

# Archives of Physical Medicine and Rehabilitation

journal homepage: www.archives-pmr.org Archives of Physical Medicine and Rehabilitation 2017;98:1308-15



# **ORIGINAL RESEARCH**

# Participation Restriction in People With Multiple Sclerosis: Prevalence and Correlations With Cognitive, Walking, Balance, and Upper Limb Impairments



Davide Cattaneo, PhD,<sup>a</sup> Ilse Lamers, PhD,<sup>b</sup> Rita Bertoni, MSc,<sup>a</sup> Peter Feys, PhD,<sup>b</sup> Johanna Jonsdottir, PhD<sup>a</sup>

From the <sup>a</sup>LaRiCE Lab: Gait and Balance Disorders Laboratory; Don Gnocchi Foundation IRCCS, Rome, Italy; and <sup>b</sup>REVAL—Rehabilitation Research Institute, BIOMED—Biomedical Research Institute, Faculty of Medicine and Life Sciences, Hasselt University, Hasselt, Belgium.

### Abstract

**Objectives:** To calculate the percentage of participation restrictions according to disability level in multiple sclerosis (MS), and to assess the relationship between participation restrictions and cognitive, gait, balance, and upper limb deficits.

Design: Cross-sectional study.

Setting: Rehabilitation unit.

Participants: Participants (N=125) consisted of people with MS (n=105) and healthy subjects (HS; n=20).

Interventions: Not applicable.

Main Outcome Measures: The Community integration Questionnaire was used to assess participation in home, social, and productive activities. Percentages of people with MS having Community Integration Questionnaire scores lower than the 10th percentile of those of HS were calculated for each subscale to categorize the persons with participation restrictions. Cognitive deficits (Symbol Digit Modalities Test), walking disability (25-ft walking test/Expanded Disability Status Scale [EDSS]), balance disorders (Bohannon Standing Balance Test), and manual dexterity (Nine Hole Peg Test) were recorded.

**Results:** Seventy-seven percent of participants showed participation restrictions, which increased with higher EDSS scores from 40% (EDSS<4) to 82% (EDSS>5.5). Social participation was more restricted than home integration, with <20% of participants shopping for groceries alone. Cognitive deficits were more highly associated (r=.60) with participation restrictions than balance (r=.47), gait (r=.45), and hand dexterity (r=.45) limitations.

**Conclusions:** Participation restrictions are present in MS and increase with disability level. However, the results also show that MS does not restrict participation in all domains. Participation restrictions at home are less restricted compared with social participation. Cognitive disorders are more associated with participation restrictions than physical limitations. Archives of Physical Medicine and Rehabilitation 2017;98:1308-15

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Participation, defined as involvement in life situations, is often considered to be associated with quality of life and has been proposed as one determinant of health status.<sup>1</sup> Indeed, participation is recently suggested as a primary outcome of interventions aiming to improve quality of life.<sup>2,3</sup>

Participation restrictions, defined as "problems an individual may experience in involvement in life situations,"<sup>4(p14)</sup> can result from a combination of personal factors, impairments, activity

Disclosures: none.

limitations, and environmental factors<sup>5</sup> that can differently affect the execution of home, social, and productive activities.

Although participation has its own definition and should be viewed as an independent construct, quality of life and independency in activities of daily living are often used to measure participation restrictions. An early survey<sup>6</sup> reported that two thirds of 166 people with multiple sclerosis (PwMS) had limitations in performing activities without assistance and having an independent social/lifestyle. A later study<sup>7</sup> similarly revealed that 47% of 240 PwMS were not completely independent in their domestic life. Finally, a study by Argento et al<sup>8</sup> reported differences

0003-9993/17/\$36 - see front matter © 2017 by the American Congress of Rehabilitation Medicine http://dx.doi.org/10.1016/j.apmr.2017.02.015

between PwMS and healthy subjects (HS) in time spent at home with other people and use of domestic help.

Several studies have also been conducted to investigate the relationship between variables related to quality of life and activity limitation and multiple sclerosis (MS)—related disorders. Mikula et al<sup>9</sup> found that health-related quality of life is associated with disease severity and age in MS. Ben Ari Shevel et al<sup>10</sup> found a correlation between activity limitation measured as restriction in outdoor activities and depression, cognitive disorders, and leisure and domestic activities. Finally, Yorkston et al<sup>11</sup> inquired on satisfaction with participation and found that participation is associated with fatigue, pain, depression, stress, anxiety, and well-being in MS. Furthermore, the frequency with which participants reported participating in active leisure was associated with mobility impairments.<sup>12</sup>

While it is known that gait impairments can lead to limitations in activity and potentially restrict participation, balance disturbances,<sup>13</sup> hand dexterity dysfunctions<sup>14,15</sup> and cognitive deficits<sup>16</sup> also have a potentially deleterious effect on different domains of participation. However, the relationship between cognitive deficits, impairments at activity level, and participation restrictions is not well understood. Moreover, physical and cognitive parameters have not been studied together in connection with participation in life domains, such as home activities, social participation, and work activities.

