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Review Article

Exploring the needs of the family caregiver of persons with spinal cord injury: An integrative review

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ABSTRACT

Background & Aim: A spinal cord injury is a critical event that results in significant life changes for the injured person and the family and caregiver. This study aimed to identify and describe the primary needs of family members that are caregivers of patients with spinal cord injuries.
Methods & Materials: An integrative review study was conducted. The studies were collected from five databases, with no time limit until December 2021: MEDLINE® (Medical Literature Analysis and Retrieval System Online), CINAHL® (Cumulative Index to Nursing and Allied Health Literature), Psychology and Behavioural Sciences Collection, SCOPUS, SciELO (Scientific Electronic Library Online). The inclusion criteria for the accessed literature were: adults over 18 years of age who are caregivers of individuals with spinal cord injury; encompassing all the existing needs experienced by caregivers; including care recipients over 18 years old and who spinal cord injury patients are; and primary studies published without time limit. We performed a synthesis of the contents with an a priori categorization.
Results: The search resulted in 1018 bibliographic records. A total of 17 articles published between 1981 and 2020 that met the inclusion criteria were selected. The priority categorization process resulted from the study by Fernandes and Angelo in the following five thematic areas: the transition to care, being responsible for everything, the importance of support, access to formal support, communication, and information processes.
Conclusion: Family caregivers are important to support people with spinal cord injury, and they present numerous needs that should be the target of intervention by nurses at all stages of rehabilitation.

Introduction

Spinal cord injury (SCI) corresponds to a critical event that is sudden and unexpected, which causes the affected individual changes in the anatomical or physiological structure of the spine or spinal cord (1). This result in varied consequences in the sensory and/or motor control of the main body segments including the trunk and upper and lower limbs, as well as other activities of reflex function (1). All these changes result in decreased functional capacity, decreased perceived quality of life, and, mainly, dependence on other people to perform self-care and activities of daily living (2, 3).

The patient's family also experiences an abrupt change in their life, often becoming the caregiver with the greatest burden attributed to the task of providing care to the patient (1). This unpremeditated function requires the acquisition of new knowledge and specific skills to care for an individual with SCI, namely, bladder care (intermittent vesical catheters), bowel care, breathing, skincare, and adaptation to the surrounding environmental conditions. In addition, all the

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previous tasks inherent to the remaining family roles are added (4-6).

SCI corresponds to a critical and devastating pathological event, causing tragic consequences for the individual, their family, or significant elements of the social network, as well as for the society in which he belongs. (1, 3). The family members of these patients are the main actors in the provision of care for the individual with SCI, requiring them to carry out a greater load of tasks than other caregivers in the general population (7).

Caregivers face significant difficulties adapting to their role, as the acquisition of complex skills is required (8). Also, it is a role that lasts over time, in which the degree of difficulty increases with the aging (1, 8).

One previous study divided the transition processes of these caregivers into three integral stages, which accompany the caregiver's progression from the rehabilitation phase through hospital discharge and then integration to domestic environment; calling this process the caregiver metamorphosis (1). Caregivers of individuals with SCI need a lot of support due to the burden they are exposed to, such as the appearance of new tasks and new needs (8). This path results in developing a new identity with new responsibilities (3). In addition, rehabilitation services focus on the self-management of individuals with SCI, with limited attention being given to the needs of family caregivers (8). The transition into the caregiver role is complex and incorporates different needs throughout the process. Five thematic areas were identified by these authors in a review, about different caregivers, like a transition into care, being responsible for everything, the importance of support, access to formal support, communication, and information in decision-making processes (9).

The beginning of transition process to the role of caregiver occurs during the patient's hospitalization and is a difficult and long process (1). Transitioning into the role of being a caregiver for a dependent person is a complex process that involves many variables (9).

The feeling of being responsible for everything is a fundamental characteristic that caregivers’s experience, stringing together various needs and weighing on caregivers (9), creating a burden (3). Also, caregivers refer to the importance of support related to emotional and interpersonal needs and the importance of access to formal related to Social needs, support network for caregivers, and financial and structural support (9). Lastly, communication between health care professionals and caregivers is crucial, especially for those new to this role. Therefore, we consider that this could be a way to synthesize the analysis of the results we could find in this review about.

Given the complexity of this transition and the existence of little knowledge about this subject, we carried out this review. It should be noted that, by knowing the caregiver's needs, it is possible to raise awareness of the importance of prioritizing the caregiver in the intervention plan of nurses because supporting the caregiver promotes health and prevents illnesses in the care receiver. At the heart of identifying and clarifying the needs of family caregivers of patients with SCI, it is essential to locate and understand what exists in the literature on this subject. Thus, we performed an integrative review to identify and describe the primary needs of family members that are caregivers of patients with spinal cord injuries.

Methods

Review Design

This review study was carried out using Whittemore and Knafl's integrative review method (10). The integrative review method is the only approach that allows for the combination of diverse methodologies and has the potential to play a greater role in evidence-based practice for nursing. This review method has the potential to allow for diverse primary research methods to become a greater part of evidence-based practice initiatives (10).

The research question was formulated by choosing the mnemonic PCC (Population, Concept, and Context) (11). The inclusion criteria for the accessed literature were: Population: adults over 18 years of age and who are caregivers of individuals with SCI; Concept: encompassing all the existing needs experienced by caregivers; Context: including care recipients over 18 years old and who are SCI patients; Publication date: Primary studies published without time limit; Language in Portuguese, English, and/or Spanish; All types of research methodology were included.

