

Original Article

Understanding difficulties and contextual factors in the daily activities of people with multiple sclerosis: a pilot study

Compreensão das dificuldades e dos fatores contextuais nas atividades cotidianas de pessoas com esclerose múltipla: um estudo piloto

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Abstract

Introduction: Multiple sclerosis (MS) is characterized by the degeneration of the nervous system structures. This health condition can cause difficulties in carrying out activities of daily living and impact the individual's quality of life. **Objective:** To understand the difficulties and contextual factors (environmental and personal) that act in the daily activities of people with MS. **Method:** Pilot, cross-sectional, descriptive, exploratory study with a quantitative and qualitative approach. The 36-item WHODAS 2.0 form and semi-structured interview were used in order to understand the difficulties and contextual factors that affect the daily activities of people with MS. **Results:** Participants had greater difficulties in terms of mobility and life activities, such as walking long distances and performing household chores. The most used assistive technology resources are wheelchairs, canes and walkers. The installations of grab bars, handrails and ramps were described as modifications made to the environment. **Conclusion:** The findings of this research contributed to verifying the possibility of recruiting a larger sample, exploring the causes of the difficulties, deepening the investigations about the use of assistive technology resources, adaptations in the environment and emphasizing the possible association of the intensity of the difficulties with the mobility aids and environmental adaptations.

Keywords: Activities of Daily, Living International Classification of Functioning, Disability and Health, Self-Help Devices.

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Resumo

Introdução: A esclerose múltipla (EM) é caracterizada pela degeneração de estruturas do sistema nervoso. Essa condição de saúde pode causar dificuldades na realização das atividades de vida diária e impactar a qualidade de vida do indivíduo.

Objetivo: Compreender as dificuldades e os fatores contextuais (ambientais e pessoais) que atuam nas atividades cotidianas das pessoas com EM. **Método:** Estudo piloto, transversal, descritivo, exploratório e de abordagem quantitativa e qualitativa. Utilizou-se o formulário WHODAS 2.0 de 36 itens e entrevista semiestruturada, a fim de compreender as dificuldades e os fatores contextuais que atuam nas atividades cotidianas das pessoas com EM. **Resultados:** Os participantes apresentaram maiores dificuldades em relação à mobilidade e em atividades de vida, como caminhar por longas distâncias e à realização de tarefas domésticas. Os recursos de tecnologia assistiva mais utilizados são as cadeiras de rodas, bengalas e andadores. As instalações de barras de apoio, corrimãos e rampas foram descritas como modificações realizadas no ambiente. **Conclusão:** Os achados desta pesquisa contribuíram para verificar a possibilidade de recrutamento de uma amostragem maior, explorar as causas das dificuldades, aprofundar as investigações acerca do uso de recursos de tecnologia assistiva, adaptações no ambiente e enfatizar eventual associação da intensidade das dificuldades com os recursos auxiliares de locomoção e adaptações ambientais.

Palavras-chave: Atividades Cotidianas, Classificação Internacional de Funcionalidade, Incapacidade e Saúde, Tecnologia Assistiva.

Introduction

Multiple sclerosis (MS) is an inflammatory, chronic and demyelinating neurological disorder of the central nervous system that causes widespread lesions or plaques in the white matter and spinal cord (Silva & Silva, 2014). MS is the most frequent non-traumatic cause of disability in people between 20 and 40 years of age (Guimarães & Sá, 2014), being twice as common in women as in men (Multiple Sclerosis International Federation, 2013).

MS affects an average of 15 to 18 people per 100,000 people (Finkelsztein et al., 2014). Epidemiological studies of MS in Brazil are scarce; however, it is estimated that there are 25,000 people with MS, mostly in the Southeast region (Mesquita, 2013). The causes of MS are still unknown, but studies suggest that genetic predisposition and environmental factors may be related to the development of the disease (Oliveira-Kumakura et al., 2019; Cotsapas et al., 2018). Among the most frequent symptoms of MS are: fatigue, pain, and changes in motor skills and sensitivity (Silva & Cavalcanti, 2019).

