

# Social participation and personal autonomy of individuals with spinal cord injury

*Participação social e autonomia pessoal de indivíduos com lesão medular*

*Participación social y autonomía personal de individuos con lesión medular*

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## ABSTRACT

**Objective:** To investigate, based on scientific literature, evidence on social participation and personal autonomy of individuals with spinal cord injury. **Method:** Integrative review of the literature including studies published between January 2006 and September 2016, obtained in the databases PubMed, CINAHL and LILACS. The guiding question was: "What evidence is available in the scientific literature about the social participation and/or personal autonomy of individuals with spinal cord injury?" The data were processed by IRaMuTeQ and analyzed by the Hierarchical Descending Classification, according to the expertise of the researchers. **Results:** Six selected studies discussed social participation, one discussed personal autonomy and two discussed both. 107 text segments were retained and gave rise to five classes. **Conclusion:** There is little specificity regarding the characteristics of social participation and personal autonomy of individuals with spinal cord injury. The existence of barriers forces them to adopt strategies to participate autonomously.

**Descriptors:** Community Participation; Social Participation; Personal Autonomy; Spinal Cord Injuries; Rehabilitation.

## RESUMO

**Objetivo:** Investigar, a partir da literatura, evidências acerca da participação social e autonomia pessoal de indivíduos com lesão medular. **Método:** Revisão integrativa incluindo estudos publicados entre janeiro de 2006 e setembro de 2016 obtidos nas bases PubMed, CINAHL e LILACS. Definiu-se como questão norteadora: "Quais são as evidências disponibilizadas na literatura científica acerca da participação social e/ou da autonomia pessoal de indivíduos com lesão medular?" Os dados foram processados pelo IRaMuTeQ e analisados pela Classificação Hierárquica Descendente em conformidade com a expertise dos pesquisadores no tema. **Resultados:** Seis estudos selecionados discorreram sobre a participação social, um sobre a autonomia pessoal e dois sobre ambas. Foram retidos 107 segmentos de texto, resultando na formação de cinco classes. **Conclusão:** Há pouca especificidade em relação às características da participação social e da autonomia pessoal de indivíduos com lesão medular. A existência de barreiras obriga-os a adotar táticas para participar de forma autônoma.

**Descritores:** Participação da Comunidade; Participação Social; Autonomia Pessoal; Traumatismos da Medula Espinal; Reabilitação.

## RESUMEN

**Objetivo:** Investigar, a partir de la literatura, evidencias sobre la participación social y la autonomía personal de individuos con lesión medular. **Método:** Se trata de una revisión integradora que incluye estudios publicados entre enero de 2006 y septiembre de 2016, obtenidos en las bases PubMed, CINAHL y LILACS. Se definió como pregunta directriz: "¿Cuáles son las evidencias disponibles en la literatura científica acerca de la participación social y/o de la autonomía personal de individuos con lesión medular?" Los datos se procesaron con el IRaMuTeQ y se analizaron mediante la Clasificación Jerárquica Descendente de acuerdo con la experticia de los investigadores del tema. **Resultados:** Se seleccionaron seis estudios que discurrían sobre la participación social, uno que trataba sobre la autonomía personal y dos, sobre ambas. Se retuvieron 107 segmentos de textos, lo que derivó en la formación de cinco clases. **Conclusión:** Es evidente la falta de datos específicos sobre las características de la participación social y de la autonomía personal de individuos con lesión medular. La existencia de estas barreras los obliga a adoptar táticas para participar de forma autónoma.

**Descriptor:** Participación de la Comunidad; Participación Social; Autonomía Personal; Traumatismos de la Médula Espinal; Rehabilitación.