As exclusion criteria, studies were excluded if the samples of individuals presented other main pathologies other than the spinal cord lesion. Next, articles were further removed where caregivers were under 18 years of age. Then, the concepts referring to population, concept, and context were isolated along with a defined set of synonyms and related terms that, when included, would enrich and express the obtained research better.

We perform the Boolean search phrases according to the descriptors of the respective databases.Other free terms were added to increase the number of variations of each term using the "*" technique along with non-indexed terms. These strategies ensure systematic quality in the search technique (12,13).

In December 2021, a detailed search was carried out in the "EBSCOhost Web" content aggregator, using the electronic databases: "CINAHL® Complete,"; "Psychology & Behavioural Sciences Collection,"; "Medline (MEDLINE with Full Text)." Additionally, a search was carried out in the reference databases: SCOPUS and SCIELO. For each database, the following phrases were constructed, as shown in Table 1. In addition, additional studies were searched for in the reference lists of all publications included through "Backward citation searching, but without results.

Table 1. Boolean phrases in each database

Database	**Search strategy**
CINAHL®	_(((MM "Caregivers") OR (MM "Parents") OR (MM "Spouses")(MM "Significant other") OR (MM "Family") OR (MM "Extended Family") OR ("Caregiver*) OR ("Family") OR ("Parents") OR ("Spouse*") OR ("Care provider*") OR ("Care giver*") OR ("caretake*") OR ("Family caregiver*") OR ("Family members") OR ("Informal caregiver*") OR ("non-professional caregiver*") OR ("partner-caregiver") OR ("Relatives caregivers") OR ("Spouse caregiver*") OR ("Extended Family") ("Families") OR ("Parents caregiver*) OR ("Relatives") OR ("significant other")) AND ((MH "Needs Assessment") OR (MM "Health Services Needs and Demand") OR (MM "Respite Care") OR (MM "Caregiver Burden") OR (MH"caregiver support") OR (MH"information needs") OR (MH "Support, Psychosocial") OR ("Social Support") OR ("Psychosocial Support") OR ("Need* Assessment") OR ("Need*") OR ("Health Services Needs and Demand") OR ("Respite Care") OR ("Caregiver Burden") OR ("Burnout, Psychological") OR ("Caregiver Support") OR ("burnout") OR ("strain") OR ("Support need*") OR ("burden") OR ("care needs assessment") OR ("Health Services Needs") OR ("Need* of Education") OR ("Need* of training") OR ("Need* of support") OR ("Need* of Information") OR ("Training") OR ("Support") OR ("education") OR ("information") OR ("information needs") OR ("Support, Psychosocial")) AND ((MM "Wheelchairs") OR (MH "Spinal Cord Injuries") OR (MM "Spinal Cord Diseases") OR (MH "Paraplegia") OR (MM "Quadriplegia") OR ("Spinal Cord Injur*") OR ("Wheelchair*") OR ("Spinal Cord Diseases") OR ("Paraplegia") OR ("parapleg*") OR ("Spinal cord surgery") OR ("Spinal Cord Damage") OR ("tetrapleg*") OR ("Quadriplegia") OR ("Quadriplegi*")))_
Medline	_(((MM "Family") OR (MM "Caregivers") OR (MM "Parents") OR (MM "Spouses") OR ("Caregiver*) OR ("Family") OR ("Parents") OR ("Spouse*") OR ("Care provider*") OR ("Care giver*") OR ("caretake*") OR ("Family caregiver*") OR ("Family members") OR ("Informal caregiver*") OR ("non-professional caregiver*") OR ("partner-caregiver") OR ("Relatives caregivers") OR ("Spouse caregiver*") OR ("Extended Family") ("Families") OR ("Parents caregiver*) OR ("Relatives") OR ("significant other")) AND ((MH "Needs Assessment") OR (MM "Social Support") OR (MH "Psychosocial Support") OR (MM "Health Services Needs and Demand") OR (MM "Respite Care") OR (MM "Caregiver Burden") OR (MM "Burnout, Psychological") OR ("Social Support") OR ("Psychosocial Support") OR ("Need* Assessment") OR ("Need*") OR ("Health Services Needs and Demand") OR ("Respite Care") OR ("Caregiver Burden") OR ("Burnout, Psychological") OR ("Caregiver_

