EVIDENCE OF FAMILY FUNCTIONALITY AND COPING AFTER SPINAL INJURY
EVIDÊNCIAS DA FUNCIONALIDADE FAMILIAR E DO ENFRENTAMENTO APÓS LESÃO MEDULAR
EVIDENCIA DE FUNCIONALIDAD FAMILIAR Y ENFRENTAMIENTO DESPUÉS DE UNA LESIÓN ESPINAL

Mayara Araújo Rocha¹, Alexsandro Silva Coura², Isabella Joyce Silva de Almeida³, Renata Ferreira de Araújo⁴, Bruna Lys Morais Caminha⁵, Inácia Sátiro Xavier de França⁶.

ABSTRACT

Objective: to evaluate family functionality and coping strategies used by adults with spinal cord injury. Method: an integrative review was conducted in October 2018, with an advanced search on the platforms: Pubmed, Scopus, Lilacs, Scielo, Bdenf, Ibecs, and Web of Science. The search that made up the sample was carried out in a double-blind manner. Eleven studies that answered the guiding question, published in English, Portuguese or Spanish, in the last ten years, were eligible. For the data collection, a validated form was used and, for the analysis, Bardin's thematic content categorization was used. Results: most articles were derived from Pubmed and presented a cross-sectional design, with evidence level V. Two categories emerged: “Family functionality: from positive self-reported evidence to caregivers' weaknesses” and “Coping strategies: mishaps between negative feelings and problem-focusing”. Conclusion: there is a good family functioning among people with spinal cord injury, based on self-reporting; however, there are weaknesses in the family composition, especially in aspects related to the caregivers and external relatives. Coping strategies for people with SCI include problem-focusing and strategies focused on positive reappraisal, helplessness, and spirituality.

Descriptors: Nursing Research; Spinal Cord Injuries; Psychological Adaptation; Family Relationships.

RESUMO

Objetivo: avaliar a funcionalidade familiar e estratégias de enfrentamento em adultos com lesão medular. Método: revisão integrativa, realizada no mês de outubro de 2018, com busca avançada nas plataformas: Pubmed, Scopus, Lilacs, Scielo, Bdenf, Ibecs e Web of Science. A busca dos artigos que compuseram a amostra foi realizada a duplo-cego. Foram elegíveis para a pesquisa 11 estudos
que respondiam à questão norteadora e publicados nos últimos dez anos, nas línguas inglesa, portuguesa ou espanhola. Para a coleta, utilizou-se formulário validado e, para a análise, a categorização de conteúdo temática de Bardin. **Resultados:** verificou-se que a maioria dos artigos se derivaram da Pubmed e apresentam tipo de estudo transversal, com nível de evidência V. Emergiram duas categorias: “Funcionalidade familiar: das positivas evidências autorreferidas às fragilidades dos cuidadores” e “Estratégias de enfrentamento: percalços entre sentimentos negativos e o foco no problema”. **Conclusão:** há um bom funcionamento familiar de pessoas com lesão medular, quando autorreferido, porém, constataram-se fragilidades na composição familiar, sobretudo de aspectos relacionados ao cuidador e parentes externos. As estratégias de enfrentamento de pessoas com LM são focadas no problema, reavaliação positiva, desamparo e espiritualidade.

