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Original Article

Functional disability of adult individuals with spinal cord injury and its association with socio-demographic characteristics[1]

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The aim was to investigate the Functional Disability degree in adults with spinal cord injury and its association with socio-demographic characteristics. The Barthel Index was used and 75 subjects answered a questionnaire with socio-demographic variables. The Chi-Square, Cronbach's Alpha and Fisher tests were used in the analysis. The mean age was 42.23 years. Cronbach's Alpha for the Barthel Index was 0.807. The activities that were more difficult to perform were Climbing and Descending Stairs (92%) and Walking (82.7%). The mean Barthel Index score was 64 points. The tests of association demonstrated values with p>0.05. Even though this population demonstrated a low degree of dependency and no association was identified between the socio-demographic variables and Functional Disability, the study contributes to nursing care for individuals with spinal cord injury, considering the limitations the condition imposes on their self-care.

Descriptors: Disabled Persons; Spinal Cord Injuries; Socioeconomic Factors; Activities of Daily Living; Nursing.

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Incapacidade funcional e associações com aspectos sociodemográficos em adultos com lesão medular

Objetivou-se investigar o grau de incapacidade funcional de adultos com lesão medular e a sua associação com as características sociodemográficas. Utilizaram-se o índice de Barthel e um questionário com variáveis sociodemográficas. Participaram 75 sujeitos. Efetuaram-se os teste qui-quadrado, Cronbach e Fisher. A média de idade foi de 43,23 anos. O alfa de Cronbach para o índice de Barthel foi de 0,807. As atividades nas quais se verificou maior dificuldade de realização foram subir e descer escadas (92%) e deambular (82,7%). O escore médio do índice de Barthel foi de 64 pontos. Os testes de associação apresentaram valores de p>0,05. Apesar de a população apresentar grau leve de dependência e não se identificar associação entre as variáveis sociodemográficas e a incapacidade funcional, considera-se que o estudo contribui para a assistência de enfermagem, por possibilitar reflexões na busca de se amenizar algumas limitações que a lesão medular impõe ao autocuidado.

Descritores: Pessoas com Deficiência; Traumatismos da Medula Espinhal; Fatores Socioeconômicos; Atividades cotidianas; Enfermagem.

Incapacidad funcional y asociaciones con aspectos socio-demográficos en adultos con lesión medular

El objetivo fue investigar el grado de Incapacidad Funcional de adultos con lesión medular y su asociación con las características socio-demográficas. Se utilizó el Índice de Barthel y un cuestionario con variables socio-demográficas. Participaron 75 sujetos. Se efectuaron las pruebas: Chi-cuadrado, Cronbach y Fisher. El promedio de edad fue de 43,23 años. El Alfa de Cronbach para el Índice de Barthel fue de 0,807. Las actividades en las cuales se verificó mayor dificultad de realización fueron Subir y Bajar escaleras (92%) y Deambular (82,7%). La mediana del Índice de Barthel fue de 64 puntos. Las pruebas de asociación presentaron valores de p>0,05. A pesar de que la población presenta un grado leve de dependencia y no se identificaron asociaciones entre las variables socio-demográficas y la Incapacidad Funcional, se considera que el estudio contribuye para la asistencia de enfermería, debido a algunas limitaciones que la lesión medular impone en el auto-cuidado.

Descriptores: Personas con Discapacidad; Traumatismos de la Médula Espinal; Factores Socioeconómicos; Actividades Cotidianas; Enfermería.

Introduction

Incidence levels of external health problems are high, including spinal cord injury (SCI), due to the increased number of car and motorcycle accidents and urban violence, representing a public health problem(1). In 2007, the Unified Health System attended 832,858 users who were hospitalized for external causes. In Sarah Network Hospitals alone, 1,787 people were hospitalized due to external causes in the first semester of 2009(2). North American statistics reveal that the incidence of SCI ranges between 28 and 55 cases per million people, reaching 10,000 new cases per year, 55% of which refer to paraplegia and 44% to quadriplegia. In Brazil, there are about 130 thousand people with SCI(3).

SCI victims may present complications, which include: neuromuscular, respiratory and circulatory impairment, metabolic alterations, sphincter control difficulty and spasticity(4). As a result of these conditions, some health problems may emerge, such as obesity, coronary disease and type 2 diabetes mellitus(5). In combination with health problems, these complications may lead to functional disability (FD) for SCI patients to accomplish activities of daily living (ADLs).

