing Diagnoses of the North American Nursing Diagnosis Association (NANDA), in the care of people with spinal cord injury, at the hospital level.<sup>(16,54)</sup> and ambulatory<sup>(49,55)</sup> it is viable, and its use has had an impact on nursing practice. It also brings greater precision and details in the planning of rehabilitation care. It is also suggested that the combined application<sup>(57)</sup> the International Classification of Functionality, Disability and Health and the Classification of Nursing Diagnoses by NANDA, should be used by nurses, and in a combined way, as it increases the quality of the results of rehabilitation nursing actions to people with spinal cord injury.

Of the 60 articles selected in this integrative literature review, 33% (n=20) are related to nursing care, with regard to the prevention and treatment of complications resulting from spinal cord trauma. It is assumed that this fact is related to the multiple limitations faced by the person

with spinal cord injury and his family, in their EVERYDAY, and, therefore, requires complex care and knowledge about the subject.

In a multicenter study<sup>(57)</sup>, in the USA, developed by the research project SCI-Rehab, the time spent by nurses in six Rehabilitation Centers for five years was analyzed, with a sample of six hundred people with traumatic spinal cord injury, using portable electronic devices with personalized software or a page newly developed system of electronic documentation systems. The study reveals that the average total time involving educational activities and care delivery per patient was 30,6 hours (range 1,2 - 126,1, standard deviation (SD) 20,7, median 25,5). The average number of minutes per week was 264,3 (range 33,2 - 1253, median 241,9). The time that nurses spend in each activity was significantly different in each group with neurological injury. Fifty percent of the care time was dedicated to psychosocial support, while medication, skin care, bladder, bowel and pain management were the central themes of educational activities. In another observational, prospective SCI Rehab Project study<sup>(58)</sup>, in order to investigate the association between nursing guidelines and participatory care for people with spinal cord injury, it was found that the greater participation of these people in nursing activities is associated with better results.

In contrast, in the Brazilian reality, a study developed in Maringá, (Paraná - Brazil), with 32 people with spinal cord injury, at home<sup>(12)</sup>, reveals that 31,2% of people did not receive any guidance on the care to be adopted later. Among the others, (68,8%), more than methadone, 68 people reported having received at least two types of guidance at the time of hospital discharge, specifically related to the care of the person with spinal cord injury. The most frequent guidelines were related to the need to undergo physical therapy (23%), change of position frequently (19%), healthy eating (12%) and special mattress (9%). As for psychological assis-

tance, 46,9% of individuals refer that this occurred only during the hospitalization period, the same percentage states that they never received it, and only two individuals (6,25%) were under treatment. Regarding long-term care needs<sup>(59)</sup>, people with spinal cord injuries are dissatisfied with the attention they receive.

As important as rehabilitation care in the hospital environment is the maintenance of this care throughout the life of people with spinal cord injuries and their families, in order to prevent complications. In this sense, research in rehabilitation nursing<sup>(12,16,50,60-61)</sup> have focused on detailing the main clinical complications resulting from spinal cord injury and on discussing nursing interventions that can assist in health promotion and in improving the quality of life of these people. Namely, in order of greater appearance: psychosocial changes, pressure ulcer, vesicho-sphincter dysfunction (neurogenic bladder), intestinal dysfunction (neurogenic intestine), infections, spasticity, orthostatic hypotension, autonomic dysreflexia, deformities, deep venous thrombosis and respiratory failure.

Relating the profile of people with traumatic spinal cord injury and the occurrence of pressure ulcers in a university hospital<sup>(62)</sup>, through the survey of the records of 47 medical records, it was observed the occurrence in 20 people (42,5%), with the most frequent location being the sacral region and calcaneus. In another study, with 32 people with spinal cord injury<sup>(12)</sup>, a similar occurrence was observed: sacro-coccygeal region (37,5%), calcaneal region (20%) and ischiatic region (14%). It was also found, in this study, that most people with spinal cord injury already had pressure ulcers (59,4%), or had pressure ulcers (21,9%), although the majority (81,3%) reported performing some kind of care to avoid them.

