Functional independence analysis in persons with spinal cord injury

Análise da independência funcional em indivíduos com lesão da medula espinal

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Abstract

Introduction: Spinal cord injury (SCI) radically changes a person’s life because of alterations in body dynamics, leading to disabilities and reduced functionality. Objective: To analyze the functional independence of individuals with spinal cord injury and compare the groups. Methods: Individuals with SCI were interviewed about their functional independence using the Brazilian version of the Spinal Cord Independence Measure - Self-Reported Version (brSCIM-SR) and later their respective domains and subdomains were compared between diagnostic groups, time since injury and sex. Results: The sample consisted of fifty individuals aged 40.92 ± 13.93 years, predominantly men and diagnosed with paraplegia. In most brSCIM-SR domains, all respondents achieved good independence in self-care, respiration and sphincter management, and in the total brSCIM-SR, except for mobility. In paraplegia, chronic SCIs and both sexes achieved excellent independence in most subdomains and in the total. Significantly low values were found for tetraplegia and recent SCI in the self-care subdomain. In most subdomains, tetraplegia reached significantly lower values. In the subdomains of respiration and sphincter management, the participants were independent in the breathing function, but in tetraplegia, they showed significant dependence on transfer to the toilet. In terms of mobility, there was great dependence on the items going up and down stairs and transfer from the floor to the wheelchair. Conclusion: The brSCIM-SR measures the degree of functionality, allowing health professionals and the patient to quantify and locate the items that indicate their deficits or gains during the rehabilitation process. Here, individuals with SCI showed good functional independence, with worse performance in the tetraplegia and recent SCI in the self-care subdomain. In most subdomains, tetraplegia reached significantly lower values. In the subdomains of respiration and sphincter management, the participants were independent in the breathing function, but in tetraplegia, they showed significant dependence on transfer to the toilet. In terms of mobility, there was great dependence on the items going up and down stairs and transfer from the floor to the wheelchair. Conclusion: The brSCIM-SR measures the degree of functionality, allowing health professionals and the patient to quantify and locate the items that indicate their deficits or gains during the rehabilitation process. Here, individuals with SCI showed good functional independence, with worse performance in the tetraplegia and recent SCI in the self-care subdomain. In most subdomains, tetraplegia reached significantly lower values. In the subdomains of respiration and sphincter management, the participants were independent in the breathing function, but in tetraplegia, they showed significant dependence on transfer to the toilet. In terms of mobility, there was great dependence on the items going up and down stairs and transfer from the floor to the wheelchair. Conclusion: The brSCIM-SR measures the degree of functionality, allowing health professionals and the patient to quantify and locate the items that indicate their deficits or gains during the rehabilitation process. Here, individuals with SCI showed good functional independence, with worse performance in the tetraplegia and recent SCI in the self-care subdomain. In most subdomains, tetraplegia reached significantly lower values. In the subdomains of respiration and sphincter management, the participants were independent in the breathing function, but in tetraplegia, they showed significant dependence on transfer to the toilet. In terms of mobility, there was great dependence on the items going up and down stairs and transfer from the floor to the wheelchair. Conclusion: The brSCIM-SR measures the degree of functionality, allowing health professionals and the patient to quantify and locate the items that indicate their deficits or gains during the rehabilitation process. Here, individuals with SCI showed good functional independence, with worse performance in the tetraplegia and recent SCI in the self-care subdomain. In most subdomains, tetraplegia reached significantly lower values. In the subdomains of respiration and sphincter management, the participants were independent in the breathing function, but in tetraplegia, they showed significant dependence on transfer to the toilet. In terms of mobility, there was great dependence on the items going up and down stairs and transfer from the floor to the wheelchair. Conclusion: The brSCIM-SR measures the degree of functionality, allowing health professionals and the patient to quantify and locate the items that indicate their deficits or gains during the rehabilitation process. 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Keywords: Functional independence. Physiotherapy. Spinal cord injury.
Resumo

Introdução: A lesão na medula espinal (LME) muda radicalmente a vida da pessoa devido às alterações na dinâmica corporal, levando à incapacidades e redução da funcionalidade.

Objetivo: Analisar a independência funcional de indivíduos com LME e comparar os grupos. Métodos: Indivíduos com LME foram entrevistados sobre sua independência funcional por meio da versão brasileira do Spinal Cord Independence Measure - Self-Reported Version (brSCIM-SR) e posteriormente seus respectivos domínios e subdomínios foram comparados entre os grupos diagnósticos, tempo de lesão e gênero.

Resultados: A amostra foi composta por 50 indivíduos com idade de 40,92 ± 13,93 anos, prevalecendo homens e diagnóstico de paraplegia. Na maioria dos domínios do brSCIM-SR todos os entrevistados atingiram boa independência no autocuidado, na respiração e controle esfínteriano e no total do brSCIM-SR, exceto na mobilidade. Na paraplegia, as LMEs crônicas e ambos os sexos alcançaram excelente independência na maioria dos subdomínios e no total do instrumento. Valores significantemente baixos foram encontrados na tetraplegia e nas LMEs recentes no subdomínio autocuidado. Na maioria dos subdomínios, a tetraplegia atingiu valores significativamente inferiores. Nos subdomínios da respiração e controle esfínteriano, os participantes eram independentes na função respiração, mas nas t tetraplegias apresentaram significativa dependência nas transferências para o vaso sanitário. Na mobilidade houve grande dependência nos itens subir e descer escalas e transferir-se do chão para a cadeira de rodas. Conclusão: Os indivíduos com LME demonstraram boa independência funcional, com pior desempenho na tetraplegia e lesões recentes, mas a mobilidade apresentou parcial dependência nos participantes.

Palavras-chave: Independência funcional. Fisioterapia. Traumatismos da medula espinal.

