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Assessment of the occupational performance of people with multiple sclerosis

Avaliação do desempenho ocupacional de pessoas com esclerose múltipla

Evaluación del rendimiento laboral de las personas con esclerosis múltiple

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Objective: to evaluate the occupational performance of people with MS in the categories of self-care, productivity and leisure. **Methods:** quantitative cross-sectional study, carried out from November 2021 to April 2022, using the Canadian Occupational Performance Measure. **Results:** 115 occupations were considered difficult to perform, with 42 occupations (36.5%) in the "Self-care" category, 34 (29.5%) in the "Productivity" category and 39 (33.9%) in the "Leisure" category. Among the subcategories, the most cited occupations were "Household management" 21 (18.2%), "Active recreation" 21 (18.2%) and "Functional mobility" 20 (17.3%). Occupations related to "Functional mobility" and "Household management" received the lowest performance rates (averages of 5.2). Furthermore, these occupations also received the lowest satisfaction ratings, being 4.7 and 5.1 respectively. **Conclusion:** the functional disabilities of Multiple Sclerosis impacted performance and satisfaction in the occupation categories: Self-care, Productivity and Leisure.
Descriptors: Occupational therapy; Activities of daily living; Multiple sclerosis.

Objetivo: avaliar o desempenho ocupacional de pessoas com EM nas áreas do autocuidado, produtividade e lazer. **Método:** estudo transversal de caráter quantitativo, realizado de novembro de 2021 e abril de 2022, utilizando a Medida Canadense de Desempenho Ocupacional. **Resultados:** 115 ocupações foram consideradas difíceis de serem desempenhadas, sendo 42 ocupações (36,5%) na área "autocuidado", 34 (29,5%) na área "produtividade" e 39 (33,9%) na área "lazer". Dentre as subáreas, as ocupações mais citadas foram "tarefas domésticas" 21 (18,2%), "recreação ativa" 21 (18,2%) e "mobilidade funcional" 20 (17,3%). As ocupações relacionadas a "mobilidade funcional" e "tarefas domésticas" receberam os menores índices de desempenho (médias de 5,2). Além disso, essas ocupações também receberam os menores índices de satisfação, sendo 4,7 e 5,1 respectivamente. **Conclusão:** as incapacidades funcionais da Esclerose Múltipla impactaram o desempenho e satisfação nas categorias de ocupação: autocuidado, produtividade e lazer.
Descritores: Terapia ocupacional; Atividades cotidianas; Esclerose múltipla.

Objetivo: evaluar el rendimiento ocupacional de las personas con EM en las áreas de autocuidado, productividad y ocio. **Método:** estudio cuantitativo transversal, realizado entre noviembre de 2021 y abril de 2022, utilizando la Medida Canadiense de Rendimiento Ocupacional. **Resultados:** 115 ocupaciones se consideraron difíciles de realizar, con 42 ocupaciones (36,5%) en el área de "autocuidado", 34 (29,5%) en el área de "productividad" y 39 (33,9%) en el área de "ocio". Entre las subáreas, las ocupaciones más citadas fueron "tareas domésticas" 21 (18,2%), "ocio activo" 21 (18,2%) y "movilidad funcional" 20 (17,3%). Las ocupaciones relacionadas con la "movilidad funcional" y las "tareas domésticas" recibieron las puntuaciones de rendimiento más bajas (medias de 5,2). Además, estas ocupaciones también recibieron las puntuaciones de satisfacción más bajas, 4,7 y 5,1 respectivamente. **Conclusión:** Las discapacidades funcionales de la Esclerosis Múltiple repercutieron en el rendimiento y la satisfacción en las categorías de ocupación: autocuidado, productividad y ocio
Descriptores: Terapia ocupacional; Actividades cotidianas; Esclerosis múltiple.

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INTRODUCTION

Multiple Sclerosis (MS) is a neurological, progressive and chronic disease, characterized by an inflammatory process in the white matter, with the formation of fibrous scar tissue called sclerotic plaques, which impair the conduction of nerve impulses in any area of the Central Nervous System[1].

The epidemiology of MS peaks between 20 and 30 years of age, generally occurring more in women. It is estimated that 2.8 million people have the disease all over the world, and it is more common in European and North American countries. In Brazil, Multiple Sclerosis has a prevalence rate of 15 cases for every 100,000 (one hundred thousand)[2].