**Descritores:** Pesquisa em Enfermagem; Traumatismos da Medula Espinal; Adaptação Psicológica; Relações Familiares.

**RESUMEN**

**Objetivo:** evaluar la funcionalidad familiar y estrategias de afrontamiento utilizadas por adultos con lesión medular. **Método:** se realizó una revisión integradora en octubre de 2018, con búsqueda avanzada en las plataformas: Pubmed, Scopus, Lilacs, Scielo, Bdenf, Ibecys y Web of Science. La búsqueda que compuso la muestra se realizó de forma doble ciego. Fueron elegibles once estudios que respondieron a la pregunta orientadora, publicados en inglés, portugués o español, en los últimos diez años. Para la recolección de datos se utilizó un formulario validado y, para el análisis, se utilizó la categorización de contenido temático de Bardin. **Resultados:** la mayoría de los artículos se derivaron de Pubmed y presentaron un diseño transversal, con nivel de evidencia V. Surgieron dos categorías: “Funcionalidad familiar: desde evidencia autoinformada positiva hasta las debilidades de los cuidadores” y “Estrategias de afrontamiento: percances entre sentimientos negativos y enfoque de problemas”. **Conclusión:** existe un buen funcionamiento familiar entre las personas con lesión medular, basado en el autoinforme; sin embargo, existen debilidades en la composición familiar, especialmente en aspectos relacionados con los cuidadores y familiares externos. Las estrategias de afrontamiento para las personas con LME incluyen el enfoque de problemas y estrategias enfocadas en la reevaluación positiva, el desamparo y la espiritualidad.

**Descritores:** Investigación en Enfermería; Lesiones de la Médula Espinal; Adaptación Psicológica; Relaciones Familiares.

---

1Universidade Estadual da Paraíba/UEPB. Campina Grande (PB), Brasil. [https://orcid.org/0000-0002-4991-0430](https://orcid.org/0000-0002-4991-0430)
2Universidade Estadual da Paraíba/UEPB. Campina Grande (PB), Brasil. [https://orcid.org/0000-0002-0628-648X](https://orcid.org/0000-0002-0628-648X)
3Universidade de Pernambuco/UPE. Petrolina (PE), Brasil. [https://orcid.org/0000-0001-8360-5897](https://orcid.org/0000-0001-8360-5897)
4Universidade Estadual da Paraíba/UEPB. Campina Grande (PB), Brasil. [https://orcid.org/0000-0002-2604-9035](https://orcid.org/0000-0002-2604-9035)
INTRODUCTION

Spinal Cord Injury (SCI) is one of the most unexpected, devastating, and tragic events that could ever have to deal with. Such morbidity refers to the involvement/damage to any segment of the spinal cord or to a nerve root.1

Worldwide, the incidence of SCI is approximately 10 cases per 100,000 people, which results in a quantity greater than 700,000 new cases per year. In Brazil, few studies show epidemiological aspects of SCI, but the incidence is estimated to be 16 to 26 cases per million annually. It is believed that, with the population aging process, these numbers may increase due to falls.2

SCI can compromise several aspects that make up the Quality of Life (QL), thus impacting the individual's life and ability to perform activities. In this sense, SCI becomes a stressful situation that comprises a cluster of physical and psychological symptoms.4

The main consequences of a stressful situation include lack of socialization, altered mood, and the way the individual can withstand various situations, including coping with the morbid process. Therefore, it is necessary to use coping strategies to reduce stress and obtain a sense of psychological well-being.4

In this context, coping strategies are stimuli of cognitive origin to proceed with an event resulting from stress. Strategies emerge in four main forms: social support, religious practices/fantasy thinking, problem-focusing, and emotion-focused strategies.2,3

However, it is also believed that the greater the available social support, especially from family, the better the emotional adjustment, thus compiling a better use of coping strategies in the situation and a better emotional prognosis.5

As for individuals with SCI, the investigation of family functionality is essential. This investigation deals with how the components of family functionality work the functions in a way that generates harmony, considering the context of the social environment. When the family system is classified as functional or dysfunctional, this conclusion refers to how relationships and forms of
adaptation occur in the face of a need for family reformulation, such as, for example, the occurrence of SCI.\textsuperscript{2,4}

Therefore, it is considered that the central point of support for SCI individuals is the family, and that structure greatly influences the rehabilitation process. When talking about adaptation of a person with SCI, the focus is not only on the person, but also on his/her family; that is, the adaptation process takes place mainly collectively.

The relevance of the theme mentioned above is related to the care of individuals with SCI, in the Primary Health Care context, and within the Family Health Strategy, serving as a theoretical basis for health promotion and prevention of secondary complications resulting from SCI, including depression. In this sense, the evidence in this study can support actions in the context of nursing practice, which are essential for the professional performance as this category provides continuous care for patients.

**OBJECTIVE**

To evaluate family functionality and coping strategies used by adults with spinal cord injury.

