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The “Managing Fatigue” programme – experiences shared by MS participants

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ABSTRACT

Background: The “Managing Fatigue” (MF) programme can help people living with Multiple sclerosis (MS) manage fatigue in their everyday lives. The programme has been proven feasible with Swedish occupational therapists, but there is a lack of knowledge of how MS participants experience the programme, and what they learned from participating in the programme.

Aim: To describe how Swedish MS participants experience the content and structure of the Swedish MF programme, as well as what they learned from participating in the programme.

Material and Methods: Qualitative interviews were performed with nine MS participants, and data were analysed according to direct content analysis.

Results: Participants experienced programme material was relevant, and they valued the structured sessions that utilised different teaching forms. Participants described the group format and the experienced course leader nurtured their learning process. They learned occupational skills to save energy, to re-value daily occupations, and initiated a process of change, but individual support is needed after programme completion.

Conclusion and Significance: Findings support programme feasibility among MS participants, and show the importance of being able to practice skills to handle fatigue in everyday life. Future studies should consider adding outcome measures focussing on engagement in occupations when evaluating programme effectiveness.

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Introduction

Multiple Sclerosis (MS) is a neurodegenerative disease of the central nervous system with a prevalence of over 18 000 individuals in Sweden [1]. About 65–90% of all people with MS report they have fatigue [2,3], a symptom that can be physical as well as mental. Fatigue can have a significant impact on a person’s ability to manage everyday life, especially to maintain work and manage household occupations [4,5]. People who live with fatigue experience they are excluded because they are not able to participate in wanted activities as others are [6]. At the same time, many with MS-fatigue state they do not receive any fatigue treatment [7] although medical treatment (pharmacological therapy) and different types of exercise and educational programmes (non-

pharmacological therapy) are available [8]. Two reviews [9,10], concluded educational programmes have the best potential to reduce fatigue and fatigue impact. The existing educational fatigue programmes are delivered as a face-to-face group format [11–14], individually [15], as a teleconference [16,17] or as an online intervention [18]. Many of these were developed from the ‘Managing Fatigue’ (MF) programme [19], introduced already in the mid 90’s, and the content in the different programmes is therefore similar. Being an educational programme, the content of the MF programme was inspired by psychoeducational group theory [20], where knowledge is provided through information-sharing. By teaching self-management skills [21], participants learn how to prioritise and find a balance among daily occupations, how

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to plan rest, to communicate needs to others, and to apply compensatory techniques and technical equipment to reduce fatigue in everyday occupations.

The original MF programme [19] is group-based, and delivered during a six-week period. It is provided by occupational therapists in a course format where each session comprises a short interactive lecture, group discussions, practice of newly learned skills, and an introduction to homework performed between sessions. The Swedish translation of the MF programme [22] has been shown feasible, and highly relevant within a Swedish context with Swedish therapists [23]. The therapists described how the MS participants appreciated the MF programme, and therapists also believed the programme supported their clients' involvement in the rehabilitation process. Still, the data were not directly collected from the MS participants but from the therapists' perspective, and there is therefore a lack of studies of how Swedish participants experience the MF programme. In other studies [24,25], MS participants have reported similar experiences previously. However, the primary aims of these studies were to develop and test online versions of fatigue programmes, and not benefits gained from participation in the programme. Two qualitative studies described experiences from the perspectives of MS participants in fatigue programmes. Pétrin *et al* [26] described how people with MS fatigue, who used the online platform 'MS INFoRm', experienced a shift in knowledge and behaviours with respect of fatigue self-management, and Twomey and Robinson [27] showed participants in a community-based fatigue programme experienced ownership, active participation and empowerment. To sum up, very few qualitative studies have described how people with MS experience their participation in a fatigue management intervention, and especially how it has contributed to managing the fatigue in everyday occupations. The aim of the present study was therefore to describe how Swedish MS participants experience the content, and structure of the MF programme and what they learned from participating in the programme.

Material and methods

Study design

Since the aim was to capture MS participants' individual experiences of specific aspects in relation to the MF programme, a qualitative descriptive research design [28] was chosen. Data was analysed according

to a deductive approach, following the guidelines for direct content analysis [29].