Currently, MS has four known clinical manifestations. Recurring Remitting Multiple Sclerosis (RRMS) is characterized by the acute worsening of disease symptoms accompanied by total or partial functional recovery over time. While Secondary Progressive Multiple Sclerosis (SPMS) is the natural evolution of the RRMS form, in which the disease becomes more progressive, with or without relapses[3].

Primary Progressive Multiple Sclerosis (PPMS) is characterized by the presence of functional decline since the onset of symptoms. While the progressive form with flare-ups occurs when the disease goes through a period of progression with specific flare-ups, whether or not there is, soon after, a full recovery of the affected functions, with subsequent progressive worsening outside the flare-up period[3].

The manifestations of the disease, permanent or transient, are related to generalized weakness, fatigue, spasticity, gait disturbances, altered pronunciation in speech, visual impairment, cognitive deficits, paralysis, aphasia and sphincter changes[4]. These functional disabilities directly impact the way people with MS carry out their occupations[5].

In turn, the Occupational Therapist is the professional who prioritizes occupational goals in their interventions, respecting performance standards, possible difficulties during engagement in activities and their real needs[6].

Occupational performance is conceptualized as the ability of an individual in performing tasks and play roles, taking into account three main components, which are: person, environment and occupation. The person is analyzed according to the elements that surround them, whether physical, affective, social or cognitive. The environment refers to cultural, virtual and institutional elements. And the occupation, in which leisure, self-care and productivity are observed[6].

Therefore, considering that MS is a disabling disease that affects an individual's life in a multidimensional way, this study aimed to evaluate the occupational performance of people with MS in the areas of self-care, productivity and leisure.

METHODS

This is a quantitative and descriptive research, conducted in person or remotely (via Google Meet). This research included people over the age of 18 years, with a confirmed diagnosis of Multiple Sclerosis; who had one of the four clinical manifestations of the disease and who reported the symptoms. The study took place from November 2021 to April 2022.

The instrument used was the Canadian Occupational Performance Measure (COPM). The COPM was created by the Canadian Association of Occupational Therapists, for the use of occupational therapists, and has been validated and standardized. It is an individualized scale that aims to identify occupational problems, analyze performance and satisfaction in areas of occupation, verify self-perception throughout treatments regarding the patient's performance[6].

COPM has three occupational categories, each comprising three different subcategories: “Self-care” (personal care, functional mobility and independence outside the home); “Productivity” (work, household management and play/school); and “Leisure” (quiet recreation, active recreation and socialization).

Initially, research participants should identify the activities they wanted, needed or expected to do. Participants were then encouraged to reflect on which of these activities are difficult to carry out.

The importance of each occupation that was difficult to perform was assessed by participants using a scale ranging from 1 (not important) to 10 (extremely important). The occupations with the highest scores were considered as “priority occupations”, with a maximum of 5. Each participant was then asked to classify each priority occupation according to the level of performance and occupational satisfaction.

The performance scale ranges from 1 ("unable to do") to 10 ("able to do extremely well"). The total performance score is the result of the sum of the scores acquired in each activity divided by the number of problems.

The satisfaction scale ranges from 1 (“not satisfied at all”) to 10 (“extremely satisfied”). Similarly, the total satisfaction score is the result of the sum of the scores acquired in each activity divided by the number of problems.

The work was approved by the Ethics and Research Committee of the Universidade Federal do Pará, through CAAE 49143621.5.0000.0018 of CEP/UFPA opinion: 4.924.840. All

those surveyed who agreed to participate in the research signed the Free and Informed Consent Form (FICF) and the Terms of Use of Image and Sound.

Data analysis was performed using descriptive statistical analysis[8], obtaining means and percentages of the demographic characterization of the participants in this research, as well as data relating to the importance of occupations, occupational performance, occupational satisfaction and the percentage values of each occupation categorical variable. The database, tables and graphs were made in Microsoft Excel 2019.

RESULTS

Sociodemographic data and clinical characteristics

It was found that there is a predominance of women (78.9%) aged over 31 (thirty-one) years, as well as those from states of the Southeastern (36.8%) and Northern (26.3%) regions of Brazil. Most of the participants (12) still work, 04 are already retired due to disability and 03 are receiving illness benefits from the National Institute of Social Security (*Instituto Nacional de Seguridade Social* - INSS) (Table 1).

