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To cite this article: Emmanuelle Opsommer, Carla Ribeiro, Sophie Carrard, Roger Hilfiker & Josiane Mbarga (04 Dec 2024): Exploring the integration and patient engagement of balance home exercises in the daily management of multiple sclerosis: a comprehensive qualitative analysis, *Disability and Rehabilitation*, DOI: [10.1080/09638288.2024.2435519](https://doi.org/10.1080/09638288.2024.2435519)

To link to this article: <https://doi.org/10.1080/09638288.2024.2435519>



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Published online: 04 Dec 2024.



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Exploring the integration and patient engagement of balance home exercises in the daily management of multiple sclerosis: a comprehensive qualitative analysis

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ABSTRACT

Purpose: This study investigated the perceptions and experiences of patients with multiple sclerosis (MS) regarding a home-based balance exercises program, focusing on its practicality and perceived effects for daily management and the factors influencing its implementation.

Materials and Methods: Employing a qualitative approach, semi-structured interviews were conducted with 18 patients with MS in Switzerland (13 women, 5 men; mean age 53±11 years). The study used purposive sampling to ensure diverse representations. The exercise program included 19 tailored exercises, adapted by physiotherapists for each participant. Data analysis involved inductive thematic analysis to understand the practical implementation, challenges, and perceived benefits.

Results: Key themes emerged, such as adaptability of exercises, implementation variability, approaches to integration, facilitators, obstacles, and perceived effects. Adaptability to fluctuating symptoms, individual lifestyle impacts, and variability in exercise practices were notable. Facilitators included personalized support from physiotherapists, while obstacles ranged from fatigue to complex exercise variants. Perceived effects varied, with some patients reporting physical and psychological benefits.

Conclusions: The study highlights diverse patient experiences with the balance exercises program. Key challenges included physical exertion and adapting to MS symptoms. Physiotherapists played a pivotal role in personalization and guidance. Despite challenges, patients demonstrated adaptability and proactive integration of exercises into their MS management.

ARTICLE HISTORY

Received 29 February 2024
Revised 8 November 2024
Accepted 22 November 2024

KEYWORDS

Multiple sclerosis; balance; home-based exercises; rehabilitation; qualitative research; semi-structured interviews

Introduction



Multiple sclerosis (MS), a chronic degenerative disease of the central nervous system (CNS), is characterized by inflammation and destruction of myelin. It ranks among the most prevalent neurological disorders in young adults and stands as a prominent cause of non-traumatic disability in individuals of young and middle age [1]. It manifests in a combination of physical, cognitive, and emotional symptoms. Due to the diverse locations of sclerosis within the CNS, the symptoms of the disease exhibit substantial variation among patients. These symptoms encompass muscle weakness, spasticity, pain, fatigue, impaired coordination of movements, visual and speech difficulties, balance issues, digestive and urinary disorders, as well as sensory, emotional, and cognitive challenges that significantly impact the quality of life [2].


Balance issues in individuals with MS significantly increases the risk of falls [3]. Falls are associated with a higher likelihood of sustaining fractures [4], instilling fear of falling [5], and reducing overall quality of life [6]. To prevent falls in individuals with MS, it is advisable to implement interventions that target the reduction of balance impairments. Existing evidence suggests that physiotherapy interventions have the potential to improve balance among individuals in this patient population [7]. Numerous

balance exercise programs have been suggested including group exercise programs, a home-based balance training program, and an individualized balance training program [8].

Furthermore, Sattelmayer et al. (2021) developed a home-based balance exercise program for individuals with MS to improve walking and reduce falls. This program, consisting of 19 key exercises across three dimensions ("stable base of support," "sway," and "step and walk"), was created using Rasch analysis and experts' evaluation. The exercises were tailored to disease progression and individual capabilities, with difficulty levels assigned for personalized training [9].

The individuals who have experienced these exercises during physiotherapy sessions have expressed interest in them. However, their practical implementation in the homes of individuals with MS has yet to be explored, primarily due to the challenge of fully grasping the comprehensive concerns and experiences of patients solely through questionnaires. Hence, this study aimed to explore the perception of patients with MS regarding the proposed home-exercise program and its integration into their daily illness management. Employing a qualitative approach, the study examined how patients appropriate the exercises and identified factors that facilitate or hinder their implementation.

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 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/09638288.2024.2435519>.

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Materials and methods

The study adopted a qualitative methodology to allow in-depth reporting of individual viewpoints and perspectives. Semi-structured interviews (two per participant) were completed to uncover the lived experiences and needs of individuals with MS in adopting a balance exercise program at home. This study was reported in accordance with the consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups [10].

The study was approved by the local ethic committee in Switzerland (CER-VD 2021-01238) and was conducted according to principles stated in the Declaration of Helsinki. All participants signed a written informed consent.