Participants

Participants were recruited among eleven MS clients who completed the MF programme, in different groups, during the autumn 2016 or spring 2017 at a University hospital in Sweden. Following the recruitment process, according to the MF manual [30], participants had to be ≥ 18 years old, have a self-perceived fatigue of ≥ 4 according to Fatigue Severity Scale (FSS) [29], i.e. a fatigue that influence everyday life. Potential participants had to understand Swedish and have no cognitive impairment or depression that could be a barrier for participating in a group discussion. None of the referred, potential participants had any of these problems. The eleven MS clients received written and verbal information about the study and were invited to participate. Nine clients – eight women and one man – agreed to participate and signed an informed consent form prior to the data collection.

The nine participants had a mean age of 49 years (range 33–64 years). Six lived with a partner/family member, and three lived alone. Eight were working part time (25 to 75%), and one had disability pension. They had a median disease severity of 3.6 (range 1,5–8), according to the Expanded Disability Status Scale (EDSS) [31]. The EDSS scale ranges from 0 to 10; higher scores indicate higher levels of disability. Our participants had a wide range from no disability to severe disability, including participants who used a wheelchair. Prior to, and after completion of the programme, all participants also rated the physical and psychological impact of MS in their daily life, according to the Multiple Sclerosis Impact Scale (MSIS-29) [32]. The total MSIS-29 sum score can vary between 29 to 145; with greater disability the higher scores reported. The MS participants reported MSIS-29 mean ratings of 107 prior to participating in the MF programme, and a mean score of 76 after programme completion.

Ethical considerations

The Regional Ethical Review Board in Stockholm approved the study (no.2017/879-31/4). All participants received verbal and written information about the study and were informed they could withdraw from the study at any time without any explanation.

All data were treated confidentially to ensure no individual could be identified.

The 'Managing Fatigue' (MF) programme

The MF programme was delivered by a clinical occupational therapist (first author) to two groups with participants in weekly, two-hour sessions during six consecutive weeks. All of them participated in the ordinary six sessions; except two participants who missed one group session. These two participants asked for an additional session, which they attended. The different sessions in the programme address importance of rest, strategies to handle fatigue in their everyday lives, and how fatigue and individual needs can be communicated to others. Participants learn about body mechanics, how to organise and modify workspace environments and use appropriate technology to save energy. They learn how to do an activity analysis, e.g. to break down an activity into smaller components in order to modify the complexity of the activity, and thereby experience less fatigue. Participants also discuss how to plan a weekly schedule to obtain a balanced lifestyle, to change norms and to prioritise among occupations in daily life. An overview of the different session is presented in Table 1.

In-between sessions, participants are expected to perform homework that provide them with an opportunity to practice strategies learned during sessions, in occupations relevant for their own home setting. During the sessions, the occupational therapist teaches self-management skills [21] where participants learn strategies that help them manage and reduce the impact of the MS-fatigue in their everyday lives. The programme is based on client-centred occupational

therapy practice [33], social cognitive [34], and problem-solving theories [35], utilising a programme content and structure developed from the PRECEDE model [36] and psychoeducational group theory [20]. That is, the programme is focussing on each client's specific needs, and at the same time takes advantage of the fact that the group members share thoughts and experiences during the programme. Learning problem-solving skills in a mix of educational and practical sessions, with a goal to strengthen each participant's self-efficacy and give them skills to manage fatigue in everyday life occupations.

Data collection

The interviews were based on a semi-structured interview guide, focussing on the participants' experience of the content and structure of the MF programme, and what they had learned from participating in the programme. The interview guide comprised questions concerning how the person experienced the content in the programme, if they thought important aspects had not been addressed, and their opinion of participating in a group programme, instead of an individual programme. Questions were also asked that concerned if they had learnt anything from participating in the programme, if anything in their everyday life had changed after participation, and if they felt they had received enough support after programme completion. The semi-structured format gave each participant the opportunity to elaborate on his or her answers, and follow-up questions were posed when relevant. Each participant decided where he or she wanted the interview to take place; either in their home environment or at the occupational therapy

Table 1. Overview of the sessions in the 'Managing Fatigue' Programme [19].

