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The “Managing Fatigue” programme for people with multiple sclerosis – acceptance and feasibility with Swedish occupational therapists

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\textbf{ABSTRACT}

\textbf{Background:} Fatigue is common among people with multiple sclerosis (MS), and significantly influences engagement in occupations. The Managing Fatigue (MF) programme is an evidence-based occupational therapy group-based intervention, utilising self-management science that provides people with tools to manage fatigue. Although the national MS-guidelines in Sweden cite this as best practice, a Swedish version is not available.

\textbf{Aim:} To translate and investigate the feasibility of a Swedish MF programme delivered by occupational therapists working with MS clients in Sweden.

\textbf{Material and methods:} We used a mixed-methods design. Eight recruited occupational therapists, participated in a workshop prior to delivering the MF programme. Following programme delivery, they completed a questionnaire and participated in focus group interviews.

\textbf{Results:} Each therapist conducted one programme with 5–9 MS clients. Overall, therapists were satisfied with programme content, and delivery was followed. Minor improvements were suggested, specifically in relation to how cognitive fatigue can be managed. Therapists acknowledged challenges moving from “expert” to supporting self-management.

\textbf{Conclusion:} The MF programme is feasible in Sweden, and its client-centred and occupation focus is consistent with therapists’ scope of practice. In the future, acceptability and satisfaction from the perspectives of MS participants should be examined. Larger, more robust intervention studies evaluating effectiveness are also warranted.

\textbf{Introduction}

In Sweden, approximately 18,500 people live with Multiple Sclerosis (MS), many diagnosed during their working years [1]. Fatigue is one of the most frequent and disabling symptoms in MS [2]. One international study of 2469 people with confirmed MS found that 65% of participants screened positive for MS-fatigue [3], and consider it their most troubling symptom [2,4], because of its impact on work and household management [5,6]. People with MS describe their fatigue as “weariness”, “having no motivation”, “having no energy or being drained of energy”; “being zonked”, “wiped out” or like “wilted lettuce” [7].

In December 2016, The Swedish National Board of Health and Welfare published guidelines for interventions for MS and Parkinson’s disease, including interventions for MS-fatigue [8]. The Managing Fatigue (MF) programme [9], a 6-week, group-based programme conducted by occupational therapists, was highlighted as effective in helping people manage fatigue in everyday life (Table 1). In fact, the guidelines [8] rated the MF programme and aerobic and strength training as having stronger scientific evidence than medication. Prior to publication of the guidelines, few patients were referred to occupational therapy for assistance with their fatigue. The recommended intervention protocol was not available in Swedish. The guidelines have altered these referral patterns.

The recommended 6-week MF programme, delivered in weekly, 2-h sessions to closed groups of eight to twelve participants, is designed to support and facilitate participants to learn, try out, and select self-management strategies [10] of most relevance to their own lives. Each session includes a short-form, interactive lecture, group discussions, practice of presented strategies and activities, and an introduction to...
homework activities designed to personalise and apply strategies between sessions. The programme is based on client-centred occupational therapy practice [11] and is aligned with social cognitive [12] and problem-solving theories [13]. Content was selected using the PRECEDE model [14], and programme structure was informed by psychoeducational group theory [15]. The different sessions address the importance of rest and managing fatigue strategies, how to communicate fatigue and individual needs to others, body mechanics, how to organise and modify workspace environments and use appropriate technology to save energy. The sessions also comprise activity analysis (breaking down an activity into components) to modify the complexity of the activity to experience less fatigue, how to plan a weekly schedule and have a balanced lifestyle, and change standards and prioritise activities in daily life.

The MF programme has demonstrated effectiveness in managing the impact of MS-fatigue when implemented in the group format [16,17], by teleconference [18,19], and online [20]. When compared to no intervention, it resulted in significant decreases in fatigue impact [16,17,19,21–23], and increases in quality of life [16,18,19], self-efficacy [16,18,21,22], and mental health [21]. Benefits have been maintained at 7–9 months [23] as well 1 year [24], though these beneficial effects were not compared with a control group [25]. Accumulating evidence indicates differential effects on fatigue severity and fatigue impact. As a behavioural intervention, it is not surprising that the programme shows limited to no change on measures of fatigue severity which often measure physical fatigue [23,26,27]. By contrast, all studies testing effectiveness, with the exception of one [27] have suggested that the MF programme reduces the impact of fatigue on everyday life. In summary, the weight of evidence points to fact that the MF programme reduces the impact of fatigue and improves self-efficacy and quality of life.