People with MS may have disabilities, disadvantage and limitations in daily activities and situations. Impairments in performance ability usually start due to fatigue and weakness, later on, and may progress to other symptoms, such as paraparesis or hemiparesis, spasticity, motor incoordination and involuntary tremors (Pimentel & Toldrá, 2017; Oliveira-Kumakura et al., 2019). These motor changes can cause limitations in activities such as transfers and locomotion. Optical, bladder, bowel, and cognitive changes are also common in this population (Blake & Bodine, 2002). These

symptoms may constitute limitations for carrying out activities such as reading, sexual intercourse and decision-making (Blake & Bodine, 2002).

Several studies used the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) to assess the level of disability in people with MS, concluding that this instrument provides a useful framework to assess different aspects of disability in this population (Chopra et al., 2008; Gomes & Carvalho, 2019; Pokryszko-Dragan et al., 2020; Wu et al., 2020). WHODAS 2.0 was developed by the World Health Organization (2010) and had its Brazilian version validated for use in the process of measuring functionality in people with MS, being considered a useful tool both in clinical practice, to identify areas with deficits and that need of additional interventions and as a research instrument (Cardoso et al., 2020). This instrument proved to be effective in providing valuable information regarding different aspects of the impact of the disease on the individual (Chopra et al., 2008; Wu et al., 2020), as well as for assessing the level of physical disability and correlating it with depressive conditions. (Gomes & Carvalho, 2019) and quality of social participation (Pokryszko-Dragan et al., 2020).

According to the WHO's International Classification of Functioning, Disability and Health (ICF) (Organização Mundial da Saúde, 2013), biopsychosocial model of disability, a person's level of functionality occurs due to a dynamic interaction between their health condition, environmental factors and personal factors. That is, disability should not be related only to physical or mental limitations (health condition), but considered as a dysfunction of the interface between an individual and their context (Organização Mundial da Saúde, 2013). Contextual factors are made up of environmental and personal factors. Environmental factors are defined as access to resources such as assistive technology (AT), accessibility of streets, buildings and means of transport. Personal factors are composed of attitudes of other people, public priorities and availability of services (Organização Mundial da Saúde, 2013). Understanding these factors can help to reduce possible barriers and, thus, facilitate the participation of people with MS.

People with MS who have low occupational performance use assistive technology (AT) devices in order to improve or maintain their functional capacity (Blake & Bodine, 2002). Wheelchairs, canes and walkers are the most used devices due to the limitation in mobility caused by the disease (Blake & Bodine, 2002; Souza et al., 2010; Backus, 2016). The use of AT can increase the quality of life (QoL) of people with MS (Devitt, Chau & Jutai, 2004) and act as a facilitator during ADLs, promoting greater participation for people with MS (Ferreira et al., 2017).

Adaptations and structural changes in the environment are also actions developed for people with MS (Blake & Bodine, 2002). The use of assistive resources and the implementation of architectural changes are generally carried out in the home, work and vehicle contexts (Blake & Bodine, 2002). These interventions help to reduce limitations due to functional status and, consequently, increase social participation in their meaningful activities (Blake & Bodine, 2002).

According to the Conselho Federal de Fisioterapia e Terapia Ocupacional (2015), the occupational therapist is the professional qualified to prescribe, guide and develop mobility aids and structural adaptations that promote increased occupational performance. In the process of rehabilitation of the person with MS, the occupational

therapist contributes with health actions that allow greater participation in self-care, work and leisure activities (Steultjens et al., 2003). Interventions such as rehabilitation, health promotion and fatigue management programs can promote greater functional performance and level of participation in people with MS (Yu & Mathiowetz, 2014a). Occupational therapy can also promote benefits to cognitive, motor and emotion regulation functions in people with MS (Yu & Mathiowetz, 2014b).