FD, in turn, can cause dependence on third parties to develop daily and intimate activities. Nursing care plays a very important role in this process. The Consortium for Spinal Cord Medicine recommends constant monitoring and assessment of functional ability during rehabilitation, as well as the maximization of functional results through clinical strategies. Therefore, one of the priorities when treating SCI patients is the optimization of functional independence(6).

SCI patients need to develop a set of skills to cope with the repercussions of this problem for family, affective, social and occupational relations, and also for self-care. In nursing care, nurses need to believe in patients' self-care potential and be prepared to check these individuals' ability to be continuous and effective self-care agents(7).

Concerning socio-demographic aspects, disabled people face difficulties to guarantee their human development, as the economic parameters of social justice, including the Gini Coefficient, appoint that only 10% of the Brazilian population concentrates significant *per capita* income rates. Thus, although disabled people have already conquered specific legislation that guarantees their right to citizenship, they face social conditions that make it difficult for them to overcome poverty, due to limiting factors in health, education and work(8).

The researchers departed from the premise that, besides illnesses, disabilities or impaired health conditions, some social and demographic aspects can influence people's ability to put in practice ADLs, in accordance with another study(9). In that perspective, the goal of this research was to investigate the degree of FD among adults with spinal cord injury and its association with socio-demographic characteristics.

This study's pertinence derives from the existing gap in literature with regard to research on SCI patients' FD, a factor that hampers nursing care with emphasis on self-care. As disabled people are a research priority, according to the National Health Research Priority Agenda(10). Pertinence also derives from the potential social impact the research can create, as knowledge on the existing associations between FD and socio-demographic aspects of SCI patients can support the (re)formulation of public policies that guarantee these individuals' citizenship and social (re) inclusion.

Methods

Cross-sectional, quantitative census study. The research was developed at the Basic Family Health Units (UBSFs) in the urban area of the Agreste da Borborema Micro-region (MAB) between August 2009 and November 2010. This micro-region is one of the seven parts of the *Compartimento da Borborema*, located on the *Planalto da Borborema*, in the Brazilian Northeast. The region includes the following cities: Areial, Campina Grande, Esperança, Fagundes, Lagoa Seca, Massaranduba, Montadas, Pocinhos, Puxinanã, Queimadas, Remígio and Solânea.

The population comprised all 75 SCI patients living in the MAB, registered in any of the 99 urban UBSF's that exist in MAB cities. The following eligibility criteria were determined to participate in the study: people aged 18 years or older, male and female, with a specialized diagnosis of SCI, including paraplegia or quadriplegia, with cognitive skills to answer questions, living in the urban region of the MAB and who accepted to participate in the research.

Two instruments were used: Questionnaire I, to investigate socio-demographic variables, and Questionnaire II, called the Barthel Index (BI). The researchers filled out these instruments based on the participants' answers.

The BI(11) permitted assessing the subjects' functional ability for ADLs. This index contains ten mobility items that constitute the ADLs: dressing, bathing, feeding, grooming, transfers from bed to chair and back, bladder and bowels control, toilet use, mobility and climbing stairs. Each item contains questions scored as 0, 5, 10 or 15, depending on the person's ability to perform the activity. The global result ranges from 0 to 100 points. Score 100 means total independence; 60-95 indicates mild dependence; 40-55 moderate dependence; 20-35 grave dependence; and <20 total dependence.

The collected data were inserted in an electronic database (double-entry), analyzed using Statistical Package for the Social Sciences (SPSS) software, version 15.0 for Windows and presented in tables. A 95% confidence interval was considered for the investigated associations.

To analyze the socio-demographic data and BI scores, descriptive statistics was used/ To check the significance level of associations between the socio-demographic aspects and FD for ADLs, the BI variables were dichotomized (Dependent=moderate, severe or total disability; Independent=mild disability or full functional ability), the prevalence rate was calculated and prevalence proportions were compared through the chi-square test. For cases below five, however, Fisher's test was considered. The reliability of the Barthel Index questionnaire was checked using the Cronbach Test, considering total Alpha, Correlation with corrected items and Alpha with deleted items. This test permits checking the instrument's reliability, i.e. its internal consistency.

The project was submitted to the Institutional Review Board at *Universidade Estadual da Paraíba* (CEP/UEPB), under CAAE: 0490.0.133.000-08. Data collection started after approval had been obtained. The Informed Consent Term (ICT) was presented and, next, those subjects who complied with the inclusion criteria signed the ICT, in compliance with National Health Council Resolution 196/96.