Introduction

Spinal cord injury (SCI) brings radical changes to the individual, his family and the social environment, because of changes in body dynamics and abrupt transformations, leading to disabilities, reduced functionality and readjustment to a new lifestyle. 1-3 During the rehabilitation process, specific assessments are necessary to determine a physiotherapeutic program and interventions, ensuring a better quality of life and functional independence in activities of daily living (ADLs). 2,7 ADLs are inherent qualities of the human being that involve self-care, mobility and feeding; functionality is the interaction or complex relationship between the health condition and contextual factors. 4

There are questionnaires that can be used in the assessment of functional independence in SCI, such as the functional independence measure (FIM), 2,7,10 which assigns scores or classifications to people with disabilities, according to the care required according to such limitations, and identifies the level of independence. 5,8 The FIM is an instrument that has reliability and validity for SCI; however, it has been little used for this population. 1,10 Other instruments can be used to assess the level of functionality, such as the quality of life questionnaire in individuals with spinal cord injury ("QVLM"), the health status questionnaire (SF-36), as well as the International Classification of Functioning, Disability and Health (ICF), 8,10,11 which analyzes several health components and other related ones such as education and work for the description and evaluation of a population. 8

An important and specific instrument to assess the functional independence of people with SCI is the Spinal Cord Independence Measure - Self-Reported Version (brSCIM-SR), 11-15 which was derived from the third version, SCIM III. brSCIM-SR has already been validated for Brazilian Portuguese; 5 however, it was not in the form of self-report. This instrument and its versions analyze specific activities in domains and subdomains, being more sensitive to changes compared to the MIF scale. 4 Thus, the aim of the present work was to analyze the functional independence of individuals with SCI and compare each domain and their respective subdomains of the brSCIM-SR questionnaire with different groups (diagnosis, time since SCI and sex).

Methods

The sample size calculation was performed using the online version of the PSS Health tool. 16 To estimate this calculation, the confidence interval for the mean was chosen, with an absolute error margin of 5% and 95% confidence level. Considering the expected standard deviation of 15.8 points, as mentioned in Tánnus et al., 3 a total sample of 41 individuals was reached, but an increase of 10% was made due to possible losses, giving a sample size of at least 46 participants. 16

Benedicto AJ et al.
This was a cross-sectional study carried out at University Hospital of the State University of Londrina (HU-UEL), Paraná, Brazil. The work was approved by the Ethics Committee in Research Involving Human Beings of UEL (CAAE: 10348919.5.00005231). Individuals with SCI of both sexes aged 18 years or older and with more than 6 months since injury were included. Those with a diagnostic hypothesis of spinal cord syndrome and with other associated neurological diseases were excluded.

Participants were recruited from the Neurofunctional Physiotherapy service at HU-UEL. All were interviewed about personal data, and clinical information was collected from the patients' medical records according to the medical diagnosis in paraplegia and tetraplegia. They were then evaluated by a second year neurofunctional physical therapy resident, previously trained in the American Spinal Injury Association (ASIA),\textsuperscript{8,17} to determine the neurological level and type of lesion. Subsequently, the brSCIM-SR\textsuperscript{7,9,11,13,15} questionnaire was administered by the person responsible for the research, who was trained in the questioning and familiarized with its content. For a better understanding of the functional independence of individuals with SCI, participants were analyzed in subgroups, according to diagnosis (paraplegia and tetraplegia), time since injury (< or >2 years) and sex (male and female).

The brSCIM-SR questionnaire

The SCIM-SR is a specific and validated questionnaire for people with SCI that quantifies functionality in their ADLs. Its first version was published in 1997.\textsuperscript{5} The Brazilian version (brSCIM-SR) originated from the brSCIM III version, in the self-report format,\textsuperscript{5,12} consisting of 17 questions about daily tasks grouped into three domains, where each domain has its subdomains, with their respective items. The items, which must be marked by the interviewee, are scored by the degree of difficulty and ability of the individual to perform the tasks.\textsuperscript{2,3} The sum of each value of the scored item is then made, where the higher the score, the higher the functional performance is.

The domain self-care (from 0 to 20 points) contains four subdomains: 1. Eating and drinking (0-3 points); 2A. Washing your upper body and head (0-3 points); 2B. Washing your lower body (0-3 points); 3A. Dressing your upper body (0-4 points); 3B. Dressing your lower body (0-4 points); and 4. Personal hygiene (0-3 points).\textsuperscript{3,7,12} In each subdomain there are several items such as: for example, in 4: Please think about activities such as washing your hands and face, brushing your teeth, combing your hair, shaving or putting on make-up and choose the option that best expresses your current situation. [0] I need total help; [1] I need a little help; [2] I am independent using adaptation devices; [3] I am independent without adaptation devices.

The domain respiration and sphincter management (from 0 to 40 points) has eight subdomains: 5. Respiration (0-10 points); 6A. Use of a urinary catheter (0-1 point); 6B. Intermittent catheterization (0-7 points); 6C. Use of external drainage instruments (e.g., condom-type urine collector, diapers, sanitary napkins, etc.) (0-7 points); 7A. Do you need help with bowel control (e.g., administering suppositories)? (0-2 points); 7B. My bowel movements are (0-4 points); 7C. Loss of stool ("accidents") happens... (0-4 points); 8. Use of the toilet (0-5 points).\textsuperscript{7,12} In this subdomain there are also several items: for example, in 7B. [0] irregular or rare (less than once in 3 days); [1] regular (once every 3 days or more often).