Participants

People were recruited by physiotherapists, external to the research team, in physiotherapy clinics or private practices between October 2021 and June 2022 and were selected according to a purposive sample [10, 11]. Individuals with MS (men and women, with different levels of education and employed or not) were eligible for this study if they were: (1) adults over 18 years old, (2) diagnosed with MS by a medical doctor, (3) able to walk a minimum of 20 m independently, with or without the use of walking aids, (4) able to stand for more than 3 s without help or aids, (5) able to understand and execute project-related instructions (project, exercise, etc.) and could communicate in French and, (6) allowed to perform exercises (i.e., a prescription for active physiotherapy). Individuals with cognitive impairment or severe psychiatric disease as well as those who have contraindications to physical exercise (according to medical advice) were excluded.

The sample was purposive, which is consistent with standard qualitative research practices. It allowed for a deeper understanding of the integration of home-based exercise into MS management, specifically from the perspective of “competent people” [12]. The criteria for data saturation were not predetermined, and data collection continued until no new themes emerged. This approach ensured that the sample size was sufficient to explore the phenomenon under study [13].

Balance exercise program

The proposed exercises are part of a 19-exercise home-based balance program for people with MS, developed by a team of physiotherapists and revised by other professions, such as sports scientists, to improve walking and reduce falls. The program was created using a multi-step process based on Rasch analysis. Initially, a pool of 98 balance exercises was developed, with the ability to be adjusted according to disease progression and individual capabilities. Health professionals, including experts in the field, evaluated these exercises and determined their difficulty levels, ranging from easy to challenging. The most relevant balance exercises, identified as “key” exercises by these experts, were selected, resulting in the final set of 19 exercises. Each exercise in this program has different variations of increasing difficulty [9]. Some illustrations of these exercises are provided in [Appendix 1](#). In collaboration with each patient, each physiotherapist involved in the current study selected four or five exercises appropriate for the patient, which could be performed in the patient's home. To support understanding, each physiotherapist provided illustrated cards to assist patients with the exercises. From the progression line - from the easiest to the most difficult - the

physiotherapist determined the patient's starting level, which could be adapted according to the patient's abilities and the evolution of their pathology. Both the progression line and the exercise variations could be modified during interactions between the patient and the physiotherapist in their regular physiotherapy sessions, which were independent of this study.

Interviews

For each participant, involvement in the project spanned a period of approximately 14 weeks between the first contact with the clinical physiotherapist and the last contact with a member of the research team. The first interview was conducted two weeks after each participant's physiotherapist introduced the exercise program, and the second interview took place three months later.

The researcher in charge of conducting the interviews is a woman (CR), holding a PhD in Health Sociology. With a background rooted in social sciences, she is well-equipped with training and robust skills in qualitative research. Prior to the interviews, she established telephone contact with the participants. During these initial conversations, the researcher introduced her professional background and thoroughly explained the study's aims, fieldwork modalities, and the objectives of the interviews. Importantly, she emphasized to the participants that she was not a health professional. She assured them that any information collected would be confined to the research team and would not influence their medical care.

We conducted comprehensive interviews, as they allow the interviewee to testify about their practice and lived experience in narrative form [14, 15]. To ensure the transparency and validity of the findings, all interviews were conducted in accordance with a semi-structured interview guide [15].

We performed two interviews per participant, all conducted by one single researcher (CR). Interviews were performed at the patients' home, and during the interviews, there were no other people present besides the researcher and the participant. The first interview, lasting about 30 to 60 min, took place two weeks after the physiotherapist has proposed the exercise program. This time allowed the patients to put into practice the exercises. This first interview addressed: the relevance and appropriateness of the exercises selected with each participant's physiotherapist, their implementation, the obstacles, difficulties, or facilitating elements of the integration of the exercises in the illness management as well as the usefulness of the exercise program, its potential effects, and the interactions with the physiotherapist. Finally, the subjective experience of the illness (illness course, consequences of the illness and coping strategies) and the life context of the patients was also explored to better understand their discourse and practices.

The second interview, lasting about 18 to 50 min, was conducted three months later to give sufficient time to indicate the interest, motivation, and practice of the patients over time. This second interview aimed to highlight the dynamics of the implementation of the exercise program and its appropriation over time. It focussed on factors related to compliance, long-term effects, evolution or fluctuations in the choice of exercise progression level and, reviewed barriers and difficulties encountered, facilitators, interactions with and expectations of physiotherapists, and themes related to changes in illness course and life context.

All interviews were audio-recorded and transcribed “ad verbatim” in their entirety. The recordings and transcripts were stored in a password-protected server, which was accessible to authorized research personnel only. A participant code was assigned to each participant to ensure anonymity.

Data analysis

An inductive thematic analysis was used, using a shared coded book in French [11]. A code list was developed from the first three exploratory interviews conducted in both rounds (two weeks after the physiotherapist introduced the exercise program, and three months later). Three team members coded the data, including two social sciences researchers and one physiotherapist. A tree structure with the themes to be analyzed and the associated codes was developed by the team.

