Understanding the difficulties in the daily activities of individuals with multiple sclerosis: a pilot study

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INTRODUCTION

Multiple sclerosis (MS) is characterized by the degeneration of nervous system structures. This health condition can cause difficulties in carrying out activities of daily living (ADLs) and impact the individual's quality of life [1]. Providing In order to promote greater functionality and autonomy in ADLs, people who have low occupational performance use assistive technology (AT) devices [2]. Wheelchairs, walking sticks and walkers are the most used devices due to the limited mobility caused by the disease [2]. The use of AT can increase the quality of life (QOL) of people with MS and act as a facilitator during the performance of ADLs and ultimately promoting greater participation [3]. The overall aim of this study was to understand the difficulties encountered in carrying out daily activities by people with MS and the context factors (facilitators and barriers) that lead to social participation.

METHODS

Protocol

This is a cross-sectional, descriptive, and exploratory research study with a quantitative and qualitative approach. A convenience sample was used to obtain subjects from association of MS in the city of Santos and São Paulo in Brazil. Institutional Review Board approval was obtained. Individuals with diagnosis of MS provided written informed consent. The Inclusion criteria were to be at 18 years old, be diagnosed with multiple sclerosis for more than 6 months and have no diagnosis of dementia, severe cognitive impairment or mental disorder. The exclusion criteria were to be under 18 years old, be diagnosed with multiple sclerosis less than 6 months and have a diagnosis of dementia, severe cognitive impairment or mental disorder. Firstly, participants had to answer an open question survey with demographic information, type of AT used, description of contextual factors and services utilized. Next, the *World Health Organization Disability Assessment Schedule* (WHODAS 2.0) was used [4].

The *World Health Organization Disability Assessment Schedule* (WHODAS 2.0)

The WHODAS 2.0 covers 6 domains of functioning: (1) Cognition: understanding & communicating; (2) Mobility: moving & getting around; (3) Self-care: hygiene, dressing, eating & staying alone; (4) Getting along: interacting with other people; (5) Life activities: domestic responsibilities, leisure, work & school and (6) Participation: joining in community activities. The simple calculation was performed, proposed by the WHODAS manual. The assigning score was from 0 to 100 to each item, in addition to a total score from the questionnaire (WHO, 2010). Each participant reports their level of difficulty in each activity according to a scale of 5 levels: "1 - no difficulty" counting 0 points, "2 - light difficulty" (25 points), "3 - moderate difficulty" (50 points), "4 - severe difficulty" (75 points) and "5 - extreme difficulty / I cannot perform this activity" worth 100 points. That is, the closer the score is to 100, the greater the difficulty [4]. The average score for each domain was calculated considering the sum of the scores for each related activity, divided by the number of items in the domain. The total score was calculated with the sum of the scores from all domains, divided by the total number of items in the questionnaire, which were 36 items [4].

Data Analysis

Data were tabulated using Microsoft Excel (Microsoft; Redmond, WA). Statistical analysis was performed using Software R. [5]. Descriptive statistics for continuous variables (age and WHODAS scores) and frequencies for categorical variables (gender, diagnosis and type of AT) were used to describe the study sample. The mean and standard deviation of each domain of the WHODAS were calculated as well as the total score. No correction was made for multiple statistical comparisons because of the relatively small sample size. Significance level was set at a priori at less than $p \leq 0.05$.

RESULTS

This is an ongoing study and to date we have collected data from 25 participants. Two men and twenty-three women aged from 27 to 64 years, mean 45.77 years (SD 11.15). Twenty uses AT and nine did not reported any kind of AT. Among those who use it, the majority (n = 14) had their TA paid with their own resources. Two participants received the TA resource by donation from an institution. Regarding the types of technology used, the participants reported using only a cane (n = 8), a cane and a walker (n = 4), a walker and a wheelchair (n = 8). Eleven participants made changes to the environment (home, workplace or car), such as the installation of support bars, handrails on the stairs, ramps in the areas where there were steps, raising the toilet seat and buying an adapted car. Fourteen participants said they had not made any changes. All participants who made adaptations claimed that they were important for carrying out daily activities and, therefore, acted as a facilitator. In addition, all participants reported having people (family, friends and neighbors) who act as facilitators in their daily lives.