The domain mobility (from 0 to 40 points) has nine subdomains: 9. How many of the next four activities can you do without help or electrical appliances? (0-6 points); - Rolling your upper body on the bed. - Rolling your lower body on the bed. - Sitting in the wheelchair, lifting the trunk up with the strength of your arms (with or without adaptation devices); 10. Transfer from bed to wheelchair (0-2 points); 11. Transfer from wheelchair to toilet/bath (0-2 points); 12. Moving around indoors (0-8 points); 13. Going moderate distances (10 to 100 m) (0-8 points); 14. Moving around outdoors for more than 100 m (0-8 points); 15. Going up or down stairs (0-3 points); 16. Transfer from wheelchair to car (0-2 points); 17. Transfer from floor to wheelchair (0-1 point). The total score of the brSCIM-SR is 100 points, with higher scores reflecting higher levels of independence.\textsuperscript{3,5,7,12,13,15} In this subdomain, there are also several items, for example, 15: [0] I am unable to go up and down stairs; I can go up and down at least 3 steps... [1] but only with help or supervision; [2] but only with auxiliary device such as handrail, crutch or cane; [3] without any help, supervision or device.

In the present work, for a better understanding of the scores in the subdomains 6A, 6B, 6C, 7B and 7C of the brSCIM-SR, the values were adjusted to facilitate their calculations, because when a certain item in the bladder (6) and intestinal (7) subdomains is marked by the participant, there are instructions to consult the appendices of that instrument on the sum of them.
Statistical analysis

Sociodemographic and clinical variables were presented as mean and standard deviation or as median and interquartile range, according to the Kolmogorov-Smirnov normality test, and as absolute and relative frequencies. The Mann-Whitney U test was used to compare subgroups (paraplegia and tetraplegia; less and more than two years since injury; male and female), with the scores for each of the three domains and the total of the brSCIM-SR and their respective seventeen subdomains. Analyses were performed with a significance level of 5% (p < 0.05), using the Statistical Package for Social Science (SPSS) version 21.0 for Windows®.16

Results

The mean age of the 50 participants was 40.92 ± 13.93 years. In Table 1 is the information about medical diagnosis, time since SCI, sex and etiology.

Table 1 - Sociodemographic and clinical information and of the participants (n = 50)

| Parameters                          | n (%)  |
|-------------------------------------|--------|
| **Sex**                             |        |
| Male                                | 40 (80) |
| Female                              | 10 (20) |
| **Diagnosis**                       |        |
| Paraplegia                          | 40 (80) |
| Tetraplegia                         | 10 (20) |
| **Time since spinal cord injury**   |        |
| < 2 years                           | 5 (10)  |
| 2 to 5 years                        | 45 (90) |
| **Etiology**                        |        |
| Motor vehicle accident              | 18 (36) |
| Firearm injury                      | 14 (28) |
| Stabbing injury                     | 1 (2)   |
| Diving                              | 5 (10)  |
| Others (inflammatory and oncological)| 12 (24) |

Table 2 shows the scores of all participants and the comparisons by the Mann-Whitney test of the subgroups with the three domains and of the total brSCIM-SR. In self-care, all achieved excellent scores and similar values were observed in paraplegia and in individuals more than two years of SCI. Those with tetraplegia and those with less than two years of SCI achieved significantly lower scores. In respiration and sphincter management, all achieved a good score, except for tetraplegia, which was significantly lower compared to paraplegia. In terms of mobility, surprisingly, all had a low score, with a better performance for paraplegia, for those with more than two years since SCI and for men. In the brSCIM-SR total score, most participants achieved a good score, except for tetraplegia, which was significantly lower.

Table 3 shows the comparisons by the Mann-Whitney test of the subgroups with the four subdomains of self-care. In 1. Eating and drinking, the groups paraplegia and both recent and chronic injuries, and both sexes checked the item “I eat/drink independently without help or adaptation devices”, and the tetraplegia group checked “I eat/drink independently, but I need adaptation devices or help to cut food, serve drinks or open containers”. In 2A. Washing upper part of body and head, the paraplegia and chronic injuries groups and both sexes indicated “I am independent and do not need adaptation devices or specific equipment”, and the tetraplegia group indicated “I am independent, but I need adaptation devices or specific equipment (e.g., bars, chair)”, while the recent injuries group indicated “I need a little help”. In 2B. Washing lower part of body, the paraplegia and chronic injuries groups and both sexes indicated “I am independent and do not need adaptation devices or specific equipment”, the tetraplegia group indicated “I need a little help”, and the recent injuries group indicated “I am independent, but I need adaptation devices or specific equipment (e.g., bars, chair)”. No 3A. Dressing upper part of body and 3B. Dressing lower part of body, the paraplegia and chronic injuries groups and both sexes indicated “I am completely independent”, and the tetraplegia group indicated “I do not need help with easy-to-wear clothes, but I do need adaptation devices or specific equipment”, while the recent injuries group indicated “I am independent with easy-to-wear clothes and only need help or adaptation devices or a specific fit with difficult-to-wear clothes”. 
In 4. Personal hygiene, the paraplegia and chronic injuries groups and both sexes marked “I am independent without adaptation devices”, and the recent injuries group marked “I need a little help”. It can be seen that tetraplegia was significantly lower, except in subdomains 1 and 4 of self-care. As for time since SCI, individuals with chronic injury also reached maximum scores in the same subdomains as paraplegia; however, those with recent injury had significantly lower scores in subdomain 2A (Table 3).