**METHOD**

An integrative review (IR) was carried out, which presents itself as a significant methodology for synthesizing scientific knowledge in an expanded and systematic way\textsuperscript{7}. The following steps were taken to build the IR: formulation of the guiding question, literature search or sampling, data collection, critical analysis of eligible studies, thematic categorization, discussion of the results, and presentation of the integrative review. The entire process was carried out using an integrative review protocol created by the authors.

The guiding question of the research was, "what is the scientific evidence with regard to family functionality and coping strategies used by adults with spinal cord injury?". This question was created using the PICO (P – Problem/patient/group; I – Intervention; C – Control or Comparison, defined as a standard intervention, most used intervention, or no intervention; and O – Outcome) framework. In this research, P = individuals with SCI, I = investigation of family functionality and coping strategies, C = no intervention, and O = creation of a support network as a facilitating coping process.

The search was carried out in October 2018, in the following databases: SciVerse Scopus, Latin American and Caribbean Health Sciences Literature (LILACS), Scientific Electronic Library Online (SCIELO), Nursing Database (BDENF), Spanish Bibliographic Index of Health Sciences (Ibecs), Web of Science, and Pubmed.

The following health descriptors were used for database searching: "Traumatismos da Medula Espinal", "Adaptação Psicológica" and "Relações Familiares", as well as the corresponding Mesh
Terms: "Spinal Cord Injuries", "Adaptation, Psychological" and "Family Relations". Search expressions were formed using the Boolean operator "AND", and the following combinations were used: (a) “traumatismos da medula espinal” AND “adaptação psicológica”; (b) “traumatismos da medula espinal” AND “relações familiares” and (c) “traumatismos da medula espinal” AND “adaptação psicológica” AND “relações familiares”.

When constructing the IR, the "Preferred Reporting Items for Systematic Reviews and Meta-Analyses" (PRISMA) framework was considered. Thus, studies that answered the guiding question, published in English, Portuguese or Spanish, in the last ten years, were considered eligible. Studies that were not available in full, and those that did not fit in the scientific article format such as articles in newspapers, conference proceedings, editorial papers, theses, and dissertations, were excluded.

The search was carried out in a double-blind manner, in which divergences that emerged during the sampling process were discussed, thus avoiding collection biases. The number of eligible references to compose this review is shown in Figure 1, with the final sample consisting of 11 articles.

![Flow diagram of search adapted from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA, 2009). Campina Grande (PB), Brazil, 2020.](image_url)
After a thorough reading, an instrument validated by Ursi and Galvão (2006) was used to annotate data from the articles carefully. The levels of evidence proposed by Melnyk (2011) were also used, comprising seven categories: I. evidence resulting from systematic reviews or meta-analysis of randomized clinical trials considered relevant; II. evidence from clinical trials with good methodology; III. evidence obtained from well-designed clinical trials without randomization; IV. evidence from well-designed cohort and case-control studies; V. evidence from reviews of descriptive and qualitative studies; VI. evidence from a single descriptive or qualitative study; and VII. evidence proposed by experienced authorities or committees.

Bardin's thematic content analysis was used to discuss better the phases of the analysis' organization, codification, categorization, and results' treatment and interpretation. The organization of the analysis was carried out by reading the manuscripts for later codification. The categorization of the manuscripts was carried out according to the approximation of the theme/results, in which two categories, presented in the discussion, emerged ("Family functionality: from positive self-reported evidence to caregivers' weaknesses" and "Coping strategies: mishaps between negative feelings and problem-focusing") and, in the end, interpretations were made, according to the categories mentioned above.

**RESULTS**

After reading the references eligible for the study, it was possible to construct Table 1, which shows the databases of origin, first author, year of publication, level of evidence, country of origin, type of study, and main results from each study.

Most studies were published in 2016 (27.3%), from Brazil (18.0%), Iran (18.0%), and the USA (18.0%), with the level of evidence V (90.9%), and had a cross-sectional design (70.7%).

**Table 1.** Bibliometric and methodological characteristics of the studies according to the first author, year, country, database of origin, level of evidence, type of study, and main results.