Results

Socio-demographic profile

In Table 1, socio-demographic data are presented. The majority is male (81.3%), with a proportion of 4.35 men for every woman. Most of the 75 participants are Catholic (66.7%), non-White (54.7%), with unfinished primary education (56%), living without a partner (50.7%) and gaining up to two minimum wages (70.7%). The most frequent current age range is between 50 and 65 years (36%), while the most representative age range at the time of the SCI was between 18 and 33 years (50.7%). The participants' mean age was 43.23 years. At the time of the SCI, on the other hand, the mean age was 30.73 years. It is important to highlight the long time since the SCI was diagnosed, i.e. more than 10 years.

Table 1 – Socio-demographic profile of adults with spinal cord injury. *Agreste da Borborema* micro-region, Brazil, 2009-2010

Variables	n	%
Gender		
Male	61	81.3
Female	14	18.7
Religious belief		
No belief	02	2.7
Catholic	50	66.7
Evangelic	20	26.7
Kardecist	03	4.0
Ethnic origin		
White	34	45.3
Black	17	22.7
Mulatto	22	29.3
Yellow	02	2.7
Education		
Primary 1	15	20.0
Primary 2	42	56.0
Secondary	08	10.7
Higher	09	12.0
Graduate	01	1.3
Marital status		
Single	26	34.7
Married	29	38.7
Widowed	02	2.7
Divorced	10	13.3
Fixed partner	08	10.7
Income		
1 minimum wage	24	32.0
2 minimum wages	29	38.7
3 minimum wages	13	17.3
≥ 4 minimum wages	09	12.0
Current age range		
18-33 years	25	33.3
34-49 years	17	22.7
50-65 years	27	36.0
66-81 years	06	8.0
Age range at the time of the SCI		
2-17 years	10	13.3
18-33 years	38	50.7
34-49 years	19	25.3
50-65 years	07	9.3
66-81 years	01	1.3

n = 75; Minimum wage = R$510.00.

It should be highlighted that most participants come from cities in Paraíba State (86.7%), followed by Pernambuco (8%), Rio de Janeiro (2.7%) and Bahia and Ceará, both corresponding to 1.3%. On average, they had lived in the MAB for 32.47 years (±16.7; x_{min}=1, x_{max}=74).

Barthel Index reliability test

Although the Barthel Index is a tested and validated instrument, its reliability was assessed using Cronbach's Test, according to Table 2. Reliability was satisfactory, with total Cronbach's Alpha = 0.807, total correlation of corrected items >0.3 and Cronbach's Alpha with deleted item >0.7.

Table 2 – Barthel Index Questionnaire tested using Cronbach's Alpha

Barthel Index Items	Total correlation of corrected items	Cronbach's Alpha with deleted item	Total Cronbach's Alpha
Feeding	0.366	0.803	0.807
Bathing	0.534	0.789	
Dressing	0.530	0.785	
Grooming	0.365	0.804	
Bowel control	0.423	0.798	
Bladder control	0.388	0.805	
Toilet use	0.665	0.767	
Transfers	0.637	0.770	
Mobility	0.590	0.777	
Climbing stairs	0.484	0.790	

Functional Ability

The prevalence rates of FD for the ADLs are displayed in Table 3. In percentage terms, the most difficult activities to accomplish were Climbing and getting down the stairs (92%) and Walking (82.7%). The highest independence levels were found for Feeding (93.3%) and Grooming (88%). When stratified according to gender, the FD frequencies for the ADLs were higher among women, except for bladder control.

Table 3 – Prevalence of functional disability among people with bone marrow injury according to gender. *Agreste da Borborema* micro-region, Brazil, 2009-2010