This list took into account the themes dealt with in the interview guide, i.e., for the first interview (1) personal information, (2) trajectory and experience of the illness, (3) therapeutic trajectory and management of the illness, (4) relevance and appropriateness of the exercises proposed by each physiotherapist, (5) implementation and integration of the exercises into the management of the illness and into daily life and, for the second interview, (1) biographical and therapeutic trajectory, (2) dynamics of the implementation of the exercise program and appropriation over time, (3) effects of the exercises on the management of the illness and daily life, (4) expectations toward their physiotherapists. The themes were developed according to the research objectives. The list of codes was enriched by new themes that emerged during the review of the transcribed interviews. Qualitative data analysis software program (MaxQDA, Berlin, VERBI Software, 2021) was then used for the coding of each interview. The team engaged in collaborative analysis until a consensus was established, taking into consideration professional backgrounds specificities of team members (physiotherapists, sociologist, and anthropologist).

For each theme or sub-theme, the associated verbatims were extracted from the software. Then, these verbatims were analyzed by correlating the patients' experiences with their socio-demographic characteristics and their life context, and about the theories and concepts that make it possible to explain the phenomena in progress.

Results

In addition to highlighting the characteristics of the population, the analysis of the data revealed several key themes related to balance exercises at home, which will be explored in detail in the following sections. These themes included: (a) patients' views on the exercises, (b) the practical application of the balance exercise program, (c) exclusive and inclusive approaches, (d) obstacles and challenges encountered by patients, (e) facilitators, and (f) patients' perceived effects of the exercise program.

Participant socio-demographic characteristics and medical conditions

Eighteen individuals (13 women, 5 men) experiencing MS living in French-speaking Switzerland were recruited through physiotherapists (Table 1). Table 1 and Appendix II provide the characteristics of the population and individual participant profiles, respectively. The participants, predominantly of Swiss nationality ($n=14/18$), were on average 53 ± 11 years old at the time of the interview (range: 29–78 years old) and 39 ± 14 years old at diagnosis (range: 20–65 years old). On average, participants had been living with MS for 14.4 ± 10.2 years (range: 2–41 years), further illustrating the varied experiences of disease progression within the cohort. This age range highlights the diversity of MS onset ages and emphasizes the unpredictable nature of MS's onset. Marital status among the cohort varied (10 live with a partner,

Table 1. Characteristics of the population.

Characteristic	n ± s.d.
Gender	
Women	13
Men	5
Age (years)	
Mean	53 ± 11
Minimum	29
Maximum	78
Employment status	
Receiving disability insurance (DI)	8
Employed, part-time	4
Employed, part-time (10–30%) with pending DI	2
Unemployed	2
Retired	2
Marital status	
Married	10
Separated	2
Divorced	3
Single	2
Widow	1
Education	
Undefined level	2
Secondary level	14
Tertiary level	2

while the others live alone) and thirteen of the participants had children (between 1 and 3 children), suggesting familial responsibilities might intersect with illness management. Educational backgrounds were diverse, with professional training in fields such as commerce, nursing, and teaching. Employment status was notably impacted, as evidenced by the number of participants either partially employed or reliant on disability insurance (6 in part-time employment, with the remaining 12 unemployed), which underscored the economic and professional implications of MS.

Among the 18 participants, we identified the following main forms of MS: relapsing-remitting MS ($n=5$), characterized by inflammatory attacks spaced variably over time; primary progressive MS ($n=1$), reported by one patient with a disease that progressed continuously from the outset; secondary progressive MS ($n=8$), observed in patients who experienced a transition from relapsing-remitting MS to progressive MS after several years. Information on the specific type of MS for 4 participants was not provided.

The participants reported a variety of symptoms related to their medical conditions. Common symptoms included significant fatigue, walking difficulties, muscle weakness, and frequent falls. Many experienced legs pain, muscle mass loss, and issues with balance and concentration. Specific symptoms like optic neuritis, limb unresponsiveness, memory loss, and urinary incontinence were also noted. In terms of symptoms specifically associated with MS, participants reported increasing difficulties in walking, fatigue impacting both physical and mental capacities, balance issues, and cognitive challenges. Tingling sensations and other autoimmune disease-related symptoms, as well as back and neck pain, were common. Several participants highlighted fatigue as the most troublesome symptom, affecting daily activities and mobility. Pain, particularly in the hips and spine, was also noted as a significant issue, with some cases possibly linked to other underlying conditions. Overall, the symptoms varied widely among participants but generally had, according to them, a profound impact on their daily lives and activities. These changes in turn affected self-perception and fueled the fear of being stigmatized. Indeed, there was a desire among participants to avoid being stigmatized due to their illness, yet they also expressed a need for empathy, understanding, and practical support, including

financial assistance and physiotherapy. A complex relationship with self-perception emerged. Participants expressed a desire not to be labeled by their disease. For example, P1 said: "I don't want to be labeled with multiple sclerosis." But they also said they were looking for empathy and support, including practical assistance: "Oh my God! This woman has multiple sclerosis!, no, I don't want that, but I do want people to have empathy and to recognize that we have this disease and that it greatly changes our lives and that we are helped in every way possible, that we are listened to, that we are supported. That's it." (P1).