Table 2 - The scores of all participants (n = 50) comparing the subgroups with the domains and with the total of the brSCIM-SR

|                      | Participants | Diagnosis | Time since SCI | Sex |
|----------------------|--------------|-----------|----------------|-----|
|                      | Self-care (0-20 points) | Respiration and sphincter management (0-40 points) | Mobility (0-40 points) | Total brSCIM-SR (0-100 points) |
| Paraplegia           | 19.00 [17.00-20.00] | 36.00 [36.00-39.00] | 17.50 [14.00-19.00] | 72.00 [66.00-76.00] |
| Time since SCI       |              |           |                |     |
| < 2 years            |              |           |                |     |
| 2 to 5 years         | 19.00 [17.00-20.00] | 36.00 [33.50-36.00] | 18.00 [14.50-19.00] | 72.00 [66.00-76.00] |
| Sex                  |              |           |                |     |
| Male                 | 18.50 [17.00-20.00] | 36.00 [32.25-38.00] | 18.00 [15.25-19.00] | 72.00 [66.00-76.00] |
| Female               | 19.00 [17.25-20.00] | 36.50 [34.00-39.00] | 15.50 [08.75-18.25] | 71.00 [63.00-76.50] |

Note: brSCIM-SR = Brazilian version of the questionnaire Spinal Cord Independence Measure – Self-Reported Version; SCI = spinal cord injury.

*Significant values by the Mann-Whitney U test.

Table 4 shows the comparisons by the Mann-Whitney U test of the subgroups with the eight subdomains of respiration and sphincter management. In 5. Respiration, all marked “I do not need a breathing tube (tracheal) and I can breathe and cough independently without any help or adaptation device”. In 6A. Use of a bladder catheter, all marked “I do not use a bladder catheter” in 6B. Intermittent catheterization, all marked “I do not use it”. In 6C. Use of external drainage instruments (e.g., condom-type urine collector, diapers, sanitary pads, etc.), the majority indicated “I have urinary control and do not use external drainage instruments”, the tetraplegia and recent injuries groups indicated “I need a little help putting them on.” In 7A. Do you need help with bowel control (e.g., for the application of suppositories)?, the majority indicated “I do not need help with bowel control”, and the group with recent injuries indicated “I still need help with bowel control”. In 7B. My bowel movements are..., the majority marked “My bowel movements are regular or not often (less than once in 3 days)”, and the tetraplegia and recent injury groups marked “My bowel movements are irregular or not often (less than once in 3 days)”. In 7C. Loss of stool (“accidents”) happens..., almost all of them marked “There is no stool loss (accidents)”, but not those with recent SCI who marked “There is loss of stool (accidents) once a month”. In 8. Use of the toilet, almost all of them marked “I do not need help, but I need adaptation devices (e.g., bars) or a place with special adjustments (e.g., bathroom with wheelchair access)”, and the tetraplegia group indicated “I need a little help and I can clean myself on the toilet”, reaching a significant low value.
### Table 3 - The scores of each subgroup and the comparison with the subdomains of the brSCIM-SR self-care domain

| Diagnosis   | 1 (0-3 points) | 2A (0-3 points) | 2B (0-3 points) | 3A (0-4 points) | 3B (0-4 points) | 4 (0-3 points) |
|-------------|----------------|-----------------|-----------------|-----------------|-----------------|----------------|
| Paraplegia  | 3.00 [2.25-3.00] | 3.00 [3.00-3.00] | 3.00 [2.00-3.00] | 4.00 [4.00-4.00] | 4.00 [4.00-4.00] | 3.00 [3.00-3.00] |
| Tetraplegia | 2.00 [1.50-3.00] | 2.00 [0.75-3.00] | 1.00 [0.00-2.25] | 2.00 [0.75-3.25] | 2.00 [0.00-3.00] | 3.00 [0.75-3.00] |
| p-value     | 0.15            | 0.02*           | < 0.01*         | < 0.01*         | < 0.01*         | 0.07           |

| Time since SCI |  |  |  |  |  |  |
|----------------|-----------------|-----------------|-----------------|-----------------|-----------------|----------------|
| < 2 years      | 3.00 [1.00-3.00] | 1.00 [0.50-2.50] | 2.00 [0.00-3.00] | 3.00 [1.50-4.00] | 3.00 [1.50-4.00] | 2.00 [1.00-3.00] |
| 2 to 5 years   | 3.00 [2.00-3.00] | 3.00 [3.00-3.00] | 3.00 [2.00-3.00] | 4.00 [4.00-4.00] | 4.00 [3.00-4.00] | 3.00 [3.00-3.00] |
| p-value        | 0.59            | < 0.01*         | 0.25            | 0.17            | 0.31            | 0.05           |

| Sex           |  |  |  |  |  |  |
|---------------|-----------------|-----------------|-----------------|-----------------|-----------------|----------------|
| Male          | 3.00 [2.00-3.00] | 3.00 [2.00-3.00] | 3.00 [2.00-3.00] | 4.00 [3.00-4.00] | 4.00 [3.00-4.00] | 3.00 [3.00-3.00] |
| Female        | 3.00 [2.00-3.00] | 3.00 [2.75-3.00] | 3.00 [2.00-3.00] | 4.00 [4.00-4.00] | 4.00 [2.50-4.00] | 3.00 [3.00-3.00] |
| p-value       | 0.91            | 0.54            | 0.35            | 0.30            | 0.67            | 0.87           |

Note: brSCIM-SR = Brazilian version of the questionnaire Spinal Cord Independence Measure – Self-Reported Version; SCI = spinal cord injury. Subdomains: 1 = Eating and drinking; 2A = Washing upper body and head; 2B = Washing lower body; 3A = Dressing upper body; 3B = Dressing lower body; 4 = Personal hygiene. * Significant values by the Mann-Whitney U test.

