ORIGINAL ARTICLE

OBJN
Online Brazilian Journal of Nursing
ISSN: 1676 - 4285 | www.objnursing.uff.br

Submission: 17-Dec-2025
Approved: 20-Feb-2026

EXPERIENCES OF PEOPLE WITH SPINAL CORD INJURY IN THE TRANSITION FROM HOSPITAL TO HOME*

VIVÊNCIAS DE PESSOAS COM LESÃO MEDULAR NA TRANSIÇÃO HOSPITALAR PARA O DOMICÍLIO

EXPERIENCIAS DE PERSONAS CON LESIÓN MEDULAR EN LA TRANSICIÓN DEL HOSPITAL AL HOGAR

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Como citar: Dias MG, Amarante LB, Wegner W, Damaceno AN, Treviso P, Pierotto AAS. Experiences of people with spinal cord injury in the transition from hospital to home. Online Braz J Nurs. 2026;25(1):e20266922. https://doi.org/10.17665/1676-4285.20266922

RESUMO

Objetivo: Compreender as vivências de pessoas com lesão medular no processo de transição da alta hospitalar para os cuidados no domicílio. **Método:** Trata-se de uma pesquisa de campo, descritiva, de abordagem qualitativa. Participaram 15 pessoas adultas com lesão medular, frequentadoras de uma associação localizada no sul do Brasil. A coleta de dados ocorreu entre abril e agosto de 2023, por meio de entrevistas semiestruturadas, gravadas, transcritas na íntegra e submetidas à análise de conteúdo. **Resultados:** A análise revelou vivências marcadas por sentimentos de tristeza, revolta, rejeição e choque diante do diagnóstico, além de mudanças significativas no cotidiano, com repercussões na autonomia, nas atividades de vida diária, nas relações familiares e conjugais, na vida social, na sexualidade e na estabilidade financeira. Identificaram-se fragilidades nas orientações recebidas no momento da alta hospitalar, especialmente relacionadas ao autocuidado, à prevenção de complicações e à adaptação no domicílio. **Conclusão:** Os achados reforçam a necessidade de uma atuação sistematizada da enfermagem, com foco no planejamento da alta, na educação em saúde e no fortalecimento da rede de apoio, contribuindo para a adaptação, a autonomia e a qualidade de vida dessas pessoas.

Descritores: Traumatismos da Medula Espinhal; Enfermagem; Alta do Paciente; Reabilitação; Qualidade de Vida.

ABSTRACT

Objective: To understand the experiences of people with spinal cord injury during the transition from hospital discharge to home care. **Method:** This is a descriptive field study with a qualitative approach. Fifteen adults with spinal cord injury who attended an association located in southern Brazil participated. Data collection took place between April and August 2023 through semi-structured interviews, which were audio-recorded, fully transcribed, and subjected to content analysis. **Results:** The analysis revealed experiences marked by feelings of sadness, anger, rejection, and shock in response to the diagnosis, as well as significant changes in daily life, with repercussions for autonomy, activities of daily living, family and marital relationships, social life, sexuality, and financial stability. Weaknesses were identified in the guidance provided at the time of hospital discharge, particularly regarding self-care, prevention of complications, and adaptation at home. **Conclusion:** The findings reinforce the need for a systematized nursing approach focused on discharge planning, health education, and strengthening support networks, contributing to adaptation, autonomy, and quality of life for these individuals.

Descriptors: Spinal Cord Injuries; Nursing; Patient Discharge; Rehabilitation; Quality of Life.

RESUMEN

Objetivo: Comprender las experiencias de personas con lesión medular durante la transición del alta hospitalaria a la atención domiciliaria. **Método:** Estudio de campo descriptivo con enfoque cualitativo. Participaron quince adultos con lesión medular que asistían a una asociación ubicada en el sur de Brasil. La recolección de datos se llevó a cabo entre abril y agosto de 2023 a través de entrevistas semiestructuradas, las cuales fueron grabadas en audio, transcritas íntegramente y sometidas a análisis de contenido. **Resultados:** El análisis reveló experiencias marcadas por sentimientos de tristeza, ira, rechazo y shock en respuesta al diagnóstico, así como cambios significativos en la vida diaria, con repercusiones en la autonomía, las actividades de la vida diaria, las relaciones familiares y conyugales, la vida social, la sexualidad y la estabilidad financiera. Se identificaron debilidades en la orientación brindada al momento del alta hospitalaria, particularmente en lo que respecta al autocuidado, la prevención de complicaciones y la adaptación en el hogar. **Conclusión:** Los hallazgos refuerzan la necesidad de un enfoque de enfermería sistematizado centrado en la planificación del alta, la educación para la salud y el fortalecimiento de las redes de apoyo, contribuyendo a la adaptación, autonomía y calidad de vida de estas personas.