	Support”) OR (“burnout”) OR (“strain”) OR (“Support need*”) OR (“burden”) OR (“care needs assessment”) OR (“Health Services Needs”) OR (“Need* of Education”) OR (“Need* of training”) OR (“Need* of support”) OR (“Need* of Information”) OR (“Training”) OR (“Support”) OR (“education”) OR (“information”) OR (“information needs”) OR ("Support, Psychosocial")) AND ((MM "Wheelchairs") OR (MH "Spinal Cord Injuries") OR (MM "Spinal Cord Diseases") OR (MH "Paraplegia") OR (MM "Quadriplegia") OR ("Spinal Cord Injur*") OR (“Wheelchair*”) OR ("Spinal Cord Diseases") OR ("Paraplegia") OR (“parapleg*”) OR (“Spinal cord surgery”) OR (“Spinal Cord Damage”) OR (“tetrapleg*”) OR ("Quadriplegia") OR ("Quadriplegi*")))
Psychology & behavioural sciences collection	(((DE "Caregivers") OR (DE "Parents") OR (DE "Spouses") OR (DE "Significant others") OR (DE "Families") OR (DE "Extended Families") OR (DE ”Relatives”) OR (“Caregiver*) OR ("Family") OR ("Parents") OR ("Spouse*") OR (“Care provider*”) OR (“Care giver*”) OR (“caretake*”) OR (“Family caregiver*”) OR (“Family members”) OR (“Informal caregiver*”) OR (“non-professional caregiver*”) OR (“partner-caregiver”) OR (“Relatives caregivers”) OR (“Spouse caregiver*”) OR (“Extended Family”) OR (“Families”) OR (“Parents caregiver*) OR (“Relatives”) OR (“significant other”)) AND ((DE "Needs Assessment") OR (DE”information needs”) OR (DE”Burden of Care”) OR (DE "Caregiver Education”) OR ("Social Support") OR ("Psychosocial Support") OR ("Need* Assessment") OR ("Need*”) OR ("Health Services Needs and Demand") OR ("Respite Care") OR ("Caregiver Burden") OR ("Burnout, Psychological") OR (“Caregiver Support”) OR (“burnout”) OR (“strain”) OR (“Support need*”) OR (“burden”) OR (“care needs assessment”) OR (“Health Services Needs”) OR (“Need* of Education”) OR (“Need* of training”) OR (“Need* of support”) OR (“Need* of Information”) OR (“Training”) OR (“Support”) OR (“education”) OR (“information”) OR (“information needs”) OR ("Support, Psychosocial")) AND ((DE "Wheelchairs") OR (DE "Spinal Cord Injuries") OR (DE "Spinal Cord Diseases") OR (DE "Paraplegia") OR (DE "Quadriplegics") OR (DE “Spinal cord surgery”) OR (DE "Paraplegics") OR ("Spinal Cord Injur*") OR (“Wheelchair*”) OR ("Spinal Cord Diseases") OR ("Paraplegia") OR (“SCI”) OR (“parapleg*”) OR (“Spinal cord surgery”) OR (“Spinal Cord Damage”) OR (“tetrapleg*”) OR ("Quadriplegia") OR ("Quadriplegi*")))
SCOPUS	(TITLE-ABS-KEY((“Caregiver) OR ("Family") OR ("Parents") OR ("Spouse") OR (“Care provider”) OR (“Care giver*”) OR (“caretake”) OR (“Family caregiver”) OR (“Family members”) OR (“Informal caregiver”) OR (“non-professional caregiver”) OR (“partner-caregiver”) OR (“Relatives caregivers”) OR (“Spouse caregiver”) OR (“Extended Family”) (“Families”) OR (“Parents caregiver) OR (“Relatives”) OR (“significant other”)) AND TITLE-ABS-KEY (("Social Support") OR ("Psychosocial Support") OR ("Need Assessment") OR ("Need”) OR ("Health Services Needs and Demand") OR ("Respite Care") OR ("Caregiver Burden") OR ("Burnout, Psychological") OR (“Caregiver Support”) OR (“burnout”) OR (“strain”) OR (“Support need”) OR (“burden”) OR (“care needs assessment”) OR (“Health Services Needs”) OR (“Need of Education”) OR (“Need of training”) OR (“Need of support”) OR (“Need of Information”) OR (“Training”) OR (“Support”) OR (“education”) OR (“information”) OR (“information needs”) OR ("Support, Psychosocial")) AND TITLE-ABS-KEY (("Spinal Cord Injurie") OR (“Wheelchair”) OR ("Spinal Cord Diseases") OR ("Paraplegia") OR (“paraplegic”) OR (“Spinal cord surgery”) OR (“Spinal Cord Damage”) OR (“tetraplegic”) OR ("Quadriplegia") OR ("Quadriplegic")))
SCIELO	(TITLE-ABS-KEY((“Caregiver) OR ("Family") OR ("Parents") OR ("Spouse") OR (“Care provider”) OR (“Care giver*”) OR (“caretake”) OR (“Family caregiver”) OR (“Family members”) OR (“Informal caregiver”) OR (“non-professional caregiver”) OR (“partner-caregiver”) OR (“Relatives caregivers”) OR (“Spouse caregiver”) OR (“Extended Family”) (“Families”) OR (“Parents caregiver) OR (“Relatives”) OR (“significant other”)) AND TITLE-ABS-KEY (("Social Support") OR ("Psychosocial Support") OR ("Need Assessment") OR ("Need”) OR ("Health Services Needs and Demand") OR ("Respite Care") OR ("Caregiver Burden") OR ("Burnout, Psychological") OR (“Caregiver Support”) OR (“burnout”) OR (“strain”) OR (“Support need”) OR (“burden”) OR (“care needs assessment”) OR (“Health Services Needs”) OR (“Need of Education”) OR (“Need of training”) OR (“Need of support”) OR (“Need of Information”) OR (“Training”) OR (“Support”) OR (“education”) OR (“information”) OR (“information needs”) OR ("Support, Psychosocial")) AND TITLE-ABS-KEY (("Spinal Cord Injurie") OR (“Wheelchair”) OR ("Spinal Cord Diseases") OR ("Paraplegia") OR (“paraplegic”) OR (“Spinal cord surgery”) OR (“Spinal Cord Damage”) OR (“tetraplegic”) OR ("Quadriplegia") OR ("Quadriplegic")))

The identified articles were analyzed by the authors using the Rayyan® platform. The evaluation and selection process of the studies was carried out independently by two researchers. A third investigator resolved any disagreements. All these processes were documented by the researchers, verifying the choices of studies for inclusion in the integrative review through the use of the PRISMA flowchart (Preferred Reporting Items for Systematic Reviews and Meta-Analyses), integrating the total of articles collected, analyzed, and selected (12,13).