To date the programme’s effectiveness has primarily been tested in North America [16,22,28] and Australia [20]; its merits are only beginning to be examined in European countries [23,29]. As such, despite its presence in the Swedish guidelines, the programme was essentially non-available in Sweden and there is a lack of research describing its use and feasibility in a Swedish context, with Swedish MS participants, and Swedish occupational therapists. Thus, the aim of this study was to investigate the feasibility of a Swedish translation of the programme delivered by occupational therapists who work with people with MS in Sweden.

**Material and methods**

**Study design**

We used a mixed-methods, exploratory sequential design [30] to investigate occupational therapists’ perspectives on the feasibility of a Swedish translation of the MF programme delivered within a practice setting. After having delivered the programme, therapists completed an individual study-specific questionnaire. These results then informed the topics and issues for elaboration via focus group discussions with the therapists [31].

**Participants**

Occupational therapists were recruited through an advertisement on the Swedish Association of Occupational Therapy (short: The Swedish Association)
webpage. To be eligible to participate, occupational therapists were required to: (1) have employers’ approval to participate; (2) participate in a 2-day training workshop and (3) conduct at least one 6-week programme for a group of MS clients, during a 6-month period. Seventeen occupational therapists applied, eight of whom were selected based on the inclusion criteria and the use of a purposive sampling procedure [32], designed to include occupational therapists from different geographical and practice areas.

This study was not associated with ethical risk criteria in Sweden [33,34], meaning that ethical approval was not required. The study was performed according to the ethical guidelines and recommendations for good research practice for research in the humanities and social sciences of the Swedish Research Council [35].

Procedure

Translation of the manual

The second author translated the original version of the Canadian intervention manual [9], including an updated version of the first chapter provided by the last author (the original author who also provided permission for translation). A chapter summarising research findings in relation to the programme was also added and translated. The first author validated the translation procedure, in an iterative process with the second author, until consensus was reached. To ensure accuracy during this process, the Swedish text was extensively checked, and compared to the original English language version. When needed, questions were posed to the last (original) author.

Training workshop for occupational therapist participants

The final draft of the Swedish Managing Fatigue programme (Swedish MF programme) [36] was introduced to the eight selected occupational therapists during a 2-day training workshop in August 2016 designed to prepare the occupational therapists to conduct the 6-week programme. All attending occupational therapists received the translated manual in advance of the workshop, which began with short lectures about the theoretical background and scientific evidence of the programme. This was followed by discussions regarding the content of the manual, as well as how to plan and implement the programme. The first author led the workshop and the last author contributed in a skype-lecture on the theory and processes of behaviour change. As a feasibility study, participating occupational therapists were provided with sufficient details of the study design (overall goal, data collection procedure, time frames) to actively and meaningfully participate in the programme’s evaluation.

Data collection and procedure

Following the workshop, each occupational therapist recruited MS participants and conducted at least one MF programme at their respective clinics, using the Swedish MF programme. During this process, the occupational therapists were asked to keep notes on usability of the draft manual/protocol, including worksheets, handouts, and PowerPoint presentations, and to take specific notes of sections, text or content that needed clarification. They were also asked to make notes regarding the delivery fidelity (amount and extent of programme delivered as per protocol), and to prepare written reflections about running the programme in the Swedish context, including their own experience, as well as reflections and reactions described by the MS clients who participated in the programme. They used their notes and reflections to answer the survey, and as an aid to remember important observations during the focus group discussions.