Patient views on the exercises: suitability and complexity

Patients' opinions about the exercise program varied, with a general consensus on its potential benefits for managing MS and improving balance. However, the suitability and effectiveness of the exercises were closely tied to individual challenges and conditions. Importantly, no patients reported any falls during the home-based training session. Patients found the exercises easy in theory, adapted to their pathology, physical abilities and capacities, but when it came to putting them into practice, they appeared quite complex. Indeed, no exercise was perceived as difficult in itself, but it became challenging when the body could no longer keep up, particularly when it could no longer perform certain movements or maintain certain postures. For example, P12 said:

At first, I thought it would be easy [...] done in two minutes, snap! Well, no. They seem like nothing, but I can't manage them. They're complicated for me, so it takes me about 15 minutes to get through them all. (P12, under the mean age)

The complexity applied both to the basic exercises and their variations, as each exercise followed a progression level from the simplest to the most complex.

Implementation of the balance exercise program

The frequency and method of implementing the exercise program varied significantly among participants. Some patients, like P7 and P3 (over the mean age and the mean age of diagnosis), performed the exercises multiple times a day which demonstrates their high level of commitment. P3 has adapted the daily exercise routine to fit his energy levels and P7's approach reflects a more integrated routine, where exercises became a natural part of everyday activities. P3, for his part, stated that he can do all the exercises, but not for very long and still do them every day: "I continue to do them every day, yes. I spread the exercises throughout the day. I do it for a little while, then I stop, go sit down, and do it again." P7, who did them every day without even realizing it said: "I still do them every day, regularly, and so I think I do them without even realizing it. So, I'm still the same, but I always do my exercises, and I also do sports, so there you go, I continue to try to maintain myself." In contrast, others had an irregular rhythm, practicing less frequently due to factors like fatigue or other daily commitments.

While most were assigned a set of four exercises, the actual practice ranged from daily execution to less regular routines. This variability was often influenced by individual factors such as fatigue, pain, or personal schedules. Additionally, physiotherapists' recommendations varied: some advised daily exercises (e.g., P16, P15, P12), while others suggested a frequency of two to three times a week (e.g., P7, P1), considering patient habits. A few did not specify a frequency (e.g., P17, P9, P8), leading to diverse

practice patterns among patients. Indicating a high level of commitment and discipline, some patients reported performing the exercises multiple times a day. Others, however, had an irregular rhythm, practicing "every other day" or "when remembered," which acknowledged the importance of the exercises but facing challenges in consistent implementation.

The experience of some patients such as P17 (under the mean age and the mean age of diagnosis) illustrated a change in the consistency of exercise routines. Initially adhering to a regular schedule, she faced challenges in maintaining this routine over time: "It was twice a week. Since the last four weeks, I haven't been doing it. No. I think I used to do it 2, 3 times a week, twice a week for sure, and then these last four weeks, the whole month, honestly, it was... just not possible."

Approaches to exercise integration (exclusive vs. inclusive)

Patients adopted different approaches to integrating the exercises into their daily lives, with some opting for an exclusive approach and others for an inclusive one. The exclusive approach involved setting aside specific times for exercises, treating them as distinct activities separate from daily routines. This method was often chosen by those who required more structured or focused exercise sessions due to their physical condition or personal preferences:

Yes, it's one more thing to do but at the same time, it only takes me fifteen minutes, so it's just a matter... I need to make my schedule and integrate it into that, I need to find the right time, that's the issue. It's always... even if it's only twice a week, maybe sometimes I do it, 3, 4 but let's say, twice a week, that works. I integrate it into the day. (P18, under the mean age)

Generally, I set up in a small room, a guest room, where I lay out my little mat, and because in addition to these exercises, I also do some planking and a bit of strength training every day. (...) For every day, for daily life, I do these little series of exercises. It's a ritual, actually. It's in the morning, I get up, I start with that and once it's done, I get dressed and go have breakfast and then take care of the rest of the day. It takes me about 20–25 minutes, tops, every day, it's nothing. (P16, under the mean age)

In contrast, the inclusive approach involved integrating exercises seamlessly into daily activities. For example, some participants performed exercises while engaged in other tasks, like household chores or personal routines, making the exercises a natural part of their day. P5, like P13, for instance, integrated exercises with routine tasks like brushing teeth or walking, which illustrated an adaptable and practical approach:

Primarily, I do that exercise because I had already incorporated it into my routine in the bathroom while brushing my teeth that way, I can lean on the sink if needed [...] it's an exercise I do regularly. I wouldn't say every day, but almost, while brushing my teeth. We all brush our teeth daily. Well, not necessarily three times a day, but at least in the morning, it's part of getting started, yes. (P5, above the mean age)

When I am in front of the.... to prepare the meal, when I have a few minutes to wait, I try to do them. I wait until the water boils, or I watch something start, I have the time. For example, I do this... this, with my daughter, we do the front foot, like this. (P13, under the mean age)

Furthermore, participant P12's perspective encapsulated the essence of the inclusive approach: "It must be a part of our life. Otherwise, it remains something artificial and something, a little bit, that we can do or choose not to do, do or not do." This statement underscored the importance of natural integration of exercises into daily life, rather than treating them as optional or separate tasks.