Activities of daily living	General		Gender			
			M		F	
	n	%	n	%	n	%
Feeding						
Independent	70	93.3	58	95.1	12	85.7
Help	03	4.0	02	3.3	01	7.1
Dependent	02	2.7	01	1.6	01	7.1
Bathing						
Independent	46	61.3	39	63.9	07	50.0
Dependent	29	38.7	22	36.1	07	50.0
Dressing						
Independent	49	65.3	40	65.6	02	14.3
Help	20	26.7	17	27.9	03	21.4
Dependent	06	8.0	04	6.6	09	64.3
Grooming						
Independent	66	88.0	56	91.8	10	71.4
Dependent	09	12.0	05	8.2	04	28.6
Bowel control						
Normal continence	28	37.3	23	37.7	05	35.7
Occasional accident	25	33.3	21	34.4	04	28.6
Incontinent	22	29.3	17	27.9	05	35.7
Bladder control						
Normal continence	42	56.0	34	55.7	08	57.1
Occasional accident	12	16.0	10	16.4	02	14.3
Incontinent	21	28.0	17	27.9	04	28.6
Toilet use						
Independent	41	54.7	35	57.4	06	42.9
Help	21	28.0	17	27.9	04	28.6
Dependent	13	17.3	09	14.8	04	28.6
Transfers						
Independent	53	70.7	46	75.4	07	50.0
Small help	09	12.0	06	9.8	03	21.4
Large help	08	10.7	05	8.2	03	21.4
Dependent	05	6.7	04	6.6	01	7.1
Mobility						
Independent	13	17.3	11	18.0	02	14.3
Help	05	6.7	03	4.9	02	14.3
Wheelchair user	46	61.3	38	62.3	08	57.1
Dependent	11	14.7	09	14.8	02	14.3
Climbing stairs						
Independent	06	8.0	06	9.8	-	-
Help	10	13.3	07	11.5	03	21.4
Dependent	59	78.7	48	78.7	11	78.6

(continue...)
Table 3 - (contination)

Source: Research data

The mean score was 64 points (±21,3; $x_{min}=0$, $x_{max}=100$), classifying the sample in general at the mild dependence level. Nevertheless, for 25.4% (n = 19) of participants, the classification ranged from Moderate to Total dependence.

Relation between socio-demographic variables and functional ability

As presented in Table 4, no assocation was found between socio-demographic variables and functional ability, but a higher prevalence rate was found for independence among subjects with a religious belief.

Table 4 – Unadjusted associations between socio-demographic factors and functional ability of SCI patients. *Agreste da Borborema* micro-region, Brazil, 2009-2010

Socio-demographic variables	Functional ability				PR (CI - 95%)	X2*	Pd
	Dependent		Independent				
	N	%	n	%			
Gender							
Male	17	27.9	44	72.1	1.95 (0.50-7.48)	1.223	0.269
Female	02	14.3	12	85.7			
Religion							
No belief	01	50	01	50	2.02 (0.47-8.58)	0.661	0.445
Belief	18	24.7	55	75.3			
Ethnic origin							
Non-white	10	25	30	75	0.97 (0.44-2.11)	0.005	0.943
White	09	25.7	26	74.3			
Education							
<10 years	17	27	46	73	1.61 (0.42-6.11)	0.611	0.434
≥10 years	02	16.7	10	83.3			
Marital status							
No partner	08	21.1	30	78.9	0.70 (0.32-1.56)	0.746	0.388
With partner	11	29.7	26	70.3			
Income							
Up to 3 MW	16	24.2	50	75.8	0.72 (0.26-2.01)	0.329	0.566
More than 3 MW	03	33.3	06	66.7			
Current age							
<65 years	13	23.2	53	76.8	0.46 (0.18-1.15)	2.098	0.166
≥65 years	03	50	03	50			
Age at the time of SCI							
<65 years	18	24.3	56	75.7	0.24 (0.16-0.36)	-	-
≥65 years	01	100	-	-			

Dependent = moderate, severe or total disability; Independent = mild disability or total functional ability; MW = minimum wage; *For cases below five, Fisher's test was considered.

Discussion

The larger proportion of male subjects in the population is similar to research results in Brazil and other countries. In a study at *Centro Hospitalar Sarah* in Brasília, 84.7% of men were observed among SCI patients(12). A similar percentage (86.7%) was identified in a research involving a population of 60 paraplegic patients in São Paulo(13). In France, in a national survey of 1,668 subjects, there were four with SCI for each woman, corresponding to 79.9% of subjects in this category(14).

As for the larger frequency of Catholic subjects, this is also in accordance with literature. In line with data from the Brazilian Institute of Geography and Statistics (IBGE), most Brazilians (73.8%) are Catholic(15).

The relative balance between percentages of white and non-white participants in the study population is in accordance with a study developed in Campinas-SP(16), which affirms that, in Brazil, multi-polar racial classification is predominant, that is, there are blacks, mulattos, dark, mixed, colored, white people etc. In a documentary research at the Ribeirão Preto Medical School *Hospital das Clínicas*, considering the files of adult patients hospitalized with traumatic spinal cord injury, the majority was white (68.1%)(17).

Like in the present study, the low education level was also verified in a scientific study by researchers from Brasília, in which most (53.2%) participants had only finished primary education(12).

The low income levels in this study are similar to the data found in a study that involved a sample of 32 subjects in Fortaleza-CE, in which the majority survives on up to one minimum wage(18). In view of financial limitations, it can be inferred that these people's living conditions are impaired.