Analysis and evaluation of studies

A careful review of the content of the articles was performed, presented in a table format with the categorization of the most important content for the review: author; year; study site; study objectives; study type; data collection instrument; population/sample–highlighting the characteristics of caregivers and care, recipients, which stage after SCI was, finally, the reported needs.

To facilitate the presentation and discussion of the different needs listed in the different studies, we used the à priori categories proposed in the study developed by the present authors on “Family caregivers: what do they need?” (9), like the transition to care, being responsible for everything, the importance of support, access to formal support, communication and information processes. Through the a priori categories, it was possible to identify and synthesize common elements in all research results. The subthemes resulted from the content analysis of the main needs identified within each category. These data resulted from the needs identified in table 2.

Results

The search resulted in 1018 bibliographic records. After excluding duplicates and screening and excluding irrelevant studies, the full texts of 31 studies were analyzed; 14 studies were excluded, and 17 were included as the final sample. The authors followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) reporting guidelines throughout the article and used the PRISMA flowchart to summarise the steps taken throughout the research process (Figure 1).

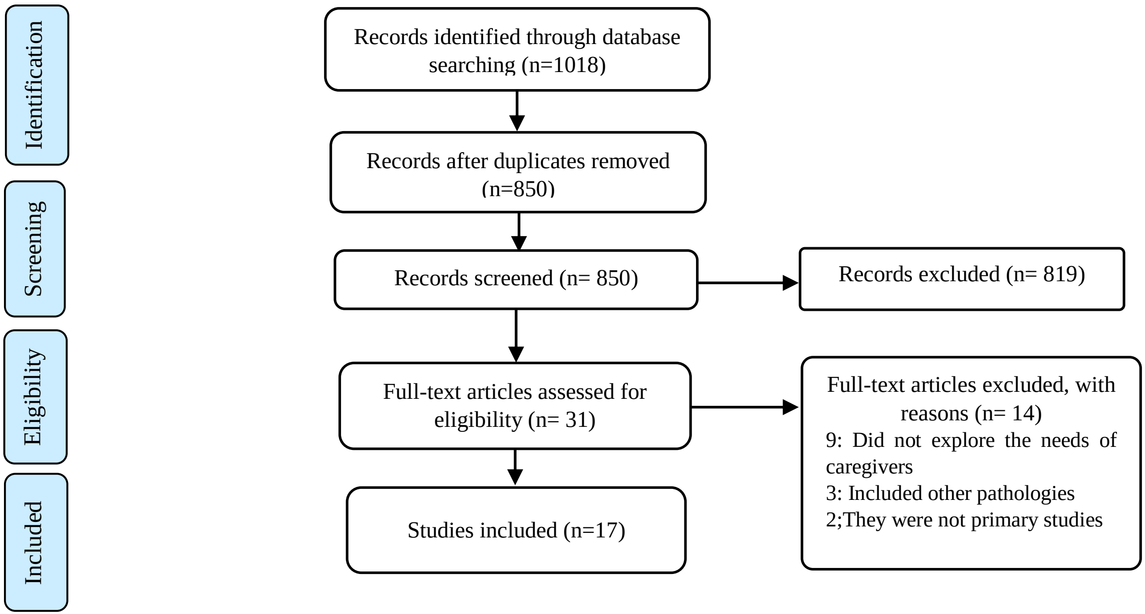

Figure 1. PRISMA flow diagram: Process of identification and inclusion of articles

Characterization of the included studies

Table 2 summarises the characteristics of the studies included in the review, with regard to authors, year, country, study design, study objective, participants, SCI phase, needs, and JBI score. In order to facilitate the presentation and discussion of the results, the articles were coded from E1 to E17 (1, 3, 7, 8, 14-26).

The articles selected for integrative review are all published in multidisciplinary scientific journals; however, those in the clinical area of rehabilitation and specific to SCI stand out in numerical superiority. The publications are distributed on a time scale between 1981 and 2020; it should be remembered that the research was carried out without a time limit. The studies concentration is higher from 2010 to 2020, with a total of 8 publications.

When evaluating the articles using the JBI analysis grids, articles of relevant methodological quality were obtained, given the score obtained in each one (Table 2). Of note, almost all articles have relevant methodological quality, with scores above the average value. Study designs were primarily qualitative (n=8) or cross-sectional studies (n=7).