Obstacles and challenges in exercise implementation

Patients faced various obstacles that affected their ability to consistently engage with the exercises. Such obstacles included fatigue, fluctuating health conditions, psychological impact of facing physical limitations during exercises as well as personal life constraints which often hampered consistent practice:

Yes, and on the days, I work, it's complicated because I'm tired and then the exercises are harder to do. It's strange because the day before or two days before, I did them well except on the days I work when it becomes a bit chaotic. (P2, under the mean age)

Some days, I need to take breaks when I do the exercises. It varies from day to day, but also... I feel like it's becoming increasingly difficult to do all the exercises one after the other. I need to take breaks. [...] The hardest part for me is the mental aspect. It's an additional confrontation with the illness. [...] Because I must do exercises that are very simple for a normal person but are difficult for me. (P10, under the mean age)

Several patients highlighted the significant effort and energy required, particularly due to MS-related fatigue. As an illustration, P1 (under the mean age) viewed the exercises as beneficial yet demanding considerable energy: "Exercises, activities are beneficial for both sick people and those who are not (...) it's something that is really good but to do that, you have to fight, it takes a lot of energy." P18 also highlighted the substantial energy and effort needed to perform the exercises, with an emphasis on the necessity of managing daily energy levels. He said: "It's yet another thing that drains my energy. [...] I feel like I have a small quota of energy, and if I use it in the morning, I know I won't have it for the rest of the day. It's a choice. Either I do my exercises, but then I can't do anything else... it limits everything else even more than usual."

Difficulties in performing certain movements and maintaining postures were inherent due to balance issues, a common obstacle for individuals with MS. The complexity of exercise variants also constituted significant difficulty. Exercises performed with eyes closed, for example, were generally avoided as they were considered risky, heightening the fear of falling. Movements like turning the head, leaning forward and backward, twisting the torso, and lifting arms were described as extremely difficult by participants. Moreover, this complexity was further compounded by the occurrence of other health problems, adding to the difficulty in maintaining a consistent exercise routine.

Additionally, a lack of motivation and a sense of security were frequently cited as barriers. The sentiment was aptly summarized by P5, a 57-year-old participant on disability insurance, who stated, "It's very difficult to conduct a project like this alone." This highlighted the need for external support and motivation in managing an exercise regimen. Alongside these physical challenges, some participants also mentioned the psychological impact of facing their physical limitations during exercises, which underscored the importance of emotional support alongside physical treatment.

Overcoming difficulties and performing the exercises despite obstacles were real challenges for all the participants. They often needed to adjust exercises based on their daily condition, their specific capabilities and limitations, with some expressing the need to adapt exercises according to daily abilities. For example, P18 mentioned adapting exercises depending on the day's physical state, a sentiment echoed by others who tailored their routines to their energy levels and physical limitations. Other said:

If it's too simple, I make it complicated. If it's already complicated as it is, I stop there. (P18, under the mean age)

There are days when it goes better than others, and then, there is one body side that is better than the other (...) there are days that are more difficult than others. (P9, above the mean age)

It depends on the day. There are times when it goes better than others. (P6, above the mean age)

The patients' comments clearly reflected the fluctuating nature of MS and the variability of their perception of exercises performance. For instance, some found the exercises beneficial and manageable independently. P10 said: "I believe these are exercises to work the body, and they are good, and they are also exercises that I can do alone, without help, which is important because my husband works, and he can't help all the time."

Facilitators in exercises implementation

Our study identified several key facilitators that significantly influenced the implementation and adherence to home-based balance exercises among individuals with MS. These included personalized support, adaptability of exercises, and the involvement of each participant's physiotherapist. The presence and support of physiotherapists during regular sessions, in addition to the individual home balance exercise program, were universally valued, providing a sense of security and self-efficacy, particularly for exercises perceived as challenging or risky to perform alone at home. For example, P15 and P5 said:

For me, it's crucial to have someone to accompany us in doing this (understanding the exercises). In any case, for me, the day I can no longer do physiotherapy, I think I won't do it anymore. And I believe there is no other solution than to be... coached, stimulated. (P15, under the mean age)

I think that my physiotherapist... because he checks from time to time where I am at, thanks to my physiotherapist, I continue to do it [at home] and sometimes, he motivates me, he tells me: Ah no, these exercises, keep going! He has a stimulating aspect, and he gives me a framework. So, he motivates me. I think that doing it alone would have been difficult. (P5, above the mean age)

Patients appreciated the guidance, adaptation of exercises, and the reassurance provided by healthcare professionals. Specifically, patients reported that the information provided by physiotherapists, through both verbal explanations and physical demonstrations, was sufficient for understanding and executing the exercises at home (P18, P17, P14, P11, P10, P9, P8, P7, P6, P5). The use of illustrative cards and annotations by physiotherapists further enhanced understanding, especially for patients with memory difficulties (P16, P7). Crucially, the guidance and external support from physiotherapists provided were essential, particularly for patients who were new to exercise routines or lacked motivation (P16, P15, P7, P5). Several patients expressed that understanding the objectives of the exercises, such as improving balance and preventing falls, was motivating (P18, P17, P13, P10, P7, P2, P1). This understanding helped them set realistic goals, adapt the exercises, and monitor their progress subjectively. Equally important was the adaptability of exercises to the individual's capability level as a key facilitator (P16, P12). The flexibility to choose from multiple variants within each exercise ensured that the program could cater to a wide range of abilities and allowed for personalization based on individual progress and fluctuations in symptoms.