Table 1: Sociodemographic data of people with MS, Belém/Pará, Brazil, 2022.

Participants information	No	%
Age		
19 - 30 years	07	36.8
31 - 40 years	06	31.5
41 - 50 years	06	31.5
Sex		
Male	04	21.0
Female	15	78.9
Region		
North	05	26.3
Northeast	02	10.5
Central-West	01	05.2
Southwest	07	36.8
South	04	21.0
Work situation		
Still working	12	63.1
Retired due to disability	04	21.0
Recipient of illness benefits	03	15.7

The majority of participants (73.6%) had Recurrent Remitting MS and 63.1% were diagnosed less than 5 years ago (Table 2).

Table 2: Clinical characteristics of people with MS, Belém, Pará, Brazil, 2022.

Participants information	No	%
MS classification		
Recurrent Remitting	14	73.60
Primary Progressive	01	05.20
Secondary Progressive	04	21.00
Time of diagnosis		
01 - 05 years	12	63.10
06 - 10 years	03	15.70
11 - 15 years	04	21.00

Occupational performance

In total, 115 occupations were considered difficult to perform, 36.5% in the "Self-care" category, 29.5% in the "Productivity" category and 33.9% in the "Leisure" category. Among the subcategories, the most cited occupations were "Household management" (18.2%), "Active recreation" (18.2%) and "Functional mobility" (17.3%). While the least cited subcategories were "Play/School" (0.8%) and "Quiet recreation" (4.3%), shown in Table 3.

Average importance ratings were high. The occupations with the highest average importance are related to "Play/School" (10) and "Personal care" (9.6). While the lowest averages are related to "Socialization" (5.2) and "Independence out of the home" (6.08), as in Table 3.

Individuals prioritized 71 occupations, 30% in the "Self-care" category, 34% in "Productivity" and 39% in "Leisure". Among the subcategories, the most prioritized occupations were "Functional mobility" (23.9%) and "Household management" (19.7%). While the least prioritized were "Play/School" (1.4%), "Socialization" (1.4%) and "Community management" (4.2%) as shown in Table 3.

Performance averages were low; the lowest was in "Functional mobility" (average 5.2) and "Household management" (average 5.2). The highest averages are related to "Play/School" (average 9) and "Socialization" (average 8). Satisfaction averages were low; "Functional mobility" (average 4.7) and "Household management" (average 5.1) (Table 3).

Table 3: Occupational performance of people with MS, Belém, Pará, Brazil, 2022.

		Total: 115		Priority: 71		
Categories	**Subcategories**	**No (%)**	**Av. Importance**	**No (%)**	**Av. Performance**	**Av. Satisfaction**
	Personal Care	11 (09.50%)	9.60 (8-10)	10(14.08%)	5.90 (01-10)	5.6 (01-10)
Self-care	Functional Mobility	20 (17.30%)	9.10 (5-10)	17 (23.90%)	5.20 (01-08)	4.7 (01-10)
	Community management	11 (09.50%)	6.08 (1-10)	03 (04.20%)	7.30 (05-09)	07 (06-08)
	Total:	42 (36.50%)		30 (42.20%)		
	Work	12 (10.40%)	8.60 (1-10)	10 (14.08%)	6.0 (01-10)	6.3 (01-10)
Productivity	Household management	21 (18.20%)	7.30 (2-10)	14 (19.70%)	5.2 (01-08)	5.1 (01-10)
	Play/School	01 (00.80%)	10	01 (01.40%)	09	08
	Total:	34 (29.50%)		25 (35.20%)		
	Quiet Recreation	05 (04.30%)	08.20 (7-10)	04 (05.60%)	6.2 (04-08)	5.7 (03-08)
Leisure	Active Recreation	21 (18.20%)	07.10 (1-10)	11 (15.40%)	6.3 (01-08)	7.5 (01-10)
	Socialization	13 (11.30%)	05.20 (1-10)	01 (01.40%)	08	10
	Total	**39 (33.90%)**		**16 (22.50%)**		

DISCUSSION

Sociodemographic data and clinical characteristics

The majority of people with MS in Brazil show their first symptoms around the age of 30 and are diagnosed by the age of 45[9]. However, the majority of research participants (36.8%) were already diagnosed before the age of 30. And 63.1% had lived with the diagnosis for less than 5 years.