Checking the profile of the problems presented by the people studied<sup>(15)</sup> in 15 people with spinal cord injuries admitted and their association with the development of pressure ulcers, it was found that most of the research subjects presented

nutritional deficit, partial immobility and exhaustion, fatigue, intermittent sleep, insomnia, intestinal incontinence and urinary incontinence.

It is suggested that knowledge about the prevention of pressure ulcers and treatment should be properly focused on the person who suffered the injury, the family and the health team, and reinforced over time.<sup>(63)</sup> In a prospective study, seeking to assess differences in knowledge about pressure ulcers between rehabilitation nurses and doctors<sup>(64)</sup>, it was found that doctors perform better than nurses in matters of prevention ( $P < 0,005$ ), but worse in terms of care ( $P < 0,05$ ). There was a significant difference in the provision of care ( $P < 0,001$ ) between nurses working in the two rehabilitation units, but not in the knowledge of prevention ( $P < 0,5$ ) and, interestingly, years of experience did not correlate with performance ( $P < 0,2$  for prevention) and ( $P < 0,5$  for care planning issues). Although knowledge does not necessarily reflect practice, it calls for better standardization and implementation of wound care possibilities.

Regarding preventive care for pressure ulcers by people with spinal cord injury<sup>(65)</sup>, it was found in a study with 20 participants, that most participants believed they were susceptible to pressure ulcers and that preventive care was important, but paradoxical statements about preventive beliefs and behaviors were common. Regarding the knowledge of preventive pressure ulcer care by family members/caregivers of people with spinal cord injury<sup>(30)</sup>, it was observed in a descriptive, cross-sectional study, with 50 participants, that most families reported having knowledge about risk factors, however, some preventive care was below expectations, such as: 88% of the people interviewed did not perform inspection of the daily, 80% did not use a moving sheet for transfer, 74% did not reposition the patient every two hours.

With regard to nursing care technologies, the application of the Waterlow scale<sup>(14,66)</sup> in hospitalized people suffering from spinal cord injury, it is effective in



assessing the risk factors for pressure ulcers, as well as for knowing the Nursing guidelines received, however, it requires strategies <sup>(67)</sup> to enable its application. In a cross-sectional, retrospective study <sup>(17)</sup>, with analysis of 228 medical records, the functional gain of people with traumatic paraplegia, participating in a rehabilitation program, was investigated using the Functional Independence Measure Scale (FIM). The results show that the average functional age occurs in all categories of body care; sphincter control; transfer; locomotion and stairs. The lowest functional gain occurred in the food and toilet item. It appears that rehabilitation promotes gains in functional independence, being fundamental for the recovery and autonomy of people with spinal cord injury, particularly for Nursing care, the FIM can direct actions aimed at the independence of the person with spinal cord injury, regarding self-care.

In a comparative study on the benefits of the wheelchair seat cushion in 48 people with spinal cord injury <sup>(68)</sup>, in terms of pressure distribution and contact surface on the pad-user interface, in Toledo, Spain, it was found that of the four pad models analyzed (low-profile air, high-profile air, double compartment air, and gel and firm foam), presented in a randomized order, the double compartment air cushion presented the best pressure distribution and the largest contact surface of the cushion compared to the other three cushions studied.

Still, with regard to studies on complications in people with spinal cord injury, it is observed that urinary tract infection represents one of the most common complications in this population. In a study of 32 people with spinal cord injury <sup>(12)</sup>, it was found that, (93.8%) already had urinary tract infection and, (43,7%) had this type of infection at the time of the home visit, although only 3 people were using antibiotic therapy. Among the types of accessories to promote urinary elimination, 15 people (46,8%) used uripen with a collector, 6 people (18,7%) performed intermittent

clean technique bladder catheterization and 2 people (6,25%), bladder catheterization delay. Only 5 people (15,6%) used the toilet and 7 of them (21,8%) performed the Crede maneuver.

