# Investigation of exercise barriers-benefits, kinesiophobia, physical activity, fatigue and depression in individuals with multiple sclerosis

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# Abstract

*Background & Objective:* Despite the benefits of exercise for individuals with multiple sclerosis (MS), physical activity levels in people with MS (pwMS) remain lower than in healthy controls. Identifying barriers to exercise and related factors is crucial for promoting physical activity in pwMS. This study aimed to examine perceived exercise barriers and benefits, along with fatigue, kinesiophobia, physical activity levels, and depressive symptoms in pwMS. *Methods:* This cross-sectional study included 104 participants (60 pwMS, 44 healthy controls). The Exercise Benefits and Barriers Scale (EBBS) assessed perceived exercise barriers and benefits. Kinesiophobia, physical activity, fatigue, and depression were evaluated using the "Tampa Scale for Kinesiophobia and Fatigue (TSK-F), the International Physical Activity Questionnaire-Short Form (IPAQ-SF), the "Fatigue Severity Scale (FSS), and the "Depression, Anxiety, and Stress Scale (DASS-21). *Results:* EBBS scores were significantly higher in pwMS than in healthy controls (p<0.001). The pwMS group also showed higher TSK-F, FSS, and DASS-21 scores (p<0.001) and lower IPAQ-SF scores (p<0.001). EBBS scores correlated significantly with TSK-F (r=0.306) and IPAQ-SF (r=-0.328, p<0.05). A positive correlation was found between EBBS-barriers and TSK-F (r=0.358, p<0.001), while EBBS-benefits correlated with TSK-F and IPAQ-SF (r=0.281, r=-0.307, p<0.05).

*Conclusion:* PwMS had lower awareness of exercise benefits and perceived greater barriers. Higher kinesiophobia, fatigue, and depression were evident, along with lower physical activity levels. A stronger perception of exercise barriers was associated with greater kinesiophobia and lower physical activity in pwMS. Enhancing exercise awareness and reducing barriers may improve physical activity, fatigue, and mental health in pwMS, guiding future interventions.

Keywords: Anxiety, exercise participation, kinesiophobia, fatigue, depression

## INTRODUCTION

Multiple Sclerosis (MS) is a demyelinating, chronic, autoimmune disease of the central nervous system (CNS) with rising prevalence and incidence.<sup>1,2</sup> MS is the most prominent cause of neurological disability in the productive life spans of individuals.<sup>3-5</sup>MS causes various symptoms by affecting different parts of the CNS. The most common symptoms of MS are gait disturbances, sensory-visual problems, bladder dysfunction, fatigue, pain, spasticity, depressive symptoms, and cognitive dysfunction.<sup>6</sup> Among these symptoms,

fatigue is a prevalent and debilitating symptom in people with MS (pwMS).<sup>7</sup> Increased fatigue levels can lead to a sedentary lifestyle and disrupt the individual's attendance at rehabilitation programs.<sup>8</sup> This avoidance of physical activity can result in kinesiophobia. Kinesiophobia and related clinical manifestations have not been adequately studied in neurological disorders. Recent studies have revealed that fatigue-related kinesiophobia negatively affects the quality of life and physical function.<sup>9</sup>

Physical parameters should be considered

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together with the psychological state in pwMS. Depression and anxiety rates are higher in pwMS than in healthy controls and people with other chronic conditions.<sup>10,11</sup> Contemporary investigations demonstrate that depressive symptoms in pwMS have a significant negative impact on functional outcomes.<sup>12</sup> Current MS treatment involves disease-modifying therapies (DMTs), physical therapy interventions, lifestyle modifications, and psychological approaches. Recent investigations are exploring refreshed approaches to minimize the symptoms of MS.

Exercise is a well-known and secure symptomatic treatment option for pwMS with also a potential disease-modifying effect.<sup>13</sup> Physical exercise positively affects fatigue, cognitive function, mobility, physical fitness, depressive symptoms, and balance in pwMS.<sup>14</sup> Despite well-recognized beneficial effects of exercise, studies reveal that pwMS has lower levels of physical activity than recommended levels and performs exercise at more inferior intensities than healthy controls.<sup>15,16</sup> In two studies involving pwMS, between 29% and 45% of the participants were reported to perform exercise regularly.<sup>17,18</sup>

Exercise behavior adaptation is a multivariate process. In order to facilitate exercise behavior, it is crucial to identify perceived barriers and benefits of exercise in pwMS.<sup>13</sup> In a study conducted by Plow and colleagues, pwMS reported issues that are related to the environment, health symptoms, and social responsibilities as barriers to physical activity.<sup>19</sup> Another study by Asona and colleagues revealed three barriers to physical activity: fatigue, impairment, and lack of time in 417 pwMS.<sup>20</sup> Despite previous studies attempting to identify the factors influencing exercise participation, it is also crucial to examine the impact of multiple variables on exercise barriers, given that MS is a disorder affecting multiple systems.

