

## Mobility Barriers for People with Multiple Sclerosis: a Qualitative Study

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### ABSTRACT

**Background & Objectives:** The purpose of this study was to identify the experiences of people with multiple sclerosis (MS) from mobility barriers they are faced with.

**Methods:** This study included 13 patients with MS (7 women and 6 men), with informed consent, whose average age is 43 years. A qualitative content analysis approach was used. According to the EDSS criteria, the severity of their disability was between 8-4. The sampling was carried out purposefully with maximum variation, and the data was collected through semi-structured in-depth interviews. Immediately after each interview, the data was analyzed using the Cheevakumjorn's method.

**Results:** After analyzing the obtained data and categorizing the resulting codes; three main categories were observed: "disease-affected barriers", "personal barriers" and "environmental barriers". The data of each theme were classified as subthemes.

**Conclusion:** Based on research findings and experiences of the participants, rehabilitation specialists during the assessment, management and treatment of patients with MS should alert and educate patients about personal mobility barriers and try to help them fit in their physical environment.

**Keywords:** Multiple sclerosis, Mobility barriers, Qualitative study, Lived experiences

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### Introduction

Multiple Sclerosis is a chronic neurological and autoimmune disease of the central nervous system that results in a wide range of progressive disabilities and disorders in young people (Cattaneo & Jonsdottir, 2009; Zwibel, 2009). Mobility impairment is a known complication in patients with MS that can be affected by other symptoms such as weakness, spasticity, fatigue, sensory and vision impairment (Dunn, 2010).

Mobility problems in patients cause disability and disorder in transfer and walking, and affects functional activity, participation and social communication and have physical, social and economic consequences (Finlayson & van Denend, 2003).

In addition to the problems and disabilities caused by mobility restrictions, these patients encounter a series of environmental, interpersonal and intrapersonal barriers when present in society, which makes

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it difficult for them to transfer and carry out physical activity (Stuifbergen, 1999). Numerous pieces of evidence demonstrated that fatigue in patients with MS is one of the most important barriers to the mobility of these individuals (Becker & Stuifbergen, 2004; Kayes, McPherson, Taylor, Schlüter, & Kolt, 2011; Vanner, Block, Christodoulou, Horowitz, & Krupp, 2008). In addition, physiological and psychological disorders such as depression, stress and cognitive impairment add to their functional barriers (Vanner et al., 2008).

Becker and et al. touched on the cultural and individual barriers in patients such as educational level, the income level and accessibility to health services. These were affected by beliefs, communication and demographic differences. Also, they expressed that over-weight problems, smoking and nutrition were among intrapersonal barriers of patients (Becker & Stuifbergen, 2004). In a qualitative study, Keyes, while investigating the functional barriers of patients with MS, stated that the experiences of each individual are unique to that person and his environment, and that the patient should investigate the limitations and barriers of that environment (Kayes et al., 2011). Another study looked at the environmental structure as an important factor in improving the health of individuals, indicating that the functional barriers of patients with MS differ in urban and rural environments (Stuifbergen, 1999).

Considering the various factors affecting the mobility of patients with MS, and also the different insights of people in different environments and cultures, we tried to explain what people with MS experience on the mobility barriers. Identifying these diverse findings can help practitioners resolve barriers of patient's mobility based on what they express and not what therapists think.

### Materials and Methods

In this study, 13 patients with MS (7 women and 6 men), with an average age of 43 years were included into this study with their consent which was conducted through qualitative content analysis and. In this way, the data was interpreted internally and

profoundly. The individuals that were enrolled into this study were diagnosed by a neurologist. They had score above 21 in the MMSE<sup>1</sup> criterion, and a disability score between 4 to 8 in the EDSS<sup>2</sup> criterion. Moreover, they were able to move with or without the need for assistive devices. Patient sampling was continued based on the purpose required and continued until data saturation.