Sessions	Content	Homework
Session 1: The Importance of Rest	Introduction Fatigue, importance of rest and fatigue management strategies. Activity: Assessing Rest Habits and Creating a rest plan	Plan rest into daily schedule
Session 2: Communication and Body Mechanics	Review homework Communicating and expressing needs to others Structure of body, and how to use body properly	Communication with others
Session 3: Activity Stations	Review homework Organization of needed environments/workspace, and the use of technology to save energy	Re-organise workspace to save energy
Session 4: Priorities and Standards	Review homework Activity analysis – analysing components of activities Budgeting energy, making decisions about priorities and standards	Analysing and modifying an activity to experience less fatigue
Session 5: Balancing Your Schedule	Review homework Components of a balanced lifestyle, planning a weekly schedule	Planning a day to manage fatigue
Session 6: Course Review and Future Plans	Review homework Course review Short-term and long-term goal setting Conclusion	No homework

clinic. Interviews were conducted by the first author, two to three months after discharge except for three participants who were interviewed five months (two participants) and nine months (one participant) after discharge from the MF programme. The delay in time was due to sickness, and difficulty finding a time when the interview could take place. Interviews lasted between 17–63 min and were tape-recorded and transcribed verbatim.

Analysis

The data analysis followed the guidelines for direct content analysis [29], a deductive approach where the analysis is guided by a theory, model or certain key concepts. In this study, the analysis focussed on the key concepts; content and structure of the MF programme, together with aspects participants experienced they had learnt from participating in the programme. All authors initially read all interviews to get a sense of the whole material. Proceeding with the analysis, parts of the text that reflected similar aspects were divided into meaningful units, and each meaningful unit were given a code. Codes were then clustered to the different key concepts, i.e. predetermined categories, depending on the meaning of the code. In the next step, codes within each of the two predetermined categories were further scrutinised and collapsed into a set of codes that were clustered into sub-categories. Finally, each of the two predetermined categories comprised a final set of subcategories, and codes. At this point, all data within each predetermined category were reviewed a last time, and given a name that better reflected the content of that particular category. The first author was responsible for the main analysis but all steps in the analysis were validated by the other authors in an iterative process.

Results

The results are built on the two main categories – ‘The MF programme was relevant and delivered in a structured way’ and ‘Learned skills that improve

engagement in occupations’ – that comprised three and four subcategories, respectively. (Table 2).

The MF programme was relevant and delivered in a structured way

A clear structure with a mix of teaching forms

The participants described how the different themes in each session built on the next, and all sessions were structured the same way. They appreciated the mix of teaching forms, and some said this nurtured their learning process. Many highlighted the importance of the practice sessions, and said being able to try out things by themselves facilitated their learning process. That is, to learn about, and test different types of technical devices and everyday technology that potentially could help them save energy in their everyday life.

The homework in-between sessions gave them an opportunity to practice skills learned during the group sessions, in their own home environment. Some thought the homework were easy to use whereas others argued the material was too extensive which made it difficult to understand. A few called the course leader to clarify the instructions, whereas others did not want to reveal they had difficulties understanding the instructions although this affected their ability to complete their homework. Despite being challenging, the homework made them reflect on their MS-fatigue, and how it interfered with their occupational performance. As described by one participant:

The homework was sometimes tricky, I really had to consider them carefully, but it was positive... you really had to think through... how did I perform [the activity] in this situation, what do I do... I had to reflect on things that make me tired. I think it is good to do some homework, otherwise you forget what you have been talking about. Maybe, if you are lucky, some good stuff can stick to your brain! (Participant 3).

Another aspect discussed regarding the handouts, was how they were used during the different sessions. One participant said she had impaired fine motor skills and therefore had problems turning the pages, and having to flip back and forth between pages took a lot of energy. Further, a digital version of the programme

Table 2. An overview of the main categories and subcategories.

Main categories	The MF Programme was relevant and delivered in a structured way	Learned skills that improved engagement in occupations
Subcategories	A clear structure with a mix of teaching forms A programme update needs to include cognitive fatigue management An experienced course leader and the group format were important mediators	Learned to accept my new self and to decrease demands Learned skills that helped me adapt my occupational performance Learned to prioritise and find a balance among activities Learned how to make a change but have only started this process

was suggested. Such a version could be used during the course sessions as well as help participants to perform the homework, and potentially enable repetition of programme content after course completion.