### Table 4 - The subgroup scores and the comparison with the subdomains of the domain respiration and sphincter management of the brSCIM-SR

| Respiration and sphincter management (0-40 points) |
|-----------------------------------------------|
| 5 (0-10 points) | 6A (0-1 point) | 6B (0-7 points) | 6C (0-7 points) | 7A (0-2 points) | 7B (0-4 points) | 7C (0-4 points) | 8 (0-5 points) |
|----------------|--------------|-----------------|-----------------|-----------------|-----------------|-----------------|----------------|
| Diagnóstico   |              |                 |                 |                 |                 |                 |                 |
| Paraplegia    | 10.00        | 1.00            | 7.00            | 7.00            | 2.00            | 4.00            | 4.00            |
|               | [10.00-10.00]| [1.00-1.00]     | [7.00-7.00]     | [6.00-7.00]     | [2.00-2.00]     | [0.00-4.00]     | [3.00-4.00]     |
| Tetraplegia   | 10.00        | 1.00            | 7.00            | 7.00            | 2.00            | 0.00            | 4.00            |
|               | [10.00-10.00]| [0.00-1.00]     | [6.00-7.00]     | [4.75-7.00]     | [0.00-2.00]     | [0.00-4.00]     | [3.00-4.00]     |
| Value-p       | 0.82         | 0.15            | 0.57            | 0.45            | 0.15            | 0.05            | 0.91            |
| Time since SCI|              |                 |                 |                 |                 |                 |                 |
| < 2 years     | 10.00        | 1.00            | 7.00            | 6.00            | 2.00            | 0.00            | 3.00            |
|               | [9.00-10.00] | [0.50-1.00]     | [6.50-7.00]     | [6.00-7.00]     | [0.00-2.00]     | [0.00-4.00]     | [1.50-4.00]     |
| 2 to 5 years  | 10.00        | 1.00            | 7.00            | 7.00            | 2.00            | 4.00            | 4.00            |
|               | [10.00-10.00]| [1.00-1.00]     | [7.00-7.00]     | [6.00-7.00]     | [2.00-2.00]     | [0.00-4.00]     | [3.00-4.00]     |
| p-value       | 0.59         | 0.59            | 0.92            | 0.31            | 0.34            | 0.39            | 0.26            |
| Sex           |              |                 |                 |                 |                 |                 |                 |
| Male          | 10.00        | 1.00            | 7.00            | 7.00            | 2.00            | 4.00            | 4.00            |
|               | [10.00-10.00]| [1.00-1.00]     | [6.00-7.00]     | [6.00-7.00]     | [2.00-2.00]     | [0.00-4.00]     | [3.00-4.00]     |
| Female        | 10.00        | 1.00            | 7.00            | 7.00            | 2.00            | 4.00            | 4.00            |
|               | [10.00-10.00]| [1.00-1.00]     | [7.00-7.00]     | [7.00-7.00]     | [2.00-2.00]     | [3.00-4.00]     | [2.00-4.25]     |
| p-value       | 0.82         | 0.72            | 0.18            | 0.05            | 0.72            | 0.28            | 0.67            |

Note: brSCIM-SR = Brazilian version of the questionnaire Spinal Cord Independence Measure – Self-Reported Version; SCI = spinal cord injury. Subdomains: 5 = Breathing; 6A = Use of urinary catheter; 6B = Intermittent catheterization; 6C = Use of external drainage instruments (e.g., condom-type urine collector, diapers, sanitary pads, etc.); 7A = Do you need help with bowel control (e.g., for the application of suppositories)?; 7B = My bowel movements are...; 7C = Stool loss (“accidents”) happens...; 8 = Use of toilet. *Significant values by the Mann-Whitney U test.
Table 5 shows the comparisons by the Mann-Whitney U test of the subgroups with the nine mobility subdomains. In 9. How many of the next four activities can you do without help or electrical appliances? - Rolling your upper body on the bed; - Rolling your lower body on the bed; - Sitting on the bed; - While sitting in the wheelchair, lifting your trunk up with the strength of your arms (with or without adaptation devices), all marked "I perform all activities without help". In 10. Transfer from bed to wheelchair, all marked "I do not need any help, supervision or adaptation devices". In 11. Transfer from wheelchair to toilet/bath, the majority marked "I do not need any help or adaptation devices" and the tetraplegia and women groups marked "I need some help". In 12. Moving around indoors using a wheelchair, all marked "I am independent with a manual wheelchair but cannot walk". In 13. Going moderate distances (10 to 100 meters) and 14. Going outdoors more than 100 meters using a wheelchair, the majority indicated "I am independent with a manual wheelchair, but not able to walk", and the women marked "I need some help". In 15. Going up or down stairs, everyone marked "I cannot". In 16. Transfer from wheelchair to car, the majority reached the maximum score, as they marked "I do not need any help or adaptation device", except for tetraplegics and women who marked "I need a little help, supervision or adaptation devices". In 17. Transfer from floor to wheelchair, all marked "I need help".

Table 5 - The scores of the subgroups and the comparison with subdomains of the mobility domain of brSCIM-SR