Intermittent catheterization is the most suitable technique for complete emptying of the bladder for people with neurogenic bladder - sequelae of spinal cord injury. In a randomized control study <sup>(69)</sup>, Comparing the clean and sterile technique, it was found that of the 36 people with spinal cord injury, 15 (43%) developed a symptomatic urinary tract infection, with 37% of them being in the clean group and 45% performing the sterile technique. The average time for the appearance of urinary tract infection for the group was 3.0 weeks for the clean group and 3.6 weeks for the sterile group. The most common urinary organisms at the onset of symptomatic urinary infection were *Enterococcus* species followed by *Klebsiella*. Clean intermittent catheterization in the rehabilitation setting does not put the person with spinal cord injury at greater risk of developing symptomatic urinary infection, has a low cost for the Health System, promotes time savings and reintegrates the person into society. The College Of Nursing in the USA has developed an information website <sup>(70)</sup> for people with spinal cord injuries, with a focus on urinary care, it was found that 1.162 accesses over a period of 13 months and that the internet can provide health education for people living with disabilities, with limited access to other sources of information.

### Quality of life of the person with spinal cord injury and his family

The quality of life of the person with spinal cord injury goes through the process of rehabilitation of the activities of daily life and their reintegration with the environment in which they live. In a study on quality of life <sup>(18)</sup> of people with spinal cord injury and its correlation with the four domains: Physical, Environmental, Social and Psychological Relations, using the WHOQOL-bref instrument, there is

dissatisfaction among those investigated with quality of life, domains with lower scores: Environmental (55,20 points); Physical (58,59 points). Facets that most compromise the domains: mobility (55,3%), work (55,3%), money (80,9%), information (51%), leisure (68,1%); sexual life (34%). In a similar study <sup>(71-72)</sup>, it is concluded that the majority (55,3%) of the participants are dissatisfied with the quality of life and that the domains, environmental and social <sup>(19)</sup> have a greater correlation with quality of life.

Assessing the burden of care and the impact on health-related quality of life of families of people with spinal cord injuries <sup>(20)</sup>, in an observational, cross-sectional study, through review of medical records and application of questionnaires (Short Form 36 scales (SF-36) to assess health-related quality of life (HRQoL) and Caregiver Burden Scale (CBScale) for overload of care), it was found that the clinical characteristics that contributed to greater care overload, and worse HRQoL, especially individuals with quadriplegia and secondary complications. In the analysis of the results of the correlations between the burden of care and the HRQoL of families, it was observed that all correlations were negative, indicating that the greater the burden of care, the worse the HRQoL of the family. Thus, preventing family overload through strategies to prepare for discharge, integration of the support network and access to health services, could minimize the effects of family overload and contribute to better HRQoL.

As important as the guidelines for preventive care and treatment of complications arising from spinal trauma, social re-inclusion, through the development of activities that give them pleasure, whether by returning to work, or the development of physical activity, leisure, among others, is fundamental to improve the quality of life of people with spinal cord injury and their families.

The increase in a social support network, composed of several people, spouses, family members, neighbors, friends,

especially health professionals, stand out as the pillar of support for the resumption of activities of daily life.

It was found in a study <sup>(12)</sup> with 32 people with spinal cord injury, that most of these people (66%) did not perform any type of physical activity, and among those who do (34%), the most frequent activity was swimming, practiced by five people (45,4%) followed by weight training, practiced by three people (27,3%), riding by two people (18,2%) and basketball, by one person (9,1%). Despite dependence and disabilities, four people (12.5%) work (as a craftsman, street vendor or volunteer) and two people (6,3%) study. It is important to note that some people who performed some form of physical activity were keen to point out that they are mainly used for therapeutic purposes.