Descriptores: Traumatismos de la Médula Espinal; Enfermería; Alta del Paciente; Rehabilitación; Calidad de Vida.

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INTRODUCTION

Spinal cord injury is an event with a high potential for disability, characterized by structural and functional changes in the spinal canal that result in significant physical, psychological, and social impairments for the affected individual[1]. The consequences of this condition extend beyond motor and sensory limitations, significantly affecting autonomy, social participation, and quality of life over time.

In Brazil, the main cause of spinal cord injury is related to traumatic events, especially motor vehicle accidents, falls, and firearm injuries, with an estimated incidence of more than 10,000 new cases annually. Most affected individuals are young men of working age[2]. This epidemiological profile increases the social and economic impact of spinal cord injury, as it prematurely compromises the functional and productive capacity of these individuals.

The functional changes and losses resulting from spinal cord injury directly affect not only the life of the affected person but also that of family members and caregivers, requiring profound lifestyle changes, environmental adaptations, reorganization of daily routines, and partial or total dependence for activities of daily living, such as hygiene, feeding, and mobility[2]. Clinical manifestations vary according to the level and extent of spinal cord involvement and may include paralysis or paresis of the limbs, sensory deficits, sphincter dysfunction, thermoregulation disorders, and vasomotor and sexual dysfunctions[2-4].

In addition to primary neurological deficits, individuals with spinal cord injury are susceptible to secondary complications, such as neurogenic bladder and bowel, neuropathic pain, autonomic dysreflexia, spasticity, pressure injuries, respiratory problems, and changes in sexuality[1,2]. These conditions require continuous monitoring and specific care, as the absence of appropriate management may result in frequent readmissions and worsening health status.

In this context, the rehabilitation and social reintegration of individuals with spinal cord injury require coordinated multiprofessional action, in which nursing plays a central role. Nurses work at different levels of the health care network, from the hospital setting to home care and rehabilitation services, and are responsible for care planning, health education, promotion of self-care, and psychosocial support, especially during care transitions and hospital discharge[5,6].

Although guidelines and public policies aimed at the care of individuals with spinal cord injury exist, weaknesses are still observed in the implementation of these actions, particularly regarding the guidance provided at the time of hospital discharge and the preparation of individuals and their support networks for home care[4]. Furthermore, despite advances in rehabilitation research, there is a scarcity of qualitative studies that explore, from the perspective of individuals with spinal cord injury themselves, the guidance received regarding post-discharge care to be carried out at home.

Given this context, this study aims to understand the experiences of individuals with spinal cord injury during the transition from hospital discharge to home care.

METHOD

This is an exploratory and descriptive field study with a qualitative approach. The study was conducted and reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ). Data collection was carried out at an association that brings together approximately 300 individuals with spinal cord injury, located in southern Brazil. The setting was selected because it includes individuals with different durations of experience living with spinal cord injury and facilitates access to participants.

The sample consisted of 15 adults with spinal cord injury who attended the association. Individuals aged 18 years or older with traumatic or non-traumatic spinal cord injury were included, regardless of the time since injury. Individuals presenting speech or cognitive impairments that prevented the interview from being conducted were excluded. The number of participants was determined based on the data saturation criterion[7].

Data collection took place in person between April and August 2023 at the association's headquarters. Interviews were conducted individually in a private room, on dates and at times previously scheduled with the participants and the institution's administrative staff, ensuring privacy and comfort. A semi-structured interview guide, developed by the principal researcher, a nursing undergraduate student, under the supervision of the academic advisor, was used. The guide included open- and closed-ended questions guided by the research question: "What experiences, perceptions, and adaptations impact the life of an individual with spinal cord injury?"