The study of the relation between participation restrictions and physical and cognitive factors is important because they are mostly modifiable factors that might respond to rehabilitation. Further, investigation of the magnitude of these relationships with tools commonly used in rehabilitation to measure attention and activity limitation might indicate their appropriateness as predictors of participation restrictions. Altogether, this may contribute to our developing more focused clinical rehabilitation protocols that can lead to improved participation in home and social situations, as well as better chances of participating in productive activities.

Until now, participation restrictions have been mainly studied using scales addressing quality of life,<sup>8</sup> amount of performed activities,<sup>9</sup> or life satisfaction,<sup>12</sup> while a test specifically addressing participation might give a better picture of restrictions in different domains of life participation. Furthermore, the use of a standardized test on participation and the collection of data from a reference group of HS make it possible to calculate the true prevalence of participation restrictions.

The Community Integration Questionnaire (CIQ) was developed for people with traumatic brain injury.<sup>17</sup> It is a test specifically designed to assess participation restrictions, including home, social, and productive activities, and has also been used for PwMS.<sup>2,18-21</sup>

The primary aim of this study was to use the home, social, and productive activities domains of the CIQ to calculate the prevalence of global and domain-specific participation restrictions in MS according to disability level and in relation to HS. The secondary aim was to assess the relationship between participation restrictions in

#### List of abbreviations:

BSBT	<b>Bohannon Standing Balance Test</b>
CIQ	Community Integration Questionnaire
EDSS	Expanded Disability Status Scale
HS	healthy subjects
MS	multiple sclerosis
NHPT	Nine Hole Peg Test
PwMS	people with multiple sclerosis
SDMT	Symbol Digit Modalities Test

these 3 domains and activity disorders in terms of walking and balance disturbances, hand dexterity, and cognitive deficits.

# Methods

A convenience sample of 105 people was recruited from inpatients and outpatients treated at the Rehabilitation and MS Center, Overpelt, Belgium; and the Department of Neurorehabilitation, Don Carlo Gnocchi Foundation Onlus, IRCCS, Milan, Italy. The inclusion criteria were as follows: (1) a confirmed MS diagnosis (McDonald criteria<sup>22</sup>); (2) age >18 years; (3) free from relapses or relapse-related treatments for 1 month before the study; and (4) the ability to touch the chin at least with 1 hand. Subjects unable to follow test instructions or having other diseases interfering with the execution of tests were excluded. Further information on the sample is available in Bertoni et al.<sup>15</sup>

A convenience sample of 20 HS matched for age and sex was also tested to provide CIQ comparative data. We recruited all eligible subjects having the same age range and sex as PwMS in a 2-week window. Seven were men (35%) with a mean age  $\pm$  SD of 51.9 $\pm$ 11.5 years; none of them reported any musculoskeletal or neurologic conditions.

All subjects received information regarding the study and were included after signing the informed consent forms. The study was approved by the ethical committee of each participating center.

## **Descriptive variables**

The Expanded Disability Status Scale (EDSS), type of MS, disease duration, sex, and age were retrieved from medical records as determined by the treating neurologist. Participants were asked about their employment status.

### Cognitive function and activity predictors

The cognitive level and psychomotor speed were determined by the Symbol Digit Modalities Test (SDMT).<sup>23</sup> The SDMT requires individuals to identify 9 different symbols corresponding to the numbers 1 through 9, and to practice writing the correct number under the corresponding symbol. Then they manually fill in the blank space under each symbol with the corresponding number. A score was calculated by totaling the number of correct answers over 90 seconds.

Manual dexterity was measured with the Nine Hole Peg Test (NHPT).<sup>24</sup> The time needed to place and remove 9 pegs was recorded and averaged over 2 trials. Manual dexterity speed was calculated as pegs per second and used in the analyses.<sup>14</sup> Participants who were not able to place any peg within a time limit of 300 seconds received a score of 0 pegs per second.

Walking speed (seconds) was assessed with the timed 25-ft walking test.<sup>25</sup> According to standardized instructions an average of the 2 trials was computed.

Upright balance was assessed with the Bohannon Standing Balance Test (BSBT),<sup>26</sup> with scores ranging from 0 (unable to stand) to 6 (stand on 1 foot for 30s).

### Participation

The CIQ was used to assess participation. It is scored to create a total score ranging from 0 (no community integration) to 29 (excellent community integration). The CIQ also provides scores

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