| Diagnosis   | Mobility (0-40 points) | 9 (0-6 pts) | 10 (0-2 pts) | 11 (0-2 pts) | 12 (0-8 pts) | 13 (0-8 pts) | 14 (0-8 pts) | 15 (0-3 pts) | 16 (0-2 pts) | 17 (0-1 point) |
|-------------|------------------------|-------------|--------------|--------------|--------------|--------------|--------------|--------------|--------------|----------------|
| Paraplegia  | 6.00                   | 2.00        | 2.00         | 2.00         | 2.00         | 2.00         | 0.00         | 2.00         | 0.00         | 0.00           |
|             | [4.50-6.00]            | [2.00-2.00] | [1.00-2.00]  | [2.00-2.00]  | [1.25-2.00]  | [2.00-2.00]  | [0.00-0.00]  | [1.00-2.00]  | [0.00-1.00]  |
| Tetraplegia | 6.00                   | 2.00        | 1.00         | 2.00         | 2.00         | 2.00         | 0.00         | 1.00         | 0.00         | 0.00           |
|             | [0.00-6.00]            | [0.00-2.00] | [0.00-2.00]  | [0.75-3.00]  | [0.75-2.25]  | [0.75-2.25]  | [0.00-1.25]  | [0.00-2.00]  | [0.00-0.00]  |
| p-value     | 0.57                   | 0.13        | 0.08         | 0.52         | 0.60         | 0.71         | 0.65         | 0.27         | 0.34         |
| Time since SCI |                      |             |              |              |              |              |              |              |              |
| < 2 years   | 6.00                   | 2.00        | 2.00         | 2.00         | 2.00         | 2.00         | 0.00         | 2.00         | 0.00         | 0.00           |
|             | [2.00-6.00]            | [2.00-2.00] | [1.00-2.00]  | [2.00-2.00]  | [1.00-2.00]  | [1.50-2.00]  | [0.00-0.50]  | [1.00-2.00]  | [0.00-1.00]  |
| 2 to 5 years| 6.00                   | 2.00        | 2.00         | 2.00         | 2.00         | 2.00         | 0.00         | 2.00         | 0.00         | 0.00           |
|             | [5.00-6.00]            | [2.00-2.00] | [1.00-2.00]  | [2.00-2.00]  | [1.00-2.00]  | [1.50-2.00]  | [0.00-0.50]  | [1.00-2.00]  | [0.00-0.00]  |
| p-value     | 0.55                   | 0.35        | 0.77         | 0.35         | 0.52         | 0.61         | 0.92         | 0.87         | 0.31         |
| Sex         |                       |             |              |              |              |              |              |              |              |
| Male        | 6.00                   | 2.00        | 2.00         | 2.00         | 2.00         | 2.00         | 0.00         | 2.00         | 0.00         | 0.00           |
|             | [4.50-6.00]            | [2.00-2.00] | [1.00-2.00]  | [2.00-2.00]  | [2.00-2.00]  | [2.00-2.00]  | [0.00-0.75]  | [1.00-2.00]  | [0.00-1.00]  |
| Female      | 6.00                   | 2.00        | 1.00         | 2.00         | 1.00         | 1.00         | 0.00         | 1.00         | 0.00         | 0.00           |
|             | [4.00-6.00]            | [1.00-2.00] | [0.75-2.00]  | [1.75-2.00]  | [1.00-2.00]  | [0.75-2.00]  | [0.00-0.25]  | [0.00-2.00]  | [0.00-0.25]  |
| p-value     | 0.89                   | 0.54        | 0.33         | 0.71         | 0.28         | 0.20         | 0.85         | 0.18         | 0.72         |

Note: brSCIM-SR = Brazilian version of the Spinal Cord Independence Measure - Self-Reported Version; pts = points; SCI = spinal cord injury. Subdomains: 9 = How many of the next four activities can you do without help or electrical appliances?; 10 = Transfer from bed to wheelchair; 11 = Transfer from wheelchair to toilet/bath; 12 = Moving around indoors using a wheelchair; 13 = Going moderate distances (10 to 100 meters); 14 = Going more than 100 meters outdoors using a wheelchair; 15 = Go up or down stairs; 16 = Transfer from wheelchair to car; 17 = Transfer from floor to wheelchair.
Discussion

In the present study, the brSCIM-SR was used to assess functional independence in the ADLs of individuals with SCI, who commonly face difficulties in actively returning to society, mainly due to their physical disability and the psycho-emotional barriers they face in the process of adapting to the new condition. According to Tannús et al., functional independence influences the performance of daily activities, potential occupational performance and social participation. It is worth mentioning that this study is one of the few that explored the subdomains within the context of the functionality of each brSCIM-SR domain.

It was observed that all respondents achieved excellent independence in self-care, with a median of 19 points, in agreement with two previous studies that found similar values, demonstrating good performance in their activities, but contrary to other studies that reported lower values. It is believed that the results of the present study revealed guidance and training in the acute phase of SCI. Silva et al. believe that rehabilitation programs promote independence for self-care, facilitating the return to activities with quality of life.

In respiration and sphincter management, the median was 36 points, representing good independence, but this finding is in disagreement with the literature, because some studies obtained lower values for this subdomain. Although there is no information about it, the participants in the present study may have received training from the nursing staff for such procedures, especially in the case of bowel involvement, during the hospitalization phase, as the score was maximum in respiration and sphincter management. However, the brSCIM-SR may have presented a limitation when identifying breathing and sphincter functions, since according to the brSCIM-SR these domains are grouped and evaluated together.

In mobility, the median was 17.50 points, similar as in previous studies, there are studies that presented lower values. According to Silva et al., low mobility has a direct impact on the quality of life and health of a spinal cord injured person. We believe that good mobility is explained by the fact that participants use a wheelchair, which facilitates the acquisition of greater independence than other assistive devices for locomotion.

For Neto et al., the ability in a wheelchair is defined as the ability to move around and overcome obstacles in daily activities or social commitments, which translates into independent locomotion for this population.

In the total score of brSCIM-SR, a median of 72 points corroborates previous studies, but some studies have reported lower values. The domains self-care and respiration and sphincter management were responsible for this total value, as previously mentioned, as all reported greater intestinal dependence and need for a wheelchair to move around. However, there is still no consensus in the literature on what would be a cut-off value to consider good functional independence. Neto et al. suggest that a value of 70 points in the SCIM-III could be indicated as a goal, but it is worth mentioning that the aforementioned instrument is an earlier version, not being the same used in the present research, where an approximate value was reached.