To promote physical activity in pwMS, the perceived exercise barriers and benefits and their association with other symptoms must be identified. Therefore, the present study aimed to investigate perceived exercise barriers and benefits along with fatigue, kinesiophobia, and physical activity levels, as well as depressive symptoms in pwMS and to compare these findings with those observed in healthy controls.

### METHODS

#### Study design and participants

This cross-sectional study was carried out at Ege University Neurology Department with 104

participants, including 60 pwMS and 44 healthy controls. Inclusion criteria for the pwMS group were; (1) being over 18 years old, (2) being a native Turkish speaker, and (3) having an MS diagnosis according to 2017 revision of the McDonald criteria. Exclusion criteria were; (1) experiencing no relapses in the last 30 days, and (2) having comorbidities affecting the physical and psychological condition of the individuals. The control group consisted of age and sex-matched healthy individuals without neurological and/or orthopedic conditions. The participants in the healthy group were enrolled in the study from the same clinic, including relatives of the patients and health professionals.

The reporting of our study adhered to the guidelines of the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) for observational studies. The study was carried out in accordance with the ethical principles and the Helsinki Declaration. The study protocol was approved by the ethics committee of Ege University (No: 22-1T/10).

#### Outcome measures

Eligible pwMS were interviewed face-to-face at Ege University Neurology Department Outpatient Clinic. Participants' characteristics (age, gender, education level, living conditionindividuals living in the household-) and clinical specifications (MS subtype, disease duration) data were recorded. Participants were asked to answer the questionnaires regarding kinesiophobia, depression, exercise benefits and barriers, and physical activity in a self-reporting manner. Due to the extensive nature of the inquiries present within the self-reporting process, participants were provided with intermittent rest periods and counseled by a physiotherapist at the conclusion of the questionnaires.

Participants' perceived exercise barriers and benefits were evaluated by the "Exercise Benefits and Barriers Scale (EBBS)", and kinesiophobia status was evaluated by the "Tampa Scale for Kinesiophobia and Fatigue (TSK-F)". Depression was assessed by the "Depression, Anxiety and Stress Scale. (DASS-21)". Fatigue was assessed using the "Fatigue Severity Scale (FSS)". The "International Physical Activity Questionnaire-Short Form (IPAQ-SF)" was used to determine physical activity level.

*Exercise Benefits and Barriers Scale (EBBS):* The EBBS has been developed to define individuals' perceived barriers and benefits regarding

exercise. Turkish validation study of the EBBS was conducted by Ortabağ et al. The EBBS consists of 43 items in Likert format ("Strongly Agree/Agree/Disagree/Strongly Disagree"). Lower scores indicate a better understanding of the benefits of exercise and fewer barriers to exercise participation.<sup>21</sup> The questionnaire has two subscales as "Exercise Barriers" and "Exercise Benefits". Each subscale can be evaluated separately. The exercise benefits subscale consists of 5 sections: "life enhancements (8 items), physical performance (8 items), psychological outlook (6 items), social interaction (4 items), and preventive health (3 items)". The exercise barriers subscale consists of 4 sections: "exercise milieu (6 items), time expenditure (3 items), physical exertion (3 items), and family discouragement (3 items)".<sup>22</sup>

*Tampa Scale for Kinesiophobia and Fatigue* (*TSK-F*): The TSK-F is a 17-item scale developed to measure fear of "movement/re-injury". The scale involves items of "injury/re-injury and fear-avoidance" in work and work-related activities.<sup>23</sup> Silver *et al.* modified the scale by changing the word "pain" with "fatigue" for chronic fatigue patients. This modified scale's scoring system is the same as the original. Each item is scored in a 1-4 Likert format. Higher scores indicate higher kinesiophobia levels.<sup>24</sup>

*Fatigue Severity Scale:* The scale was developed to evaluate the fatigue levels of patients. A total of 9 items are evaluated between 1 and 7 (1=strongly disagree, 7=strongly agree), and the total score is calculated by taking the average of 9 items. The cut-off value for pathological fatigue was determined as four and above. Higher scores indicate higher fatigue.<sup>25</sup>