<table>
<thead>
<tr>
<th>First author, year</th>
<th>Country of origin</th>
<th>Database of origin</th>
<th>LE</th>
<th>Type of study</th>
<th>Main results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lankveld, 2011</td>
<td>Netherlands</td>
<td>Web of science V</td>
<td>Cross-sectional</td>
<td>In the regression analysis, problem-oriented coping explained 3%, 6%, and 4% more about depression, acceptance, and happiness, respectively.</td>
<td></td>
</tr>
<tr>
<td>Angel, 2011</td>
<td>Denmark</td>
<td>Web of science V</td>
<td>Qualitative</td>
<td>Family functioning is satisfactory through partners struggling to regain a well-functioning everyday life and re-establish life as a couple. However, there is a low family functioning concerning external relatives.</td>
<td></td>
</tr>
<tr>
<td>Author(s)</td>
<td>Country</td>
<td>Database</td>
<td>Study Type</td>
<td>Summary</td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>---------</td>
<td>----------</td>
<td>------------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>Migliorini et al. (2009)</td>
<td>Australia</td>
<td>Pubmed</td>
<td>IV Cohort</td>
<td>Emotion-focused coping strategies are negatively associated with the helplessness of people with SCI.</td>
<td></td>
</tr>
<tr>
<td>Zucher et al. (2016)</td>
<td>Switzerland</td>
<td>Pubmed</td>
<td>V Cross-sectional</td>
<td>Decreased social skills are associated with increased use of denial and self-distracted coping strategies.</td>
<td></td>
</tr>
<tr>
<td>Paker et al. (2016)</td>
<td>USA</td>
<td>Pubmed</td>
<td>V Cross-sectional</td>
<td>Experimental research using the Family Crisis Oriented Personal Scales (F-COPES) to assess coping at the family level, including social/spiritual support.</td>
<td></td>
</tr>
<tr>
<td>Yazdanshenas et al. (2017)</td>
<td>Iran</td>
<td>Pubmed</td>
<td>V Cross-sectional</td>
<td>The misuse of coping strategies has triggered difficulties in psychological adjustment, requiring interventions for their best use.</td>
<td></td>
</tr>
<tr>
<td>Fekete et al. (2018)</td>
<td>Switzerland</td>
<td>Pubmed</td>
<td>V Cross-sectional</td>
<td>As for family functioning, the study shows that conflicts between family and work are related with compromised caregivers’ mental health and vitality (family), leading to dysfunctions.</td>
<td></td>
</tr>
<tr>
<td>Charlifue et al. (2016)</td>
<td>USA</td>
<td>Scopus</td>
<td>V Cross-sectional</td>
<td>Family members who assist a relative with SCI may experience degrees of tension (physical and emotional), which other family members may not endure.</td>
<td></td>
</tr>
<tr>
<td>Rahnama et al. (2015)</td>
<td>Iran</td>
<td>Scopus</td>
<td>V Cross-sectional</td>
<td>Religious coping strategies had a moderate role in the occurrence of depression and anxiety.</td>
<td></td>
</tr>
<tr>
<td>Trierveiler et al. (2015)</td>
<td>Brazil</td>
<td>Scopus</td>
<td>V Cross-sectional</td>
<td>People with SCI presented good family functionality but dissatisfaction with the family, suggesting low communication between family members.</td>
<td></td>
</tr>
<tr>
<td>Machado et al. (2010)</td>
<td>Brazil</td>
<td>Scopus</td>
<td>V Qualitative</td>
<td>Even in the face of internal (family) conflicts, parents are the main caregivers of people with SCI.</td>
<td></td>
</tr>
</tbody>
</table>

Source: The authors, 2019.

Note: LE = level of evidence.

After reading the articles that made up the sample, two main categories emerged for a better discussion of the articles: "Family functionality: from positive self-reported evidence to caregivers' weaknesses" and "Coping strategies: mishaps between negative feelings and problem-focusing".

**DISCUSSION**

**Family functionality: from positive self-reported evidence to caregivers' weaknesses**

The full-text reading of the articles revealed that a good family functioning is an essential factor for a good recovery and rehabilitation among adults with SCI. It was also found that people with SCI have good family functionality, based on self-reporting, but when caregivers were
investigated, these being family members, negative aspects emerged, remnants of family dysfunction.