Study-specific questionnaire

The study-specific questionnaire was completed by participating occupational therapists in November 2016 following their delivery of the Swedish MF programme. All authors constructed the questionnaire collaboratively. It contained two open- and 23 closed-ended questions, using a variety of response options: numerical or categorical response scales, yes/no options, and short written answers. The study-specific questionnaire asked therapists to rate, using a scale of 1–5 (with 1 being low and 5 being high), the value of each session with respect to relevance, importance, understandability, and cultural appropriateness. Demographic information of participating occupational therapists, and programme delivery data were gathered. Therapists self-reported on the delivery fidelity of each of five components; introduction, homework review, interactive lecture, activity, and homework assignment. No data were collected from MS participants attending the MF programme. Data relating to participant attendance rates were gathered and the therapists were also asked to answer seven questions (yes/no) about their impressions of clients’
engagement with the programme content. The study-specific questionnaire also included questions related to experiences of implementing the MF programme within the Swedish context, in order to inform subsequent focus group discussions. The questionnaire can be requested from the first author.

Focus group discussions

Two focus groups, each with four occupational therapists, were conducted via teleconference. Questions were designed to provide opportunities to clarify ambiguous or contradictory information and expand on results gathered from the study-specific questionnaire. For example, the participants were asked to articulate their rationale for changing and/or adding material and content to the programme, and to describe how they structured the sessions.

The first author posed most of the interview questions and moderated the discussions. The second author took a more passive role, listening and making notes during discussions. Just before the end of each focus group, the second author asked questions to clarify discussed content and explore areas less thoroughly discussed. Each focus group lasted approximately 2 h and was audio recorded then transcribed verbatim.

Data analysis

Analysis of study-specific questionnaire

Demographic and quantitative data collected via the survey-specific questionnaire were analysed using descriptive statistics (frequency, percentage, median and range). Text based answers were compiled by the second author, and answers with the same meaning were clustered. Combined with the quantitative data, they were then used to inform the construction of questions in the focus group interview guide.

Analysis of focus group discussions

Focus group data were analysed according to methods described by Krueger and Casey [31]. Initially, both audio and transcribed versions were reviewed several times to become familiar with the material. In the next step, text units from the discussions relevant to the aim of the study were identified and clustered into preliminary categories. The text units in each preliminary category were then further scrutinised until each category comprised a set of sub-categories. At this point, each of the two focus group interviews was analysed separately. When the preliminary results from the two interviews were merged, data were further compared, contrasted and collapsed until a final set of sub-categories and categories emerged. The first author performed all steps of the initial analysis, then discussed with the second author in an iterative process until consensus was reached. All data analysis was conducted in Swedish, the language of data collection.

Results

Participant demographics

All participants held at least a bachelor’s degree in occupational therapy \( (n = 8) \), with some holding master’s degrees (3/8), as well as a council certification as a specialist in occupational therapy (3/8). Most (5/8) had between 1 and 5 years of experience, while three had at least 11 years of experience. Most of the occupational therapists had experience leading patient education programmes (7/8), and six reported having additional education in their area of expertise. Of the eight, all worked in neurological care, with five reporting that their main area of work was with MS clients. Therapists represented different units with a geographical distribution from the north to the south of Sweden.

Programme strengths

Therapists believed the programme supported clients’ participation in their own rehabilitation (8/8 therapists), that it was client-centred (7/8), and that it supported clients to identify resources and possibilities for adaptation (7/8). Further, five out of eight thought the programme used a holistic approach and that it was an evidence-based programme. Interestingly, half of the occupational therapists (4/8) reported the programme was easy to administer, whereas the other half (4/8) stated it was difficult to administer.

Session content delivered (fidelity)

Over the course of the 6 weeks, 81.3% of programme components were delivered to MS clients during the MF programme sessions (range delivered: 74.4–93.6% of planned components) (Table 2). The most consistently delivered components were the interactive lecture component, delivered 93.6% of the planned times and the homework review, at 89.7% of the planned times. All other components were delivered 75% or more of the planned times.

The percentage of components delivered per session also varied. Therapists delivered almost all
components in session one (93.8% of the planned components), but only 67% of components in session two when only 4/8 therapists delivered the activity component. Other than session two, the percentage of components delivered per session ranged from 77.5 to 93.8%.

Attendance rates and therapist impressions of programme acceptability

Attendance rates per group ranged from 73.7 to 93.8% (range 2–9 MS participants per session) over the six sessions (Table 3). Attendance at the first session was highest for all groups with an attendance rate of 100% participants (61/61 participants). Attendance at Session 5 was particularly low for two groups (2/5 and 3/8), however, attendance at the following session (Session 6) improved with an overall attendance of 81%.