Individuals with paraplegia, with chronic SCI and both sexes had excellent performance in self-care, which is in agreement with the literature, as the preservation of upper limb muscles and more time to adapt to the new style of life favored these results. According to Tannus et al. and Dantas et al., the higher the neurological level, the greater the limitations are in functional activities. As for the time since injury, Dantas et al. believe that patients with SCI followed up for approximately three months of hospitalization show the greatest gain in independence. Guidance during the hospital/acute period was not questioned by the brSCIM-SR, but we believe that the lack of initial guidance after the injury is related to functional dependence. On the other hand, Denis et al. warn that the occurrence of complications and long periods of hospitalization should be considered important factors for the reduction of scores in tetraplegia; however, we did not investigate these.

In respiration and sphincter management, excellent independence was found in most subgroups, except for recent SCIs, as also observed in tetraplegia, with significant functional dependence for this domain, in line with other studies. The neurogenic intestine after SCI favors impaction, constipation and fecal incontinence, lowering quality of life and socializing, especially in the initial phase of the injury, where there is still no training for gastrointestinal re-education. In terms of mobility, independence was low in all groups, with
worse performance in tetraplegia and women, which is in agreement with a previous study, where a significant reduction in wheelchair skills was observed compared to patients with paraplegia.

In the total brSCIM-SR score, the majority achieved good functional independence, except for those with tetraplegia, who had significantly lower performance, which is in agreement with other studies. It is noteworthy that participants with recent SCI had lower values (more dependent) than those with chronic injuries, which can be explained by the delay in acquiring a wheelchair or assistive devices for walking. According to Tannús et al., functional disability can cause varying degrees of dependence with regard to ADLs, especially in relation to self-care, sphincter management and mobility, among others. In the work by Prodinger et al., none of the participants had a worse total SCIM-SR score and some responded to each item with the maximum score, indicating that they experienced the highest level of independence that can be assessed by this instrument.

It is believed that scores are better understood when the subdomains of each domain are discussed. Only one European study explored subdomains and their respective items like the present study. We found that individuals with paraplegia showed independence in performing activities in all the subdomains 1, 2A, 2B, 3A, 3B and 4, corroborating the results of another study, which confirmed that fine motor activities tend to be more difficult in tetraplegia and may be impaired by balance deficits or by the interference of spasticity during the performance of these activities. On the other hand, recent injuries favored a dependence on the subdomains 2A, 2B, 3A, 3B and 4, which was expected, since the longer training time and development of strategies facilitate the execution of functional tasks, which has been corroborated in previous studies, in which spinal cord injured patients with greater functionality also had longer time since injury and adequate training. Such findings were also confirmed in the analyses of the present study, as the participants needed a little help in self-care. As for the sexes, no differences were observed between men and women, owing to the guidelines and indications of adaptations for carrying out such activities.

In subdomains 5, 6A, 6B and 7A, all reached total independence, as no one needed breathing devices, urinary catheter, catheterization and bowel aid, in agreement with another study. As for respiration, despite the fact that in the present work without mentioning the neurological level, Dantas et al. state that tetraplegia still has preservation of the spinal segments responsible for the innervation of the respiratory muscles. It is worth mentioning that the bladder and intestinal items scored showed that our study subjects received all the necessary guidelines to perform such activities within the subdomains. In 6C, only participants with recent SCI needed a little help to place drainage instruments, which was expected, as they are still in a stage of receiving guidance, training and adjustments for such devices.

In 7B and 7C, the tetraplegia and recent SCI groups had their bowel movements irregular or not often, with the latter subdomain being characterized by stool loss at least once a month in recent SCIs, in agreement with other studies, which may be explained by the high neurological level and the lack of adjustment of the gastrointestinal system in both subgroups or by some integrity, even if partial, of the sacral medullary segments. Silva et al. found that the longer the time since injury, the greater the independence was for bowel management.

In subdomain 8 (toilet use), only those with tetraplegia had a significant dependence, as they needed help, which was expected due to the involvement of the upper limbs, especially for transfers and for the hygiene procedure. Therefore, transfer training for these individuals is necessary. The work by Ilha et al. provides interesting information about the bladder subdomains, as in their pre-test the participants considered the questions related to bladder control (6A, 6B and 6C) more difficult to understand and answer, however, all participants were able to respond adequately to the instrument, with no need for further adaptations after this validation process.

In subdomains 9 and 10, all subgroups achieved total independence, performing all the activities questioned about and managing to move themselves from bed to wheelchair, corroborating the literature. The integrity of the trunk and upper limbs muscles, even if partial in cervical injuries, are essential for these activities. In subdomain 11, only women and tetraplegics needed help, which is in agreement with a previous study and as expected for high injuries, since two people are needed to help with this transfer. As for the result for women, it is believed that it may be due to the small sample, since the prevalence of spinal cord involvement is in males.
In subdomain 12, individuals in this study who used a wheelchair were independent indoors, but could not walk, as found in a previous study. It is believed that the absence of an adapted home and the presence of architectural barriers are responsible for the low score, because in no subdomain was there mention of such obstacles as those evaluated by the ICF. In subdomains 13 and 14, all respondents were independent using a wheelchair outdoors and for moderate distances, but were unable to walk, as found in a previous survey. It can be interpreted that individuals prefer to achieve their independence through a wheelchair and not through orthotic devices for ambulation, which translates into independent ambulation. In subdomain 15, all answered being dependent on going up or down stairs, similarly to what is seen in the literature. Probably the lack of detail of the dimensions of the steps of the stairs provided an interpretation of momentary incapacity for such execution. In subdomain 16, those with tetraplegia and women reported needing a little help or adaptive devices to transfer to the car, and in 17, all needed full help, as found in an earlier study.

Regarding the limitations of the present study, one can comment on the scarce literature on the specificity of each item of the brSCIM-SR subdomains, which were covered in our work. Accordingly, the reflections in the discussion came more from clinical reasoning than from comparison with other investigations. Another limitation of the study was the discrepancy between the number of individuals with paraplegia and tetraplegia; therefore, further studies are needed to strengthen these findings.

