



Research Paper

Mobility Compensatory Strategies in Individuals With Multiple Sclerosis (A Qualitative Study)



Atefeh Saadati Qamsari¹ , Shohreh Noorizadeh Dehkordi^{1*} , Mehdi Dadgoo¹

1. Department of Physiotherapy, Rehabilitation Research Centre, Iranian Centre of Excellence in Physiotherapy, Iran University of Medical Sciences, Tehran, Iran.



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Conflict of interest

The authors declared no conflict of interest.

ABSTRACT

Background and Objectives: The complications and motor disorders caused by multiple sclerosis (MS) not only affect the individual's movement abilities but also play a crucial and valuable role in how these individuals carry out their daily activities. In this way, patients with MS use certain compensatory methods, depending on individual differences, their environment, and their family's support, to help with the complications of this disorder. For this reason, this study aims to identify the compensatory strategies that people with MS use to adapt to their mobility limitations.

Methods: In this study, 13 patients with MS (7 women and 6 men), with informed consent, an average age of 43 years, and a qualitative content analysis approach, were included in the study. The sampling was performed purposefully with maximum variation, and the data was collected via quasi-structured in-depth interviews. Immediately after each interview, the data was analyzed using Cheevakumjom's method.

Results: After analyzing the data and extracting the resulting codes, the codes were classified according to their similarities and differences. Ultimately, three main components of "compensatory strategies for home mobility", "compensatory strategies for outdoor mobility", and "compensatory strategies for carrying out daily activities" were formed.

Conclusion: Although families play a major role in compensating for the mobility problems of these patients, it is necessary for health providers to reduce the burden placed on their families, and to educate MS people on self-care and adjust their living environment. Furthermore, providing mobility assistive devices for the patients should be done according to their differences and their environment.

Keywords: Multiple sclerosis (MS), Mobility limitations, Compensatory strategies, Qualitative study



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* Corresponding Author:

Shohreh Noorizadeh Dehkordi, Associated Professor.

Address: Department of Physiotherapy, Rehabilitation Research Centre, Iranian Centre of Excellence in Physiotherapy, Iran University of Medical Sciences, Tehran, Iran.

Tel: +98 (21) 22227124

E-mail: Noorizadeh.sh@iums.ac.ir

↑ *What is “already known” in this topic:*

People living with chronic diseases like multiple sclerosis (MS) self-manage their conditions. They decide to change their lifestyle, adhere to medical routines, participate in social activities and roles, and use the healthcare resources available to them.

→ *What this article adds:*

The current study aimed to identify the compensatory strategies that patients with MS use to adapt to their mobility limitations depending on individual differences, their environmental context, and the support of their family.

Introduction

Impairments in mobility and the ability to walk are the most common reasons for disability in patients with multiple sclerosis (MS) [1]. Since the disease progresses, impairments in disability increase. The individual's ability to perform daily activities, their role within the community, and their families all decrease [2-4].

In the early stages of the disease, when mobility impairments are mild, medical interventions often focus on alleviating the patient's neurological signs and symptoms [5, 6]. Since the MS disease progresses, the impairments and disabilities experienced usually become chronic and more numerous, people with MS have to develop coping strategies to find solutions to mobility problems and gain independence in lonely situations. The self-managing methods can empower patients and their families in their fight against this lifelong disease, and decrease the need for medications [7].

Based on the Calgary Cambridge model, in addition to the pathological pattern of the disease itself, a negative pattern of experiences exists that the patient associates with their disease. The thoughts, beliefs, and concerns of patients under the influence of the culture of the community lead to different experiences of patients from the same disease. This not only affects their ability to adapt to the disease but also the physical aspects of the individual, therefore they cannot use the same treatment course to manage the disease in all patients. Moreover, because the beliefs and expectations of the patients are affected by their living environment, the problem in each affects the other [8, 9]. Ultimately, patient strategies depend on individual differences of their environmental context and the support of their family. Thus, this study was conducted to identify the compensatory strategies

that patients with MS use to adapt to their mobility limitations, and qualitative data collection is an ideal way to learn how people with MS cope with their symptoms and can inform efforts to compensate for their mobility problems.