The present study is configured as a pilot study. In other words, a preliminary study with the purpose of verifying the feasibility of the method outlined to carry out future investigations on a larger scale (In, 2017). Pilot studies prove to be an important step in mitigating planning and method risks when designing the main study (In, 2017; Thabane et al., 2010). In this way, this study can contribute to the understanding of the investigated target population, the related assessment instruments, the possible relationship of previous data and future challenges regarding the difficulties and contextual factors found in the daily lives of people with MS (In, 2017; Thabane et al., 2010).

Based on this perspective, it is believed that the main study will be able to provide information to occupational therapists about difficulties, AT devices and personal factors commonly reported by people with MS. Furthermore, it will allow possible associations between difficulties in relation to different types of activities, evaluated by WHODAS 2.0, and contextual factors (environmental and personal). Therefore, the present study aims to understand the difficulties and contextual factors (environmental and personal) that act in the daily activities of people with MS.

Method

Methodological outline

This is a cross-sectional, descriptive and exploratory pilot study with a quantitative and qualitative approach. Considering the objective of the main study, this pilot study verified the following feasibility components: procedural (challenges for the recruitment of participants); resource (applicability of research instruments); and scientific (assessment of possible relationship of previous results and challenges for the main study) (Thabane et al., 2010).

Context

This study was carried out through a partnership between the Department of Human Movement Sciences at the Federal University of São Paulo (UNIFESP) and the Brazilian Association of Multiple Sclerosis (ABEM).

Participants

The Ethics Committee of the Federal University of São Paulo, CAAE 28940519.7.0000.5505, approved this research. The present study included the participation of individuals diagnosed with multiple sclerosis. All participants signed the Free and Informed Consent Term that clarifies the rights regarding freedom of

participation and withdrawal, the right to preserved identity and the absence of risks offered to their lives, since the measures used are indirect and non-invasive.

Inclusion criteria: being diagnosed with multiple sclerosis for at least 6 months, being at least 18 years of age at the time of data collection, self-declaring no comorbidities or other chronic physical illness or disability (e.g., stroke or spinal cord injury, a diagnosis of mental illness, psychotic symptoms, or significant cognitive impairment) and agreeing to participate in the study by signing an informed consent form.

Exclusion criteria: being diagnosed with multiple sclerosis for less than 6 months, not being 18 years of age at the time of data collection, self-declaring to have comorbidity or other chronic physical illness or disability (e.g., stroke or spinal cord injury, a diagnosis of mental illness, psychotic symptoms or important cognitive alterations) and disagreeing to participate in the project, not signing the free and informed consent form.

Instruments

WHODAS 2.0

World Health Organization Disability Assessment Schedule (WHODAS 2.0) is a disability/difficulty assessment scale of the World Health Organization (WHO). WHODAS 2.0 aims to measure health and disability in a cross-cultural way. The instrument was developed based on concepts defined by the International Classification of Functioning, Disability and Health (ICF) with questions about the difficulties faced by respondents in the last 30 days and in 6 domains of life: (1) Cognition: understanding and communication; (2) Mobility: movement and locomotion; (3) Self-care: dealing with own hygiene, dressing, eating and being alone; (4) Interpersonal relationships: interactions with other people; (5) Life activities: domestic, school and work activities; (6) Participation: participating in community and society activities (World Health Organization, 2010).

For each domain, the instrument presents a general measure of functionality and disability (degree of functional limitation), without focusing on a specific disease. The WHODAS questionnaire ends with three questions about the frequency in which the participant experienced difficulties and disabilities in the last month, such as: (1) “In general, in the last 30 days, for how many days were these difficulties present?”; (2) “In the last 30 days, for how many days were you completely unable to perform your usual activities or work because of your health condition?”; (3) “In the past 30 days, not counting the days when you were totally disabled, for how many days did you cut back or reduce your usual activities or work because of health condition?” (World Health Organization, 2010).