A programme update needs to include cognitive fatigue management

Participants said the programme content was relevant, although they agreed it did not sufficiently address cognitive fatigue and strategies to manage cognitive fatigue. They also described the importance of presenting assistive devices and everyday technology that can be used to overcome cognitive fatigue, and the importance of being able to share such information in the group. As this participant narrated:

...I use a lot of apps to remember [appointments] and to stay on top of things, for instance calendar apps and things like that. The programme also needs to address these aspects [cognitive fatigue] ... common in MS but also in other [diagnostic] groups. Many with MS have cognitive limitations and probably don't think of them [apps and other solutions] as assistive devices that can be used to help you remember and such... and I think we can inform each other a lot in the group ... of how we solve things practically (Participant 1).

An experienced course leader and the group format were important mediators

The importance of having an experienced course leader was emphasised. Someone who can provide new knowledge during the lectures, such as to describe and explain MS-fatigue, how energy pacing can be performed, and show examples of assistive devices that can be used to overcome fatigue. In addition, they described how the occupational therapist's substantial experience from working with other MS clients were an important mediator during the programme.

Another aspect raised was the importance of the group format. The participants seldom met others in the same situation with whom they could share the struggle they had to undertake to handle their MS-fatigue. They emphasised how the other group participants' experiences had been crucial when reflecting upon their own situation. Not only for those who were only starting to reflect upon their life situation, but also for those who previously had made attempts to decrease the fatigue impact. As one participant narrated:

...I liked the group format, we were able to share each other's experiences, things others had tried ... setbacks and things that worked out fine ... I

learnt a lot ... One of the group participants worked 320% – no that is not realistic in the long run! – and tried to decrease the amount of working hours. Listening to her reasoning made me reflect and remember how I have struggled the same way and I could share my experiences (participant 8).

The group format also meant meeting participants with different challenges, something they in general were positive towards. After the programme, a few participants shared they at first found it difficult to meet others who had a more pronounced disability, and said it was because they feared having to face the same deterioration themselves in the future. During the programme, they reported having changed their views, and described it had been interesting to hear how, for instance, wheelchair users manage different aspects in life, including MS-fatigue.

Learned skills that improved engagement in occupations

Learned to accept my new self and to decrease demands

Participants described they had pushed themselves very hard and been too ashamed to tell others about their fatigue. They had blamed themselves for not being able to do the same number of tasks as other people and struggled to manage MS-fatigue in their everyday lives. They said they previously had received information about fatigue, but they did not associate it with problems in their everyday life. The MF programme had helped them realise the fatigue was a result of their MS, and not because they were lazy. This new way of thinking had changed their view of themselves. They shared how the new insight gave them a chance to accept their new situation, and lower demands put on themselves. Further, they described how they tried to focus on possibilities in life rather than barriers. This subcategory is exemplified in this quotation:

I am kind to myself ... I make sure I keep the energy instead of giving it away. I am damned pleased with putting myself first! I work my hours and then I go home and try to let it go [thoughts about not being at work]. I don't want people [colleagues] to gossip about me and why I am not at work. I feel they show more consideration now. I didn't dare do that [tell others] before (Participant 2).

Learned skills that helped me adapt my occupational performance

Participants described the programme had taught them multiple strategies and tools to save energy

which helped them manage everyday life. For example, they had learned to save energy by being more efficient, and to bring all tools and materials they needed from the beginning, instead of having to walk several times to fetch things they needed. This was a new mind set which they did not have prior to the programme. They had also learned how to break down an activity into smaller components, which made them realise that even a simple activity comprises many components. They described how they used this new skill to identify activity components they could omit or change to save energy. For instance, shopping at other times than during rush hours, by ordering food and heavy groceries online and have it delivered to the door instead of going to the grocery store themselves.

Another aspect they had learned during the practice sessions was to analyse components in the environment that potentially could be a barrier to their performance. By re-arranging and re-organizing their home and work environment, they were able to save energy. As narrated by this participant:

I bought new, nice pots that match my kitchen tiles, so I can leave them on the countertop and don't have to lift them in and out from the cupboards all the time... And I have re-arranged my cupboards. I have put all things I use the most up front, and the others to the back... Actually, when I think about it I have been very ambitious and cleaned out all things I don't need... and I have even re-arranged things for my cats... Cats need fresh water twice a day so I moved their food and water bowls from the floor to the sink. I save energy when I don't need to bend every time to fill the bowls (Participant 2).