## INTRODUCTION

Spinal cord injury (SCI) is an injury with a significant impact on individuals, their family and society. In developing countries, it has an incidence of 25.5/million/year and affects mainly males (82.8%) with a mean age of 32.4 years<sup>(1)</sup>. In Brazil, the incidence of traumatic SCI ranges from 16 to 26 cases per million/year. The mean age of these patients is 34.7 years and 84% of them are males<sup>(2)</sup>. SCI is associated with impairment of motor, sensory and autonomic functions, emotional and psychosocial issues, impaired professional and financial activity and reduced community participation<sup>(3)</sup>. These complications require strategies to help the individual cope with the injury<sup>(4)</sup>.

Participation, which is commonly affected by SCI, is the involvement in a life situation, as defined by the International Classification of Functioning, Disability and Health (ICF) proposed by the World Health Organization (WHO)<sup>(5)</sup>. Participation is presented in nine chapters that refer to learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life<sup>(5-6)</sup>. This term is usually associated with adverbs that clarify its meaning and admit different interpretations, such as social participation, participation in society and societal participation<sup>(7-8)</sup>.

Different obstacles to social participation are pointed out in the scientific literature, such as functional decline, chronic comorbidities, paternalistic approach and negative attitude of people, lack of clarity regarding the objectives to be achieved, and unemployment, which leads to decreased economic self-sufficiency and a consequent social burden<sup>(9-12)</sup>.

Autonomy may also be compromised in the individual affected by SCI. This term is related to freedom, privacy, individual choice and individual will<sup>(11)</sup>. Autonomous actions usually occur through the constant adaptation of individual's intentions to the opportunities and limitations encountered in their interaction with the world<sup>(10)</sup>. The term, commonly referred to as "independence" in the literature<sup>(9,13)</sup>, derives from a cluster of value and ideas which differ between persons, social groups and culture<sup>(7)</sup>. As occurs with participation, the deficiency caused by the injury may restrict the individual's autonomy<sup>(7)</sup>.

There is a relation between participation and autonomy, since autonomy is a fundamental prerequisite for participation, and this connection corresponds to a key concept for client-centered rehabilitation<sup>(7)</sup>.

The recovery of social participation and personal autonomy is fundamental and productive in the reinsertion of the individual with SCI in the social environment. For this, the rehabilitation professional must master these terms, which will allow him to assist the individual with SCI in their full rehabilitation, considering their current biopsychosocial condition.

## OBJECTIVE

To investigate, based on scientific literature, evidence on social participation and personal autonomy of individuals with spinal cord injury.

## METHOD

This study is an integrative review, a method that gathers theoretical and empirical literature, as well as researches with different

methodological approaches, in order to synthesize information on a subject of interest<sup>(14)</sup>. To do this, six steps were followed: identification of the theme and selection of the research question, establishment of inclusion and exclusion criteria, definition of information to be extracted from selected studies, evaluation of the studies, interpretation of results, and presentation of results/synthesis of knowledge<sup>(15)</sup>. The guiding question of this study was: "What evidence is available in the scientific literature about the social participation and/or personal autonomy of individuals with spinal cord injury?"

The primary studies included were in English, Spanish and Portuguese, regardless of the methodological design, published between January 2006 and December 2016. This cut-off period was used because there are few studies that analyze how people with SCI perceive the role of social participation and personal autonomy, as defined by the CIF, in their lives<sup>(16)</sup>. The search strategy was applied to the electronic databases on September 17, 2016 and updated on June 5, 2018.

The publications were obtained from the databases *National Library of Medicine National Institutes of Health* (PubMed), *Cumulative Index to Nursing and Allied Health Literature* (CINAHL) e *Latin American and Caribbean Health Sciences* (LILACS). Controlled (Medical Subject Headings/MeSH, CINAHL/MeSH Headings and Health Sciences Descriptors/DeCS) and uncontrolled descriptors (*Entry Terms* and *Synonyms* in Portuguese) were used. The Boolean operators OR and AND were used as follows to obtain the largest number of studies on the subject, as follows:

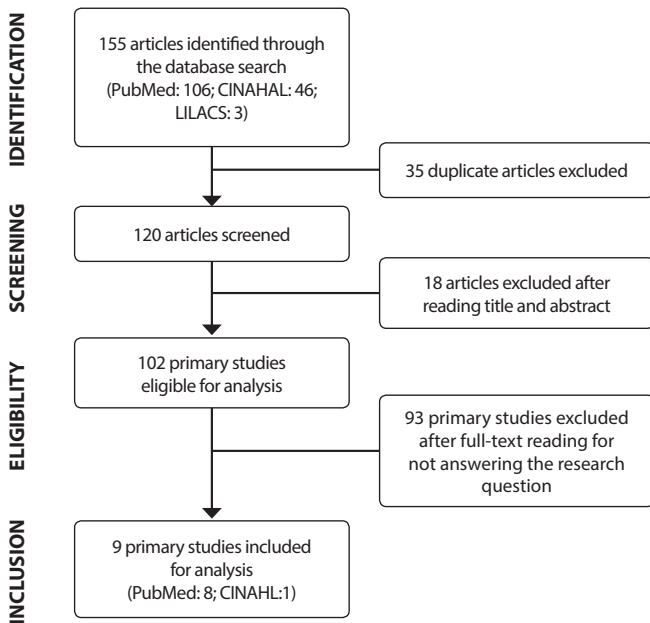
- PubMed: Social Participation OR Participation, Community OR Participation, Social OR Participation AND Personal Autonomy OR Autonomy, Personal OR Autonomy OR Self Determination OR Free Will AND Spinal Cord Injuries OR Spinal Cord Diseases OR Spinal Cord Injury.
- CINAHL: Social Participation OR Participation AND Autonomy OR Personal Autonomy AND Spinal Cord Injury OR Spinal Cord Compression OR Spinal Cord Neoplasms OR Spinal Cord Diseases OR Central Cord Syndrome.
- LILACS: *Participação Social* OR *Participação* AND *Autonomia Pessoal* OR *Autonomia* OR *Independência* OR *Autodeterminação* OR *Liberdade de Escolha* OR *Liberdade* OR *Liberdade Funcional* AND *Traumatismos da Medula Espinal* OR *Degenerações Espinocerebelares* OR *Doenças Vasculares da Medula Espinal* OR *Traumatismos da Medula Espinal* OR *Neoplasias da Medula Espinal* OR *Compressão da Medula Espinal* OR *Lesão da Medula Espinal* OR *Lesão Medular*.

Considering that the terms social participation and personal autonomy have different concepts in scientific literature, the authors adopted the definition of participation proposed by the WHO<sup>(5)</sup> and the definition of autonomy of Cardol, de Jong and Ward<sup>(7)</sup>.

The studies were selected according to the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA). Duplicated studies were considered only once (Figure 1).

After obtaining the articles, the titles and abstracts of the eligible articles were read to find those that were not primary studies, that is, reviews, case studies, thesis/dissertations, conference proceedings, responses to letters to the editor, quotes and editorials. Then, an exhaustive reading of the primary studies was

carried out to select those that answered the guiding question, which made up the sample of this study.



**Figure 1** – Flowchart of the selection of primary studies according to PRISMA

The entire process was analyzed by two independent authors. For the analysis of the selected publications, only the primary studies that obtained 100% initial agreement in the selection or resolution of discrepancies were included. Data were compiled in a script structured by the authors based on the instrument elaborated and validated by Ursi<sup>(17)</sup>. The following elements were considered: location and population, objectives and outcomes of the study.