Perceived effects of the exercise program

Patients reported varied effects of the balance exercise program on their condition and quality of life. While some felt it was too early to judge the long-term impact, others noticed immediate physical benefits like improved stability and muscle strength:

Yes, of course, of course. The balance, it's something... you don't realize it but otherwise, you're always... I bump into things less. I don't have bruises on my shoulders because before, I would hit the edges of doors and things like that... Yes, so I think I fall better! I used to say I don't fall, but no, I don't feel like falling, these are the two things that happened to me, and it had been a long time since... (P17, under the mean age)

Yes. And then I notice that I hold myself better, I have more balance. [...] Because before I did not dare to stand for long. Exactly, now I feel that I am even better than the last time. I can stand longer and then I do more work, I notice that... (P14, above the mean age)

Psychological benefits were also reported, including enhanced self-efficacy and a sense of control over their illness. However, the effectiveness of the exercises was perceived differently among participants, with some noting significant improvements in their MS symptoms and others observing more subtle or gradual changes:

I feel like I do the exercises almost every day, and in the end, it doesn't help. (...) It's like medications; in the end, they don't help because there isn't a good medication. So, it's a lot of work for fewer benefits. (P10, under the mean age)

I do a lot of physiotherapy, and not only do I not feel any improvement, but I even feel like it's getting worse (...) Then again, maybe if I didn't do them [home exercises], there would be less, less, less. (P8, under the mean age)

No matter how much I do and redo every day; I don't feel like it's making things better. I feel like it's just preventing things from getting worse. It doesn't bring improvement. (P16, under the mean age)

The overall sentiment was that, despite challenges, the exercises provided a valuable tool in managing MS, offering both physical and psychological benefits. Knowing that the home exercise program's effectiveness varied, with some observing significant benefits while others saw more gradual changes, this variance underscored the personalized nature of MS and its management.

In summary, this study revealed the complexities and varied experiences of patients with MS engaging in a home-based balance exercise program. While generally perceived as beneficial, the effectiveness and integration of the exercises into daily life depended significantly on individual challenges or individual circumstances, the support system in place, and the personal strategies adopted by each patient.

Discussion

Key findings

This qualitative study explored the integration and patient engagement of balance home exercises in the daily management of MS. Our findings provide in-depth insights into the experiences and perspectives of 18 individuals with MS in French-speaking Switzerland. A significant finding was the necessity for adaptability and personalization of the exercise program. Patients highlighted the importance of tailoring exercises to their daily physical state and capabilities that may reflect the fluctuating nature of MS. This adaptability was crucial for the practical application, safety, and efficacy of the exercises. The involvement of each participant's physiotherapist emerged as a pivotal factor, as patients performed their exercise program independently at home while maintaining regular sessions with their physiotherapist for ongoing treatment. Patients valued the guidance, adaptation of exercises, and the reassurance provided by these professionals. The support from physiotherapists was not just instrumental in understanding and

executing the exercises but also in motivating the patients and enhancing their self-efficacy to perform exercises alone at home between their regular physiotherapy sessions. We observed diverse approaches to integrating exercises into daily routines. While some patients (e.g., P16, P18) preferred setting aside specific times (exclusive approach), others (e.g., P5, P13) incorporated exercises into their daily activities (inclusive approach). This variation underlines the importance of flexibility in exercise regimen to accommodate individual lifestyles and preferences. Participants faced various challenges in consistently engaging with the exercises. Fatigue, fluctuating health conditions, and personal life constraints were commonly reported barriers. The complexity of exercises, especially those perceived as risky, and the psychological impact of confronting physical limitations were also significant obstacles. Patients reported mixed effects of the balance exercise program on their condition and quality of life. While some (e.g., P17, P14) experienced immediate physical benefits such as improved stability and muscle strength, others (e.g., P10, P8) noted the subtler or more gradual impact of the exercises. The psychological benefits, including enhanced self-efficacy and a sense of control over their illness, were also noteworthy. The effectiveness of the program varied among participants, underscoring the personalized nature of MS and its management. Some participants (e.g., P17, P14) noted significant improvements, while others (e.g., P10, P8) observed lesser or no benefits, a reflection of the complex interplay between the exercise program and individual patient factors.