Data collection was conducted through semi-structured, in-depth, face to face interviews. The participants were asked to express the mobility limitations they experienced. All the interviews began with the help of open questions to allow the participants the opportunity to express their views and experiences. Also, in order to make the interview more in-depth, participants were asked questions such as "what do you mean by this statement?", "Can you expand on this?", "why?", and "how?" Each of the interviews lasted between 30 to 115 minutes. The interviews took place at the participant's home and the time of the interviews were made to be convenient for the participants. Also, the interviews were recorded by a voice recorder. After each interview, they were transcribed word by word and immediately after each interview, the data were analyzed by using the Cheevakumjorn's method (Cheevakumjorn, 1994). Through this method, the data was re-examined and then extended to the research question and divided into a set of questions that specifies certain types of data content. Also, a classification method was created. After that, the text was re-read and its key sentences and concepts were coded and classified according to the questions.

To ensure the validity and reliability of the data, various methods were used. These included continuous data analysis, prolonged engagement and persistent observation through conducting interviews on paper, and thoroughly reviewing them until the emergence of the main elements. Furthermore, participants were chosen with the maximum variation in terms of age, education, the course of the disease, the duration of the disease, the level of disability, and the type of as-

<sup>1</sup>.Mini-Mental Status Examination

<sup>2</sup>.Expanded Disability Status Scale

sistive devices used. To increase the credibility of the data, the extracted codes were shown to the participants and members of the research team in order to make the necessary corrections. In this study, three codes were corrected by two of the participants. Furthermore, the text of the interview was coded by the researcher and three members of the research team who had several years of qualitative work experience in the field of neurology. In terms of consistency, the codes were approved. Also for triangulation, a neurologist, the mother of an individual with MS, a physiotherapist, and an occupational therapist were interviewed. As a result, similar information to what the patients had said were obtained, with the only difference being that they were expressed in specialized

medical terminology (Speziale, Streubert, & Carpenter, 2011).

The present study was approved by the Ethics Committee. The code of ethics IR.IUMS.REC 1395.9411340007 was received and the necessary licenses were issued to conduct the research.

## Results

After analyzing the data and extracting the codes from the experiences of 13 participants with an age range of 30 to 65 years old, (mean age =43 years), three themes were obtained that included “disease-affected barriers”, “personal barriers” and “environmental barriers”. The individual characteristics of the participants are presented in Table 1.

*Table 1. Individual characteristics of participants*

Row	Sex	Age	Education level	Duration the Disease (Year)	Disease Courses	Assistive Device Type	EDSS
1	Female	36	MA	4	Relapsing-Remitting	None use	4.5
2	Female	47	Elementary	11	Relapsing-Remitting	Cane	4
3	Female	30	Diploma	10	Relapsing-Remitting	Wheelchair	7.5
4	Female	47	Bachelor	7	Primary_Progressive	None use	5
5	Male	37	Bachelor	15	Relapsing-Remitting	None use	4.5
6	Male	46	Bachelor	23	Secondary-progressive	Bilateral elbow crutch	6.5
7	Male	39	Diploma	14	Relapsing-Remitting	Bilateral elbow crutch	6
8	Male	43	Bachelor	22	Relapsing-Remitting	Cane	4
9	Female	65	Bachelor	26	Relapsing-Remitting	Walker- rollator and wheelchair	8
10	Male	42	Doctoral	12	progressive-Relapsing	Wheelchair	7
11	Female	41	Diploma	12	Primary_Progressive	Wheelchair	7.5
12	Male	50	MA	15	Relapsing-Remitting	Cane	5
13	Female	42	Diploma	18	Relapsing-Remitting	Wheelchair	7

EDSS: Expanded Disability Status Scale

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### Disease-affected Barriers

The participants stated that the factors affected by the disease, such as disturbances, heaviness and stiffness in the legs and fatigue, prevented their usual mobility.

Each of the 13 participants in the study considered balance problems to be a serious obstacle for mobility. A participant acknowledged in this regard: *“I accepted my disease, but now my biggest problem is to maintain my balance, which makes it difficult for me to walk. I stumble while walking ... When standing my balance is low, when I go to the bathroom and I close my eyes or bend my knees to sit, my balance is lost and my movement becomes harder and I fall”* (p. 1). Another participant stated: *“because of the balance problem I hardly move at home.... I should walk slowly because I have low balance... I need to get up off the ground slowly, others get up without thinking while we have to think about it due to lack of balance”*(p. 5).