The interviews were conducted by the principal researcher after prior training with the advisor. Before each interview, the researcher introduced herself to the participants and explained the study objectives and her credentials. The interviews lasted an average of 35 minutes, were audio-recorded with prior authorization from the participants using a digital device, and were subsequently transcribed in full. The audio files and transcripts will be stored for five years and then deleted.

Data analysis was performed based on the interview transcripts using the content analysis technique, which included the stages of pre-analysis, material exploration, and treatment of results with interpretation[7]. This analytical process enabled the development of thematic categories that express the experiences, perceptions, and adaptations related to the daily lives of individuals with spinal cord injury.

The study was conducted in accordance with Resolution No. 466/2012 of the National Health Council, which regulates research involving human subjects. To ensure anonymity and confidentiality, participants were identified by the letter "P" followed by a number, according to the order of the interviews (P1, P2, P3, and so on). The project was approved by the Research Ethics Committee under Opinion No. 5,814,818 and CAAE No. 65700422.2.0000.5344.

RESULTS

Fifteen individuals with spinal cord injury participated in the study, of whom 86.7% (n=13) were male, aged between 22 and 59 years. Regarding the level of injury, 73.3% (n=11) had impairment between T3 and L5, characterized as paraplegia, while 26.7% (n=4) had injuries between C3 and C6, classified as tetraplegia. All injuries were of traumatic origin, resulting from falls from height (33.3%; n=5), traffic accidents (33.3%; n=5), firearm injuries (26.7%; n=4), and pedestrian accidents (6.7%; n=1). The duration of living with spinal cord injury ranged from one and

a half to 26 years, with a mean age of 32 years at the time of injury.

Reports related to the moment of diagnosis revealed different emotional reactions associated with the communication of the clinical condition and the perception of the changes imposed by the injury. Participants expressed feelings of sadness, anger, rejection, and shock, marked by an abrupt disruption of their previous way of life. One participant reported: "*I woke up feeling very angry and very sad, imagining what my life would be like from then on*" (P1).

Difficulty in accepting the new condition was evidenced by the initial rejection of wheelchair use, accompanied by crying and emotional distress (P9). Participants also reported feelings of shock related to the interruption of previously performed activities, such as work and mobility, associated with the impossibility of resuming their previous life in the same way (P13).

In contrast, one participant described a personal coping strategy, stating that, despite understanding the severity of the injury, he tried to view the hospitalization period as a stage of gradual adaptation, believing in the possibility of resuming his activities, even if at a slower pace (P15).

Following the initial impact of the diagnosis, participants described significant changes in daily life, mainly related to dependence for activities of daily living, reorganization of family routines, and adaptations to the home environment. These changes involved different dimensions of living with spinal cord injury, summarized in Chart 1, and were particularly marked at the beginning of the adaptation process, when participants reported not having adequate resources or environmental adaptations. The need for assistance with hygiene, feeding, and mobility was recurrent, with reports of dependence on others to "*help with bathing, reach things, and do almost everything*" (P2).

Chart 1 - Feelings and emotional reactions at the time of spinal cord injury diagnosis (n=15). São Leopoldo, RS, Brazil, 2023

Reported feelings at diagnosis	**Description in participants' statements**
Sadness (P1; P9; P12; P13; P15)	Reports of emotional distress associated with receiving the diagnosis. *"[...] I woke up feeling very angry and very sad, imagining what my life would be like from then on."* (P1).
Anger (P2; P3; P4; P5; P11)	Expressions of indignation and difficulty accepting the condition. *"Depending on someone for everything is not easy either, knowing that I will not walk again. [...] Someone has to take care of you, someone has to bathe you, someone has to get everything for you. At first, I had no adaptations, not even to use the phone or to eat, nothing!"* (P2).
Rejection and Shock (P6; P7; P8; P9; P10)	Initial difficulty accepting the injury and wheelchair use, as well as reactions of surprise and impact due to the abrupt life change. *"[...] not walking again, not doing what you used to do, work, having to quit your job. [...] It was a shock, yes! But I took it like this, how can I tell you, I took it in a positive way, right?! What am I going to do? Crying and complaining won't help, right?! It would only make things worse."* (P13).
Positive coping strategies (P2; P4; P6; P14)	Attempts to adapt and reframe the lived experience. *"[...] I had to accept it and gradually adapt to the new routine, there was nothing else to do, my dear [...]"* (P5).

