## **Research Article**



# Investigating the Occupational Performance Problems in Individuals with Multiple Sclerosis in Relapsing-Remitting Phase: A Cross-Sectional Study

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## ABSTRACT

**Introduction:** Multiple sclerosis (MS) is one of the most common disabling neurologic diseases worldwide. Although occupational performance problems are reported in many people living with MS, there is little information on these problems in people with relapsing-remitting MS (RRMS). This study aims to determine occupational performance problems in people with RRMS.

**Materials and Methods:** The Canadian occupational performance measure was used to collect data from 58 participants in the age range of 20 to 50 years. The participants were recruited via the convenience sampling method from a neurology outpatient unit in a general hospital in Tehran City, Iran, in 2020. The data were analyzed using the Spearman, Man-Whitney, and Kruskal-Wallis tests.

**Results:** A total of 91 activities in self-care, 96 activities in productivity, and 67 activities in leisure were identified by the participants as their priorities. No significant difference was observed between the mean scores of occupational performance with age, gender, employment status, and marital status. Still, there was a considerable difference between occupational performance and education level.

Keywords:

Multiple sclerosis; Self-care; Leisure activities; Occupational therapy **Conclusion:** People with RRMS suffer from many occupational performance problems, especially in productivity areas. Although occupational therapy interventions are essential in promoting self-care and activities of daily living, engaging in productive and instrumental activities of daily living is more cost-effective and valuable to promote independence in people with RRMS.

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## 1. Introduction

he National Institutes of Health (NIH) (2013) describes multiple sclerosis (MS) as a nervous system disease that destroys the myelin sheath in the brain along with the spinal cord. Without the myelin sheath, the nerve is damaged, disrupting neurotransmission between the brain and the body [1, 2]. Nerve damage and disorders cause common symptoms of MS, such as numbness, muscle weakness, visual disturbances, as well as balance and coordination disorder [1, 3]. Disease severity and symptoms vary widely among individuals with MS [4, 5]. Symptoms usually appear between the ages of 20 and 50 years [6, 7]. The 4 types of MS are relapsing-remitting MS (RRMS), primary progressive MS (PPMS), secondary progressive MS (SPMS), and progressive relapsing MS (PRMS) [8-10]. The most common type is RRMS, and approximately 85% of individuals with MS have this type of disorder [11-13].

RRMS is characterized by clearly defined attacks, called relapses or exacerbations, followed by periods of recovery and stabilization, called remissions. About 10% to 15% of people with MS experience a PPMS period, and from the onset of the disease, progress is gradual, with minimal improvement. The secondary progressive period generates the following progression of the RR period, and 50% of the individuals become secondary progressive after 10 years. The PRMS type is a period with definite and acute relapse, which may or may not improve. The periods of relapses are associated with the continued progression of the disease [14]. More than 400000 people in North America, about 500000 in Europe, and about 2.5 million people worldwide with MS [14-17]. The prevalence of MS clinical courses in Iran was estimated to be as follows: RRMS 77.1%, PPMS 6.2%, SPMS 9.5%, and PRMS 0.4% [18]. The prevalence of MS is significantly increasing in Tehran City, Iran [19]. The prevalence of MS was 115.94 per 100000 persons in 2015. In Tehran Province, the percentage of patients with a positive family history of MS is higher compared to other regions in Iran (12.2%) [20].

Although potential treatments are constantly emerging, no proven treatment for MS has been reported [1]. People with MS gradually lose their occupational performance [21]. Occupational performance refers to the ability to choose, organize, and satisfactorily perform meaningful occupations that are culturally defined and age-appropriate for looking after the self, enjoying life, and contributing to the social and economic fabric of the community [22]. Occupational performance reflects self-care, productivity, and leisure activities [23]. Occupational therapy can play an influential role in improving the occupational performance of individuals with MS [24]. Occupational therapists can help people with MS to manage their symptoms and limitations in occupational performance and maintain their performance independence [21]. The Canadian occupational performance measure (COPM) is one of the unique tools designed for occupational therapists to identify clients' changes in their occupational performance over time. This scale includes the occupational performance areas, namely self-care, productivity, and leisure, and allows clients to identify and prioritize their main problems [25].

During the last decade, various studies have been performed on the impact of MS on occupational performance. Several studies have shown that individuals with MS often reported self-care, productivity, and leisure [26, 27]. The study by Dehghan et al. in 2019 determined the occupational performance of individuals with MS based on their disability level in Iran [28]. Accordingly, the occupational performance priorities of individuals with RRMS, the most common type of MS and the stage before the secondary progressive type, have not been studied. Hence, this study aims to investigate the occupational performance problems of individuals with RRMS and examine the relationship between occupational performance and gender, age, marital status, work status, and level of education.