Another barrier to mobility caused by MS disease is muscle weakness and stiffness. A participant mentioned: *“When I walk my left foot gets stuck to the ground, I cannot lift my foot too much, so I lose my balance and fall”* (p. 4). Another participant stated: *“My only problem is that when walking my legs are dry and my steps are shortened, about 20 centimeters... sometimes in the bath, my legs become stiff and I cannot go outside the bathroom until I relax a little. .... Sometimes I feel the lead (weight) in my legs”* (p. 10).

Most participants (9 people) reported that fatigue is an important barrier to mobility for daily activities, or even an obstacle to their out-of-home mobility. A participant mentioned: *“The problem with my housework is fatigue. I get tired very fast, I cannot do anything for a long time. For example, my daughter does vacuum cleaning because this work tires me and it sounds annoying to me”* (p. 2). *“I try not to go out too much, I’m very tired, especially when I walk. When I get tired, my knees become sort of empty and I fall”* (p. 7). Another participant said: *“I have a feeling of weakness in my body, I’m tired of even a little work ... I’m tired when I think too much and because my work is designing the circuit, when I work for a long*

*time, my eyes don’t see correctly and I cannot walk properly”*(p. 8).

### Personal Barriers

Participants described individual factors as limiting their mobility. They expressed lifestyle and sometimes individual habits, psychological problems, fear of falling, and some people used mobility aids as a means to deal with mobility barriers.

A number of patients with MS (eight participants) considered their own personal habits, such as smoking and alcohol, eating habits and sleeping time, as a barrier to mobility. A participant said: *“I used to smoke and drink alcohol which lead to the exacerbation of my mobility and balance problems, but now I control it...Low sleep lowers my balance so I always try to set my sleep...I also adhere to food consumption to prevent obesity, I eat less salt, when my weight increases movement become harder for me”*(p.1). Another participant said commenting on his nutritional habits, *“Consumption of cold-natured diet makes me feel worse and I try not eat cold-natured food such as dairy”* (p. 5).

According to participants, mental health problems and stress in life are among other important issues of their lives that exacerbate their mobility problems, with presence in uncomfortable and stressful places topping the list of what many participants identified as one of the reasons for mental issues. A participant stated: *“Stress and mourning events have a lot effect on my movements, my situation becomes worse with crying. Whenever I went to a mourning ceremony, I would never be able to get up from the floor and my son would lift me up and help me”*(p. 2).

One of the reasons that led to nervous problems and mobility problems, was the inability caused by MS disease and its complications, which the participant explained as follows: *“when I think about my sickness getting get very nervous and cannot do a lot of things, which makes it worse for me. But when I am calm I am more comfortable in moving.”*(p. 3).

A group of participants in the study considered the use of assistive devices as a limiting factor to mobility which even prevented patients from leaving their



home. One participant said: *“For the first year when I had balance problems, I used a cane but was embarrassed to come out of the house. I would say to myself why should neighbors see me with a cane, I was embarrassed”*(p. 6). Another participant said: *“I have a cane and walker, but I do not use them much, because I’m afraid I might fall with them, but when I take someone, I’m more confident and less afraid. In addition, the use of assistive devices tire me and it is difficult for me to carry them”* (p. 4).

Findings of the research show that the fear of falling in participants who have a history of falling leads to sort of a restriction and difficulty of mobility outdoors. One participant said: *“I went shopping last year and I hit the ground and fainted, my face was injured, nobody helped me, so I tried not to get out anymore”* (p. 2). Another participant said: *“When I am on the street and I want to cross over the barriers, I always have this fear that I might fall. I’ve fallen before, so I would usually never cross.”* (p. 7).

### **Environmental barriers**

Participants considered the third obstacle to mobility as environmental factors. Most people in the study considered the inappropriate urban environment to impede their mobility. They believed that the bumpiness of streets and passages, traffic on stairs, street barriers, noise and ambient temperature and the pessimistic look of people would disturb them while walking.