The results of the selected studies were verified <sup>(12,27)</sup>, that people with spinal cord injuries experience great difficulties in achieving the best living conditions, whether of a financial nature, or due to the scarcity of public and specialized services. In a study of 32 people with spinal cord injury <sup>(12)</sup>, (37,5%) reported difficulties related to the economic and, (18,8%) the lack of physical structure in the city, which includes the lack of transportation, employment, physical activity and prejudice (6.2%). With regard to the profession, it is observed that the majority (81.3%) of people with spinal cord injuries worked regularly and contributed to the family income. Until the mid-1980s, people with spinal cord injury <sup>(73)</sup> they belonged to the social class with the best socioeconomic status, with a family income above 15 minimum wages; today, there is a drop in the economic standard of victims of this type of trauma, due to the socioeconomic changes that occurred in the country, associated with the facility, through financing, for example - in the purchase of consumer goods, such as cars and motorcycles.

The study carried out with people from a rehabilitation service <sup>(74-75)</sup> points the question of the impossibility for work as a concern for people with spinal cord injury,

as it constitutes a need, not only to acquire income, but to assume a social role as a rescue of their identity. This, in turn, reveals the need for socioeconomic support and the promotion of activities that favor coexistence and the exchange of information and experiences, as a strategy to improve the daily lives of these people. <sup>(27)</sup>

Regarding access to public services <sup>(27)</sup>, it is observed that after the implementation of the Family Health Strategy (FHS), in a given study, only (21,9%) of people with spinal cord injury did not face difficulty in accessing services, however, in the same group studied, (53,1%) reported great difficulty related to: the structure of the service that encompasses manifestations about transport difficulties, deficiency in the physical plant (absence of ramps), existence of a queue for assistance and shortage in the specialized care necessary for cases of complications, as well as a shortage of other types of procedures necessary for an individual with spinal cord injury, such as: consultations with specialists - neurologists, in addition to physical therapy and the technical and human unpreparedness of health professionals to provide care to people with spinal cord injury and their families.

In an ethnographic study <sup>(76)</sup>, in Chile, with 22 people who suffered spinal trauma, little care was observed at the Primary Health Care Centers in the rehabilitation of people with spinal cord injuries. In Brazil, the reality is also worrying. In a study <sup>(77)</sup>, in the northeastern interior, it was investigated which actions were carried out in twenty Basic Family Health Units to meet the demands of adults with spinal cord injury. Twenty doctors and twenty nurses participated in this study at random. It was found that the professional was disqualified to assist the person with spinal cord injury, fragmented care, difficulties in scheduling appointments and exams, difficulties in referral and counter-referral.

However, people with disabilities have in their favor the guidelines of the National Health Policy for People with Disabilities <sup>(78)</sup> that, in partnership with the Ministry of

Education, recommends the inclusion of curricular components in the undergraduate curricula of professions in the health area, which focus on prevention, care and rehabilitation for people with disabilities, the promotion of research and extension projects in this area of the knowledge, the qualification of human resources and the reorganization of services, making it possible to guarantee the reference and counter-referral, the allocation of necessary resources, as essential assumptions for health care.

However, it is still seen that few Higher Education Institutions offer a curricular approach that highlights assistance to people with physical disabilities. The results of the aforementioned studies and the impressions arising from my professional practice are linked to the findings of several studies that have also found and discussed the need to focus care on a humanistic dimension, pointing out the importance of building approaches, truly welcoming, partnerships between institutions, between health professionals, between health professionals and users, and, fundamentally, qualified to serve people with physical disabilities, represented in this study by people with spinal cord injuries and their families.

## CONCLUSION

The present study provided an impactful dive into the scenario of care for people with spinal cord injuries and their families, making us (co)responsible for seeking better quality care, which enables the social inclusion of these people, above all, involving healthier life practices.

When analyzing scientific productions, different meanings were observed in living and living with spinal cord injury. The family became the main source of support for people with spinal cord injuries, who experience an ambiguity of feelings and also need to be cared for.

Studies have also pointed out that, as important as preventive and treatment care arising from a spinal cord injury, social re-inclusion is necessary, and it is a

"si ne qua non" condition to rescue these people's identity. Therefore, it is necessary to invest, not only in professional training, in order to guarantee new appro-

aches and new parameters of assisting and caring for people and families who experience the condition of the spinal cord injury, but also to carry out studies

that allow to know in greater depth what emerges from everyday life and interactions, with their limits and powers, in the family and rehabilitation context. 🐦

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