Materials and Methods

In this study, 13 patients with MS (7 women and 6 men) with an average age of 43 years, with qualitative content analysis and informed consent, were included. In this way, the data was interpreted internally and profoundly. The individuals enrolled in this study were diagnosed by a neurologist. They had a score above 21 in the Mini-mental status examination (MMSE) criterion, and a disability score between 4 to 8 in the Expanded disability status scale (EDSS) criterion. Moreover, they could move with or without the need for devices. Patient sampling continued based on purpose and continued until data saturation. Data were collected via quasi-structured, in-depth, face-to-face interviews. The participants were asked to express the mobility limitations they experienced. All the interviews began with open-end questions to allow the participants the opportunity to express their views and experiences. Also, to deepen the interview, 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 according to what was convenient for the participants. With the consent of the participants, 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 using Cheevakumjorn's method [10]. In this way, the data was re-examined and then extended to the research question and divided into a set of questions that speci-

fies certain types of data content, and 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, course of the disease, duration of the disease, level of disability, and the type of assistive devices used. To increase the credibility of the data, the extracted codes were shown to the participants and members of the research team to make the necessary corrections. In this study, two participants corrected three codes. 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 was obtained, with the only difference being that they were expressed in specialized medical terminology.

Results

After analyzing the data and extracting the codes from the experience of the 13 contributors, with an age range of 30 to 65 years, the results included 3 main elements, “compensatory strategies for home mobility”, “compensatory strategies for outdoor mobility”, and “compensatory strategies for performing daily activities”. [Table 1](#) presents the patient profile for each of the participants of this study.

Compensatory strategies for home mobility

The results of the present study and the codes obtained from the interviews showed that they use various methods to compensate for their limitations in movement inside their homes. These strategies include using home appliances, asking for help from their family, using assistive devices for walking, and moving around without walking.

Ten participants reported having to hold on to the sofa handles, walls, chairs, and other objects inside their house to move around because they experienced problems in balance and movement while walking. One of the participants stated that: “I don’t use my cane when I’m home. Instead, I have to use the wall and doors to

Table 1. Individual characteristics of participants

Row	Sex	Age (y)	Education Level	Disease Duration (y)	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 & 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.

pull myself up. But standing up is difficult for me. In the morning, when I want to get out of bed, I have to hold on to something, like the edge of the bed to stand up” (P.7).

One of the most popular strategies used by the participants in this study was asking for help from their families to compensate for the limitation in mobility at home. A participant stated that even for moving around in bed, they would require assistance: “With the abortion, I had my right leg got even worse. I would lose my balance and could not walk by myself. I was worse than this for a period. Even when I was in bed and wanted to turn to sleep on my other side I had to wake my husband up to help me” (P.3). Moreover, the participants who used a wheelchair for mobility were more dependent on others to help them. One of the participants stated that: “I use the wheelchair to move up to my bed and then I throw myself on the bed. But someone has to come and help place my legs on the bed and then I will slowly move myself onto the bed. For standing up and sitting down, I hang my legs from the bed and I use my elbows to sit. But I still need someone to help me to sit in the wheelchair” (P.9).

Some participants used assistive devices, such as crutches, forearm crutches, wheelchairs, and wheeled walkers, to facilitate mobility at home. One participant stated in this regard: “I had a cane at home for a while, but I haven’t been able to walk with a cane for the past 2 years and I use a wheeled walker at home. Some days, I feel even worse and I cannot get up at all, so they bring me a wheelchair” (P.9).

The extent of disability in some of the participants meant that they could stand and extend their knees. These participants moved on their knees, and they performed their daily routines with this compensatory solution. One of the participants stated that: “I cannot walk around the house at all or use a wheelchair. I have had carpeting done on the floor so that I can move around on my knees. When I wake up in the morning, I use my knees to go to the kitchen and turn the kettle on” (P.11). Some participants unable to straighten their knees to stand or even keep their balance moving around on their knees, compensated by crawling around on all fours. One of the participants stated: “For the last 7-8 months, I cannot extend and straighten my knees due to the shortening of my muscles. So it’s been very difficult for me because I can’t walk and when I’m at home I have to move around on all fours” (P.13).

Compensatory strategies for out-of-home mobility

The experience of the individuals taking part in this study showed that the participants used several strategies for out-of-home mobility. These include using their surrounding objects, asking others for help, using walking aids or changing the aids they used to use, and using fences when walking up or down staircases.