Participants claimed that the plenty uneven levels of the streets would cause them to fall. A participant said: *“The uneven surface of the streets and sidewalks is excessive, even though I would hold someone’s hand, I would have got stuck in the asphalt because I could not lift up my foot too much”* (p. 4). Some contributors have stated that uneven surfaces are problematic not only for their mobility but also for moving their assistive devices. Participants mentioned this: *“Some roads that are uneven and are soft makes it difficult for me to move, because my cane sinks in the ground, so I do not go to these places”* (p. 12). *“Once, the wheelchair on the street got stuck in a hole, I pushed my wheelchair and I stumbled forward.”* (p. 9)

The findings of the study showed that the presence of

step paths in public places and sometimes a staircase without fencing and protection or lack of lifts, causes a lot of mobility problems in patients with MS. A participant said: *“Many stairs on the street do not have a bar or a guard, there are no lifts in a lot of places so I cannot go there, so I’ll go away to go there”*(p.1). Another participant who used a wheelchair stated that the staircase prevented the mobility of her assistive device. She said: *“In the urban environment, there are plenty of stairs and most of the time there is no place for wheelchairs to move or be lifted, so my husband has to piggyback me”* (p. 3).

Busy and high noise environments are one of the factors that have an impact on the balance of patients with MS. Some patients would even experience falling in such environments. Two participants stated: *“I’m annoyed by crowded places and I try not to go, because I’m afraid to fall. The environment around me sounds like a bus”* (p. 2). *“I do not go to crowded places because I feel that someone is looking at me, my concentration is lost and I fall”*(p. 5). Also, one of the participants believed the crowdedness was a source of tiredness and impeded mobility. *“It’s hard to get on the subway; and it’s a difficult situation because there is no place to sit, I cannot stand too long and I get tired soon”* (p. 7).

Another obstacle to the mobility of patients with MS outdoors is the movement on steep slopes. A participant commented, *“I am annoyed by places like a slope, with a cane because it pushes me back and disturbs my balance and does not help me even with use a cane”* (p. 7). Another participant mentioned: *“The streets are crowded and sloppy which makes movement hard. I was supposed to take an electric wheelchair, but it really was not possible because of the slope of the street”* (p. 9).

The participants of the study noted that they encountered a number of physical and social barriers from traffic on the streets and on sidewalks. Participants expressed these barriers as follows: *“The municipality has to do a series of work, for example they should build a bridge on the sidewalks so that the wheelchair can cross it, or set up some obstacles on the sidewalks*

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*that the motor racers cannot cross, but the wheelchair can pass through... Sometimes I've seen people park their cars on the sidewalk or on the bridges that others cannot cross”(p. 5), “One of my problems on the street is the construction of urban sewage systems which causes the alley to be narrow, and it's hard for me to move ... when I cross the street, I cannot use the pedestrian bridge, because its stairs are numerous and if it has an escalator, I still cannot use it and I fall “(p. 6). “I cannot get out of the street which is a boulevard. I have to go by the U-turn of the street, because I cannot lift my foot so I'm afraid that I will fall. I've fallen three times before into these obstacles” (p. 7).*

Most participants in the current study described air warming as one of the main barriers to their mobility; to the extent that it leads to disturbance in their daily activity or out-of-home affairs. A female participant said: *“Heat is very annoying. The heat of cooking food is even worse. I have to get out of the kitchen in the middle of the cooking process and go somewhere cooler to get better” (p. 4).* Some participants, in addition to the heat, also considered cold weather as the cause of mobility problems, which leads to disturbances and sluggishness in movement, for example, a participant stated: *“Cold and heat are very bad, especially the cold annoys me. One time, the weather was cold and I arrived late, I could not walk properly. I walked 3 steps in 20 minutes, I become so slow” (p. 5).*

A group of participants stated that the pessimistic look of the people and the sympathy of the surrounding people adds to their mobility problems. A participant remarked: *“Because of the people's look, it's hard for me to go out of the house, when others see me with a wheelchair, they say to themselves, look at her. They have compassion for me, I get nervous and this make my ability to move harder, so I try to get out of the house less “ (p. 3).*

### Discussion

The purpose of this study was to identify the experiences of people with Multiple Sclerosis on mobility barriers that faced them. Participants generally had mobility barriers due to symptoms of the disease, as

well as personal and environmental factors.