Table 2. Characteristics of included studies (n=17)

Code	Authors, year, country	Study design	Aim of the study	Participants	SCI phase	Needs
E1	Gemperli, Rubinelli, Zanini, Huang, Brach, & Pacheco, (2020) Switzerland	Cross-Sectional Study	Describe the living situation of family caregivers of persons with spinal cord injury	717 Family caregivers	Chronic phase, injury with more than 2 years, occurred on average 17.5 years ago	**Information needs**_about care activities in the health area (34%), followed by how to adapt the housing (26%) and about financial support (22%). The main sources of information entrusted were family medicine physicians (29%), while support groups had a lower percentage.
E2	Diviani, Zanini, Jaks, R., Brach, M., Gemperli, A., & Rubinelli, S. (2020) Switzerland	Cross-Sectional Study	Examine the information-seeking behaviour and health literacy of caregivers of individuals living with spinal cord injury in Switzerland and their impact on the caregiving experience.	717 Family caregivers	Chronic phase, injury on average 18.5 years ago	**Information needs**_on general health-related topics 195 (67.2) home adaptation 143 (49.3), finance, health insurance 135 (46.6), auxiliary equipment and devices 125 (43.1), caregiver and services of assistance 79 (27.2)
E3	Rodríguez, Ríos, Hermoso, Alonso, Costa, & Agea. (2020) Spain	Quasi-experimental Study	Evaluate the knowledge that family caregivers of individuals with spinal cord injuries acquired through the use of a high-fidelity simulation-based learning (SBL) program	10 Family caregivers	Acute phase occurred on average 7 months ago	**Learning needs** of family caregivers: Training and learning needs for family caregivers: domain of neurogenic bladder management; prevention of urinary infections; neurogenic bowel management; care of the upper airway (in the case of tracheostomised patients); Secretion aspirations; mobilisation and prevention and treatment of pressure ulcers; surveillance and detection of common disease complications of SCI (autonomic dysreflexia, spasticity and respiratory infections).
E4	Jeyathevan, Cameron, Craven, & Jaglal. (2019) Canadaa	Qualitative study	Determine the breadth of skills needed by family caregivers to enhance their competency in caring for individuals with SCI living in the community.	Individuals with SCI spinal cord injury (n= 19) and their family members (n= 15)	Chronic phase, mostly play their role for over 10 years, the rest play their role between 6 months to 2 years	29 SCI family care skills were identified and grouped into 6 care processes signifying the multiple dimensions required of SCI care: 1-Monitoring and management of physical health and prevention of disease complications 2-Provide psychosocial needs 3-Decision making 4-Time management 5-Be flexible (housing management, learning from mistakes, finding alternatives for care) 6-Navigating the health and social services system
E5	Rodriguez, Rios, Costa, Hermoso, Alonso, Agea (2018) Spain	Qualitative study	Evaluate the knowledge that family caregivers of individuals with spinal cord injuries acquired through the use of a high-fidelity simulation-based learning (SBL) program	16 Familiares caregivers and 7 health professionals	Acute Phase and Chronic Phase Injury occurred on average 7.6 years ago	Caregiver needs during the rehabilitation phase: 1. Social support 2. Economic support 3. Psychological support 4. Information needs 5. Need for care training
E6	Pullin, & McKenzie. (2017) Australia	Qualitative study	Explore long-term family carers' perceptions of how they are currently supported by health and other community-based social services	11 Family caregivers	Chronic phase, caregivers play their role between 8 and 33 years old	Findings on the experience, perceptions, and support needs of family carers 1. Formal support 2. The need to be heard and recognised 3. Health services and safety 4. Active support 5. Emotional support from formal service provide 6. Informal supports 7. The need for medical knowledge and practical support 8. Emotional support and social isolation 9. Peer support

E7	Conti, Garrino, Montanari, & Dimonte. (2015) Italy	Quallitative study	Explore the situation of informal caregivers of persons with SCI when discharged home from a SCI Unit, in relation to needs, emotional experiences, difficulties and subsequent reactions to discharge	11 Family caregivers	Acute phase, interviews conducted before discharge and 6 months after discharge	Data analysis led to the identification of five thematic areas: 1. Coping with changing perspectives 2. Search for a reference 3. Changing role identities 4. Hope for the future 5. Modifications to everyday
E8	Lucke, Martinez, Mendez, & Arevalo-Flechas, (2013) USA	Quallitative study	Describe the experiences and identify the support needs of family caregivers of patients with SCI, in terms of information, decision-making, interpersonal, and resources, during the first two years after discharge from the rehabilitation service.	9 Family caregivers	Acute and chronic phase, caregivers have been playing their role for less than 2 years	"Resolving to go forward" was the core category that emerged from two simultaneous processes of "learning to care for" and "getting through" during the initial years as the primary informal caregiver. The majority of the caregivers reported feeling alone and abandoned after the person with SCI went home.
E9	Arango-Lasprilla, Plaza, Drew, Romero, Pizarro, Francis, & Kreutzer. (2010) Colombia	Cross-Sectional Study	1) To determine the most frequent needs in a group of family caregivers of individuals with spinal cord injury in Neiva Colombia; 2) to describe caregivers' psychosocial functioning; and 3) to examine the relationship between caregiver needs and caregiver psychosocial functioning.	37 Family caregivers	Chronic phase: injury on average 12 years ago	The results showed that information, economic, emotional, community support and rest needs were among the most frequently reported needs. 1. Information Needs 4.07 (1.08) 2. Economic Support Needs 3.67 (1.29) 3. Emotional Support Needs 3.52 (0.84) 4. Community Support Needs 3.32 (0.91) 5. Respite Needs 3.17 (0.82) 6. Physical Needs 2.96 (0.99) 7. Sleep Needs 2.88 (1.05) 8. Household Help Needs 2.68 (0.92) 9. Psychological Support Needs 2.56 (0.63)
E10	Chen, & Boore. (2008) Taiwan	Qualitative study	Explored family carers' experiences of taking care of a relative who has a spinal cord injury	15 Family caregivers	Chronic phase: selected caregivers who have performed their role for more than 1 year	The findings resulted in the core category "living with a relative who has a spinal cord injury" and identified the "experience of taking care for a relative who has a spinal cord injury". Three stages were identified, including four categories: stage 1 'A catastrophic life event'; stage 2 'Confronting challenges'; and stage 3 'Family resilience' or 'Family breakdown'.
E11	Ellenbogen,. Meade, Jackson, & Barrett. (2006) [19] USA	Qualitative study	Describes and explores the impact of spinal cord injury (SCI) on the employment of family members, especially those who act as primary caregivers, of individuals with SCI	9 Family caregivers	Chronic phase, critical event occurring between the first year and more than 10 years.	Four primary themes emerged from our study: 1. Caregivers had to create flexibility in their employment situation in order to successfully maintain employment, especially immediately after the injury; 2. Family caregivers struggled to balance work, caregiving responsibilities, and their own, personal needs; 3. Responsibilities left little time for the caregivers to engage in leisure, maintain social connection, spend time with their spouse, or take time to care for their own personal needs: 4. Caregivers' employment was affected by the lack of available Certified Nursing Aides.
E12	Boschen, Tonack, & Gargaro. (2005) [20] Canada	Mixed method study	Examine the personal impact of being a support provider (SP) to a community-dwelling person with a spinal cord injury (SCI). S	Caregiver: Quantitative sample (n=100) Qualitative subsample (n=41)	Chronic phase: caregivers lasting between 1 to 7 years	The needs that the sample of participants defined as being best met were: relationship with their families (77%); having and raising children (72%); comfort materials or resources (70%, ranking 12th in importance). It should be noted that at least a third of the sample (33%) classifies that their needs were not met in these areas
E13	Post, Bloemen, & De Witte. (2005) Holand	Cross-Sectional Study	Describe the support given to persons with spinal cord injuries (SCI) by their partners, (2) Describe the perceived burden of support by partners and (3) examine predictors of perceived burden of support.	461 persons with SCI and 265 couples	Chronic phase, injury on average 13.2 years ago	Needs for support, information, support groups or couple therapy are highlighted. Caregivers report a greater need for telephone consultation; home visit; caregiver support groups; nursing support, and cleaning services.