**Chart 1** - Characterization of the primary studies included in the study

Objectives	Location	Population	Study design	Main findings
Describe how individuals with SCI control their life and find positive meaning and continuity despite their injury, managing social participation and social relationships <sup>(24)</sup>	Japan	29 individuals with SCI (C1 to C6) Mean age: 48.1 years Males and females	Descriptive study	Through self-help groups, participants gave priority to activities aimed at setting new social goals after the injury. Social participation was sought by individuals with SCI to transcend the limitations of disability.
Investigate how individuals with SCI describe their local community <sup>(25)</sup>	Australia	269 individuals with SCI (C1 to S5) 15-55 years Men and women	Descriptive study	The community was described as a 'place'. The participants highlighted positive points (social and relationship aspects) and negative points (related to physical space and accessibility).
Explore "person perceived participation" in individuals with SCI <sup>(26)</sup>	Belgian	11 individuals with SCI (T6 to T12) 25-56 anos Men	Descriptive study	Participation was conceptualized as a set of values, including freedom to carry out activities, to act according to the person's identity, to experience personal growth, to experience trust and security, to feel validated, to have a sense of control, to experience a sense of importance and to find equal identities.
To examine the change in life satisfaction over time and potential contributing factors among adults with pediatric-onset spinal SCI <sup>(27)</sup>	United States	605 individuals with SCI (C1 to T5) 24-37 years Men and women	Prospective longitudinal study.	After adjusting for potential confounding factors related to SCI, life satisfaction was higher for women and those who were married/living with a partner; were employed/students; did not use illicit drugs; were more independent; had better mental health and better social integration.

To be continued

The software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRaMuTeQ), version 0.7 alpha 2 was used for processing textual data. It is widely used in the scientific literature and it allows the statistical analysis of text corpus<sup>(18-20)</sup>.

The text corpus was composed by the original contributions of the primary studies, taken from their discussions and conclusions. The findings of the data processing were carefully analyzed by the authors, based on the descending hierarchical classification (DHC), according to which texts are classified according to their respective words and the sets are divided by the frequency of the reduced forms<sup>(21)</sup>.

Classes of text segments that presented vocabularies similar to each other and different from the segments of the other classes were obtained. Through the DHC, the words were organized in a dendrogram that represented the quantity and lexical composition of the classes arising from the grouping of terms<sup>(22)</sup>.

For the configuration of the classes, the authors considered lexical forms with frequency higher than twice the mean number of occurrences in the corpus and with chi-square ( $\chi^2$ ) with significance value  $p \leq 0.01$ , which, according to Fisher's Significance Scale, corresponds to strong evidence<sup>(23)</sup>.

## RESULTS

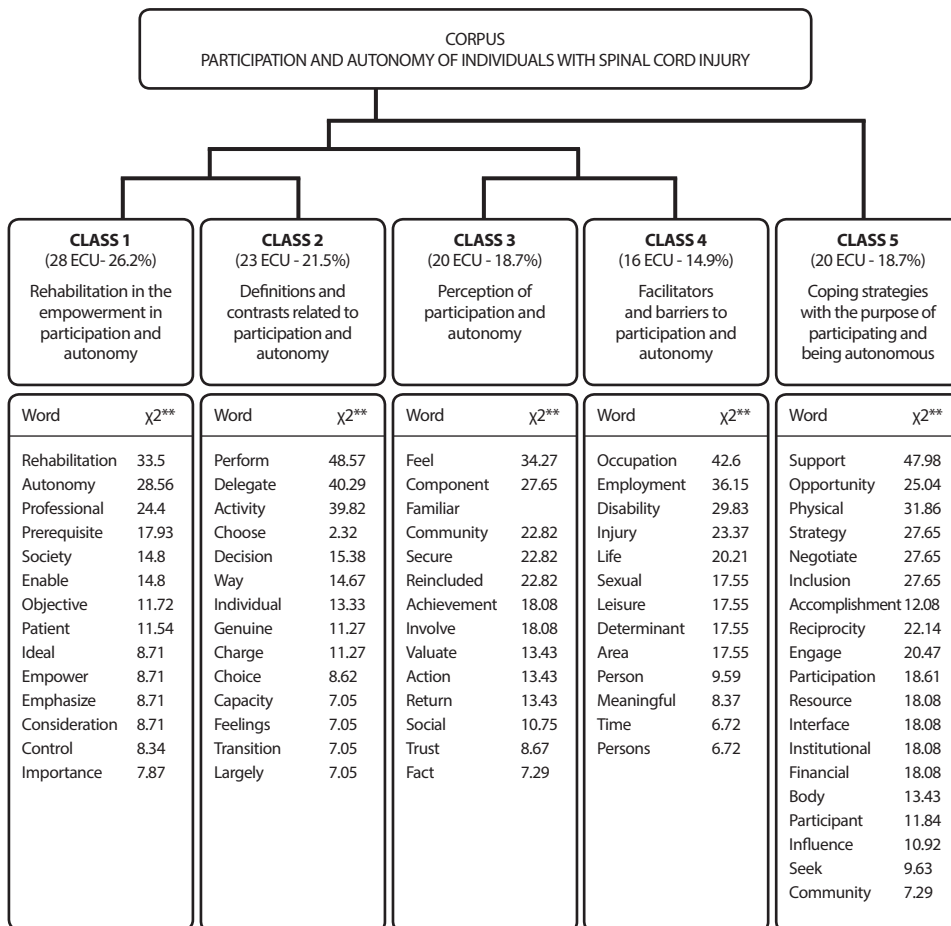
After reading the titles and abstracts, 102 were considered primary studies and were selected for full text reading. After identifying those that answered the research question initially proposed, nine of them composed the sample of this study.