#### Disease-affected Barriers

Balance impairment is a common symptom of MS, and it affects more people with disease progression (Cattaneo & Jonsdottir, 2009). The results of this study showed that all participants considered equilibrium disturbances as a barrier to mobility and a factor that made walking difficult and slow. The results of Cameron et al. are consistent with the results of this study. He cited that equilibrium problems are reasons for decreased ability to maintain position and delayed response to postural perturbations (Cameron & Lord, 2010). According to the participants, in addition to balance problems, stiffness and heaviness in the legs caused by spasticity and muscle weakness in the lower extremity, affects balance and the ability to lift legs. The study of Sosnoff et al. showed that lower limb spasticity has negative effects on tolerance and speed of walking in patients with MS (Sosnoff, Gappmaier, Frame, & Motl, 2011). Another complication of MS disease is fatigue, which was expressed by most contributors as a barrier to mobility and implementation of daily activities and community participation. As past evidence suggests, fatigue is one of the most effective factors in postural control and is one of the common causes of falling (Nilsagård, Denison, Gunnarsson, & Boström, 2009; Van Emmerik, Remelius, Johnson, Chung, & Kent-Braun, 2010). Participants in the study also experienced fatigue-related fall, and therefore avoided getting out the home and traversing long paths.

#### Personal Barriers

Personal barriers include individual characteristics and factors that include gender, fitness, lifestyle and individual habits, psychological characteristics of individuals, and past experiences. Individual habits and lifestyles, in many aspects, affect people's health, and its management has a significant role in improving the health of these patients (Organization, 2007). In the present study, individual habits such as nutrition, exercise, weight control, smoking and psychological stress were crucial for the mobility of people. Participants considered consuming cold-natured foods,

overweight, smoking and alcohol as personal habits that restricted mobility. Also in a qualitative study, Ploughman et al. showed that individual healthy habits in life, such as exercise, low-fat diet, smoking cessation and stress management, have been effective in slowing down people's disability and improving their quality of life (Ploughman et al., 2012). Participants also stated that the existence of mental stress in life, the attendance in mourning ceremonies and family disputes, which are widespread in society these days, lead to the intensification of their mobility problems. Mohr et al. in a meta-analysis showed that stressful events lead to an exacerbation of MS symptoms (Mohr, Hart, Julian, Cox, & Pelletier, 2004). In addition, participants' concerns and worries, such as deterioration of health condition and immobility, loss of job, loneliness, and frustration expand their mental health issues. Even previous studies reported that mobility impairment and stress of patients with MS lead to their depression (Suh, Weikert, Dlugonski, Sandroff, & Motl, 2012). Some contributors stated that they felt ashamed and embarrassed while using aids, and even prefer not to leave the house. Also, the results of the present study showed that mobility assistive devices lead to the fatigue and falling of some participants and therefore, fears of falling prevent them from going out. These results confirm some of the previous evidence (Coote, Finlayson, & Sosnoff, 2014; Gunn, Newell, Haas, Marsden, & Freeman, 2013). Tajali et al. also considered the fear of falling as having an impact on mobility performance of patients with MS, and they described it as one of the causes of falling (Tajali et al., 2017).

### **Environmental Barriers**

Environmental factors include the physical and social-attitude environment that individuals continue to live in (Salminen, Brandt, Samuelsson, Töytäri, & Malmivaara, 2009). The present study shows the effect of all three parts of the environment on the mobility of people with MS. Participants in the study saw that inappropriate cover of passages, inadequate parking of cars in the streets and successive excavations of the pavements are considered to be obstacles to their move-

ment. They also said that in order to cross the street, in addition to slow motion and equilibrium disturbances, they are encountered with obstacles such as a number of stairs on the streets, middle roads along the street, the absence of pedestrian crossings and the lack of attention of drivers to pedestrians. Also, there are many pathways without railing or the lack elevators, which has made independent walking for these patients impossible. Finlayson et al. reported on the experiences of patients with MS, saying that environmental factors such as physical barriers, stairs, and social support are a barrier to the mobility of patients with MS (Finlayson & van Denend, 2003). Staying in busy and high noise gatherings will challenge the participants' balance and increase their risk of falling, which makes them avoid being present in crowded environments. Temperature variation is another barrier to mobility in patients with MS. The results showed that sensitivity to heat was present in most participants and sometimes led to disruptions in their daily routine activities. Nilsagard et al. referred to heat as a factor in the falling of people with MS (Nilsagård et al., 2009). In the meantime, some participants stated that cold weather could also slow their movement and even make them fall, and Petrilli also showed in his qualitative study that temperature changes have a significant role in mobility problems of patients (Petrilli et al., 2004).