Source: prepared by the authors, 2025.

Emotional difficulties upon returning home were also reported, including fear of using a wheelchair and prolonged bed rest, associated with feelings of sadness and discouragement (P3). Changes in family and marital relationships were described, highlighting conflicts with spouses, loss of financial autonomy, and concerns about the ability to provide for the family (P4).

Structural adaptations to the home were described as necessary to enable mobility, especially in residences with more than one floor or with bathrooms unsuitable for wheelchair use (P5). Issues related to sexuality also emerged, with participants expressing concerns about sexual potency and the impact of spinal cord injury on marital life (P11).

Regarding the guidance received at the time of hospital discharge, participants reported heterogeneous experiences. Some mentioned receiving information related to physiotherapy and urinary management, such as learning bladder catheterization during hospitalization (P8). However, most described limited or insufficient guidance, mainly restricted to intermittent urinary catheterization, without explanations about hygiene care, bathing, transfers, prevention of pressure injuries, or adaptation of the home routine.

There were reports that learning about the care required after hospital discharge occurred predominantly through self-directed efforts over time, following the return home (P1). Other participants described occasional or insufficient guidance, such as recommendations for diaper use or sporadic catheterization during hospitalization (P9), as well as the exclusive indication of physiotherapy as post-discharge care (P15). In some cases, family support was identified as a central element for the continuity of care at home, especially when family members had a background in health care (P7). The guidance and care reported by participants at the time of hospital discharge are summarized in Chart 2.

Chart 2 - Guidance reported by participants at the time of hospital discharge and home care (n=15). São Leopoldo, RS, Brazil, 2023

Type of guidance/care reported	**Description in participants' statements**
Physiotherapy (P1; P10; P15)	Mentions of referrals or recommendations for physiotherapy treatment.
Intermittent bladder catheterization (P2; P4; P7; P11; P12)	Reports of guidance focused on urinary management.
Transfer and mobility (P3; P5; P10)	Occasional references to performing transfers and mobility activities.
Hygiene and bathing care (P3; P4; P6; P8; P9; P12; P14)	Sporadic mentions of guidance related to personal care.
Prevention of pressure injuries (P1; P13)	Limited reports regarding preventive measures.

Source: prepared by the authors, 2025.

DISCUSSION

The results of this study deepen the understanding of the experiences of individuals with spinal cord injury by demonstrating that the condition has integrated repercussions across emotional, functional, and care-related dimensions, permeating the entire rehabilitation and care transition process and reinforcing the impact of this condition on young and working-age populations. The predominance of male participants and traumatic causes of spinal cord injury is consistent with national and international epidemiological data indicating that most individuals with spinal cord injury are men and that the causes are predominantly traumatic, especially firearm injuries and fall-related trauma, followed by motor vehicle accidents[1,2,8,9]. The mean age higher than that described in official reports suggests possible regional and contextual variations, indicating the need for epidemiological analyses that are more sensitive to local realities. In this study, due to the sample size (n=15) and qualitative design, epidemiological data were not generalized, being limited to the characteristics of the investigated sample.

The higher frequency of paraplegia observed differs from some international findings[8], but may be understood in light of the predominant traumatic causes among participants, such as falls and traffic accidents. This finding reaffirms traumatic spinal cord injury as an abrupt, disabling event with high biopsychosocial impact[2], requiring coordinated and continuous care responses over time.

The emotional experiences associated with the diagnosis reveal significant psychological distress, marked by sadness, anger, rejection, and shock, corroborating literature that describes grief processes, difficulties in acceptance, and changes in self-image following spinal cord injury[10,11]. Beyond reiterating these feelings, the findings highlight the heterogeneity of emotional responses, indicating that coping strategies vary according to individual trajectories. This aspect reinforces the urgent need for personalized care approaches that are sensitive to each person's uniqueness.

The repercussions of the injury on daily life demonstrate that rehabilitation extends beyond functional recovery, involving the reorganization of family, social, and financial life. Dependence for activities of daily living, home adaptations, and loss of financial autonomy reported by participants are consistent with studies indicating reduced social participation and quality of life after injury[12,13]. These findings reinforce the importance of interdisciplinary interventions that consider the life context and material conditions of individuals with spinal cord injury.