Eight of the primary studies of this integrative review were available in PubMed and one in CINAHL. Six of them discussed only the social participation of the individual with SCI<sup>(24-29)</sup>, one focused exclusively on personal autonomy<sup>(30)</sup> and two covered both<sup>(31-32)</sup> (Chart 1).

Chart 1 (concluded)

Objectives	Location	Population	Study design	Main findings
To gain an understanding of how women with SCI experienced human encounters in occupations and how these influenced their participation <sup>(28)</sup>	Sweden	13 individuals with SCI 25-61 years Females	Descriptive study	Women struggled with conflicts, supported other persons that were insecure and reevaluated their apprehension about persons in their social network. Their experiences with human encounters changed over time and enabled them to regain participation in occupations.
To examine unmet needs related to quality of life and social participation after spinal cord injury across four European countries <sup>(29)</sup>	United Kingdom	1000 individuals with SCI (C1 to S5) 48-49 years Men and women	Cross-sectional study	Quality of life and social participation are long-term processes in which occupation, sexual activity and pain relief are the least met needs among patients with SCI.
To discuss the concept of autonomy as a precursor for participation in individuals with SCI <sup>(30)</sup>	Belgium	11 individuals with SCI (T6 to T12) 25-56 years Men	Descriptive study	Autonomy and independence can be considered prerequisites for participation.
To determine factors that contribute and predict social participation following discharge of the patient with SCI <sup>(31)</sup>	Australia	71 individuals with SCI (C1 to S5) Mean: 42.6 years Men and women	Prospective longitudinal study	Factors that predicted social participation and autonomy: younger age, having a higher cognitive capacity. Factors that did not predict participation: low perceived self-efficacy, pain and alcohol use.
To understand how adults with SCI participate in their daily life and within their communities, to promote opportunity for participation <sup>(32)</sup>	Canada	19 individuals with SCI (C1 to C8) Age: ≥ 20 years Men	Descriptive study	The participants live in a changed world, one that is perceived differently after SCI, and use various strategies to interact within their environment and to participate

Note: SCI: spinal cord injury.



Note: ECU: Elementary Context Units; χ<sup>2</sup>\*\*: Statistically significant chi-square values (p ≤ 0.01).

**Figure 2** – Thematic structure of social participation and personal autonomy of the individual with spinal cord injury according to the Descending Hierarchical Classification

The results of the primary studies presented in Chart 1 were included in a text corpus and analyzed by the DHC. The content of the corpus recognized by IRaMuTeQ was composed of texts that contained 940 active words that appeared 5079 times. A total of 139 text segments were analyzed, with a 76.98% text segment retention, corresponding to 107 text segments.

After data processing, five classes emerged and were subdivided and grouped according to their correlation, related to aspects of the participation and autonomy of the individual with SCI (Figure 2).