Concerning marital status, the frequency levels found are distributed among the categories almost equivalently. When the variable was dichotomized between "with partner" and "without partner", however, like in the literature, the majority lives without a partner. One research example for this inference is the study at the Ribeirão Preto *Hospital das Clínicas*(19), in which 80% of the study sample lives without a partner. In a study in the Federal District, then, 61.3% of the subjects affirmed living without and 38.7% with a partner(12).

As for the age range, SCI is more concentrated in the range between 16 and 30 years(20). Hence, the data are in line with the literature. Another study(21) in São Paulo City points in the same sense, as most participants (40%) were between 23 and 32 years old on the occasion.

Thus, most research subjects are: men, Catholic, with low education and low income level, without partners and suffered the SCI when they were young. These characteristics can entail interdependent consequences: the low education level can entail difficulties to get a job, resulting in insufficient financial means. Health prevention and promotion are more difficult on a low income, as well as health service access, mainly at the secondary health care level.

In daily health practices, it is observed that SCI patients' access to services happens in the same form as care delivery to the plural society, including increased access to technical help, which corresponds to the free acquisition of orthoses and prostheses. This practice makes it difficult to monitor these people's health condition and to set up a support network that helps these people to improve their health, based on their expectations. In the attempt to attend to disabled people's demands, the State sanctioned the National Policy for the Integration of Disabled People and the National Health Policy for Disabled People. These recommend, among other guidelines: comprehensive health care, quality of life promotion, functional organization of care services for disabled people and human resource training in the area(22).

The prevalence of FD for ADLs among SCI patients was considered high, but this fact was only verified for some items. Also, the researchers expected to identify a high level of FD, a fact that was not confirmed. A study based on discharge reports of patients monitored at the SCI outpatient clinics of the Rehabilitation Medicine Division between 2000 and 2002 and at the Rehabilitation Center Umarizal of the University of São Paulo appointed the lowest scores for climbing the stairs and dressing with regard to the functional ability of SCI patients(23). In a study accomplished in Fortaleza, the score for the Functional Ability domain was 20.75 on a scale from 0 to 100, indicating a 53.75% prevalence rate of FD among the 32 subjects(18).

Although the results do not indicate any statistically significant association between the socio-demographic factors and the FD, it is believed that a relation exists between these variables, as countless local or systemic factors influence the ability to perform tasks, such as pain.

No studies with similar methods were located that found associations between socio-demographic variables and functional ability to perform ADLs, using the Barthel Index in SCI patients. This difficulty made it impossible to compare the data with other studies at a more in-depth level. Therefore, as a suggestion, this method could be replicated in other Brazilian regions and around the world.

Study limitations derive from the impossibility to determine the direction of the associations, due to the risk of a reverse causality bias, as risk and protection factors and outcomes are verified at the same time (typical limitation of cross-sectional research). The following can also be considered limitations: impossibility to distinguish people victims of complete or incomplete SCI, difficulties to identify the injury level and the limited number of participants.

Based on the confirmation of the Barthel Index' internal consistency, the instrument can be considered reliable. The tool can be used to quantify people's functional ability. Health professionals can use this questionnaire in their care routine, as its application demands few financial resources and time. The instrument was elaborated for application in the plural society though, and is not specific for SCI patients.

In nursing care practice, it is important to highlight that technologies are very important tools to increase care quality. Nevertheless, a balance should exist between physical/hard instruments and nursing work, so as to guarantee the role of nursing in the health care system. Therefore, like care, the role any technology plays derives from relations and socially constructed significance(24). In this perspective, instruments are important for the sake of articulation and intervention in the objects. No specific instrument for SCI patients is known though, which permits verifying the functional ability. A technology could be developed and validated in this sense, which can improve nursing care for SCI patients.

Conclusion

SCI patients in the urban region of the MAB are mostly young men living on a low income and with low education levels. The sequelae the SCI causes significantly impair people's ability to perform some daily activity, mainly those that put a strain on musculoskeletal functions, such as: transfers, walking and climbing stairs. Thus, high prevalence levels of FD are confirmed for some items only in SCI patients. The general functional ability level was identified as mild. It was also verified that no statistical association existed between socio-demographic variables and functional disability. Hence, besides providing important epidemiological support for health and nursing action planning, this study contributes to scientific knowledge by indicating the need to strengthen nursing actions for self-care among SCI patients and to reflect on the relation between these actions and social and demographic issues, permitting the disclosure of a theoretical issue that still needs to be unveiled.

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