Nursing, as an essential member of the multiprofessional team, plays a crucial role in assessing home environment adaptation needs, providing guidance on the use of assistive technologies, and coordinating with social and community support networks. By facilitating reintegration and minimizing social and financial barriers, nurses directly contribute to patient autonomy and quality of life after discharge.

In this context, sexuality emerges as a dimension frequently neglected in care, despite its impact on quality of life and marital relationships. The literature indicates that changes in sexual function and satisfaction are common after spinal cord injury and may be minimized through appropriate educational and therapeutic interventions[14–16]. The reported fragility of guidance highlights gaps in comprehensive care, particularly during hospitalization and discharge preparation.

This study reinforces the need for nurses to address sexuality proactively, sensitively, and without judgment throughout the care process. This includes providing clear, evidence-based information, demystifying taboos, and referring patients to specialized professionals when necessary. The explicit inclusion of this topic in discharge planning is essential for promoting comprehensive health, quality of life, and the maintenance of healthy relationships after spinal cord injury.

A central finding concerns the guidance provided at the time of hospital discharge, often described as limited to urinary management or physiotherapy. The absence of systematized guidance on self-care, prevention of complications, and home adaptation is consistent with national evidence indicating shortcomings in discharge planning and care transitions[3,17]. Hospital discharge, as a strategic stage, requires organized nursing action, including an individualized care plan, health education, and coordination within the health care network[17], in order to prevent avoidable complications and readmissions[2,3,18].

In this context, nursing assumes a central role in promoting self-care, providing guidance on bladder and bowel management, skin care, mobility, and the use of assistive technologies, as well as supporting progressive adaptation to the new life condition[19,20]. Longitudinal and integrated care is essential to improve rehabilitation outcomes and autonomy among individuals with spinal cord injury.

This study advances knowledge by highlighting, from the users' own perspective, specific gaps in hospital discharge planning, offering concrete support for strengthening nursing practice in care transitions. By making visible lived experiences and unmet needs, the findings contribute to improving care practices, nursing education, and the alignment of care actions with guidelines and public policies aimed at comprehensive care for individuals with spinal cord injury.

CONCLUSION

This study made it possible to understand the experiences of individuals with spinal cord injury during the transition from hospital discharge to home care, showing that this period is marked by intense emotions and significant changes in daily life that directly influence adaptation to the new life condition. The reported experiences revealed important repercussions on autonomy, activities of daily living, family and marital relationships, social life, sexuality, and financial stability.

Weaknesses were identified in discharge preparation, with guidance often insufficient or fragmented, particularly regarding self-care, prevention of complications, and adaptation to the home environment. These gaps compromise the safety of the care transition, increase dependence on family members or caregivers, and favor the occurrence of potentially preventable complications.

The findings reinforce the need for a systematized and longitudinal nursing approach in hospital discharge planning, including structured educational actions, person-centered care, and strengthening of support networks. Such strategies are essential to promote adaptation, autonomy, and quality of life for individuals with spinal cord injury in the home context.

*Article extracted from the Undergraduate Graduation Thesis titled "Before, during, and after spinal cord injury: the life of individuals with spinal cord injury," presented to the Nursing Course at Unisinos, São Leopoldo, Rio Grande do Sul, Brazil, in 2023.

ACKNOWLEDGEMENTS

The authors thank the people with spinal cord injury who participated in this study and their support networks for their welcome, availability to share their experiences, and essential contribution to the research.

CONFLICT OF INTERESTS

The authors declare no conflict of interest.

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AUTHORSHIP CONTRIBUTIONS
Study design: Dias MG, Wegner W, Treviso P, Pierotto AAS. Data collection: Dias MG, Damaceno AN, Pierotto AAS. Data analysis: Wegner W, Treviso P, Pierotto AAS. Data interpretation: Dias MG, Wegner W, Treviso P, Amarante LB, Pierotto AAS. All authors are responsible for the textual writing and critical review of the intellectual content, the final version published, and all ethical, legal, and scientific aspects related to the accuracy and integrity of the study.

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