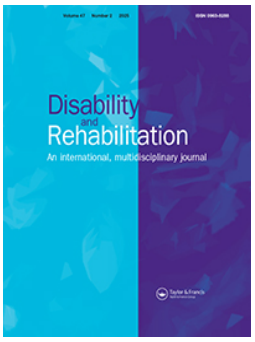

Disability and Rehabilitation

ISSN: 0963-8288 (Print) 1464-5165 (Online) Journal homepage: www.tandfonline.com/journals/idre20

Preventing falls in multiple sclerosis: a qualitative study on user requirements for a self-management programme

Ulrika Meijer, Maria Flink, Susanna Tuvemo Johnson, Marie Kierkegaard, Kristina Gottberg & Charlotte Ytterberg

To cite this article: Ulrika Meijer, Maria Flink, Susanna Tuvemo Johnson, Marie Kierkegaard, Kristina Gottberg & Charlotte Ytterberg (2025) Preventing falls in multiple sclerosis: a qualitative study on user requirements for a self-management programme, Disability and Rehabilitation, 47:2, 398-405, DOI: 10.1080/09638288.2024.2348725

To link to this article: https://doi.org/10.1080/09638288.2024.2348725

© 2024 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

Published online: 07 May 2024.

Submit your article to this journal

Article views: 1680

View related articles

View Crossmark data

Citing articles: 4 View citing articles

Full Terms & Conditions of access and use can be found at
https://www.tandfonline.com/action/journalInformation?journalCode=idre20

DISABILITY AND REHABILITATION
2025, VOL. 47, NO. 2, 398–405
https://doi.org/10.1080/09638288.2024.2348725

Taylor & Francis
Taylor & Francis Group

RESEARCH ARTICLE

OPEN ACCESS

Check for updates

Preventing falls in multiple sclerosis: a qualitative study on user requirements for a self-management programme

Ulrika Meijer[a], Maria Flink[a], Susanna Tuvemo Johnson[a,b], Marie Kierkegaard[a,c], Kristina Gottberg[a] and Charlotte Ytterberg[a,d]

[a]Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Huddinge, Sweden; [b]Department of Women's and children's health, Uppsala University, Uppsala, Sweden; [c]Academic Specialist Center, Center of Neurology, Stockholm Health Services, Stockholm, Sweden; [d]Women's Health and Allied Health Professionals Theme, Karolinska University Hospital, Stockholm, Sweden

ABSTRACT

Purpose: To explore perspectives of ambulatory and non-ambulatory people with MS (PwMS) and health care professionals (HCPs) on falls and falls management to gain a deeper understanding of how a self-management programme can be designed to fit the needs of end users.

Materials and methods: Twelve PwMS and seven HCPs participated in three four-hour workshops based on Design Thinking. Collected data were field notes and digital post-it notes gathered at the workshops. Data were analyzed using qualitative content analysis with an inductive approach.

Results: Two main categories, "Managing the complexity of fall-risk behaviour" and "Embracing diversity to establish group engagement", comprising a total of seven categories were constructed from the analysis. The first main category reflects the challenges PwMS face in managing fall risk in their daily lives, and the support needed to address these challenges. The second main category highlights how engaging in peer learning activities can fulfil individual needs and improve learning outcomes for PwMS.

Conclusion: A self-management fall prevention programme that is relevant to PwMS regardless of ambulation level should include the development of self-tailored behavioural strategies to prevent falls along with interactive learning activities with other PwMS.

ARTICLE HISTORY
Received 7 July 2023
Revised 20 April 2024
Accepted 24 April 2024

KEYWORDS
Multiple sclerosis; health care professionals; fall prevention; self-management; user requirements; co-design; qualitative content analysis

IMPLICATIONS FOR REHABILITATION

- A self-management fall prevention programme should be customized to individual fall prevention needs and circumstances in daily life.
- A self-management fall prevention programme conducted online can enable accessibility for ambulatory and non-ambulatory people with multiple sclerosis (PwMS).
- Peer learning in groups with other PwMS can facilitate the development of self-tailored fall prevention strategies and provide positive reinforcement to support behavioral change.

Introduction

Managing the risk of falls can cause considerable limitations in daily life for people with multiple sclerosis (PwMS). Falls are common in multiple sclerosis (MS), with approximately 71% of PwMS experiencing one or more falls within six months [1]. In addition, the consequences of falls can be severe, as PwMS are more susceptible to fall-related injuries than the general population [2–4] and fear of falling can lead to activity curtailment and have a negative impact on the well-being of PwMS [5,6].

Due to varying symptoms and disease severity, PwMS have a range of fall risk factors. Further, the unpredictable nature of MS symptoms and their fluctuation over time aggravate the challenges of managing fall risk in daily life. As the disease progresses it often impairs gait function, rendering approximately 25% of PwMS non-ambulatory (unable to ambulate functional distances in their home) [7]. While using mobility aids such as wheelchairs or scooters may provide safer mobility and reduce concerns about falling [6], non-ambulatory PwMS remain at a high risk of injurious falls. Unique and modifiable fall risk factors have been identified for non-ambulatory PwMS [8], and the circumstances surrounding their falls differ from those of ambulatory PwMS [9]. Hence, fall prevention needs may vary between ambulatory and non-ambulatory PwMS, implying a need to assess fall prevention requirements for both groups.