The participants had an average score of 43.8 (±32.6) in "Mobility", indicating moderate difficulty. In "Life Activities" the average score was 41.40 (±35.01), difficulty between mild and moderate. In the "Social Participation", "Self-care" and "Cognition" domains, the participants presented mild difficulty with average scores of 36.53 (±26.8), 41.4 (+35.01) and 14.24(+19, 3), respectively. The domains "Mobility", "Life activities" and "Self-care" had the highest average score, that is, the domains in which the participants had more difficulties. On the other hand, the domain "Interpersonal Relations" had an average score below the others (7.5; ±8.9), showing less difficulty in these activities when compared to the other domains. The average of the total score of the participants was 26.3 (+11.6), that is, they presented mild difficulty in the activities mentioned in the questionnaire in general (Table 1).

Table 1. WHODAS scores in each domain.

Domains	Mean (±SD)	Min	Max
Mobility	43.8 (±32.6)	0.0	100
ADLs	41.4 (±35.01)	0.0	100
Participation	36.5 (±26.8)	0	75
Self-care	41.4 (±35,0)	0	75
Cognition	22.16 (±21.97)	0	62
Interpersonal relations	14.45 (±19.39)	0	75
Total	30.5 (±22.13)	0	74

DISCUSSION

The present study aimed to understand the difficulties encountered in carrying out the daily activities of people with multiple sclerosis (MS). The results show that participants with MS find greater difficulties in relation to mobility, such as walking long distances and standing for long periods and performing household chores. Most participants reported making use of assistive technology (AT) devices and resources, and all described these as facilitators during activities. The most used resources are wheelchairs, canes and walkers. The installations of support bars, handrails and ramps were described as changes made to the environment.

The findings regarding mobility difficulties and carrying out domestic tasks corroborate other studies in the literature. Mobility especially performed safely and independently, is the function that presents the greatest limitation in people with MS [6]. Standing activities are more compromised by MS, followed by household chores and circulation outside the home [3].

n this study, social participation presented itself as the third domain of greatest difficulty, mainly for leisure activities, due to the barriers and obstacles encountered. The lack of accessibility was mentioned by 25% (n = 2) of the participants. Social participation is affected across the spectrum of severity of MS, but this phenomenon is more intense in advanced cases of the disease. This is due to the cognitive losses and motor difficulties that occur in the most severe cases of MS, since more complex commitments and social activities require not only walking (for example, moving around outside the home), but also different cognitive skills, such as memory , attention and executive functioning [7]

This study has some limitations regarding the outcome measures. First, it is known that the WHODAS 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 probably 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. Therefore, it is recommended for future investigations to conduct interviews that explore the causes of the difficulties verified by the WHODAS 2.0 questionnaire. About TAs, one can explore in which activities and contexts they are used, such as, for example, checking the types of wheelchairs (motorized, monobloc, X-folding, etc.) and in which environment these devices are used. Therefore, it is relevant to deepen the study regarding the changes made in the environment, not only to understand how these facilitate the activities of daily living, but also the way they were indicated and installed (if they were indicated by a health professional, planned by the user, etc.). In addition, we suggest relating the level of motor impairment and the stage of the disease (initial or advanced) with the intensity of the difficulties in the activities, to check if there are any significant correlations.

CONCLUSION

The findings of this research contributed to identify and increase the understanding of the main difficulties and barriers encountered in the daily lives of people with MS, providing understanding about the issues involved in participation restrictions and functional disabilities. This pilot study proved to be an important part of the definitive research process, being possible to observe limitations in the conduction of instruments and procedures and, from these observations, create methodological possibilities for future studies on the theme.

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