International Physical Activity Questionnaire-Short Form (IPAQ-SF): The IPAQ-SF is a 7-item self-assessment scale about physical activity in the previous seven days. The scale provides information about time spent sitting, walking, and performing activities at moderate and vigorous intensities. The IPAQ-SF score is obtained by multiplying minute, day, and metabolic equivalent values.<sup>27</sup>

Depression Anxiety and Stress Scale-21 (DASS-21): The scale was developed to measure symptoms of anxiety, depression, and stress in both healthy and clinical populations as a 42-item scale. Afterwards, the 21-item short form

was created. The DASS-21 has 5 points Likert format scoring system. Higher scores indicate a greater level of symptoms.<sup>28</sup>

### Power and statistical analysis

Considering Cohen's d coefficient (intermediate level: 0.5) in the calculation for the sample size, effect size=0.50 was calculated using the G\*power software with an error probability of 0.05 and a statistical power of 0.95. For each group, a minimum of 34 cases were found to be sufficient.28 The datasets were analyzed using the SPSS software (Statistical Package for Social Sciences) for Windows v25.0 (SPSS Inc, IBM Corp, Armonk, New York, USA). The variables are provided as mean, standard deviation (SD), and percentage. The statistical significance level was 0.05. The normality of the variables is demonstrated using the "one-sample Kolmogorov-Smirnov test" and a "Histogram". Linear regression and Pearson correlation coefficient analysis was used for the relationship between the parameters, and t-test was used for determining the difference between the evaluation parameters when comparing pwMS and healthy controls.

# RESULTS

The mean age of the pwMS and healthy controls were 42.31±17.68 and 41.50±14.89 years, respectively. The characteristics of the participants are presented in Table 1. The pwMS and control group were homogenous in terms of age, gender, body mass index (BMI), and living condition (p>0.05). Table 2 shows clinical assessment outcomes of pwMS and healthy controls. The mean EBBS, EBBS-barriers subscale and EBBSbenefits subscale scores of the pwMS were 102.86±17.21, 35.91±6.75, and 66.95±13.40, respectively. EBBS scores of the pwMS were significantly higher than those of healthy peers (p<0.001). In addition, TSK-F, FSS, and DASS-21 scores were also higher in the pwMS group (p<0.001). The IPAQ-SF score of the pwMS were lower than that of the control group (p < 0.001).

Correlation between EBBS and other clinical scores are presented in Table 3. There was a significant correlation between the EBBS-total score with TSK-F and IPAQ-SF scores ( $r_1$ =0.306,  $r_2$ =-0.328, p<0.05). The EBSS-total score was not related with FSS and DASS-21 scores ( $r_1$ =0.195,  $r_2$ =-0.155, p>0.05). There was significant positive correlation between the EBBS-barriers scale and the TSK-F ( $r_1$ =0.358, p<0.001). However, the EBBS-barriers scale was not associated

	pwMS (n=60)	Control group (n=44)	р
Age (years, mean±SD)	42.31±17.68	41.50±14.89	0.804ª
Gender (women/men, n)	39/21	21/15	0.546 <sup>b</sup>
BMI (kg/m <sup>2</sup> , mean±SD)	24.53±5.12	26.79±6.33	0.055ª
MS duration (years, mean±SD)	7.56±6.65	N/A	N/A
Living condition (alone/others, n)	8/52	10/30	0.096 <sup>b</sup>

#### Table 1: Characteristics of the individuals

**pwMS:** People with Multiple Sclerosis, **MS:** Multiple Sclerosis, **n:** Number, **SD:** Standard Deviation, **BMI:** Body Mass Index, **N/A:** Not applicable, **a:** Independent samples t test, **b:** Pearson Chi-Square test

with the FSS, the IPAQ-SF, and the DASS-21 ( $r_1$ =0.216,  $r_2$ =-0.219,  $r_3$ =-0.153, p>0.05). There was a significant relationship between the EBBSbenefits scale and the TSK-F and the IPAQ-SF ( $r_1$ =0.281,  $r_2$ =-0.307, p<0.05). On the other hand, the EBSS-benefits score was not correlated with FSS and DASS-21 scores ( $r_1$ =0.141,  $r_2$ =0.120, p>0.05).

## DISCUSSION

The present study conducted in Izmir, Turkey demonstrated that pwMS had a lower perception of exercise benefits and barriers. Also, the level of fatigue-related kinesiophobia was higher in pwMS. PwMS were more sedentary, with a score of about half that of healthy controls in terms of physical activity. As expected, fatigue and depression levels were higher in pwMS. Low perception of exercise benefits and barriers was associated with high kinesiophobia and low physical activity in pwMS. On the other hand, higher perceived exercise barriers were associated only with higher levels of kinesiophobia.