Despite falls being a major concern for PwMS, few fall prevention interventions are designed explicitly for PwMS. Additionally, most of the existing interventions have a primary focus on exercise and often exclude non-ambulatory PwMS [10]. As our understanding of the complex interactions between diverse fall risk factors in MS increases, multifactorial interventions that in addition to exercise also address psychological and behavioural fall risk factors have been highlighted as a priority [10,11].

Supporting PwMS on how to self-manage their fall risk has been suggested as a sustainable approach to fall prevention [11]. Self-management is defined by Barlow et al. [12] as, "The individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living

CONTACT Ulrika Meijer ulrika.meijer@ki.se Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Alfred Nobels allé 23, Huddinge 141 83, Sweden

© 2024 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group
This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

with chronic conditions." The self-management practice has a solid evidence base for improving quality of life and reducing healthcare utilization in the treatment of chronic disease [13]. Yet, research on self-management interventions for fall prevention in MS is still in its infancy. A recent scoping review of self-management-based fall prevention interventions for PwMS [14] showed promising results regarding improved self-efficacy and reduced fall incidence. However, the interventions primarily targeted ambulatory PwMS. The varied approaches to self-management applied in these interventions make it challenging to identify intervention content that effectively supports self-management of falls in both ambulatory and non-ambulatory PwMS.

Both ambulatory and non-ambulatory PwMS may benefit from fall prevention interventions that employ self-management strategies and address multifactorial fall risk factors. Therefore, we aimed to develop a comprehensive self-management fall prevention programme for ambulatory and non-ambulatory PwMS. It is essential to include the perspectives of both PwMS and health care professionals (HCPs) in intervention development to ensure relevance to end users [15]. However, to our knowledge, only two published studies have incorporated the views of PwMS when creating fall prevention interventions. A study by Kesgin et al. [16] investigated PwMS' perspectives on an exercise-based fall prevention programme, although all PwMS in this study were ambulatory, and no HCPs were included. Another study by Comber et al. [17] included clinician interviews with physiotherapists and occupational therapists, while PwMS completed a survey on the causes and context of falls and preferences regarding intervention content and structure.

Thus, the aim of this study was to explore perspectives of ambulatory and non-ambulatory PwMS and HCPs on falls and falls management to gain a deeper understanding of how a self-management programme can be designed to fit the needs of the end users.

Material and methods

Design and data collection

This qualitative study was based on an iterative co-production process [18] that incorporated experiences from PwMS and HCPs working in MS care and rehabilitation. Three structured workshops were held in December 2020 *via* a video platform (Zoom video Communication). The workshops were led by a facilitator and were based on the concept of Design Thinking [19,20]. Design Thinking is a creative participatory process that includes five steps: Empathize, Define, Ideate, Prototype and Test, whereof the first three were applied in the workshops. Each workshop lasted four hours and included two 15-min breaks. After initial planning meetings of the research group, a facilitator (innovation manager) and three research team members (CY, MF, STJ) participated in a preparatory meeting to plan for three workshops. In the three workshops, the facilitator and research team members collaborated with PwMS (workshops 1 and 3) and HCPs (workshop 2). The main topics addressed in these workshops were:

> Regarding a self-management programme to prevent falls in MS, what are your thoughts and ideas about programme content, programme format, and maintenance of behaviour obtained through the programme?

The PwMS discussed the topics based on their experience of falls and having MS; and the HCPs based on their professional experience of falls, MS care and MS rehabilitation.

In a final meeting, the research team members and the facilitator summarized the findings from the workshops.

The data collected were field notes, and digital post-it notes gathered at the workshops. Two researchers (CY and MF) took field notes during the workshops while the facilitator used a digital whiteboard to write, sort, and display the post-it notes from the participants. The digital whiteboards for each workshop were saved as screenshots. The post-it notes were often shorter statements, while the field notes were more detailed in descriptions.

Participants

Criteria for participating PwMS were community-dwelling; aged ≥ 18 years, able to understand and communicate in Swedish; able to use and access technical devices for online meetings. Criteria for participating HCPs were professional experience of MS from various health care occupations. Both PwMS and HCPs were recruited *via* convenience sampling. The PwMS were recruited through Neuro Sweden, a national patient organization, and the research team's networks. In total, 12 PwMS (10 women, two men) with an age span of 36–71 years (median 56 years) and 2-–24 years since diagnosis (median 13.5 years) agreed to participate in workshop 1 or 3, all with experience of falls or near falls. The PwMS were diverse with regard to place of residence in Sweden, age, disease severity and time since diagnosis. Eight of the PwMS were ambulatory and four were non-ambulatory. The HCPs were recruited through the research team's networks to represent a diversity of expertise in MS care and rehabilitation. One MS nurse, two physiotherapists, one assistant nurse, two occupational therapists, and one social worker with 9-24 years (median 14 years) of experience in MS care and rehabilitation participated in workshop 2. All participants gave oral and written consent. In the recruitment of both PwMS and HCPs, all participants received information of the length of the workshop and that no reimbursement was provided.