In Figure 2 it is possible to observe the importance of the rehabilitation professional in the process of autonomy of the individual with SCI, since this professional empowers the patient to control his ideals on his own. Despite the paradox between the terms autonomy and independence, being autonomous, as conceptualized by the individual with SCI, corresponds to choosing for themselves or

delegating to others. By reflecting on the words participation and autonomy, the individual with SCI is presented with the idea of returning to the familiar community environment, a fact that makes him feel safe to be re-engaged and, consequently, to participate. To participate autonomously, the individual with SCI reports that it is necessary to adopt strategies after observing its facilitators and barriers. In doing so, the lexical forms used refer to the need to adopt strategies and negotiations.

## DISCUSSION

The promotion of autonomy for the rehabilitation of the individual with SCI is observed in the primary studies that indicate how the rehabilitation professional allows the individual to explore his own interests in the way he wants, cooperates so that he disconnects from what he considers to be the ideal of independence as a prerequisite for autonomy<sup>(7,31)</sup>, helps him take control of his environment and encourages him to develop strategies to overcome possible obstacles related to SCI<sup>(7,25,28)</sup>.

We found that the ultimate goal of rehabilitation is to recover and retain the highest possible level of autonomy of the individual in order to maximize their participation. The role and efficiency of rehabilitation in the autonomy of disabled individuals are highlighted, pointing out that the rehabilitation professional is concerned with maintaining the autonomy of these individuals by encouraging their participation in activities they value, ensuring that their personal, social and health needs are met, and cooperating to reduce the various limitations related to disease in social activities<sup>(6,11,13)</sup>.

Articles that discuss autonomy, when referring to individuals with SCI, use terms such as participation, independence, self-determination, identification, freedom from control and external restraints, opportunity to choose activities to perform and ability to perform activities by themselves due to the absence of environmental barriers when they accept to delegate the act of doing to other individuals<sup>(9,30)</sup>. We observed, therefore, that the great number of words used to define autonomy illustrates the lack of clarity on this term, seen not only among individuals with SCI, but also in the community and among rehabilitation professionals.

Among the terminologies adopted to define autonomy, the term "independence" is commonly used, not only by the individual with SCI, but also by professionals and the community in general<sup>(13,30-32)</sup>. Being independent means being able to deal with yourself without the help of others or being free from control and external restraints<sup>(7,30-32)</sup>.

In fact, it is common to observe in the scientific literature the use of the term independence referring to the term autonomy, which leads to the idea of a relationship between both<sup>(9,30)</sup>. Independence is desired by the patient and induced by society, due to the existence of an internalized ideal of freedom as an objective<sup>(30)</sup>, and a lack of recognition of the importance or necessity of interdependence with others<sup>(7)</sup>.

We found that the fact that the individual with SCI refers to autonomy as independence can lead to a misinterpretation of the real concept of both terms and limit the importance and necessity of others in their life, even if partially, as help to succeed in the execution of the activities of interest.

Commonly referred to as "social participation"<sup>(12)</sup> in the scientific literature, participation is the occupation that gives individuals with SCI the feeling of being part of their social context<sup>(25,27-29,31)</sup>. In fact, as pointed by the WHO, participation corresponds to actions or tasks performed in the social environment and represents the societal perspective of functioning<sup>(5,7)</sup>.

Based on the breadth of such terms, it was possible to perceive that there is no knowledge of the concrete meaning of participation by individuals with SCI. According to them, the term participation is associated with varied vocabulary such as autonomy, inclusion, achievement, occupation, reciprocity, employment, financial self-sufficiency, family life and familiar community, neighborhood, social context, sexual activity, self-care and leisure<sup>(26,29,32)</sup>.

Our findings indicate that there are barriers to ideal participation, related to the sociocultural condition and the life context of the individual with SCI, as well as the SCI itself and its consequences. Attitudes of the rehabilitation professional or caregiver (such as overprotection of the patient) or of society (such as judging or depriving the individual of their ability to participate socially), as well as issues in architectural structures and consequent lack of accessibility to services and general aids, make it difficult or even impossible for the individual with SCI to participate<sup>(28,31)</sup>.