## 2. Materials and Methods

## Participants, recruitment, and data collection

All individuals with MSRR in a Neurology Outpatient Unit in Tehran General Hospital were invited to participate during their visits to the neurologist in 2020. A total of 58 individuals with RRMS (n=34 [female] and n=24 [male]) in the age range of 20 to 50 years, with no history of other neurological diseases, rheumatology, and acute mental illness, were selected based on the specialist referral form in Tehran General Hospital. Meanwhile, the exclusion criterion was the lack of information or poor-quality responses. Before the COPM interview, volunteers were asked to complete a demographic questionnaire (demographic information of the participants is provided in Table 1).

## Study instruments

COPM is a client-centered outcome measure, focusing on occupational performance in 3 areas, including self-care (personal care, functional mobility, community management), productivity (paid/unpaid work, household management, play/school), and leisure (quiet recreation, active recreation, socializing) activities [23, 29, 30]. This scale was performed as a semi-structured interview by an occupational therapist in 5 steps and lasted 20 to 30 min. In the first step, the therapist asked the client to think about a day in their life and determine what they need, want, or are expected to do but are unable to do, or doing does not satisfy them. In the second step, the clients were asked to rate each activity according to the importance in their life based on a 10-point Likert scale (1="does not matter" and 10=the most important). In the third step, using the obtained information, the clients were asked to select the 5 most important problems. In the last two steps for each of these problems, based on the 10-point Likert scale, clients determined the expected performance in that area (1=no performance and 10=maximum performance) and the level of satisfaction in its average performance (1=no satisfaction and 10=the most satisfaction) [31, 32].

### Data collection and analysis

The data were collected from the participants' COPM reports. We used the Persian version of COPM, which has demonstrated good reliability and validity [22]. Descriptive statistics were used to analyze demographic data, such as sex, age, duration of disease, level of education, and marital and employment status (Table 1). Meanwhile, the 3 main areas of COPM along with its 9 subareas were obtained (Table 2). This study used the Spearman correlation test to analyze the relationship between age and mean performance scores. The Kruskal-Wallis test was applied to the relationship between the mean performance scores, marital status, and education level. The Mann-Whitney test was used to correlate the mean performance scores with gender and employment status. A significant level of less than 0.05 was considered, and the obtained data were analyzed using the SPSS software, version 26.

## 3. Results

The participants prioritized 254 activities (91 activities in the field of self-care, 96 activities in the field of productivity, and 67 activities in the field of leisure). The most frequent problems were expressed in the subareas of community management (44%), paid/unpaid work (56%), and active recreation (49%). The mean performance ratings were generally low. Accordingly, the lowest rating was in leisure and the highest was in the productivity area. However, the lowest number of priorities was related to leisure. The highest number of priorities was related to being productive, and according to Table 2, the mean in the field of self-care equaled 5.16, in the area of productivity equaled 6.04, in the field of leisure was 4.12, and in the field of occupational performance equaled 0.92.

There was no significant relationship between age and mean performance scores (P=0.13), gender, and mean performance scores (P=0.58), marital status scores and average occupational performance scores (P=0.48), and employment status and average occupational performance scores (P=0.134). However, there was a significant relationship between education level and average scores of occupational performance (P=0.048).

## Self-care

## Personal care

The participants considered the most prioritized activities in the personal care subareas related to marriage, such as sexual activity. They also experienced problems with personal hygiene, such as shaving their face and body, and bathing. Moreover, they reported issues with having daily routines, self-cleaning, and taking medicine.

## **Functional mobility**

Most participants had functional mobility problems outside the home, such as climbing the stairs, long walks, moving in bed, leaving home, walking downhill, and sitting for a long time.

#### **Community management**

Many participants reported financial problems. Some participants described problems with intra-city commuting, such as driving through the volume of traffic, long distances, and planning for driving as complex. Problems with performance in a social context, such as, at stores and shopping centers, and phone calls were described. Moreover, the participants described difficulties with short-term and long-term planning, such as budgeting.

### Productivity

## Paid and unpaid work

The participants discussed issues relevant to their present work condition, including managing the job because of memory and concentration difficulties and challenges in the initiative, planning, and accomplishing work tasks. Some also mentioned issues with stress, workrelated and personal demands, the desire to be praised,

Clinical Features	Variables	No. (%)/Mean±SD
Sex	Female	34(58.6)
	Male	24(41.4)
Age (y)		95.25±7.34
Duration of MS (y)		22.63±3.4
Work status	Employed	33(56.9)
	Unemployed	25(43.1)
Marital status	Single	27(46.6)
	Married	30(51.7)
	Divorced	1(1.7)
	High school	3(5.2)
Level of education	Diploma	9(15.5)
	Associate degree	2(3.4)
	Bachelor degree	28(48.3)
	Masters	12(20.7)
	PhD	4(6.9)

Table 1. Demographic characteristics of individuals with multiple sclerosis (n=58)

Abbreviations: MS: Multiple sclerosis; SD: Standard deviation; RRMS: Relapsing-remitting multiple sclerosis.