Data analysis

The unit of analysis was the data collected in the workshops on PwMS experience of falls and having MS and of HCPs professional experience of falls, MS care and MS rehabilitation. This data were analyzed using qualitative content analysis [21] with an inductive approach. Initially, the field notes and post-it notes from each workshop were read multiple times to gain an overall understanding. The notes were then organized by the topics discussed during the workshops. Next, all post-it notes and field notes were assigned codes to describe their relevance to the study aim. Due to the variation in detail and depth in the collected data, a latent approach to text interpretation was used cautiously, and codes did not deviate significantly from the text. One researcher (UM) began coding data from workshop 1. The coding procedure was further discussed with research team members and an agreement was reached on how to perform the coding before proceeding with coding the total amount of data. Next, the codes derived from all three workshops were combined and reorganized into groups based on identified patterns among the codes. Research team members met several times to discuss the iterative process of organizing the codes and to reflect on any underlying meaning in each set of codes that would define a category and how these categories were related. The researchers who participated in all three workshops concurred that the data interpretations accurately reflected the discussions held during the workshops. Finally, a consensus was reached on the seven categories and two main categories were constructed from the data analysis.

Ethical considerations

Ethical approval was obtained from the Swedish Ethical Review Authority (Dnr 2019-06030).

Results

Two main categories, "Managing the complexity of fall-risk behaviour" and "Embracing diversity to establish group engagement" were constructed. The first main category reflects the challenges PwMS face in managing fall risk in their daily lives, and the support needed to address these challenges in a fall prevention programme. The second main category highlights how engaging in peer learning activities in a fall prevention programme may fulfil individual needs and improve learning outcomes for PwMS. An overview of the abstraction process is presented in Table 1.

Managing the complexity of fall-risk behaviour

This main category reflects the challenges PwMS face in managing fall risk in their daily lives, and the support needed to address these challenges, as described by PwMS and HCPs. It comprises complex aspects of fall prevention that need to be addressed in the content of a self-management programme such as becoming aware of fall risks, accepting the need for adjustments, and using available resources to become more self-sufficient in managing these risks.

Awareness of the ever-present risk of falling

Previous experiences of falls and fall prevention generated a range of insights among PwMS about how to manage fall risks. For instance, some PwMS viewed falls as an inevitable part of daily life, yet the constant awareness of the potential for falls could cause fear and distress. In contrast, HCPs believed that PwMS might normalize and trivialize falls as a coping strategy for their well-being as the limitations imposed by the disease were not possible to address. This normalization of falls could make it challenging to address fall prevention.

> When falling becomes an everyday occurrence, it becomes less of an event. You can also feel the seriousness of the situation can be difficult to process. Making sure you have a margin to have the energy to cope can often be perceived as tedious and you can't behave spontaneously. (HCP ID 13, <median years of experience in providing care)

The diversity of fall risk factors was emphasized in many discussions, with environmental, social, and individual factors all believed to influence fall-risk behaviours. Environmental factors, stress, and lack of focus while performing tasks were frequently mentioned as modifiable risk factors. However, some factors, such as impaired body functions, were described by PwMS as being beyond their control. While PwMS reported using various fall prevention strategies, there were instances where these strategies were not employed despite an evident risk of falling. The constant need to plan transfers to assess fall risks was described as exhausting, making it difficult to avoid even predictable falls due to lack of energy.

Table 1. Abstraction process.

Main categories	Categories
Managing the complexity of fall-risk behaviour	Awareness of the ever-present risk of falling Accepting the need for fall prevention Finding a balance between wants and needs The ambiguity of fall prevention aid utilization Taking responsibility is key to self-managing falls
Embracing diversity to establish group engagement	Peer learning as an inspiration for behavioural change Adaptability and accessibility to meet diverse needs

> For example, when you are moving about it helps to have good shoes, but sometimes you can't be bothered fetching your shoes when you are going to move about, or to put a towel on the floor after you have showered. (PwMS ID 1, <median age, >median years since diagnosis)

> At first you are a little scared, then you can almost become angry at yourself about how stupid you can be when you know you should take things more gently. (PwMS ID 2, median age, >median years since diagnosis)

Accepting the need for fall prevention

The HCPs described it as a process for PwMS to become aware of fall risks. This process was linked to the acceptance of the disease and involved gaining insights from adjustments made to cope with its impacts. The process also involved learning to recognize the fluctuating and varied symptoms of MS and understanding how they affect different abilities. However, this transition into a new way of life, where disease-related symptoms must be taken into account, was not always straightforward. In addition, the realization that changes must be made could involve a process of grieving.

> "Solutions" are often quite simple but getting there can be difficult. We work a lot with resistance, feelings of shame and identity. It takes time and is built on mutual cooperation and trust – that the person often realises they are trying to make a change they don't want to happen. Then there is a process of grieving in parallel, but there is often relief afterwards. (HCP ID 17, median years of experience in providing care)

Embracing a new identity as an individual living with a chronic disease like MS was described as essential for managing fall risk. Holding on to the past and ignoring fall prevention needs was seen as an obstacle to finding new ways to live life to the fullest. Likewise, accepting MS-related needs without giving in to feelings of despair was considered crucial for fall prevention. Grief was acknowledged as a normal reaction in the acceptance process, but it was emphasized that acceptance did not mean resignation, and MS did not define one's entire identity. Some PwMS stressed the importance of accepting life as it is now, rather than looking back and comparing it to life before the MS diagnosis.