The results showed that some participants held onto objects and the walls of pathways in outdoor situations to walk and maintain their balance. One of the participants explained: “When there are stairs, I have to hold onto the fence. However, at work or in the elevator, I hold onto the walls and objects around me” (P.4). Seven of the participants preferred to ask someone for help when going out of the house. The kind of help the participants mentioned receiving from others was in the form of having someone hold their hand or riding on their back for mobility. A participant stated the following: “The majority of public places have not been designed for people on wheelchairs. No elevators exist so that my spouse has to carry me” (P.3). Another participant stated: “In my neighborhood, I asked people who help me out to hold my hand so that I don’t fall” (P.6).

Using assistive devices outdoors was very common among the individuals studied. The participants stated that the main reason for using assistive devices is to prevent falling. One of the participants explained the following: “I have fallen a couple of times due to my problems in movement as well as vision and seizure disorders. So, I now use a cane outside the house” (P.2). Another participant stated: “I use a wheelchair outside. For example, if I take a cab somewhere, I use a wheelchair to go up to the car and then someone will help me into the car” (P.9). Some of the participants still had trouble walking despite using an assistive device. They could compensate for this limitation by changing the type of assistive device they used. One of the participants explained the reason why they changed their assistive device in the following way: “To begin with, I used an ordinary cane. But after a while, it became difficult to keep my balance with a cane. So instead of the cane, they gave me a tripod cane. I’m more comfortable with this one” (P.12).

Compensatory strategies for mobility in carrying out daily activities

The experience of the participants of this study showed that the limitations in mobility that the individuals face in both their homes and outdoor environments cause problems in doing daily routines. The individuals in this

study explained different methods they use to overcome these problems.

A group of the participants were helped by their family members in doing housework, such as cooking, cleaning, shopping, and even banking affairs. One of the female participants stated: "I can't do the cooking, because I can't stand the heat from the stove. My mother lives near us so she does most of the cooking for us. My mother and husband help me out with the housework a lot. They have come to accept my condition" (P.1). And a male participant stated: "My sister runs my errands, such as banking and property affairs. My father does the shopping because I cannot do this myself" (P.7).

Most participants in the study described fatigue as one of the common symptoms of MS and used various strategies to control and prevent it. One participant managed his fatigue by changing his position: "I get tired easily, which makes me feel worse. I try not to tire myself out. For example, if I'm standing or walking, or sitting down or lying if I'm home" (P.6).

According to the living conditions, most participants used different compensatory methods, such as sitting on a stool, sitting on the floor, and reducing the frequency and time, when bathing. Participants expressed their methods in the following way: "I have fallen on the bathroom floor a couple of times before. But now I use a stool because when I close my eyes under the shower, I lose my balance and fall. So, I sit on a stool and I also have reduced the frequency of showering" (P.1). "I can take a shower myself, but I can't sit on the chair by myself. So I have to sit on the bathroom floor to wash and I try not to stay in the shower for too long" (P.11).

Based on the results obtained, one of the most commonly used tools inside the homes of these individuals was the installation of special handles in the bathrooms, which was taught to the patients by the healthcare team. One participant stated: "It's difficult for me to stand up when I'm on the floor, and I have to hold something. So when I went to an occupational therapist, they told me to have handles installed in my bathroom" (P.6). The participants stated that these special handles accelerated their mobility and ability to walk as well as preventing them from falling. "We have installed handles all around the bathroom walls of our home so that I can hold on to them and move around more easily. And if I'm about to fall I can easily grab them." (P.9).

Discussion

This study was conducted to discover the compensatory strategies that patients with MS use to overcome their mobility limitations. By analyzing the experience of the participants in this study, these strategies were categorized into three areas of home compensatory strategies, out-of-home compensatory strategies, and strategies for mobility when performing daily activities.