The simple calculation proposed by the WHODAS 2.0 manual (World Health Organization, 2010) was performed, assigning a score from 0 to 100 for each item, in addition to a total score of the questionnaire (World Health Organization, 2010). Each participant reported their level of difficulty in each activity according to a 5-level scale: “1 – no difficulty” accounting for 0 points, “2 – mild difficulty” (25 points), “3 – moderate difficulty” (50 points), “4 – severe difficulty” (75 points) and “5 – extreme

difficulty/I cannot perform this activity” (100 points). That is, the closer the score is to 100, the greater the difficulty (World Health Organization, 2010).

The mean score for each domain is the sum of the scores for each related activity, divided by the number of items in the domain. The total score is the sum of scores for all domains, divided by the total number of items in the questionnaire, which is 36 items (World Health Organization, 2010). The mean score values of the domains, the standard deviation and the minimum and maximum values of the measured variable referring to the total sample were presented.

Interview about context factors

A semi-structured interview was designed to identify contextual factors such as personal factors, the use of assistive devices and adaptations in the environment that permeate the daily activities of these individuals (Organização Mundial da Saúde, 2013). This interview was based on the International Classification of Functioning, Disability and Health (ICF), which is characterized by being a model for organizing and documenting information on functionality and disability.

The ICF is organized into two parts, the first on functionality and disability and the second on contextual factors, subdivided into environmental and personal factors (Organização Mundial da Saúde, 2013). The first part is subdivided into body functions/structures and activities/participation. Body functions are the physiological aspects of organ systems; the structures are the anatomical support. Activities are the actions and tasks performed by individuals; participation is defined as involvement in daily life situations. The second part of the ICF is subdivided into environmental and personal factors. Environmental factors are about the physical, social and attitudinal environment in which people live and conduct their lives. Meanwhile, personal factors are characterized by specific issues for each individual, such as gender, age, lifestyles, habits, education and profession (Organização Mundial da Saúde, 2013).

The interview contains questions about personal factors, such as: age, gender, time of diagnosis, marital status, employment status, education level and monthly income. The interview contains questions referring to environmental contextual factors, such as: “Do you use any type of assistive device in your daily life?”; “Which resource do you use the most?”; “What was the form of acquisition of AT?”; “Have you made any adaptations in your environment (home, work, car)?”; “What adaptations were made?”; “Are these adaptations characterized as barriers or facilitators?”; “Do your personal relationships act as barriers or facilitators?”. Participants also had the option to report observations that they considered significant in relation to the use of the assistive device in everyday life, as well as the architectural barriers in the environments in which they most frequent.

Procedures

Data collection took place at ABEM's headquarters in São Paulo, on March 4, 2020, with service users waiting for their appointments in the main lobby. The main researcher, constituting a convenience sample, selected the service users. Those who

agreed to participate in the research were interviewed for data collection for the present study.

Therefore, a survey was carried out using the WHODAS 2.0 form administered by the interviewer or in a self-administered form, according to the needs of each interviewee. Subsequently, the participants were interviewed in order to understand whether contextual factors act as barriers or facilitators in daily activities.

Data analysis

The descriptive analysis of the demographic data, as well as the semi-structured interview, was carried out after the procedures for coding the responses and tabulating the data (Gil, 2010). Continuous variables were grouped as mean and standard deviation. Categorical variables were grouped as absolute and relative frequencies. Data collected through WHODAS 2.0 were grouped as mean and standard deviation. Descriptive data analysis was performed using the R software (R Core Team, 2020).

Results

Sample characteristics

Eight individuals with a mean age of 47 years (± 10.60) participated in the study, of which 75% ($n=6$) were female and 87.5% ($n=7$) had been diagnosed for more than of 6 years. As for the marital status of the sample, 37.5% ($n=3$) of the participants were single, 25% ($n=2$) were married and 37.5% ($n=2$) were divorced. Regarding their current work situation, 62.5% ($n=5$) of the participants were retired and 25% ($n=2$) declared themselves in other categories, one being temporarily away from work and the other being responsible for household chores. Only one participant declared performing school or work activities.