As for the potential of the work, we found that the brSCIM-SR instrument is practical and easy to apply and includes the domains of the injury during the acute and chronic phases, and that it also makes it possible to quantify functionality, allowing the multidisciplinary team and the patient themself to follow their evolution. Thus, understanding the specificity of the brSCIM-SR subdomains better directs the care and therapeutic planning of individuals with SCI.

Conclusion

The results of the present study suggest a good functional independence for paraplegic individuals and a worse performance of individuals with tetraplegia and recent SCI. The subdomain mobility showed partial independence in relation to all subgroups studied. The brSCIM-SR proved to be an instrument that measures the degree of functionality of individuals with SCI, mainly through the isolated exploration of items in their domains, thus allowing health professionals and the patient themself to quantify and locate the items that indicate their deficits or gains during the rehabilitation process.

Authors’ contributions

AJB, AGF, MVFF, ELL and RBS were responsible for the conception and design of the study and the analysis and interpretation of the data. AJB and ALM drafted the manuscript and revised it, including important intellectual criticism of the content. All authors approved the final version.

References

1. Tannús RA, Ordonez ER, Guerra DMCS, Orcino JL, Melo RCS, Silva AMTC, et al. Análise da correlação entre independência funcional e satisfação com a tecnologia assistiva em pessoa com lesão medular. Rev Contexto Saude. 2021;21(42):52-62. DOI

2. Rahimi M, Torkaman G, Ghabaee M, Ghasem-Zadeh A. Advanced weight-bearing mat exercises combined with functional electrical stimulation to improve the ability of wheelchair-dependent people with spinal cord injury to transfer and attain independence in activities of daily living: a randomized controlled trial. Spinal Cord. 2020;58(1):78-85. DOI

3. Ribeiro Neto F. Predição da independência funcional baseada na força relativa em homens adultos com lesão medular traumática [dissertation]. Brasília: Universidade de Brasília; 2017. 112 p. Full text link

4. Batista KG, Reis KB, Campelo RCL, Lana MRV, Polese JC. Comparação da incapacidade percebida e independência funcional em indivíduos com lesão medular atletas e não atletas. Fisioter Pesqui. 2019;26(4):433-8. DOI

5. Ilha J, Avila LCM, Santos CCE, Swarowsky A. Tradução e Adaptação Transcultural da versão brasileira da Spinal Cord Independence Measure - Self-Reported Version (brSCIM-SR). Rev Bras Neurol. 2016;52(1):2-17. Full text link
6. Catz A, Itzkovich M, Agranov E, Ring H, Tamir A. The spinal cord independence measure (SCIM): sensitivity to functional changes in subgroups of spinal cord lesion patients. Spinal Cord. 2001;39(2):97-100. DOI

7. Denis AR, Feldman D, Thompson C, Mac-Thiong JM. Prediction of functional recovery six months following traumatic spinal cord injury during acute care hospitalization. J Spinal Cord Med. 2018;41(3):309-17. DOI

8. Cabral CR, Mejia DPM. Principais protocolos e testes para avaliação da funcionalidade em lesionados medular [undergraduate thesis]. Manaus: Universidade do Estado do Amazonas; 2016. 10 p. Full text link

9. Ribeiro Neto F, Costa RRG, Tanhoffer RA, Leal JC, Bottaro M, Carregaro RL. Muscle strength cutoff points for functional independence and wheelchair ability in men with spinal cord injury. Arch Phys Med Rehabil. 2020;101(6):985-93. DOI

10. Silva GA, Schoeller SD, Gelbcke FL, Carvalho ZMF, Silva EMJP. Avaliação funcional de pessoas com lesão medular: utilização da escala de independência funcional - MIF. Texto Contexto Enferm. 2012;21(4):929-36. DOI

11. Dantas D, Amaro J, Silva P, Margalho P, Lains J. Avaliação da recuperação funcional em lesionados medulares aplicando a Medida de Independência na Lesão Medular (SCIM) - Contributo para a validação da versão portuguesa. Rev Soc Port Med Fis Reab. 2012;21(2):20-7. DOI

12. Wilartratsami S, Luksanaprucksa P, Santipas B, Thanasomboonpan N, Kulprasutditlok P, Chavasiri S, et al. Cross-cultural adaptation and psychometric testing of the Thai version of the Spinal Cord Independence Measure III-Self Report. Spinal Cord. 2021;59(3):291-7. DOI

13. Prodinger B, Ballert CS, Brinkhof MW, Tennant A, Post MW. Metric properties of the Spinal Cord Independence Measure - Self Report in a community survey. J Rehabil Med. 2016;48(2):149-64. DOI

14. Fekete C, Eriks-Hoogland I, Baumberger M, Catz A, Itzkovich M, Lüthi H, et al. Development and validation of a self-report version of the Spinal Cord Independence Measure (SCIM III). Spinal Cord. 2013;51(1):40-7. DOI

15. Jones ML, Evans N, Tefertiller C, Backus D, Sweatman M, Tansey K, et al. Activity-based therapy for recovery of walking in individuals with chronic spinal cord injury: results from a randomized clinical trial. Arch Phys Med Rehabil. 2014;95(12):2239-46.e2. DOI

16. Borges RB, Mancuso ACB, Camey SA, Leotti VB, Hirakata VN, Azambuja GS, et al. Power and Sample Size for Health Researchers: uma ferramenta para cálculo de tamanho amostral e poder do teste voltado a pesquisadores da área da saúde. Clin Biomed Res. 2020;40(4):247-53. DOI

17. American Spinal Injury Association. International Standards for Neurological Classification of SCI (ISNCSCI) Worksheet [cited 2021 Mar 10]. Available from: https://tinyurl.com/5bz2ztfv