The presence of young people with little time since diagnosis in the study was possibly due to the fact that invitations to carry out the research were made via social networks, which are more frequented by young people than older adults and the elderly[10].

78.9% of those surveyed were female. This data is in line with other work, as MS affected 1.7 times more women than men[11]. Furthermore, 73% had RRMS, characterized by acute episodes of symptomatic manifestations lasting more than 24 hours, followed by remissions[12].

Secondary Progressive MS (SPMS) was present in 21%. And, approximately between 10 and 15 years, 50% of people diagnosed with RRMS will transition to SPMS, characterized by periods of disease outbreak accompanied by permanent functional losses[12].

Only one participant (5.2%) had PPMS. Unlike other manifestations of the disease, PPMS has progression of disability since its onset, with constant worsening of symptoms and without clear periods of outbreaks or remissions[13].

A demographic survey showed that 63% of a total of 442 people came from the Southeastern region of Braziol. Similarly, the present study corroborates this information, with 36% of participants from the Southeast region, mainly the state of São Paulo[14].

The region with the second highest percentage of participants was the Northern region, with a total of 26.3%. One factor that explains this result is the fact that the research was

initially carried out with people from an MS association in in the state Pará, located in Northern Brazil, and was later expanded to people from other Brazilian states. However, the Northern Region of Brazil has shown a considerable increase in hospitalizations for MS since 2011[9].

Self-care

Occupations related to self-care include the activities that people perform in order to maintain themselves in a condition that allows function[6]. During the research, activities in this area were mentioned 42 times, being the most mentioned among all occupations that are difficult to carry out. This result may be due to the fact that these occupations, such as bathing, eating and brushing teeth, are considered mandatory by those surveyed.

Self-care occupations are fundamental to maintaining an individual's life, health and well-being. Thus, people with MS seek to carry out these occupations despite the difficulties imposed by the disease[15]. Therefore, self-care occupations can be more challenging for people with greater functional losses.

A similar result can be observed in a study that addressed the occupational performance of people with MS, carried out with 50 patients in Iran and showed that 125 "Self-care" occupations, out of a total of 248, were referred to as activities that were difficult to perform in a satisfactory manner[8].

Among the "Self-care" occupations, "Functional mobility" activities were the most mentioned, corresponding to 17.3% of a total of 115. One factor that may explain this is the manifestation of frequently reported symptoms: spasticity, loss of strength muscle and fatigue.

Such conditions can compromise the function of the lower limbs, limiting the performance of activities related to climbing stairs, walking and moving from one place to another[16]. The presence of these disabilities also directly impacted self-perception of the way they perform these occupations, as "Functional mobility" activities present the lowest overall performance and satisfaction scores; these being 5.2 and 4.7 respectively.

Interventions carried out by occupational therapists in "Self-care" enhance the quality of life of people with MS[17]. The occupational therapist must be aware of the different demands that this patient may present when performing their "Self-care" occupations. Consequently, such a professional must intervene through the use of different strategies, such as assistive technology resources, environmental adaptations, training in Activities of Daily Living (ADLs) and symptom management[16].

Productivity

Occupations related to productivity include occupations aimed at economic preservation, home and family maintenance, voluntary work or personal development[6]. Among the three categories, "Productivity" was the least mentioned area among the activities that are difficult to carry out.

This result can be explained by the fact that 7, out of a total of 19 participants, are retired due to disability or are receiving illness benefits, insured by the National Social Security Institute (INSS). Therefore, they are not carrying out occupations related to "Work".

Participants who keep their jobs mentioned occupations related to "Work" 12 times. Furthermore, these activities presented averages and lows in performance and satisfaction, being 6 and 6.3 respectively.

The severity of MS symptoms, such as fatigue, cognitive changes, anxiety, pain, balance, and spasticity, can affect work productivity over time[18]. The majority of participants who maintain their jobs express an interest in continuing to work for as long as possible, but understand that disabilities interfere considerably with the way they perform their work occupations.

Some participants need longer rest breaks due to fatigue, others have difficulty moving around the workplace and climbing stairs. Furthermore, it is estimated that people with MS can miss four times more work in a period of one year compared to other employees[19].