Compensatory strategies for home mobility

Sitting and sleeping on the floor is very common among Iranian participants. Therefore, one of the problems that these patients face is getting up from the floor, which the participants of this study overcame by sleeping on a bed and holding onto the objects and furniture around them while standing up and walking. But in some cases, such as mobility in bed, sitting down in a wheelchair, or getting up from it, they asked for help from the people around them. In Iranian society, the patient's family members play a crucial role in helping them [11, 12]. Therefore, the patient's expectations and dependency also increase. Becker also stated in his study that families have a great supportive role for the disabled, and the participants are very satisfied with the function and role of their family members in their lives [13]. Some of the participants in the study preferred to use assistive devices to ease mobility, maintain their independence, and prevent falling. Lezzoni et al. in a study reviewing the experiences of people with MS stated that these patients are mobile at home using assistive devices; however, when using them, they encounter certain problems that require solutions to address them [14]. Other obstacles to mobility include spasticity and weakness of the lower limb muscles, contracture, and stiffness in the knees. The participants of this study faced such problems, and to compensate for this at home, they would move around either on all fours or their knees at home. This approach in changing the way the patients walked, despite the discomfort and knee injuries, meant that the patient was less dependent on others for movement.

Compensatory strategies for out-of-home mobility

Some participants were able to maintain their balance and ability to walk outside their homes by holding onto the walls on pavements and the fence on stairways. They also noted that the frequent lack of stair railing placement along the stairway paths seen in public places was a barrier to people walking through that location. Nilsagard et al. also examined the experience of people with MS and stated that the main reason why they tend to fall when

using stairways was a lack of fencing [15]. To prevent falls, some of the patients preferred to ask the people around them for help or to have their family members help them when they encounter problems. Therefore, families have to spend time and money on accompanying the patients when going outside, which can affect the whole family's quality of life. LaRocca et al. during their study stated that most families are depressed due to the mobility problems of patients with MS, and their quality of life is decreased [16]. The results of the study showed that with the progression of the disease and the increase in mobility problems, the participants preferred to use assistive devices to maintain their independence and prevent falls, or to modify the assistive devices by their disease conditions. It is worth noting that the use of assistive devices was not accepted by all the patients. Although 77% of the participants preferred to use assistive devices, 23% believed that their assistive device was itself the cause of their falls. Research conducted from previous studies suggests that using assistive devices in patients with MS is one of the risk factors for falling in this group of patients, and other research suggests a reduction in the frequency of falls [15, 17, 18]. Also, a qualitative study showed that some people with MS felt ashamed and embarrassed while using assistive devices and were stigmatized by disability in the general public [19]. Therefore, further research is required to acquire a deeper understanding of the patient's perspective about the use of mobility devices and the prescription of assistive devices for walking in these groups of patients.

Compensatory strategies for mobility when carrying out daily routines

With increasing problems and the continuation of limitations in mobility, functional performance and carrying out daily activities are at risk for individuals [16]. The results of this study indicate that patients use the help of their family members to reduce their mobility problems and this increases the pressure on their families. Instead of providing services to facilitate the individual's contributions and providing financial assistance to them, the community healthcare providers pressure the families to provide the necessary care for these patients. Dunn et al. reported in their study that many psychosocial, physical, and economic pressures have been imposed on the family and carers of patients with MS to compensate for the mobility problems of these patients [2]. The participants acknowledged that they could control their fatigue and manage their energy conservation by planning things, resting between periods of work, or changing their position, as fatigue increases the problems in mobility and balance in these patients [20, 21]. In a meta-analysis,

Bilkman et al. showed that methods, treatment management, and energy conservation all improve fatigue in individuals with MS [22]. Furthermore, the participants of the study conducted by Kayes also reported that they were able to control their fatigue by resting and then continuing their work [23]. The participants also expressed their experiences in carrying out activities, such as bathing and going to the toilet. Most people preferred to sit down during showering and using Western-style toilets to prevent losing their balance and falling. However, some individuals used diapers or portable toilet seats to compensate because they were used to Eastern-style toilets. Others, with the training of the healthcare team, installed handles in their bathrooms which helped maintain their safety as well as independence.

Finally, the individual differences with multiple barriers in the physical environment, the policies of the Ministry of Health, educating the patients, and family support, all affect the types of compensatory strategies used by patients with MS when facing limitations in mobility.

Conclusion

Based on the results of the study, the degree of disability, limitations in mobility, and individual and environmental conditions, they were able to move with the help of their families and surrounding objects. Because families play such a crucial role in supporting these individuals when overcoming limitations in mobility inside their homes, and outside, and when carrying out daily routines, it is necessary for the [Ministry of Health and Medical Education](#) to plan to reduce the family burden and for the healthcare team to educate the patients on self-care matters and how to make their home environment more suitable.