Regarding education, 25% ($n=2$) have incomplete elementary education, 37.5% ($n=3$) have completed high school, 25% ($n=2$) have incomplete higher education and 12.5% ($n=1$) complete higher education. Regarding monthly income, 25% ($n=2$) receive up to 1 minimum wage, 37.5% ($n=3$) receive from 1 to 3 minimum wages and 37.5% ($n=3$) from 3 to 6 minimum wages a month.

Description of difficulties in carrying out daily activities and the degree of functional limitation (WHODAS 2.0)

Participants had moderate difficulty in “Mobility” ($40.9+20.7$) and in “Life Activities” ($38.3+37.1$). The domains “Social Participation” ($28.8+20.0$), “Self-care” ($25.8+31.1$) and “Cognition” ($18.2+14.6$) presented mild difficulty, while in “Interpersonal Relations”, no difficulty ($7.5+8.9$). The average total score of the participants was 26.3 ($+11.6$), that is, they had mild difficulty in the activities mentioned in the questionnaire in general (Table 1).

Table 1. Descriptive measures of variables.

Variables	Mean (\pm SD)	Minimum	Maximum
Mobility Score	40.9 (\pm 20.7)	10.0	72.0
Life activities Score	38.3 (\pm 37.1)	0.0	100.0
Participation Score	28.8 (\pm 20.0)	10.6	65.6
Self-care Score	25.8 (\pm 31.1)	0.0	75.0
Cognition Score	18.2 (\pm 14.6)	4.1	50.0
Interpersonal relations Score	7.5 (\pm 8.9)	0.0	20.0
Total score	26.3 (\pm 11.6)	13.2	46.9

Mobility

The individuals had moderate difficulty in the activities “walking for long distances such as one kilometer” (65.6 \pm 32.6) and “standing for long periods such as 30 minutes” (53.1 \pm 36.4). Meanwhile, they had mild difficulty in “getting up from a sitting position” (37.5 \pm 42.2), “leaving the house” (28.1 \pm 33.9) and “moving around inside the house” (14.3 \pm 19.7) (Table 2).

Table 2. Average score of participants in activities in the “Mobility” domain.

Mobility	Mean Score	Standard Deviation
Walking long distances, e.g. one kilometer	65.6	32.6
Standing for long periods, e.g. 30 minutes	53.1	36.4
Getting up from a sitting position	37.5	42.2
Leaving the house	28.1	33.9
Moving around indoors	14.3	19.7

Life activities: domestic, school, and work activities

In “domestic activities”, participants reported greater difficulty in “doing domestic chores at the necessary speed”, indicating moderate difficulty (53.1 \pm 41.0). Participants showed mild difficulty in “doing all the domestic chores needed” and “taking care of domestic chores”, both with a mean score of 37.5 (\pm 37.8) and “doing your most important domestic chores well” (34.4 \pm 37.6) (Table 3).

Only one participant declared performing school or work activities, that is, these items were not scored for the other participants, as instructed in the WHODAS 2.0 Manual (Organização Mundial da Saúde, 2013). Therefore, it was not possible to describe the average score of the sample in relation to this activity.

Table 3. Mean score of the participants in the activities of the domain “Life activities – Domestic Activities”.

Domestic Activities	Mean Score	Standard deviation
Doing domestic chores at the necessary speed	53.1	41.0
Doing all the domestic chores needed	37.5	37.8
Taking care of domestic chores	37.5	37.8
Doing your most important domestic chores well	34.4	37.6

Description of environmental contextual factors

As for contextual factors, 87.5% (n=7) of the participants reported using some type of AT in their daily lives, while only 12.5% (n=1) reported not using it. Most (n=6) had their AT paid with their own resources. Only two participants received the AT resource by donation. Regarding the types of technology used, participants reported using only a cane (n=2), cane and walker (n=1), walker and wheelchair (n=2) and only wheelchair (n=2).