A limited number of studies have addressed exercise barriers and benefits in pwMS.<sup>18,20,29,30</sup>

In contrast, the concept of kinesiophobia has recently emerged as a significant topic in the study of neurological diseases.<sup>9,25,32</sup> The unique contribution of this study is highlighted by its analysis of the interaction between fatigue-related fear of movement, fatigue, and physical activity, with a specific focus on exercise perception. Also, given the well-established influence of psychological state on physical conditions in pwMS<sup>33</sup>, we performed a psychosocial status assessment as part of a comprehensive assessment plan. We consolidated the relational status of our results with the correlational analysis of the parameters that showed significant changes compared to the control group.

Knowledge and perception of exercise barriers and benefits were lower in pwMS than in healthy controls among the present participants. An important reason for this outcome is that healthy individuals perform exercises for various purposes, especially for physical fitness and as a recreational activity, to obtain the symptomatic effects of pwMS within the scope of therapeutic exercise.<sup>34</sup> Increased fatigue, loss of muscle strength, spasticity, and the psychosocial burden

Table 2: The results of the	clinical data o	of the participants
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	pwMS (n=60)	Control group (n=44)	р
	Mean±SD	Mean±SD	
EBBS-Total Score	102.86±17.21	73.65±22.41	0.0001ª
EBBS-Barriers Scale	35.91±6.75	25.47±7.09	0.0001ª
EBBS-Benefits Scale	66.95±13.40	48.11±16.64	0.0001ª
TSK-F	39.40±8.75	30.18±8.93	<b>0.0001</b> <sup>a</sup>
FSS	31.98±17.53	24.43±17.18	0.031ª
IPAQ-SF	620.46±842.17	1440.56±1105.26	<b>0.0001</b> <sup>a</sup>
DASS-21	14.13±13.09	8.54±7.59	<b>0.013</b> <sup>a</sup>

**pwMS**: People with Multiple Sclerosis, **MS**: Multiple Sclerosis, **SD**: standard deviation, n: number of patients, **EBBS**: Exercise Benefits and Barriers Scale, **TSK-F**: Tampa Scale for Kinesiophobia and Fatigue, **DASS-21**: Depression, Anxiety and Stress Scale, **FSS**: Fatigue Severity Scale, **IPAQ-SF**: International Physical Activity Questionnaire-Short Form, **a**: Independent samples t test"

n: 60	<b>EBBS-Total Score</b>	<b>EBBS-Barriers Scale</b>	EBBS-Benefits Scale
	r	r	r
TSK-F	0.306*	0.358**	0.281*
FSS	0.195	0.216	0.142
IPAQ-SF	-0.328*	-0.219	-0.307*
DASS-21	0.155	0.153	0.120

Table 3: Correlation between EBBS and other clinical scores in pwMS

**pwMS: People with** Multiple Sclerosis, **MS**: Multiple Sclerosis, **n**: number of patients, **\*\***: p<0.01, **EBBS**: Exercise Benefits and Barriers Scale, **TSK-F**: Tampa Scale for Kinesiophobia and Fatigue, **DASS-21**: Depression, Anxiety and Stress Scale, **FSS**: Fatigue Severity Scale, **IPAQ-SF**: International Physical Activity Questionnaire-Short Form, **a**: Independent samples t test"

associated with these symptoms may adversely affect exercise in terms of time, space, sociability, and recreation. In some cases, MS attacks may obscure the advantages of exercise, thereby increasing barriers to exercise rather than promoting its benefits. It is necessary to focus on creating a physical and psychological condition that can overcome material and moral problems in reducing exercise barriers and addressing the benefits of exercise in pwMS at a therapeutic level.<sup>31,35</sup> Therapists should consider the exercise perceptions of pwMS more comprehensively within the scope of cognitive behavioral therapy of one-on-one exercise sessions.