E14	Meade, Taylor, Kreutzer, Marwitz, & Thomas. (2004) USA	Cross-Sectional Study	Evaluate the perceived importance of family needs and the extent to which needs were met.	17 Family caregivers	Acute phase, injury on average 45 days ago	Needs most often rated as not met are: To have my questions answered honestly. (mean=4.00) To have complete information on the patient's physical problems. (mean= 3.94) To have complete information on the medical care of traumatic injuries. (mean= 3.94) To be assured that the best possible medical care is being given to the patient. (mean=3.88) To have explanations from professionals given in terms I can understand. (mean=3.88) To have a professional to turn to for advice or services when the patient needs help. (mean=3.88) To have complete information on the patient's problems in thinking. (mean= 3.82) To have different professionals agree on the best way to help the patient. (Mean=3.82) To be told about all changes in the patient's medical status. (mean=3.82) To have enough resources for myself or the family. (mean=3.81)
E15	Weitzenkamp, Gerhart, Charlifue Whiteneck, & Gordana. (1997) USA	Cross-Sectional Study	To better understand the needs of spouses who provide care to spinal cord injury (SCI) survivors, by comparing their self-perceptions and complaints with those of their partners with disabilities and with those of spouses who do not provide care.	124 spouses of individuals with SCI	Chronic phase, SCI occurred on average 30.2 years ago	Individual Needs Percent reporting "very important" Relationships with family (63.4%) Health and safety (77.2%) Relationship with spouse/lover (80.3%) Having children (62.6%)
E16	Stanton. (1984) USA	Cross-Sectional Study	Examine the physical and psychological needs of caregivers of individuals with SCI	10 Family caregivers	It is not clear	Psychosocial needs were classified as "Important or Very Important": As for the needs of health professionals, caregivers describe the importance of acceptance by health professionals and the demonstration of concern as "very important"; Half of the caregivers describe the need and relevance of talking to the same nurse and getting to know the whole team (availability for contact); obtain concern from professionals. Still, 70% of the participants need to communicate about the patient's treatment, care and progress, classifying it as "very important and important". 90% of the participants describe communication with other professionals who help with finances, religion and family problems as "important or very important".
E17	Hart. (1981) Canada	Quallitative study	Determine the needs and anxieties of significant elements of patients with SCI	7 Relatives	Acute phase, recent injury	Needs were categorised into eight areas: Need to feel adequately informed, Need to feel helpful to the client, Need to feel able to cope with home and family responsibilities, Need for emotional support, Need to express feelings, Past experience and methods of coping with crisis situations, Need to deal with major future effects of clients' injury, Need to feel that client is getting good care.

Participant characteristics

Analyzing the profile of caregivers in the selected studies, most were female, being wives or parents of the care recipient, with a mean age between 43.9 and 59.1 years. About the educational qualifications of the participants, it was identified that the majority had an education level at or above the secondary level, except in developing countries (18).

With regard to hours of care provided, articles E2 (14) and E9 (18) include this information, reporting that between 9 and 80 hours a week (3–11.4 hours a day) per week were spent providing care. In study E12 (21), 39% of participants do not provide personal care to the care recipient; and 12% spend around 9 hours per week. In article E13 (22), most caregivers help their family members “often” or “always.”