Similarly, barriers related to the social condition of the individual with SCI are also observed. Lack of access to health care, education and labor policies, difficulties finding paid work and the consequent lack of financial self-sufficiency, and insufficient involvement in family and social activities are frequently observed. The lack of adequate social support from family, friends and caregivers, and even the lack of involvement of health professionals in the process of participation after discharge are also indicated by the studies as barriers to the participation of individuals with SCI<sup>(9,12,27-28,31)</sup>.

Despite the existence of barriers, the results demonstrate that participation can be facilitated by the socio-demographic conditions of the individual with SCI, which include lower age at the beginning of rehabilitation, higher educational level, and better accessibility in their environment and in public transportation<sup>(26,28,31)</sup>.

Good clinical conditions may also favor participation, as in the case of incomplete spinal cord injury, increased cognitive ability, low incidence of complications, better functional capacity, better self-efficacy and depressive mood, and lower fatigue index and pain level<sup>(28,32)</sup>.

Favorable social and personal conditions are also considered facilitators to participation. It is the case of the individual with SCI who has caregivers or partners, has support from friends, co-workers and health professionals, has intimate ties with the family, has self-help equipment that enables interaction with the general public, and demonstrates possibility of returning to work or engaging in sports activities<sup>(12-13,28,32)</sup>.

We verified that there are factors that impede or facilitate the autonomy of the individual with SCI. Factors such as the disability itself, the control exercised by the rehabilitation professional and/or overprotection from the caregiver, difficulty to delegate what they can't do on their own, confrontation with social factors when they cannot engage in expected activities, and physical restrictions related to the physical and social environment were pointed as barriers to autonomy<sup>(24,30)</sup>. In addition to reiterating

such information, the scientific literature points to restrictions imposed by the rehabilitation professionals when they control the patients' choices or schedules of the activities that they perform<sup>(7)</sup>.

Despite the limitations to participation and autonomy, we perceive that the individual with ICS uses mechanisms to overcome obstacles and to create opportunities to participate autonomously. Lack of resignation to current conditions and adequacy to the relation between the body (physical, cognitive and emotional) and the environment (physical, architectonic and social) are pointed out.

Similarly, modifying difficult activities, establishing objectives related to self-care, regaining independence, seeking less social dependence, carrying out activities with or without self-help equipment, creating accessible environments, returning to the family community, getting involved in family and leisure activities, acquiring new knowledge from professionals and other individuals with SCI and entering the job market are strategies to adapt to the new health condition<sup>(7,29,32)</sup>.

These findings are confirmed in the literature, which also points to a spirit of struggle, religious beliefs, involvement in various activities and in the labor market, voluntary and leisure activities, and asking for help<sup>(4,9,12-13)</sup>.

### Limitations of the study

This study had as limitation the adoption of only three languages, despite the fact most of the publications available in the period studied were in English. In order to overcome this

limitation, new research on the subject studied should be carried out with the inclusion of other languages.

Despite this limitation, we believe that this study was valid since it brought findings to produce new knowledge, generating new hypotheses for future studies.

### Contributions to health or public policies

This study provided current data, presenting, mainly, the existing barriers and the complexity in defining the terms social participation and personal autonomy. The information available here may be used in the scientific area, for the development of associated research, and by rehabilitation of professionals in the clinical area, with the objective of promoting social participation and personal autonomy of individuals with SCI, focusing on the individual, their family, the community and the professional environment.

### CONCLUSION

Our results showed little specificity in the scientific literature regarding the terms participation and autonomy, whose definitions and characteristics are not clearly understood by individuals with spinal cord injury, their caregivers and rehabilitation professionals. Factors that hinder the participation and autonomy of these individuals, forcing them to adopt strategies to participate autonomously, were evident. We consider that these findings point to the need to develop scientific studies aimed at clarifying the subject.

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