Learned to prioritise and find a balance among activities

During the programme, some participants reflected on their priorities between different activities, and concluded that they needed to change their priorities in life. After the programme, they tried to focus on activities they found important and meaningful. For example, by delegating certain activities to partners or co-workers or by paying other people for doing things for them, e.g. household activities. Some had altered their working conditions and others described they had recaptured previous leisure activities:

I have managed to take up horse-back riding again! Not so often as before but still, I do it. I think it is good for my balance too. It is really fun! (Participant 9).

In contrast, participants sometimes prioritised activities that took a lot of energy just because these activities added value to life. As an example, one

participant described she enjoyed spending time with her grandchild. Even though she knew she would be exhausted 1–2 days afterwards, this was an activity she prioritised.

Participants also described they must strive to find time for rest in their daily schedule, and to plan occupations when they had the energy. For example, by not booking many meetings at the same day and, if possible, to schedule meetings at the time of day when they had the most energy. They also tried to spread out activities they needed a lot of energy to perform during a whole week, and to plan for rest, including the type of rest they needed at different time points during the day.

Learned how to make a change but have only started this process

The participants expressed how the programme had helped them identify multiple areas in which they needed to change in order to manage the MS-fatigue. For some, this meant they had realised they needed specific rehabilitation interventions, from different professionals. For instance, they needed an individual contact with an occupational therapist that could provide assistive devices and/or everyday technology. Others said that they were less fatigued after the programme, and the extra energy could be spent with a physiotherapist or a personal trainer who could provide them with an exercise programme. A few needed to be referred to a social worker or a psychologist to get support to handle their life situation.

Participants said they were aware the process of change had only started, and more work lay ahead. Many said they felt left alone when the programme ended, and argued the need for an individual as well as a group follow-up after programme completion. They said the individual follow-up could support them during the phase when they had to implement all new skills in their everyday lives. During the group follow up, participants wanted to share experiences in relation to their process of change with the other participants. Even if some of them had kept in contact after the programme ended, they wanted a formal follow-up in connection to the programme.

I would have liked a follow-up in about a year... to see if anything had changed and it doesn't have to be the same group or anything that meet. Just interesting to see what others have changed or just as a reminder to actually deal with... I mean we were very focused when the programme ended but slowly you start to forget what you need to change. I think it would be nice with some kind of follow-up (Participant 1).

Discussion

This study describes Swedish MS participants' experiences of the MF programme. The results show they were satisfied with the programme content and believed it was relevant for people with MS-fatigue. However, they emphasised the need to also address aspects of cognitive fatigue management, and to discuss how different types of everyday technology, and assistive devices can be used to overcome cognitive fatigue. These comments are similar to those described by the Swedish occupational therapists in a previous study [23], and emphasise the importance of offering interventions that target fatigue, despite having access to new medical treatment options [37].

Our participants also discussed the delivery of the MF programme, especially difficulties to handle and organise the handouts connected to the programme. Participants suggested developing digital handouts that could be easily accessed in a smartphone application, and be used as a complementary tool within the ordinary programme. People with neurological disorders, including MS, are generally positive towards using different health apps as a support for self-management [38], and different initiatives have been taken to develop digital fatigue interventions for people with MS. For instance, the digital fatigue website 'INFoRm' [26,39], a self-management smartphone application [40] and the MS TeleCoach, a telemonitoring fatigue intervention [41]. These initiatives mainly focus on physical activity and energy management, and do not specifically include practicing of skills in relation to engagement in occupations, as the participants in our study suggested. Hence, using these apps as the only tool for managing fatigue may not be an alternative.

The mix of learning activities in the MF programme were much appreciated, and the participants especially enjoyed the practical sessions where they were able to discuss and try different solutions for managing fatigue. This is in line with previous studies of the MF programme where other participants have shared similar experiences of the programme [24,25]. This is not surprising since the programme was developed based on theories from self-management [21], and occupational therapy [33], emphasising the opportunity to practice skills. By practising skills in daily occupations, a person can learn new habits, and alter their way of performing occupations. This was also described by our participants who said they learned the skill of activity analysis, and by using this skill they were able to adapt their way of performing occupations in a less energy consuming way. As a

result, many were able to take back occupations they had not performed in a long time, often leisure occupations, and thereby experienced a better balance among occupations in life.