Characterizing the profile of participants with SCI in the selected studies, males predominate in all studies. It was identified that the person with paraplegia prevails over the person with quadriplegia. Participants had mostly complete injuries, resulting in moderate or high dependence on caregivers, and were mainly in the chronic phase (5 to 30.2 years after SCI).

Table 3. Needs of participants: Themes and subthemes identified in this review

Themes	Subthemes
The transition to care	Home adaptationE1, E2, E4
	“Learning to care for” E3, E5, E8, E10
	Dealing With Changing Perspectives E4, E7,E11
	“Getting through” E7, E8
	Hope for the future E7
	“Resolving to go forward” E8
Being responsible for everything	Decision making E4
	Time management E4
	Changing Role Identities E7, E17
	Sleep and rest need E9
	Role modifications E11
	Take care of yourself E9, E11
The importance of support	Emocional support E4, E5, E6, E17
	Family relationships E7, E13, E15, E17
	Support from informal caregivers E6, E13
Access to formal support	Health and safety services E2, E4, E6, E9, E11, E13, E14, E15, E17
	Social and community support E5, E9, E14
	Financial support E1, E5, E2, E9
	Auxiliary equipment and devices E2, E12
	Auxiliary equipment and devices E9, E13
Communication and information processes	Information needs E1, E2, E4, E6,E5, E9,E13, E14, E17
	Communication with a healthcare professional E7, E14, E16,
	The need to be recognized by professionals E6, E16

Needs of the caregivers

To facilitate the presentation and discussion of the different needs listed in the different studies, we used the categories created a priori (9), resulting in five thematic areas (Table 3): the transition to care, being responsible for everything, the importance of support, access to formal support, communication and information processes. Each thematic area will be addressed with more depth in the discussion. The subthemes resulted from the content analysis of the main needs identified within each category. These data resulted from the needs identified in table 2.

In the thematic “transition to care,” the following sub-themes were identified: Home adaptation, learning to care for, dealing with changing perspectives, getting through, hope for the future, and resolving to go forward. On the topic of “being responsible for everything,” we found the sub-themes: time management; changing role identities, sleep and rest needs; role modifications, and taking care of yourself. Subthemes were identified in the theme “the importance of support,” emotional support, family relationships, and support from informal caregivers. On the theme of “access to formal support,” with a significant number of studies, we found the following sub-themes: Health and safety services; Social and community support; Financial support; Auxiliary equipment and devices; Auxiliary equipment and devices. Finally, the "communication and information processes" theme with these subthemes: health and safety services; social and community support; financial support; auxiliary equipment and devices; auxiliary equipment and devices.

Discussion

This study is the first review that identifies and describes the main needs of caregivers of spinal cord injuries. Family members are usually the most important caregivers for a person with SCI, and although they constitute a large support group, little is known about their needs (7, 17). We analyze the results of the 17 studies. The prior categorization process resulted in the following five thematic areas: the transition to care, being responsible for everything, the importance of support, access to formal support, communication, and information processes (Table 3).

The transition to care

The transition to the role follows the caregiver's progression from the beginning of the rehabilitation of their sick family member through hospital discharge and then integration and return to the family and home environment (1, 27). The transition to this role takes place over three stages. The three stages were identified as stage 1, ‘A catastrophic life event’; stage 2, ‘Confronting challenges’; and stage 3, ‘Family resilience’ or ‘Family breakdown’ (19). This process has been called caregiver metamorphosis (1). This concept of transition is visible in the sub-theme “getting through” (E7, E8) (3, 17) and “Resolving to go forward” (E8) (17).

To care independently, the caregiver needs to acquire new knowledge and skills in the domain of self-care to satisfy all activities of daily living (9), as observed in the sub-theme “learning to care for” (E3, E5, E8, E10) (1, 15, 17, 11). The metamorphosis/transition phase that the caregiver experiences generate the needs for knowledge and skills related to the care of the individual with SCI (8, 26).

Caregivers report training and learning needs about neurogenic bladder, urinary infection prevention, neurogenic bowel; care of the upper airway (in the case of tracheostomised patients), aspiration of secretions, mobilization and prevention and treatment of pressure ulcers, surveillance, and detection of complications (autonomic dysreflexia, spasticity, respiratory infections, among others) (8, 15). These skills are learned mainly during a more acute phase, that is, less than a year after the critical event (E3, E5, E8) (1, 15, 17, 23).

Another aspect mentioned by the authors is the need to transform and adapt housing (E1, E2, E4) (7, 8, 14). It is necessary to orchestrate various renovation projects, such as the double width of the doors, access ramps, and renovated bathrooms, among others (E4). This transition process implies a change of perspectives (E4, E7, E11) (3, 7, 8, 20), namely the caregivers need to create flexibility in their employment situation to keep their job successfully, especially immediately after the injury (E11) (20), as well as throughout the metamorphosis, to keep hope for the future (E7) (3).

Being responsible for everything

The feeling of being responsible for everything represents a characteristic of the caregivers' experience, linking various needs (9), including changes in roles (E11) (20). Family caregivers struggle to balance work, care responsibilities, and their own personal needs (E11, including sleep and rest (E9)) (18), and taking care of themselves (E11) (improve their own physical health (E9)) (20). Caregivers need to integrate new tasks and new needs and redefine behaviors from prior to the critical event (8), which adds to the previous family and social roles (3).