Interpretation and contextualization

Patients' responses to the exercise program varied, which could be indicative of the diverse nature of MS. Notably, despite the varied approaches and individual challenges faced, no significant safety concerns were reported by the participants. This may highlight its effective and safe adaptation to a range of individual conditions. Many recognized the benefits but also underscored the challenges, especially in adapting exercises to their fluctuating symptoms. The adaptability aligns with previous studies by Asano et al. (2013) and Kim et al. (2023) that emphasized the need for exercises to be flexible to accommodate the unpredictable nature of MS [16, 17]. The frequency and approach to the exercise program were highly individualized (from multiple times a day to a complete irregular rhythm). This variability in exercise frequency and approach echoes the findings of Halabchi et al. (2017), who also highlighted the importance of individualizing exercise regimens for patients with MS [18]. Patients' strategies for incorporating exercises into their daily routines also varied between exclusive (separating exercises from other daily activities) and inclusive (blending exercises into daily activities) approaches. These strategies for integrating exercises in daily life, as observed in our study, provide a nuanced perspective, complementing the insights from Halabchi et al. (2017) [18]. Furthermore, our findings align with a recent meta-analysis by Salari et al. (2022), which underscored that exercise has a positive effect on balance in improving the condition of patients with MS [19]. The presence of facilitators (the guidance and adaptation provided by physiotherapists), and obstacles (the fatigue and fluctuating health conditions) played a significant role in patients' engagement with the home exercise program. This is consistent with Ricke et al. (2023), who found that tailored guidance and understanding personal barriers are crucial for effective home-based exercise programs in patients with chronic diseases [20]. In addition, the psychological impact of facing physical limitations during exercises also emerged as a significant obstacle as in Mortensen et al. (2017) [21].

In our qualitative study, the narratives from participants revealed a strong appreciation for the use of illustrated cards in understanding balance exercises, highlighting the value of visual aids alongside textual explanations. This finding aligns with Learmonth et al. (2017), who emphasized the effectiveness of visual aids in enhancing understanding of exercise regimens in MS [22]. This finding emphasizes the need for clear, intuitive, and accessible instructional methods in home-based exercise programs, as recognized by our participants who often faced challenges in remembering and executing complex exercises due to MS symptoms.

Additionally, the role of physiotherapists emerged as critical in the narratives emphasizing the need for personalized guidance and demonstrations. This personalization was found not only to enhance exercises understanding but also to significantly boost self-efficacy and motivation among patients, mirroring the observations in Mortensen et al. (2017) about the role of health professionals in enhancing treatment adherence through personalized support, which are key factors in treatment adherence [21]. In a recent study with tele-exercises for adults with MS, the absence of real-time professional guidance in the home setting was noted by the participants as a limitation impacting the effectiveness and safety of exercises [16]. Our results are also in line with those of Learmonth et al. (2017), who identified that individuals with MS prefer to receive exercise information through personal interactions with healthcare providers and in formats that are easily understandable [22]. Like our study, their research emphasized the value of healthcare professionals, particularly neurologists and physiotherapists, in providing tailored exercise advice for home exercise programs. This aligns with our findings that underscored the significance of physiotherapists in offering personalized guidance and demonstrations, which not only improve understanding but also enhance motivation and self-efficacy in patients with MS. Moreover, their study supports our observation that visual aids, like illustrated cards, were beneficial in conveying exercise information clearly and effectively, thereby aiding in the management of MS symptoms and treatment adherence [22].

While our study primarily gathered data through semi-structured interviews, offering rich narrative insights, the importance of patient perspectives in managing MS also resonates with the findings of Heesen et al. (2023) [23]. The personal accounts from our study participants echoed the themes in Heesen et al.'s work, particularly in highlighting the significance of patient empowerment and tailored approaches in MS management. Their systematic review, focusing on digital health applications, also highlighted the potential benefits of such interventions, particularly for younger patients with less severe disabilities. However, our study participants' experiences suggested that even with digital advancements, the human element in therapy, such as the empathetic presence of a physiotherapist during regular sessions, providing an opportunity to ask questions about the home exercises or to receive motivation to continue doing them, remains irreplaceable [23]. This aligns with our study's emphasis on user-friendly and tailored approaches, albeit in a non-digital context. This parallel between our study's emphasis on accessible, user-friendly exercise programs and the digital health applications highlighted by Heesen et al. suggests that effective MS management strategies, regardless of their format, must prioritize patient engagement and tailored approaches [23]. While several mobile, self-guided digital health applications for individuals with MS have been tested (including interventions for messaging, depression, fatigue, cognition, mobility, spasticity, and physical activity) and have demonstrated their utility, challenges remain in integrating them into routine care [23]. Specifically, Nasser et al. (2020) found that

while providing information through a multimedia smartphone app did not significantly increase physical activity compared to a leaflet, app users tended to show higher motivation toward an active lifestyle. Overall, participants highly appreciated the concept of using a smartphone app to support an active lifestyle in MS [24]. Furthermore, Wendrich et al. (2019), in a qualitative study focused on MS, suggested that for digital tools to be effective, they should be adaptable to the patient's situation, help interpret self-monitoring data, and be integrated into clinical care [25].