A phenomenological-hermeneutic study carried out in Denmark with partners of adults with SCI revealed that these persons are important characters of the coping process, even stating that the quality of life of injured people is higher when they are married. It was understood that the partners of individuals with SCI had to deal with the shock of the occurrence of the injury and the struggle to make the relationship work again, a trajectory that consisted of three main phases: to be harmed by the partner’s injury, to find oneself on the outside of their partner’s life, and to struggle for the injured partner and reestablishing life as a couple.

Experiencing life with a new reality, especially a painful one, is a complex task. However, when the tragic situation is adequately dealt with, the affective framework structures an important support network, which facilitates the remodeling of the daily life routine experienced by the person with SCI and their family. These are attitudes that legitimize affection and overcome the challenges inherent in daily care.

However, the burden directed at the caregiver is indisputable. From this perspective, it is eminent that multidisciplinary assistance to the individual and the caregiver (a lay family member) is essential. A systematic review on this theme emphasized that most caregivers of people with SCI are family members with low quality of life (QL).

A qualitative study, carried out with SCI, residing in the South and Southeast regions of Brazil, demonstrated that it is almost impossible to imagine what life is like for a person with SCI without the help of family members, especially in the figure of the parents, which are essential to help with daily activities of self-care. However, when parents cannot exercise the role of caregiver, other family members perform this role, even in the face of conflicts, which configures a problem of family functionality.

The concept of family functionality refers to the adaptation of the family, considering the entire reorganization of habits. In this perspective, an investigation in the metropolitan region of Florianópolis found that 61.4% of the individuals reported having good family functionality, 22.5% claimed to have mild family dysfunction, and 16.1% reported severe family dysfunction in a context in which most caregivers are female.

Caregivers are predominantly female, and this reality becomes from the fact that, historically, women have been regarded as responsible for caring processes. A social construction predestines women to the maternal, caring, and domestic roles, a particular tendency that makes it difficult for them to make their personal choices. It also generates an informal and unpaid work, carried out in the family context.
All articles in this category emphasize the health and well-being of caregivers, as spinal cord injuries can cause a psychosocial and existential crisis\(^9\) in the individual and the family. In addition, there is a strong association\(^{14}\) between conflicts in the work-family or family-work relationship, with low self-reported health indicators (mental health, vitality, well-being, and affection). Although another study carried out in rehabilitation services in the USA\(^{15}\) has shown that negative consequences can be neutralized by the positive ones (personal growth, appreciation, patience, learning, and intimacy), in this review, the negative aspects of living with a person with SCI prevailed.

**Coping strategies: mishaps between negative feelings and problem-focusing**

Overall, according to evidence from the included studies\(^{8,10,11,12,13,16}\), it was possible to identify that the coping strategies most used by people with SCI are problem-focused, or focused on positive reappraisal, helplessness, and spirituality. This finding denotes the creation of strategies to face the morbid process more effectively, reducing aspects of psychological distress.

As for coping strategies in people affected by SCI, a study with 397 patients after spinal cord injury\(^8\), whose objective was to investigate the correlation of coping strategies after rehabilitation, showed that problem- or task-oriented coping strategies achieved a higher prevalence, corroborating another study carried out with the same population\(^{11}\), in which such strategies were related to a good quality of life and better adaptation. Therefore, problem- or task-oriented coping strategies tend to be more used in the rehabilitation process.

When the strategies suggest problem-focusing, it is believed that the individual is making an effort to change the reality. In the case of SCI, the way in which the patient manages the incapacities that are imposed is considered, and multiprofessional care becomes essential for a better coping, especially for nursing professionals\(^{22}\).

Another important aspect found in the literature is that coping strategies enable the reassessment of life\(^{10}\). It is indicated that individuals with SCI do not give up, but absorb the injury according to their own confrontation, allowing the SCI not to be constantly in thoughts, so that they are able to gain control over life.