> It is important to focus on what you can do and not only on what you can't do anymore. At the same time, it has to be okay to feel sad over what you have lost and can't do anymore. You do feel down sometimes and that is just how it is. Sometimes you can feel like a snail when everyone else is travelling at motorway speeds. Sometimes you feel defiant and want to be able to do everything, but pure willpower doesn't make your legs move. (PwMS ID 5, >median age, >median years since diagnosis)

Accepting help from others was described as causing mixed feelings. The PwMS recognized the benefits of being open about their diagnosis and communicating their fall prevention needs to others, but this often required courage. The PwMS had experienced that people in their surroundings were often willing to help, but asking for assistance conflicted with the wish to be self-sufficient, particularly in a society that values independence.

> We live in a society and culture that puts an emphasis on independence. Asking for help is something that we perhaps do not do so automatically in our culture. To get to a point where you feel it is okay to ask for help. (PwMS ID 8, >median age, <median years since diagnosis)

Finding a balance between wants and needs

Not knowing when to engage in demanding activities and when to constrain due to MS was believed to cause falls among PwMS. Falls could occur when PwMS pushed themselves beyond safe limits by ignoring their MS-related needs.

> You have to test your limits so you can continue to develop, or not lose your abilities, but you have to know what your limits are so that you don't go beyond them. You have to know when you can test your limits and when you can't. It is a balancing act to challenge yourself but not push yourself too far. (PwMS ID 1, <median age, >median years since diagnosis)

Managing fatigue was identified as a significant challenge for PwMS. Determining how much rest was needed to function optimally and coping with energy loss was often problematic. Finding ways to conserve energy was crucial for avoiding falls, but this sometimes meant refraining from desired activities. The PwMS described being aware of the need for rest and recovery and the increased risk of falls if fatigue was not considered. However, allowing oneself time to rest was not always easy.

> I usually call it catch-up time. You are not being lazy just because you need recovery time. You need to have a word with yourself and decide how much recovery time did I need before and how much do I need now? (PwMS ID 8, >median age, <median years since diagnosis)

Stress management techniques were considered effective in reducing fall-risk behaviours. It was recognized that people under stress are more likely to neglect fall-prevention strategies and make poor decisions. Both PwMS and HCPs identified internal and external stress factors that could provoke fall-risk behaviours. For instance, wanting to keep up with societal expectations and the pace the person was used to before the MS diagnosis, were mentioned as internal stress factors that could be challenging to address. An example of an external stress factor is being surrounded by people who place high demands on the individual, and to cope with this PwMS considered it important to stand up for oneself and set boundaries. Stress management strategies were highlighted, such as practicing mindfulness or yoga, and careful planning of activities was seen as a necessary approach by both PwMS and HCPs.

> Stress is an important aspect. There are different types of stress and sometimes society contributes to you pressing yourself too hard. There can be financial stresses that mean you work too much. It can be about talking about control and what you can do, but then not being able to do it. (HCP ID 17, median years of experience in providing care)

The ambiguity of fall prevention aid utilization

Both PwMS and HCPs stated that assessing individual fall prevention needs and creating an inventory of available fall preventive aids (such as mobility and technical aids) are critical issues in a fall prevention programme. Some of the PwMS reported that information about fall prevention aids was given too late, and as PwMS could not foresee their future needs, they did not know what to ask from healthcare services. Not being provided appropriate aids could result in pushing oneself too hard when faced with an overwhelming situation. The PwMS also wanted more support when transitioning to using walking aids, including emotional support and practical demonstrations on using specific aids.

> People can need help with the mental aspects, support, it is not a problem. It has helped me to have this aid. My children and their friends think my electric moped is cool, they come running to have me toot my horn for them, they have always been on board and been allowed to try it. (PwMS ID 10, <median age, <median years since diagnosis)

The HCPs considered it crucial to discuss fall prevention aids with PwMS, as the risk of falling was believed to be greatest among PwMS who were not using aids. The decision of when to begin using an aid was seen as a delicate matter, and HCPs stated the need for sensitivity when addressing this topic. They described it as a process for PwMS to accept a new situation where disease progression necessitates using walking aids. The HCPs felt they needed to be mindful of when to raise this issue and allow PwMS to come to terms with the benefits of using aids.

> Some find it demeaning to need to accept walking aids. They fight against this, especially if they are younger, when a walking frame is not such a fashionable look (HCP ID 19, <median years of experience in providing care)

The PwMS recognized ambiguity about using fall prevention aids – for example, one individual described deliberately delaying the use of a walking aid despite needing it. In addition, fear of losing abilities due to inactivity and concern about the opinions of others were mentioned as reasons for not wanting to rely on fall prevention aids. However, once the decision to use a walking aid was made, it was described as a relief. Using walking aids enabled PwMS to participate in more activities and reduced the impact of the disease on their daily lives.