Five (62.5%) participants made changes to the environment (home, workplace or car), such as installing grab bars (n=2), handrails on stairs (n=2), ramps in areas where there were steps (n=1), toilet seat elevation (n=1) and purchase of an adapted car (n=1). Only three participants (37.5%) said they had not made any changes.

All participants who made adaptations claimed that they were important for carrying out daily activities and, in this way, acted as a facilitator. In addition, all participants reported having people (family, friends and neighbors) who act as facilitators in their daily lives.

In the area reserved for observations, 25% (n=2) of the participants reported that the lack of urban accessibility constitutes a barrier to full participation. No observations were made about the use of assistive devices.

Discussion

The present study aims to understand the difficulties and contextual factors (environmental and personal) that act in the daily activities of people with MS. The participants of this research presented typical characteristics predicted for people with MS in Brazil and in the world, with regard to gender, age and employment status (Andrade et al., 2014). On the other hand, in relation to the level of education, only 12.5% of the participants reported having completed higher education. This data contrasts with the findings of the study by Estrutti et al. (2019), in which 67% had completed higher education. This asymmetry is possibly caused by the difference in the size of the studied samples.

Mobility and carrying out life activities, essentially locomotion over long distances and domestic chores, were described as the most challenging activities for this population. This data is also pointed out by Backus (2016) who refers to mobility as a function with greater limitation in people with MS. In contrast, Finlayson et al. (1998) and Andrade et al. (2014) conclude that activities performed while standing, domestic activities and movement outside the home are the most compromised by MS.

MS is a disabling disease that causes impairments in the independent performance of self-care, instrumental and advanced activities of daily living (Oliveira-Kumakura et al., 2019). Activities that require locomotion over long distances and the performance of life activities may require exacerbated energy expenditure for people with MS (Hameau et al., 2017; Severijns et al., 2018). Locomotion is associated with muscle strength and spasticity (Hameau et al., 2017), while daily use of the upper limbs can generate neuromuscular fatigue (Severijns et al., 2018).

Spasticity, loss of muscle strength and fatigue are symptoms commonly present in people with MS, which can significantly impact activities of daily living (ADL). Spasticity compromises the function of the lower limbs, and, more aggravatingly, it can

limit performance in activities such as climbing stairs, walking and even sleep (Bethoux & Marrie, 2016). Other symptoms, such as limitation in muscle strength (Wang et al., 2020) and fatigue (Oliveira-Kumakura et al., 2019; Andrade et al., 2014), are correlated with the development of MS and, consequently, are limiting factors to the performance of self-care, productivity and leisure activities (Andrade et al., 2014; Wang et al., 2020).

Regarding the use of AT, it can be said that devices such as wheelchairs, canes and walkers were used to improve performance in areas of greater difficulty, since the domain that obtained the highest score was “mobility”. ATs related to mobility are often prescribed to people with MS because they have limitations during marching, such as fatigue, muscle weakness, spasticity, ataxia and imbalance (Pereira, 2020; Souza et al., 2010). This impairment can impact independent mobility, significantly interfering with activities of daily living (Van der Feen et al., 2020). Therefore, it is common for people with MS whose disability is moderate to severe to need canes and a wheelchair to perform mobility with more autonomy and independence (Pittock et al., 2004; Souza et al., 2010).

The prescription of these mobility devices should be based on the structures and functions of the body and on the contextual (environmental) factors of the person with MS, aiming to provide greater performance in mobility and participation in daily activities (Eberhardt & Finlayson, 2005). Understanding these factors is essential to reduce the risk of limiting the use and abandonment of mobility AT devices and increasing the individual's functionality according to their needs (Jiménez-Arberas & Ordóñez-Fernández, 2021).

Regarding house modifications, 62.5% of the participants reported having made some adaptation, such as installing grab bars, ramps at the entrances and raising the toilet.