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and concerns about not completing their tasks. In addition, the participants expressed feelings of loneliness due to working part-time, insufficient knowledge, and inadequate interaction with coworkers. The lack of energy, discomfort, and tiredness augmented the problems with their existing job position, making it challenging to handle the workload. This subarea also includes a loud workplace, a lack of understanding of coworkers and supervisors, in addition to workplace chaos. Finally, they encountered work-related stress, such as monotonous activities. The participants also mentioned issues related to work challenges, such as job satisfaction and job performance. All the mentioned issues caused them difficulties in maintaining their job or finding another job.

## Household management

The participants reported problems with taking care of their homes and belongings, such as cleaning, sweeping, washing the bathroom floor, and ironing. The participants reported difficulties with meal planning and grocery shopping. Because of their lack of energy, they experienced difficulties in taking care of their children, playing with them, taking care of them, and helping with their homework.

## Play and school

The participants described problems with studying, including reading, writing, concentrating, and remembering what they had read, which could cause difficulties with continued education; in addition, some experienced problems participating in sports.

## Leisure

## Quiet recreation

The participants expressed problems with quiet recreational occupations, such as reading books due to memory problems and handicrafts, carpet weaving, knitting, sewing due to vision problems, and frequent use of fingers.

## Active recreation

Many participants experienced problems performing physical activities, such as taking walks, going to the gym, playing volleyball, mountaineering, swimming,

Occupational Performance		Prioritized Occupations	Nia (0/)
		Performance*	No. (%)
Self-care	Personal care	2.17	20(21.98)
	Functional mobility	2.79	31(34.06)
	Community management	3.10	40(43.96)
	Total	5.16	91(35.83)
Productivity	Paid/Unpaid work	4.51	54(56.25)
	Household management	2.03	30(31.25)
	Play/School	1.05	12(12.50)
	Total	6.04	96(37.79)
Leisure	Quiet recreation	1.43	14(20.90)
	Active recreation	2.57	33(49.25)
	Socialization	1.91	20(29.85)
	Total	4.12	67(26.83)
Occupational performance		5.95	254(100)

Table 2. Reported occupational performance of individuals with multiple sclerosis (n=58)

\*Values are presented as mean, up to 5 problems that seem most pressing or important are presented.

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aerobics, and so on, due to a lack of energy and fatigue. For some participants, there could also be a problem with getting too much exercise. The participants also reported problems with traveling for extended periods.

## Socialization

The participants reported problems with participating in a social context, including meeting friends, visiting family and relatives, courtship, and participating in group activities due to a lack of energy and fatigue. The participants also reported problems with going to meetings, wearing unique clothes due to maintaining balance.

## 4. Discussion

People with RRMS experience several problems in all areas of occupational performance. Based on the findings of this study, the participants prioritized about 35% of activities in self-care (personal care [21.98%], functional mobility [34.06%], community management [43.96%]), 37% in productivity (paid/unpaid work [56.25%], house-hold management [31.25%], play/school [12.50%]), and 26% in leisure (quiet recreation [20.90%], active recreation [49.25%], socializing [29.85%]).

According to the results of the present study, the most important activities prioritized in the field of self-care were related to community management, which was in line with a study conducted by Dehghan et al. in 2019, aimed to determine the work performance of MS patients based on the rate of disability in Iran [28]. The participants' highest priority of occupational performance was related to the productivity area, which is consistent with a study by Squillace in 2018 to examine the relationship between fine motor skills and self-care activities, productivity, and leisure in young people with MS [33]. Lexell et al. conducted a study in 2006 to describe areas of self-care, productivity, and leisure and showed that most of the identified activities in the field of leisure were in line with the present investigation, which is related to active recreation [27]. Moreover, according to the investigation of Lexell et al., who conducted a study on self-perceived performance and satisfaction with the performance of daily activities in persons with multiple sclerosis following interdisciplinary rehabilitation, the most important priority was expressed in the field of leisure in the active recreation and quiet recreation subgroups [34]. In addition, the investigation by Dehghan in 2019 demonstrated that most identified activities in the field of leisure were in the subgroups of active recreation and quiet recreation, respectively [28].