> My daughter was a teenager when I started to need crutches – at that time we enjoyed going on shopping trips. When I eventually got a wheelchair we were able to start going on shopping trips again. We didn't need to be in and out quickly – we could spend hours at a time. (PwMS ID 1, <median age, >median years since diagnosis)

Taking responsibility is key to self-managing falls

The HCPs emphasized that healthcare services aim to support PwMS in managing their fall prevention needs as independently as possible. However, healthcare services are not available around the clock, and PwMS must navigate everyday fall-risk situations on their own. Building self-efficacy and developing self-management skills were seen by HCPs and PwMS alike as vital for preventing and managing falls. Therefore, HCPs considered it crucial for PwMS to set their own fall prevention goals and take responsibility for achieving them.

> Try to instill in the patients that it is they themselves who take control and are responsible for the changes and goal setting. There needs to be an understanding from the family, and the workplace, but it is not their responsibility. (HCP ID 15, >median years of experience in providing care)

Some PwMS expressed that managing their healthcare contacts could be challenging but necessary. They felt they had to take on the role of project manager to ensure that their needs were not overlooked. Some PwMS described healthcare services as being too passive and not providing sufficient support for fall prevention. They also stated that relying solely on healthcare was not enough and that social media had become a valuable source of information outside the healthcare system.

> The healthcare services are often passive, you have to take the initiative yourself to ask about things such as aids. Facebook groups are a good source of information and tips about what is available. (PwMS ID 1, <median age, >median years since diagnosis)

Embracing diversity to establish group engagement

This main category highlights the need for an intervention format that stimulates engagement in peer learning activities to fulfil individual needs and improve learning outcomes; and is designed for participants with diverse symptoms but with a shared understanding of living with MS.

Peer learning as an inspiration for behavioural change

Both PwMS and HCPs found meeting and discussing fall prevention in a group setting highly beneficial. While the group format may not suit everyone, it was generally seen as favourable. Meeting with peers provided a sense of belonging that could encourage the sharing of personal experiences and support. Hearing good examples from peers on how to deal with fall risk could be inspirational. Working through problems with support from the group could reinforce that one is not alone and thereby boost self-esteem. Positive influences from the group could also motivate the participants to pursue the programme.

> Experiencing the feeling that "I am not alone," means such a lot. (PwMS ID 11, >median age, >median years since diagnosis)

The HCPs agreed that advice from peers is often more well-received than advice given by HCPs, which might come across as harsh or impersonal, particularly when it involves behavioural change. The mutual understanding and shared experiences among peers make it easier to determine if the advice given is helpful.

> I believe in group rehabilitation. There is a big difference in hearing people with MS explain things to each other and share tips than when the information comes from healthcare. There is a clash between logic and emotions. It is not a matter of "just keep exercising." (HCP ID 17, median years of experience in providing care)

The HCPs expressed concern about the composition of the group, fearing that meeting people with more severe MS symptoms could cause distress and anxiety about the future for those less affected by the disease. However, this concern was not shared by PwMS, who mentioned personal chemistry, age, and life situation as more important factors for connecting with others than the level of disease progression.

> There shouldn't be too great a variation span. Some are scared of being with people who are very ill, they don't want to identify with that disease group. There should be some variation span, but not too wide a difference. (HCP ID19, <median years of experience in providing care)

> I believe that a mixed group is best, as everyone is different and it is personal chemistry that is the most important thing. It doesn't matter if you are in a wheelchair or are able to walk, as there are other factors that are more important. (PwMS ID 4, >median age, <median years since diagnosis)

It was not considered necessary that the facilitator of the sessions would be a peer. Instead, having broad knowledge about MS was seen as more important than personal experience with the disease. The involvement of next of kin in the programme was also discussed. HCPs noted that the opinions of next of kin could influence fall risk behaviour and potentially compromise fall prevention measures. However, PwMS expressed that they wanted to have the programme for themselves and not burden their next of kin. While acknowledging that next of kin could also need support, the fall prevention programme might not be the appropriate forum for this.

> When it comes to relatives, I am a bit sceptical. This is our thing. It is good they are included, but not too often. These are our lives. (PwMS ID 2, median age, >median years since diagnosis)

Adaptability and accessibility to meet diverse needs

There were various opinions on the content and format of the fall prevention programme to optimize learning outcomes for both the group and individuals. The PwMS wanted the programme to address common fall prevention needs while being adaptable to individual circumstances.

> To have a success factor it is essential to have flexibility – to meet individual needs and balance these with the needs of the group. (PwMS ID 9, >median age, >median years since diagnosis)

Both HCPs and PwMS agreed on the importance of addressing the physical and mental aspects of fall prevention, but there were different suggestions on what core content to include in the programme. While some suggested emphasizing balance training, physical exercises, or learning how to fall safely, others pointed out that these types of exercise may not be suitable for everyone. Balance training was considered a crucial aspect of fall prevention, but it was also mentioned that this must be performed regularly. The PwMS stressed that fall prevention exercises should be done at home rather than at the gym. They wanted to learn how to manage fall risk while performing everyday activities in the setting where most falls occur.