Architectural accessibility in homes for people with neurological disorders is essential for the development of a safe and functional environment. Such adaptations in the environments must be carried out in conjunction with qualified professionals. According to Bishop et al. (2013), it is common for people with MS to make adaptations in their homes and move to homes with more architectural accessibility. However, the study also points out that 1 in 4 patients has financial difficulties to make the necessary adaptations in their homes and 10% report having suffered prejudice when trying to rent a house, being denied as tenants or not obtaining authorization from the owner to make adaptations to improve accessibility (Bishop et al., 2013).

The work of the occupational therapist with the population with MS is based on the management of symptoms, aiming to maximize independence and safety in ADLs (Buzaid et al., 2013). Considering the difficulties described by people with MS in this study, the occupational therapy professional can contribute with health actions that allow greater participation in self-care, work and leisure activities (Steultjens et al., 2003). Through AT and adaptations in the environment, occupational therapy can also carry out actions to promote the functionality, autonomy and independence of people with MS. It is understood that the occupational therapist is the professional qualified to prescribe, guide and develop mobility aids, structural adaptations, training, and strategies to perform ADLs in a functional way (Buzaid et al., 2013; Conselho Federal de Fisioterapia e Terapia Ocupacional, 2015). These actions developed by occupational therapy professionals with this population are effective, indicating a diversity of

interventions that can be used as therapeutic proposals for people with MS (Campos & Toldrá, 2019).

This pilot study proposed to verify the method outlined, in order to make possible the eventual investigation about the use of WHODAS 2.0 and the semi-structured interview prepared by the authors based on the ICF, describing the difficulties and context factors that permeate the daily activities of people with MS. Regarding recruitment, it was easy to approach the participants. ABEM users were interested in answering the questionnaires and willing to discuss with the researcher. In addition, it is noteworthy that, in just one day, data from eight participants were recruited and their data collected, showing ease of collection. Therefore, it is believed that, in order to carry out the main study, it is possible to recruit a larger sample size with ease.

As for the applicability of the instruments, firstly, in relation to WHODAS 2.0, it is known that the questionnaire indicates the level of difficulty in each activity/domain, but does not document the causes of this difficulty. For example, if a person has severe fatigue, they will likely have difficulty in the activity “walking long distances”. In other words, WHODAS 2.0 would identify the existence of the difficulty, but not its cause, that is, fatigue. Thus, it is necessary to implement supplementary questions that explore the causes of the difficulties identified by the WHODAS 2.0 questionnaire.

On the other hand, in the semi-structured interview, the need to deepen investigations into the use of AT resources was observed, in order to verify in which activities and contexts they were used and implemented, for example, registering the types of wheelchairs (manual or motorized) and in which environment these devices are used. Regarding the changes made in the environment, not only describe how they facilitate ADLs, but also how they were indicated and installed (if they were indicated by a health professional, planned by the user, etc.).

Regarding the results, as we found greater difficulty in mobility activities and domestic chores and a greater predominance of mobility devices, we consider emphasizing a possible association of the intensity of the difficulties with the mobility aids and the adaptations carried out in the environments. To this end, it is necessary to apply statistical tests to the main study, in order to understand the relationship between the variables investigated.

Conclusion

Participants with MS had greater difficulties in terms of mobility and life activities, such as walking long distances, and performing household chores. Participants reported making use of assistive technology (AT) devices and resources, and all described them as facilitators during activities. The most used resources are wheelchairs, canes and walkers. The installations of grab bars, handrails and ramps were described as modifications made to the environment. This pilot study made it possible to verify: the possibility of recruiting a larger sample; needs to explore the causes of difficulties identified by the WHODAS 2.0 questionnaire; the need to deepen investigations about the use of AT resources and adaptations in the environment; and the need to emphasize possible association of the intensity of difficulties with the auxiliary resources of locomotion and adaptations carried out in environments.

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Renata Conter Franco: data collection, analysis and discussion, manuscript writing. Haidar Tafner Curi: manuscript writing, critical text review, data discussion. Luana Faroni Andrade: critical review of the text and research orientation. Eliana Chaves Ferretti: organization, analysis and discussion of data; text review and research guidance. All authors approved the final version of the text.

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