The participants also described how the MF programme gave them knowledge and skills about fatigue that helped them to accept their new self; a person who experience fatigue that affect everyday life. We know from previous research [42,43] that when people with MS struggle with maintaining engagement in occupations, they often experience an altered self that require them to live a different life than before. This is also in accordance with Charmaz [44] who described a person's self is closely related to his/her habits, and when alternative ways of engaging in occupations are presented, reconstructing one's self is possible. Interventions, such as the MF programme, that help reconstructing one's self and habits are therefore highly relevant. Interestingly, previous effect studies have mainly measured primary outcome in terms of fatigue impact, and only a few studies have chosen primary outcomes that measure aspects of engagement in occupations [15,18]. This is therefore important to consider in future effect studies of the programme. Moreover, the participants described how the programme had helped them to become aware of aspects they needed to change, and described how they had started to alter different aspects of their engagement of occupations. Still, they were aware that this process had only started. Prochaska and DiClemente [45] described the stages of change model, including five stages that an individual goes through in order to change a behaviour; pre-contemplation, contemplation, preparation, action and maintenance. From our participants' descriptions of becoming aware and starting the change process, it is clear many moved from the pre-contemplation to the preparation stages, and some even started the action stage.

Other factors expressed by the participants were the importance of the group format of the programme. Our results thereby confirm previous studies with people with MS [24], as well as other diagnostic groups and other group programmes [46,47], who all recognised the importance of sharing experiences in a group format. This is an important aspect to consider when digital delivery forms of fatigue programmes [39–41] are developed since online delivery often are provided to single individuals rather than to groups. Furthermore, although some participants had already learned about certain aspects in the programme, they appreciated hearing it again from a professional,

experienced in MS and MS-fatigue. This is also confirmed by Twomey and Robinson [27] who showed people with MS-fatigue wish to get information and tools from experienced healthcare professionals.

This study used qualitative interviews during the data collection, and it can therefore not be generalised to all people with MS. The selection of participants was based on those 11 MS clients who previously had participated in the MF programme, and nine of them gave their informed consent to participate in this study. Thus, no purposive sampling [48] was made. Still, the included participants had a diverse background, with different characteristics, and the results may therefore be transferable [49] to others in the same situation. A possible bias during the interviews is the fact that the author who performed the interviews was the same person as the programme facilitator. This may have influenced the credibility [49], i.e. the quality of the interviews since it is possible that the participants did not share their experiences as fluently as if the interviewer had been unknown to them. During the interviews, questions were posed in an open manner where participants were encouraged to share their experiences of the programme, and both positive and less positive aspects of the programme were revealed. The interviews were collected only on one occasion, and it is possible that if repeated interviews had been performed, participants would have shared more in-depth experiences in relation to participation in the programme. Further, most of the interviews were conducted two to three months after discharge except for three participants who were interviewed up to nine months after completion of the MF programme. It is possible that participants who had more time to implement changes also shared more in-depth experiences, but this also meant they needed to recall their experiences from further back in time. Still, all interviews were rich of information, which enhanced the credibility of the study.

In conclusion, this study shows that MS participants find the content and delivery forms of the MF programme are relevant, although there is a need to address not only physical but also cognitive/mental fatigue, and ways to handle it in everyday life. The practice sessions were especially appreciated and taught them skills to manage fatigue in engagement in occupations, spanning from altering their occupational performance of a specific task to re-valuing their occupations overall. This made it possible to take back leisure occupations they previously had omitted. The programme provided participants with tools to start a process of change, but we know this is

a process that can take long time. To obtain their goals, more individual support is needed after programme discharge. This is important information for occupational therapists to consider, and to plan not only follow-up sessions after programme completion but to also consider individual support in order for each participant to reach his/her goals. Further, future studies should determine which outcome measures that can best detect changes in engagement in occupations, and utilize these outcome measures when the effectiveness of the programme is evaluated.

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