> It is all about balance in daily activities. Having the situations where you have difficulty with your balance as the starting point. (PwMS ID 10, >median age, >median years since diagnosis)

The PwMS expressed wanting support in developing and maintaining fall prevention strategies tailored to individual needs and easily incorporated into everyday life, as no single solution would fit everyone. This would include identifying fall risk situations in familiar and new settings and evaluating how to handle them. The HCPs mentioned goal setting to enhance motivation and support behavioural change.

> How to set goals, change habits, and achieve continuity so that you can take responsibility for yourself. I think it is good to set goals and work independently with the goals. It is good if these can be sustainable so that you can continue the same way yourself. (HCP ID 14, <median years of experience in providing care)

Since PwMS often experience varying levels of fatigue, the programme should not compromise the need for rest and recovery. Delivering the programme in a digital format, rather than in-person meetings, was seen as facilitating learning by eliminating the need for energy-consuming travel and making the programme accessible. However, the limitations of a digital format were also mentioned. One concern was that people without the necessary technological equipment or skills would be excluded from participating in an online programme. Both HCPs and PwMS worried that some communication skills might be lost in a digital setting, potentially hindering interaction among participants. Others stated that the online format offers alternative communication channels, such as chat groups, which some may prefer. Easy access to online learning materials could increase availability and allow for more self-paced learning. In addition, the ability to reach PwMS across Sweden and tailor the fall prevention programme to local circumstances was seen as a benefit. Especially PwMS living in smaller communities, who may have fewer opportunities to meet other PwMS in person, were believed to be more interested in a digital programme.

> It is an interesting perspective. It is good to meet others but it is a big city phenomenon. Think if you are the only person in Sorsele (a small rural town in Sweden), then you probably turn more to YouTube. (HCP ID 13, <median years of experience in providing care)

Discussion

We employed a qualitative methodology to gain a deeper understanding of how a self-management programme can be designed to fit the needs of the end users as described by ambulatory and non-ambulatory PwMS and HCPs from MS care and rehabilitation. Two main categories were constructed from the qualitative content analysis: Managing the complexity of fall-risk behaviour and Embracing diversity to establish group engagement. The findings contribute to new knowledge about the need for an individualized self-management programme that considers PwMS' complex fall risk and utilizes peer-support in a group format.

Fall-risk behaviour was frequently described by PwMS and HCPs as multifaceted, with a diversity of intrinsic and extrinsic factors contributing to the individual fall risk. Due to MS being a disease with many variations in symptoms and impact on daily life, the programme should be designed to accommodate diversity among participants. For instance, the programme content should be adaptable and customizable based on individual needs and acknowledge disease-related symptoms such as fatigue. Raising awareness of personal fall risks and both developing and maintaining self-tailored strategies to prevent falls were identified as priorities for the content of a fall prevention programme. These findings align with recommendations for future fall prevention interventions for PwMS [22] and support the benefits of a self-management approach in disease management interventions for PwMS [23]. A self-management-based programme focuses on patients' concerns and applies problem-solving as a means of patient education to enhance core self-management skills and maintain wellness [24]. The suitability of self-management as an approach in a fall prevention programme was further underscored by PwMS and HCPs emphasizing goal setting and building self-efficacy as requirements for a fall prevention programme.

The HCPs described having encountered challenges when discussing fall prevention with PwMS. They specifically expressed concern that their efforts to support the development and maintenance of behavioural change could be perceived as too lecturing and coming from a position of authority. In contrast, both HCPs and PwMS discussed the value of peer learning in a group setting as a format that could be an engaging approach to supporting changes in fall prevention behaviour. Collaborative problem-solving with individuals who share a common understanding and the ability to relate to others was seen as facilitating the development of individual fall prevention strategies. These findings are also supported by the findings from the study by Comber et al. [17]. The benefits of peer support for PwMS have been recognized as one of the most significant components of rehabilitation for PwMS [25]. While PwMS want peer support, it is debatable whether the composition of the group affects the perceived benefit of the interactions. For instance, McCabe et al. [26] found that PwMS desire a wider range of peer support groups, to be able to join a group with others who have similar circumstances. This was also acknowledged by the HCPs in our study, who worried that too much variation in disability level could cause distress among participants. As a result, HCPs suggested forming more homogeneous groups. However, PwMS in our study did not share this concern and believed other personal characteristics were more likely to influence group dynamics. Hence, there was agreement from both HCPs and PwMS on the importance of learning from relatable people in a safe environment, but differences in opinions on what common traits are necessary to achieve a shared understanding. The advantages of peer learning, such as providing positive reinforcement to support behavioural change, can be explained by Social Cognitive Theory [27]. This theory suggests that supportive and collaborative environments can encourage learning and that social interactions and observations can stimulate behavioural change and help individuals in developing strategies to overcome barriers and reach their goals.