In this study, the highest priorities were paid/unpaid work activities in the productivity area, active recreation in the leisure area, and community management in the self-care area. Given that the study was performed on people with RRMS and there are extended periods of stability and recovery in this type of MS, they are in better physical condition compared to progressive courses. These people reported their most significant concern about keeping their jobs because progress in MS affects a person's ability to work and stay in a job and may lead to retirement [28]. Thus, MS can affect functional skills, quality of life, and productivity, including employment, and increase economic costs for the individual, family, and community [35]. These results emphasize the need to pay attention to employment issues in people with MS. They also reported less performance in leisure, and this issue indicates the need to pay attention to leisure in people with MS. They may not be able to perform these activities properly due to fatigue [28].

Another reported problem was the financial situation in the subareas of community management, which may be due to the poor economic status of these individuals and the staggering costs of treating the disease. Also, according to the study of Dehghan, et al. in 2019, the highest priority in self-care was in the subareas of community management [28]. This study also showed that the mean scores of occupational performance were not significantly related to gender, which is consistent with the study of Perez de Heredia Torres et al. in 2020 [26]. Also, in this study, no significant relationship was found between the mean scores of occupational performance and marital status, which was consistent with the study of Abdullah in 2017 that was conducted to assess performance and satisfaction with daily activities among people with MS in Kuwait [36]. Also, in this study, there was no significant relationship between the mean scores of occupational performance, age, and employment, which was inconsistent with the results of Abdullah in 2017 [36]. However, there was a significant relationship between the mean scores of occupational performance and education level, which was consistent with the results of Abdullah in 2017 [36]. Individuals with a high level of education are more likely to report being employed compared to people with a low level of education [12]. Individuals who continue to work and study have a better quality of life [37]; therefore, it can be concluded that higher education causes better performance in people.

On the other hand, early intervention [38] and the implementation of effective policies to reduce the burden of MS are very important [19]. Since the functional level of the individual decreases with the progression of the disease, the initial intervention of occupational therapy can increase the occupational performance of these individuals [38]. Occupational therapists can also help people with MS to manage their symptoms and limitations in occupational performance and the work involved, as well as maintain their performance independence [21]. Conducting a COPM interview before starting occupational therapy interventions is a new, easy, and economical approach to rehabilitating these individuals and can reduce the cost of multiple treatment sessions.

## Methodological considerations

The strengths of the present study were investigating people's daily problems based on the preferences of RRMS individuals. In this study, the COPM tool was used, a client-centered tool that assesses occupational performance problems. The assessment was performed in an outpatient hospital. The advantage was that the participants were easily accessible. The limitation of the present study was individuals' low motivation and their fatigue and impatience to participate in the study. Moreover, some individuals and their families did not trust the researcher enough to express their demographic information, and some individuals refused to express some problems and concerns because of cultural considerations.

## 5. Conclusion

The present study's findings showed that people with RRMS suffer from widespread concerns about occupational performance, especially productivity, and selfcare. Also, these people showed less performance in the field of leisure compared to other areas. Therefore, with the help of the results of this study, therapists will be aware of the occupational performance priorities of these people and can consider their occupational performance priorities when evaluating, planning, and performing interventions. This study shows that occupational therapy interventions have to work not only on self-care but also on productivity areas. Occupational therapists should be working on productivity areas of their clients, such as paid and unpaid work (such as finding a job, keeping a job, and job support) and managing activities in the community (e.g. travel and Inner-city income, shopping). Although occupational therapy interventions are essential in promoting self-care and activities of daily living, engaging in productive and everyday life (such as instrumental activities of daily living) is more cost-effective and critical for helping individuals become independent.

The results of this study will also be helpful for rehabilitation centers, the MS disease association, and future studies. The results will help prevent disease progression, speed up the healing process, and reduce treatment costs. It is suggested to perform an investigation on the occupational performance of different types of MS in the future. It is also recommended that occupational therapy interventions in the area of productivity and self-care of people with RRMS be done and pay special attention to the leisure of these people.

## **Ethical Considerations**

#### Compliance with ethical guidelines

This study was descriptive and cross-sectional, and approved by the Ethics Committee of Tehran University of Medical Sciences (Code: IR.TUMS.FNM. REC.1398.110). Participation was entirely voluntary, and if they did not wish to participate, they were completely free to refuse to participate. Informed consent was obtained from all participants. We assured the participants that their information would be confidential.

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#### Authors' contributions

Conceptualization: Farzaneh Askarpour and Tahmineh Mousavi; Methodology, investigation, writing original draft, review & editing: All authors; Data collection: Farzaneh Askarpour and Mohammad Hossein Harirchian; Data analysis: Farzaneh Askarpour and Tahmineh Mousavi; Supervision: Tahmineh Mousavi and Mohammad Hossein Harirchian.

#### Conflict of interest

The authors declared no conflict of interest.

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