Building on these insights, an important aspect to consider in the context of MS management is treatment adherence. Our study participants often shared that adherence to exercise routines was influenced not just by physical ability but also by mental and emotional factors, such as mood and daily motivation levels. Adherence to prescribed treatment regimens, including exercise programs, is a complex issue influenced by a multitude of factors, some of which are deeply rooted in human nature [26]. The narratives from our study highlighted that these factors could vary significantly from day to day for a person with MS, pointing to the need for adaptable and responsive exercise programs. Challenges in adherence can stem from psychological barriers, physical limitations, lifestyle constraints, and even the perceived efficacy of the treatment. Understanding and addressing these factors is essential for the success of any therapeutic program [26]. In addition to these factors, social cognitive theories like locus of control and self-efficacy play a significant role in treatment adherence. Patients with an internal locus of control, who believe they have control over their health outcomes, and high self-efficacy, confident in their ability to manage their treatment, are more likely to adhere to prescribed regimens. This highlights the need for interventions that specifically aim to enhance patients' self-belief and perceived control in their treatment process, especially in the ongoing management of chronic diseases such as MS [26]. In this context, frameworks like the Behavior Change Wheel (BCW) are recommended to guide the development of interventions that promote adherence and behavior change in people with MS [27, 28].

Several other studies have delved into the nuances of treatment adherence since it is critical to understand the nature, causes, and consequences of non-adherence to treatment, particularly in the context of chronic disease management such as MS. Treatment adherence is a behavioral process influenced by a complex interplay of factors, including patient attributes, the patient's environment such as social support, the healthcare system, and the characteristics of the disease itself [26]. Exercises, being a form of lifestyle modification, can be extraordinarily difficult for patients to both carry out and maintain, leading to notably poor treatment adherence rates. In individuals with MS, adherence to home-based exercise programs is influenced significantly by exercise self-efficacy and fatigue, as demonstrated in a recent study by Almarwani and Alosaimi [29]. Their research underlined the importance of addressing these factors in the design of exercise regimens, to not only enhance adherence but also to improve functional outcomes in MS patients. Hence, enhancing patients' self-efficacy in their ability to exercise and providing strategies to manage fatigue could be crucial steps in improving adherence to home-based exercise programs [29]. Moreover, a meta-analysis included 31 articles with a total sample of 1434 participants revealed a significant reduction in fatigue symptoms in patients with MS who engaged in physical exercise and strongly recommended the inclusion of regular exercise to alleviate fatigue symptoms in MS [30].

Healthcare providers should actively engage with patients to discuss any lapses in adhering (nonadherence) to their treatment

plans. For example, asking, “Many people have difficulty finding time for exercise. During the past week, how much physical activity have you managed?” can open up as conversation about adherence challenges. Moreover, adherence rates for treatments involving lifestyle modifications, such as exercise, diet, and smoking cessation, tend to be significantly lower, with patients often finding it more difficult to maintain changes in diet and exercise than to adhere to medication prescriptions [26]. This reiterates the importance of a holistic approach to treatment adherence, considering the various dimensions of patient care, individual disease characteristics and symptoms as well as the needs, abilities, and preferences of people with MS [31].

Finally, individuals with MS typically exhibit lower physical activity levels compared to unaffected controls. Lower physical activity in MS is associated with greater disability and poorer clinical outcomes [31]. Enhanced physical activity through such programs could improve these aspects [32]. The challenge of adhering to recommended activity levels for these patients further emphasizes the need for exercise routines that are both realistic and achievable as well as the need for tailored home-based exercise programs [33]. Our study contributes to responding to a need expressed by people with MS in previous studies to obtain supporting materials for home exercises, as well as emphasizing the promotion of exercise *via* the patient-clinician interaction [32].

Limitations of the study

The study, while offering valuable insights, has several limitations. The limitations of this study are primarily centered around its geographic scope, focusing on French-speaking Switzerland. This specific regional focus might impact the broader applicability of the findings to other populations or settings. While the sample size was adequate for achieving data saturation in a qualitative study, it is the geographic concentration that more significantly constrains the transferability of the results. Furthermore, the absence of long-term follow-up hindered the ability to assess sustained effects of the balance exercises. The study's exclusive emphasis on balance exercises might not capture the full spectrum of physical activities beneficial to patients with MS, thus limiting its scope in addressing the diversity of physical needs in MS management. Finally, as is typical of qualitative study, no quantitative data were collected, limiting generalization to the broader population.

Implications for practice

The program of 19 balance exercises, developed by Sattelmayer et al. [9], is suitable for home practice by patients with MS, recognized for its safety and adaptability, and may be recommended. These exercises, effective in maintaining or enhancing balance, benefit from the inclusion of visual aids to assist recall and adherence. Continuous motivation and support from a healthcare professional, such as a physiotherapist, are essential. Regular discussions about the exercises performed and planned between physiotherapy sessions can significantly motivate patients and encourage adherence.

Future research directions

Future research on home-based exercise programs for MS should integrate concepts like empowerment, self-monitoring, auto-determination, and self-management. These aspects can play

a significant role in enhancing patient engagement and personalizing their treatment regimen. Future studies would benefit from longitudinal designs with extended follow-up periods and larger sample sizes to obtain a more in-depth understanding of these interventions. Additionally, adopting mixed-methods research could provide valuable insights into the efficacy of these programs and strategies to enhance adherence to home-based exercises.

Acknowledgments

The authors would like to thank all participants for their time and cooperation, as well as the physiotherapists who introduced the study to their patients.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The study was supported in part by a grant from the University of Applied Sciences and Arts Western Switzerland (HES-SO) (Scientific Commission of Health_Sagex_106222).

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