The mode and format of programme delivery was also considered a critical feature. Some PwMS would prefer a digital programme over in-person meetings. This preference for a digital programme contrasts with the findings of Kesgin's study [16], where participants opposed a digital format. Although both PwMS and HCPs in our study identified challenges with digital meetings, such as a lack of technological skills and loss of communication variety, the benefits were emphasized. The COVID-19 pandemic may have influenced the positive attitudes towards online meetings observed in our study, when in-person meetings were not recommended. Additionally, since our study included both ambulatory and non-ambulatory PwMS, it represents a broader range of symptom severity compared to the Kesgin study [16]. As a result, we hypothesize that PwMS who are more severely affected by the disease would prefer to participate digitally from the comfort of their own homes. Among the advantages of a digitally delivered programme were eliminating energy-consuming travel and allowing PwMS from geographically dispersed areas in Sweden to participate. These findings are consistent with a narrative review of online peer support for PwMS [28]. Further, the review identifies informational support as the most frequently addressed benefit of online peer support for PwMS, a topic also mentioned by PwMS and HCPs in our study.

This study has both strengths and limitations. One strength is the inclusion of HCPs and both ambulatory and non-ambulatory PwMS, which provided a range of perspectives and unique insights into the research topic. Another strength is the rigorous data collection methods employed. Data were gathered during three facilitator-led workshops based on Design Thinking, with each workshop lasting four hours. Design Thinking integrates user needs and feedback into intervention development to produce usable, acceptable, and effective interventions [29]. Thus, the perspectives and opinions of end-users are thoroughly evaluated through this iterative process. This study reports on findings of the workshops including the first three steps of Design Thinking (Empathize, Define, Ideate). The following two Design Thinking steps (Prototype, Test) were conducted after the workshops. In addition, using different types of data, such as digital post-it notes and field notes collected by more than one researcher, enhances the credibility of the results. Finally, regular peer debriefing sessions among researchers during data analysis further strengthened the trustworthiness of the study.

A limitation of our study is that the PwMS we recruited were selected based on their ability to use and access technical devices for online meetings. This may have introduced bias towards the online format, hence the requirements of PwMS unable to participate in digital meetings were not assessed in this study. Another limitation is that while the PwMS recruited in this study were diverse with regard to their place of residence in Sweden, the HCPs were all employed in metropolitan regions (Stockholm, Gothenburg, and Uppsala) where MS care and rehabilitation is more readily available. MS care and rehabilitation in Sweden is not standardized across regions and HCPs' opinions on user requirements for fall prevention programmes may differ based on local healthcare services. Further research is needed to explore how user needs for fall prevention vary depending on the availability of these resources.

Conclusion

The findings of this qualitative study suggest that a self-management fall prevention programme for PwMS should include the development of self-tailored behavioural strategies to prevent falls, as well as interactive learning activities with other PwMS. Additionally, to meet the needs of both ambulatory and non-ambulatory PwMS, the programme must accommodate diversity in symptom severity and be easily accessible. This study adds to the limited knowledge about the requirements for fall prevention interventions for PwMS. It will inform the design of a novel and comprehensive self-management programme to prevent falls among PwMS.

Acknowledgements

The authors would like to thank the people with multiple sclerosis, health care professionals from Aleris Rehab Station, Academic Specialist Center, Uppsala University Hospital, Sahlgrenska University Hospital, and the facilitator who participated in the study.

Disclosure statement

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

Funding

The project was funded by the Swedish Research Council [2020-01985]; the Swedish Research Council for Health, Working Life, and Welfare (FORTE) [2019-00457]; the Strategic Research Area Health Care at the Karolinska Institutet (SFO-V); the Research School in Health Science at Karolinska Institutet; and Neuro Sweden.

ORCID

Ulrika Meijer http://orcid.org/0009-0007-6018-1703

References

[1] Cameron MH, Thielman E, Mazumder R, et al. Predicting falls in people with multiple sclerosis: fall history is as accurate as more complex measures. Mult Scler Int. 2013;2013:496325. doi: 10.1155/2013/496325.

[2] Bazelier MT, van Staa T, Uitdehaag BMJ, et al. The risk of fracture in patients with multiple sclerosis: the UK general practice research database. J Bone Miner Res. 2011;26(9):2271–2279. doi: 10.1002/jbmr.418.

[3] Mazumder R, Murchison C, Bourdette D, et al. Falls in people with multiple sclerosis compared with falls in healthy controls. PLOS One. 2014;9(9):e107620. doi: 10.1371/journal.pone.0107620.

[4] Zanotto T, Frechette ML, Koziel SR, et al. Frequency and characteristics of falls in people living with and without multiple sclerosis during the COVID-19 pandemic: a cross-sectional online survey. Mult Scler Relat Disord. 2021;54:103111. doi: 10.1016/j.msard.2021.103111.

[5] Kalron A, Aloni R, Givon U, et al. Fear of falling, not falls, impacts leisure-time physical activity in people with multiple sclerosis. Gait Posture. 2018;65:33–38. doi: 10.1016/j.gaitpost.2018.06.174.

[6] Peterson EW, Cho CC, Finlayson ML. Fear of falling and associated activity curtailment among Middle aged and older adults with multiple sclerosis. Mult Scler. 2007;13(9):1168–1175. doi: 10.1177/1352458507079260.