It is understood that people with MS may have difficulty keeping their jobs. In this sense, the occupational therapist can carry out surveillance of work environments and processes or ongoing education in worker health, with a view to promoting prevention, promotion and rehabilitation of workers with MS[20].

Furthermore, this professional can help prepare for the early retirement process of a person with MS, intervening in the possible repercussions that this may have on a young adult. Creating life projects can be an intervention that can help the individual create a new routine and find activities that fill their time in a meaningful way.

Due to the greater representation of the female gender and activities related to home management, such as sweeping, washing dishes and cooking, are still usually carried out by women, this may corroborate the fact that "Household management" concentrate the highest percentages of mentions among occupations related to "Productivity" (18.2%), being cited 21 times[21].

Even with the disabilities imposed by the disease, those surveyed still carry out occupations related to "Household management", but they perform them in an adapted way:

they perform them at longer intervals and count on the help of family members during periods of crisis.

The averages for occupational performance (5.2) and occupational satisfaction (5.1) were also low for "Household management". These occupations are difficult for people with MS to perform due to physical fatigue and the physical and mental limitations imposed by the disease[5]. The fair sharing of domestic tasks and the effective role of the partner in this process can enhance the quality of life of women with MS by reducing occupational demands in the domestic space.

Leisure

Leisure-related occupations include occupations performed by individuals when they are free from the obligations of being productive[6]. This area was the second most mentioned among research participants, being cited 39 times.

The reason why these occupations are mentioned less than those listed in "Self-care" may be related to the fact that these occupations are often interpreted as unnecessary occupations[5]. It was possible to observe that the participants understood that these occupations are important for their well-being, but they do not compensate for the effort made.

Therefore, it is common for "Leisure" activities to be passively abandoned. People with MS, as they deal with a disabling disease, are less willing to carry out activities related to fun and entertainment, such as traveling, playing games and going on trips[22]. A factor that corroborates this statement is the low predilection for occupations related to "Socialization".

Although these activities were mentioned 13 times, only one was prioritized. This low favoritism may be associated with the prejudice experienced by people with sclerosis due to the stigma of frailty and disability, which has caused many to become more reclusive, to avoid embarrassing situations with friends and relatives.

Furthermore, architectural barriers present in cultural events, public squares and restaurants restrict the social participation of people with disabilities. "Leisure" activities must be carefully planned, as aspects related to the accessibility of the building, duration of the activity and place to rest must be checked in advance to encourage the engagement of the person with MS[23].

Clear communication with companions and the development of strategies to facilitate understanding of the condition are important, as the unpredictable nature of the disease can cause flare ups, making the planned activity unfeasible.

Among leisure occupations, activities related to "Active recreation" were mentioned 21 times, being the most cited in the "Leisure" area, with the highest average satisfaction score among all - 7.5. It is possible that the encouragement of professionals practicing physical activity regularly has influenced this data.

Exercise provides an increase in circulating levels of neurotrophins, favoring neuroplasticity, which enables the preservation of total cortical volume and greater integrity of the white matter. "Active recreation" occupations, such as: practicing sports and aerobic exercise, affect the two pathophysiological processes of MS: axonal damage and demyelination[24].

Engaging in these occupations can alleviate symptoms related to feelings of fatigue, improve cardiorespiratory capacity and functional capacity, such as mobility, balance and strength. Furthermore, it can reduce psychocognitive symptoms, such as depression and anxiety[25].

The conditions of the physical environments where these occupations are carried out can make occupational engagement difficult. Outdoor activities, such as walking on the beach, can become difficult due to uneven terrain and high temperatures. While physical activities carried out indoors, such as exercises carried out in gyms, can become difficult due to the lack of accessibility.

CONCLUSION

Participants had difficulty carrying out activities in the three areas of occupations: self-care, productivity and leisure. The most difficult to perform were: "household management", "active recreation" and "functional mobility". Occupational performance and satisfaction scores were low, the lowest averages were in "functional mobility" and "household management". In this way, the symptoms of the disease directly affected the way people with MS carried out their occupations.

As a limitation of this research, the number of participants stands out, however, as it is a rare disease, the research reveals important implications for occupational issues and provides relevant descriptions of how the occupational performance of people with MS can present themselves, which reveals possible impacts and changes in an occupational dimension and offers evidence for professional occupational therapists in these interventions.

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