However, studies\(^{8,12}\) indicate helplessness as a negative factor, corroborating the Motivational Coping Theory, which addresses coping in two main ways: positive or negative. Such theory argues that when the individual cannot, by his strength, face an immutable situation, he uses helplessness as a coping strategy\(^{29}\).

In this sense, in the construct that deals with the sociodemographic aspects of people with SCI, related to coping strategies, it was found that the older patients (>32 years old) and those who suffered the injury more recently (<14 years) experienced depressed mood more frequently, positive
aspects less frequently, had a decreased satisfaction with life, purpose in life, and self-efficacy\textsuperscript{11}, impaired social skills, and used humor and denial as coping strategies more often\textsuperscript{8,10,11,12}.

The accommodation to a new reality involves deconstructing elements built with time and effort. Thus, a patient who is affected by SCI, after so-called "essential" achievements in life, such as financial, professional, family, and social stability, is indisputably shaken by this new condition, considering that he has achieved what the society considers as " apex of life”, which was abruptly replaced by a condition of dependence. Therefore, needing someone else to perform basic activities of daily living is configured as a tortured and complicated setback\textsuperscript{18}.

It is important to highlight the context of the patient-caregiver dyad concerning the social aspect. A study developed in Turkey\textsuperscript{12} has shown that the coping strategies most used by caregivers and individuals with SCI are self-confidence and optimism, with no statistical difference between the groups, indicating emotional similarity.

Nevertheless, according to a cross-sectional study carried out in Iran\textsuperscript{13}, individuals with SCI have used defense mechanisms to change their reality and maintain calm and stability, which decreases the ability to face and solve problems and, in turn, causes denial. From this perspective, such knowledge is essential for a good rehabilitation process and good planning by the multidisciplinary team.

Regarding coping strategies aimed at spirituality, another study, carried out in Iran\textsuperscript{16}, showed that the side effects most present in people with SCI are anxiety and depression. In this scenario, spirituality becomes fundamental for moderating such effects, as patients with greater spiritual support have higher levels of existential well-being and lower levels of anxiety and depression. This study has a peculiarity due to the strong influence of Islamic beliefs in these people's lives, which leads to positive thoughts and better mental health.

In this context, it is believed that nurses can act interactively with the patient to minimize negative feelings and conditions such as denial and stress. Based on this need, it is essential to create a bond with the patient through communication to identify the nursing diagnoses related to the individual needs of patients with spinal cord injury to establish actions that can foster the individual's ability to use coping strategies correctly.

Although this research comprised a period of ten years, it is suggested that more comprehensive studies be carried out on the subject, using other sources of evidence not included in the construction of this review, which constitutes a limitation.
A good family functioning of people with SCI was found, based on self-reports, but with weaknesses in the family composition, especially in aspects related to the caregiver and external relatives. Coping strategies used by people with SCI include problem-focusing, and strategies focused on positive reappraisal, helplessness, and spirituality.

From this perspective, the need for social support for people with SCI and their families is highlighted, as well as tools for emotional coping, aiming at quality care. Nursing care defines the rehabilitation process of these individuals and should consider the main findings discussed here, including the subject as a whole, considering his physiological and psychosocial needs.

Such evidence can impact the performance of nurses when considering coping strategies and family functioning in the context in which care takes place, whether in primary or high-complexity care, culminating in a holistic care delivery to patients with SCI.

Regarding bibliometric aspects, it was observed that most studies were observational, cross-sectional, and with insufficient scientific evidence, generating a relative limitation for generalizable inferences.

CONTRIBUTIONS

All authors contributed to the completion of the integrative review study, from conception to writing the final manuscript.

CONFLICT OF INTERESTS

Nothing to declare.

REFERENCES


Correspondence
Mayara Araujo Rocha
E-mail: mayararj83@gmail.com

Submission: 05/13/2020
Accepted: 05/13/2021

Copyright © 2021 Journal of Nursing UFPE on line/JNUOL. This is an open access article distributed under the CC BY 4.0 assignment Creative Commons Attribution-ShareAlike 4.0 International License, which allows others to distribute, remix, adapt and create from their work, even for commercial purposes, as long as they give it due credit for the original creation. It is recommended to maximize the dissemination and use of licensed materials.