Kinesiophobia has been emphasized in numerous studies examining movement-related fear in the context of musculoskeletal pain. Fatigue, common in pwMS, also increases kinesiophobia in pwMS compared to healthy controls.<sup>36</sup> In neurological diseases, it has been observed that individuals are sedentary due to fatigue. This study examined the relationship between kinesiophobia, physical inactivity, and the perception of exercise barriers and benefits, and revealed that increased fatigue-related kinesiophobia and low physical activity levels were associated with greater perceived exercise barriers. It can be argued that the perception of individuals not benefiting from exercise, as well as the perception of barriers to exercise, may be primarily due to fatigue at the psychological level. The beneficial effects of aerobic exercise and physical activity on fatigue have been welldocumented.37 However, this relationship may result in a detrimental cycle between fatigue and engagement in physical activity. Similar to the pain-spasm cycle described in the fear-avoidance model, it can be hypothesized that fatigue-induced inactivity in pwMS contributes to the worsening of fatigue.38 The present study indicated that the psychosocial status of pwMS, whose depression level was higher than that of healthy controls, was not associated with exercise barriers and benefits. Considering that the EBBS is a survey that also narrows down the psychosocial parameters, the lack of a relationship with the psychological states of pwMS also emphasized that fatigue is an essential parameter in terms of exercise.

Several studies have addressed exercise barriers in MS. Three studies highlighted the three leading causes of pwMS: fatigue, disease symptoms, and lack of time.<sup>20,30,39</sup> Another case-control study emphasized that disability, perseverance, fatigue, and cardiovascular comorbidities prevent participation in exercise in pwMS.<sup>39</sup> In our study, our primary focus was "fatigue", as the perception of fatigue was higher and the perception of exercise barriers/benefits were lower in pwMS compared to healthy controls. However, it was determined that the EBBS was not associated with fatigue and was correlated with the TSK-F. In this case, it was interpreted that psychological conditions such as kinesiophobia related to fatigue should be handled more comprehensively. It was also considered that pwMS, concentrating on therapeutic exercise, correlated with disease states in terms of making inferences about the benefits of exercise by associating them with symptomatic/ disability states. A qualitative study in male pwMS emphasized the importance of increasing physical activity and exercise levels despite fatigue.<sup>41</sup> The significance of providing support to individuals with MS to personalize their exercise regimens according to their unique needs and to manage fatigue is also underscored.<sup>30,41</sup> In addition, the importance of considering individuals' emotional, motivational, financial, and positional conditions while designing exercise interventions for pwMS and reducing barriers with telerehabilitation was emphasized.<sup>8</sup> Our correlational analysis suggests that promoting physical activity and exercise can positively impact perceived benefits and

barriers. On the other hand, it was deduced that training on psychological parameters of fatigue, such as kinesiophobia, could positively change individuals' perceptions of exercise.

Finally, fatigue-related kinesiophobia in pwMS has recently been a popular topic. The increase in kinesiophobia in pwMS has been emphasized in 3 recent studies.<sup>9,25,32</sup> The present study lends support to these earlier investigations. Also, from these studies, Wasiuk-Zowada et al. stated that kinesiophobia is associated with decreased physical activity in pwMS.9 The present study confirmed these results. The present study also emphasized the relationship between the perception of exercise barriers and kinesiophobia, and the correlation between fatigue-related kinesiophobia with only physical activity and the perception of exercise. The present study has demonstrated the correlation between kinesiophobia and fatigue within the context of exercise barriers and benefits. This finding has encouraged greater consideration of the psychological aspect of fatigue in relation to exercise perception as part of exercise programs.

The present study have several limitations. First, the study did not measure exercise barriers and perception towards a standardized exercise program. Whereas healthy controls considered exercises related to physical fitness, individuals with PwMS considered exercises at a therapeutic level. Therefore pwMS may have considered benefits and barriers in different contexts, considering their physical and psychological conditions. Second, there were no data based on objective accelerometer-based physical activity data. We elected to utilize the IPAQ-SF instrument due to considerations pertaining to practicality. The IPAQ-SF can serve as a metric for understanding physical activity; however, in future studies, the use of objective data to approximate exercise barriers may offer enhanced precision and clinical relevance. Finally, addressing the psychological dimensions of fatigue with a more comprehensive questionnaire can more clearly explore exercise barriers in terms of physical and psychological fatigue.

In conclusion, the present study demonstrated that pwMS have a lower knowledge and perception of exercise benefits and barriers. Also, the level of fatigue-related kinesiophobia was higher in pwMS. PwMS were more sedentary, with a score of about half that of healthy controls in terms of physical activity. As expected, fatigue was higher and depression level was lower in pwMS. Low perception of exercise benefits and barriers was associated with high kinesiophobia and low physical activity in pwMS. Conversely, exercise barriers and benefits exhibited a positive association with kinesiophobia, while exercise benefits demonstrated a negative association with physical activity.

## DISCLOSURE

Ethics: The study was carried out in accordance with the ethical principles and the Helsinki Declaration. The study protocol was approved by the ethics committee of Ege University (No: 22-1T/10).

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