Responsibilities leave little time for caregivers to devote themselves to leisure, maintain social connections, spend time with their spouses, or take time to take care of their own personal needs (E11) (20). Time management needs are related to using time effectively and productively to perform the various care tasks assigned to it E4 (8). The need to try to handle a variety of tasks simultaneously weighs heavily on caregivers (9), in addition to the responsibility in the decision-making process (E4) (8).

Caregivers affirm changes in identity and function (E7, E17) (3, 26), experiencing a new role after injury. The new role is not just about affective spheres but also about essential everyday things that take on a new form (E17) (26).

The importance of support

Emotional and interpersonal support plays a decisive role in adapting and exercising the role of caregiver, namely, being able to count on someone to vent and obtain recognition or validation for the effort of caring by friends and family are described as fundamental (9). In addition, caregivers need emotional support to express their feelings, look for words of comfort and understanding, and have someone to talk to (E4, E5, E6, E17) (1, 8, 16, 26).

The family's need is one of the needs most highlighted by several authors, whereby can be considered a facilitator throughout the process (16,29), where the help of the family in caring tasks is a fundamental element of support, especially from wives (16, 17, 19).

The need for support groups is also mentioned and considered essential for caregivers to fight social isolation, sharing feelings and difficulties with family members or people who have had similar experiences (16, 18, 26).

In the context of family relationships, needs are reflected as a couple, namely in the couple's sexuality and fertility (E13, E15, E7, E17) (3, 22, 24, 26). There are difficulties related to the physical sphere and sexuality, which contrasts with the tendency to build a symbiotic relationship at a psychological and relational level. The complex situation experienced by the participants leads them to naturally develop high emotional stress that only increases their uncertainty (E7) (3).

Access to formal support

The use of and access to formal support is crucial for an effective transition to the role of caregiver (9) because with these, it is possible to obtain health and safety services (E2, E4, E6, E9, E11, E13, E14, E15, E17) (8,14,16,18,20,22-26), social and community support (E5, E9, E14) (1,18, 23), financial support (E1, E5, E2, E9) (1, 8, 14,18), and equipment and auxiliary devices (E2, E12) (14,21). There appears to be a need for formal support at the care practice level for individuals with SCI (16, 23).

Caregivers need to have economic resources to deal with their loved one's illness or help manage economic demands (1,18). Associated with this, reconciling work with the caregiver role is extremely difficult as the responsibilities of the caregiver role and their professional situation often conflict (1, 20). In addition, having favorable socioeconomic resources has a positive influence due to the numerous costs that SCI entails for the family (1).

As for the resource needs of the community and society, caregivers need formal assistance, including external support in domestic tasks, support in caring for children, and managing family matters. In addition, there is a need for assistance with the care recipient's activities of daily living (E6, E13) (16, 22). Participants report that as the duration of care delivery progresses, the caregiver’s support network fades away (E8) (17).

Communication and information processes

The communication and information processes are highlighted by their information needs (E1, E2, E4, E5, E6, E9, E13, E14, E17) (1, 7,8, 14, 16, 18, 22, 23, 26), communication with health professionals (E7, E14, E16) (3, 23, 25), and the need to be recognised by professionals E6, E16 (16, 25).

First, it is clear how there is a need for fundamental information related to the stage of disease and health conditions associated with SCI (E1, E2, E14) (7, 14, 23). Caregivers also add that the information must be conveyed in a perceivable way and need to be able to get answers to their questions honestly. Caregivers further describe the need to have medical knowledge and be able to identify and act on changes in health status (16). Finally, during the more acute phase, caregivers rate highly the need to obtain health information about SCI, more specifically about the health status and what treatments are related to SCI (23).

In addition, caregivers need sensitivity to identify changes in the care recipient's physical, mental, and behavioral state to detect early any signs and symptoms of SCI complications and identify their cause (E4, E3) (8, 15). Caregivers added that after discovering the changes and causes, they identified that they need to act accordingly, namely, using devices to monitor health; administer and organize medication; manage the needs of the care recipient; and manage comorbidities (8). Regarding communication with health professionals, caregivers consider it insufficient, stressing that they need to be heard and recognized by health professionals and communicate with a health professional in the rehabilitation area regularly (16, 23, 25, 26).

The analysis-synthesis of our review, similar to the findings obtained by other authors (9, 30), although the unique and unrepeatable character of this role, the authors emphasized that although the results included have been developed in different socio-political contexts, the highlighted needs converge each other.

Conclusion

The analysis of the 17 articles included in this review confirms the important role of family caregivers in supporting and caring for people with SCI. The study showed multiple needs related to the transition to the role of caregiver. Our findings highlight the importance of allocating different resources (information, social support, etc.) to meet the caregiver's needs. There is an urgent need for the intervention of nurses at all stages of rehabilitation of the person with SCI due to the physical, emotional, and mental demands it entails. In particular, the needs of family caregivers must be systematically and regularly evaluated to prevent and manage caregiver burden adequately.

Despite the strengths of the current study, there is some limitations, namely the variability of study methodologies that prevented a meta-synthesis of the results from being carried out, as well as the inclusion of participants at different stages of the injury.

Finally, future research should aim to evaluate interventions that promote the self-efficacy of the family caregiver of the person with SCI during the course of rehabilitation.

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Conflict of interest

There were no conflicts of interest related to the study.

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