Ethical Considerations

Compliance with ethical guidelines

The present study was approved by the Ethics Committee of [Iran University of Medical Sciences](#) (Code :IR. IUMS.REC 1395.9411340007). The necessary licenses were issued to conduct the research.

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Authors' contributions

Conceptualization, supervision, and writing the original draft: Atefeh Saadati Qamsari and Shohreh Noorizadeh Dehkordi; Methodology: Atefeh Saadati Qamsari and Mehdi Dadgoo; Investigation, writing-review & editing: All authors. Funding acquisition and resources: Shohreh Noorizadeh Dehkordi and Mehdi Dadgoo.

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مقاله پژوهشی



راهکارهای جبرانی افراد مبتلا به ام اس برای سازگاری با محدودیت‌های تحرکی: (مطالعه کیفی)

عاطفه سعادت‌ی قمصری^۱، *شهره نوری زاده دهکردی^۱ مهدی دادگو^۱

۱. گروه فیزیوتراپی، مرکز تحقیقات توانبخشی، مرکز عالی فیزیوتراپی ایران، دانشکده علوم توانبخشی، دانشگاه علوم پزشکی ایران، تهران، ایران.

چکیده

مقدمه: عوارض و اختلالات حرکتی ناشی از بیماری ام اس نه تنها بر جابجایی افراد اثر می‌گذارد، بلکه نقش مهم و ارزنده‌ای برای مشارکت افراد در بسیاری از فعالیت‌های روزمره‌ی زندگی دارد. به همین منظور افراد مبتلا به ام اس برای جلوگیری از عوارض ناشی از این اختلال از یکسری راهکارهای جبرانی کمک می‌گیرند که به تفاوت‌های فردی، ساختار محیط و حمایت خانواده آن‌ها بستگی دارد، به همین دلیل هدف از مطالعه حاضر تبیین راهکارهای جبرانی افراد مبتلا به ام اس برای سازگاری با محدودیت‌های تحرکی آن‌ها می‌باشد.

مواد و روش‌ها: در این پژوهش ۱۳ فرد مبتلا به ام اس (۷ زن و ۶ مرد) با میانگین سنی ۴۳ سال با رویکرد کیفی تحلیل محتوا با رضایت آگاهانه و شدت ناتوانی بین ۸-۴ بر اساس معیار EDSS وارد مطالعه شدند. نمونه‌گیری به صورت هدفمند با حداکثر تنوع صورت پذیرفت و داده‌ها از طریق مصاحبه نیمه ساختار یافته عمیق و رو در رو جمع‌آوری شد و بلافاصله پس از هر مصاحبه داده‌ها به روش شیواکومچرن مورد تجزیه و تحلیل قرار گرفتند.

یافته‌ها: پس از تجزیه و تحلیل داده‌ها و استخراج کدهای حاصل از آن، با توجه به مشابهت‌ها و تفاوت‌ها کدها دسته‌بندی شده و در نهایت سه درون‌مایه اصلی "راهکارهای جبرانی تحرک داخل منزل"، "راهکارهای جبرانی تحرک خارج از منزل" و "راهکارهای جبرانی تحرک در اجرای امور روزمره" شکل گرفت.

نتیجه‌گیری: با توجه به اینکه خانواده‌ها نقش حمایتی بالایی برای جبران مشکلات تحرکی بیماران دارند، لازم است تا وزارت بهداشت در جهت کاستن بار خانواده برنامه‌ریزی کند و تیم درمانی به آموزش روش‌های خودمراقبتی و مناسب‌سازی محیط منزل به بیماران ام اس بپردازد. همچنین تجویز وسیله کمکی برای بیماران باید با توجه به تفاوت‌های فردی و محیط زندگی آن‌ها صورت بگیرد.

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مالتیپل اسکلروزیس،
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* نویسنده مسئول:

شهره نوری زاده دهکردی

نشانی: تهران، دانشگاه علوم پزشکی ایران، دانشکده علوم توانبخشی، مرکز عالی فیزیوتراپی ایران، مرکز تحقیقات توانبخشی، گروه فیزیوتراپی.

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رایانامه: Noorizadeh.sh@iums.ac.ir