[7] Rice LA, Peterson EW, Backus D, et al. Validation of an individualized reduction of falls intervention program among wheelchair and scooter users with multiple sclerosis. Medicine. 2019;98(19):e15418. doi: 10.1097/MD.0000000000015418.

[8] Rice LA, Ousley C, Sosnoff JJ. A systematic review of risk factors associated with accidental falls, outcome measures and interventions to manage fall risk in non-ambulatory adults. Disabil Rehabil. 2015;37(19):1697–1705. doi: 10.3109/09638288.2014.976718.

[9] Rice L, Kalron A, Berkowitz SH, et al. Fall prevalence in people with multiple sclerosis who use wheelchairs and scooters. Medicine. 2017;96(35):e7860. doi: 10.1097/MD.0000000000007860.

[10] Sosnoff JJ, Sung J. Reducing falls and improving mobility in multiple sclerosis. Expert Rev Neurother. 2015;15(6):655–666. doi: 10.1586/14737175.2015.1046377.

[11] Gunn H, Cameron M, Hoang P, et al. Relationship between physiological and perceived fall risk in people with multiple sclerosis: implications for assessment and management. Arch Phys Med Rehabil. 2018;99(10):2022–2029. doi: 10.1016/j.apmr.2018.03.019.

[12] Barlow J, Wright C, Sheasby J, et al. Self-management approaches for people with chronic conditions: a review. Patient Educ Couns. 2002;48(2):177–187. doi: 10.1016/s0738-3991(02)00032-0.

[13] Allegrante JP, Wells MT, Peterson JC. Interventions to support behavioral self-management of chronic diseases. Annu Rev Public Health. 2019;40(1):127–146. doi: 10.1146/annurev-publhealth-040218-044008.

[14] Tuvemo Johnson S, Flink M, Peterson E, et al. Self-management of falls in people with multiple sclerosis: a scoping review. Clin Rehabil. 2023;37(2):162–176. doi: 10.1177/02692155221128723.

[15] Coote S, Hogan N, Franklin S. Falls in people with multiple sclerosis who use a walking aid: prevalence, factors, and effect of strength and balance interventions. Arch Phys Med Rehabil. 2013;94(4):616–621. doi: 10.1016/j.apmr.2012.10.020.

[16] Kesgin F, Suddick K, Heesen C, et al. Developing a fall prevention program: what are the views and opinions of people with multiple sclerosis? Disabil Rehabil. 2021;43(8):1065–1073. doi: 10.1080/09638288.2019.1652700.

[17] Comber L, Peterson E, O'Malley N, et al. Development of the better balance program for people with multiple sclerosis: a complex fall-prevention intervention. Int J MS Care. 2021;23(3):119–127. doi: 10.7224/1537-2073.2019-105.

[18] Batalden M, Batalden P, Margolis P, et al. Coproduction of healthcare service. BMJ Qual Saf. 2016;25(7):509–517. doi: 10.1136/bmjqs-2015-004315.

[19] Björgvinsson E, Bjögvinsson E, Ehn P, et al. Design things and design thinking: contemporary participatory design challenges. Des Issues. 2012;28(3):101–116. doi: 10.1162/DESI_a_00165.

[20] Carlgren L, Rauth I, Elmquist M. Framing design thinking: the concept in idea and enactment: creativity and innovation

management. Creat Innov Manage. 2016;25(1):38–57. doi: 10.1111/caim.12153.

[21] Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs. 2008;62(1):107–115. doi: 10.1111/j.1365-2648.2007.04569.x.

[22] Coote S, Comber L, Quinn G, et al. Falls in people with multiple sclerosis: risk identification, intervention, and future directions. Int J MS Care. 2020;22(6):247–255. doi: 10.7224/1537-2073.2020-014.

[23] Knaster ES, Yorkston KM, Johnson K, et al. Perspectives on self-management in multiple sclerosis: a focus group study. Int J MS Care. 2011;13(3):146–152. doi: 10.7224/1537-2073-13.3.146.

[24] Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med. 2003;26(1):1–7. doi: 10.1207/S15324796ABM2601_01.

[25] Salminen AL, Kanelisto KJ, Karhula ME. What components of rehabilitation are helpful from the perspective of individuals with multiple sclerosis? Disabil Rehabil. 2014;36(23):1983–1989. doi: 10.3109/09638288.2014.885092.

[26] McCabe MP, Ebacioni KJ, Simmons R, et al. Unmet education, psychological and peer support needs of people with multiple sclerosis. J Psychosom Res. 2015;78(1):82–87. doi: 10.1016/j.jpsychores.2014.05.010.

[27] Bandura A. Health promotion by social cognitive means. Health Educ Behav. 2004;31(2):143–164. doi: 10.1177/1090198104263660.

[28] Gerritzen EV, Lee AR, McDermott O, et al. Online peer support for people with multiple sclerosis: a narrative synthesis systematic review. Int J MS Care. 2022;24(6):252–259. doi: 10.7224/1537-2073.2022-040.

[29] Altman M, Huang TTK, Breland JY. Design thinking in health care. Prev Chronic Dis. 2018;15:e117. doi: 10.5888/pcd15.180128.