The pessimistic look of the people towards the abnormal walking of patients with MS or them using assistive devices such as wheelchairs is one of the other impediments to the mobility of patients with MS. Participants stated that they would face the pitiful and compassionate look of surrounding people with their presence in the community which causes them annoyance and discomfort, and since these judgments are rooted in the culture of society and creates feelings of pity or humiliation towards patients, they tend to have less willingness to leave their homes. Abolhassani said in a study concurred with this study that participants hated the caring sympathy of the people. And they expect people to understand their condition instead of feel pity, and rather learn more about MS (Abolhassani, Yazdannik, Taleghani, & Zamani, 2015).

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Therefore, the experiences and lifestyles of people with MS are greatly influenced by the physical environment and social beliefs of the community. When evaluating and treating patients with MS, it is best to consider the barriers to the physical and attitudinal environment of the community to which it belongs, so that we can resolve the problems of these patients.

### Conclusion

Based on research findings and participants' experiences, the mobility barriers of patients with MS include the nature of the disease and its long-term complications, individual factors as well as the physical, social-attitudinal environment. Therefore, rehabilitation spe-

cialists in assessing and managing patients with MS are better to alert patients about individual mobility barriers and their physical environment. It is also possible to improve the attitudinal mobility barriers of the patients with the development and awareness of the community about MS and its complications.

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### Conflict of Interest Statement

The authors declare no conflict of interests.

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## موانع تحرکی افراد مبتلا به مالتیپل اسکلروزیس: یک مطالعه کیفی

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چکیده	اطلاعات مقاله
<p><b>زمینه و هدف:</b> هدف از این پژوهش، تبیین تجارب افراد مبتلا به ام اس از موانع تحرکی است که با آن مواجه هستند.</p> <p><b>روش کار:</b> در این پژوهش ۱۳ فرد مبتلا به ام اس (۷ زن و ۶ مرد) با میانگین سنی ۴۳ سال، با رویکرد کیفی تحلیل محتوا و با رضایت آگاهانه و شدت ناتوانی بین ۸-۴، براساس معیار EDSS وارد مطالعه شدند. نمونه‌گیری به صورت هدفمند و با حداکثر تنوع صورت پذیرفت و داده‌ها از طریق مصاحبه نیمه‌ساختاریافته عمیق جمع‌آوری شده و بلافاصله پس از هر مصاحبه، داده‌ها به روش شیواکومجرن تجزیه و تحلیل شدند.</p> <p><b>یافته‌ها:</b> پس از تجزیه و تحلیل داده‌های به دست آمده از تجارب افراد مبتلا به ام اس، از موانع تحرکی و دسته‌بندی کدهای حاصل از آن، سه طبقه اصلی «موانع متأثر از بیماری»، «موانع فردی» و «موانع محیطی» به دست آمد و داده‌های هر طبقه به دسته‌های زیرین تقسیم شدند.</p> <p><b>نتیجه‌گیری:</b> براساس یافته‌های تحقیق و تجارب شرکت‌کنندگان، متخصصان توان‌بخشی حین ارزیابی و مدیریت و درمان بیماران ام اس، بهتر است به آگاه‌سازی بیماران از موانع تحرکی فردی و مناسب‌سازی محیط فیزیکی آنها بپردازند.</p> <p><b>واژه‌های کلیدی:</b> مالتیپل اسکلروزیس، موانع تحرک، تجربه زیستی، مطالعه کیفی</p>	<p>تاریخ وصول: ۱۳۹۷/۰۸/۰۸</p> <p>تاریخ پذیرش: ۱۳۹۷/۰۸/۲۴</p> <p>انتشار آنلاین: ۱۳۹۷/۰۹/۲۴</p> <p><b>نویسنده مسئول:</b> شهره نوری‌زاده دهکردی دانشیار، گروه فیزیوتراپی، قطب علمی فیزیوتراپی ایران، دانشکده علوم توان‌بخشی، دانشگاه علوم پزشکی ایران، تهران، ایران</p> <p><b>پست الکترونیک:</b> Noorizadeh.sh@iums.ac.ir</p> <p><b>تلفن:</b> ۰۲۱-۲۲۲۲۷۱۲۴</p>