The occupational therapists answered seven questions about their impressions of how the MS participants perceived the programme. Therapists believed their clients ‘gained new knowledge’ (8/8 therapists), ‘learned new ways to handle fatigue’ (7/8 therapists), ‘found the programme stimulating and interesting’ (6/8 therapists) and ‘re-organised their lives in some way’ (6/8 therapists). Conversely, therapists did not perceive MS participants to be bored (1/8 therapists) or attending simply to please their physician (0/8 therapists).

Programme relevance and ease of delivery

Overall, the occupational therapists rated session content (Table 4) to be relevant, important, understandable, and culturally appropriate, as all components had a mean rating of greater than 4/5. Therapists rated understandability somewhat lower than the other three dimensions (mean = 4.02). Of the six sessions, they rated Session 3 as the least relevant, important and understandable (mean = 3.88).

Ease of delivery was evaluated, and five believed an introductory course was needed to prepare facilitators to deliver the programme, and four occupational therapists reported that the manual was difficult to use for someone delivering the course for the first time. Seven of eight therapists reported having changed their knowledge of fatigue and the way they implemented MF programmes since being introduced to the programme. Six occupational therapists reported they had added content beyond that included in the programme manual. All eight

Table 2. Delivery of programme components.

<table>
<thead>
<tr>
<th>Session Component</th>
<th>Introduction</th>
<th>Homework</th>
<th>Review</th>
<th>Interactive Lecture</th>
<th>Activity</th>
<th>Homework Assignment</th>
<th>Total Planned</th>
<th>Total Implemented</th>
<th>Sessions Delivered (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session 1, N=8</td>
<td>7</td>
<td>NA</td>
<td>8</td>
<td>8</td>
<td>7</td>
<td>32</td>
<td>30</td>
<td>93.8%</td>
<td>93.8%</td>
</tr>
<tr>
<td>Session 2, N=8</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>4</td>
<td>5</td>
<td>40</td>
<td>27</td>
<td>67.5%</td>
<td>67.5%</td>
</tr>
<tr>
<td>Session 3*</td>
<td>4</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>40</td>
<td>32</td>
<td>80.0%*</td>
<td>80.0%*</td>
</tr>
<tr>
<td>Session 4, N=8</td>
<td>5</td>
<td>7</td>
<td>8</td>
<td>6</td>
<td>6</td>
<td>40</td>
<td>32</td>
<td>80.0%</td>
<td>80.0%</td>
</tr>
<tr>
<td>Session 5, N=8</td>
<td>7</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>6</td>
<td>40</td>
<td>31</td>
<td>77.5%</td>
<td>77.5%</td>
</tr>
<tr>
<td>Session 6, N=8</td>
<td>7</td>
<td>8</td>
<td>8</td>
<td>7</td>
<td>NA</td>
<td>32</td>
<td>30</td>
<td>93.8%</td>
<td>93.8%</td>
</tr>
<tr>
<td>Percent of Component Delivered</td>
<td>74.4%</td>
<td>89.7%</td>
<td>93.6%</td>
<td>78.7%</td>
<td>79.5%</td>
<td>224</td>
<td>182</td>
<td>81.3%*</td>
<td></td>
</tr>
</tbody>
</table>

*Occupational therapist #6 cancelled session 3 due to inclement weather and provided clients with session information by mail. Reported data reflects the cancelled session.

Table 3. MS Participant attendance.

<table>
<thead>
<tr>
<th>OT1 (n=9)</th>
<th>OT2 (n=9)</th>
<th>OT3 (n=7)</th>
<th>OT4 (n=8)</th>
<th>OT5 (n=8)</th>
<th>OT6* (n=5)</th>
<th>OT7 (n=7)</th>
<th>OT8 (n=8)</th>
<th>Median attendance (range)</th>
<th>Percent planned attendance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session 1</td>
<td>9</td>
<td>9</td>
<td>7</td>
<td>8</td>
<td>8</td>
<td>5</td>
<td>7</td>
<td>8</td>
<td>8 (5–9)</td>
</tr>
<tr>
<td>Session 2</td>
<td>7</td>
<td>9</td>
<td>7</td>
<td>8</td>
<td>8</td>
<td>4</td>
<td>7</td>
<td>7</td>
<td>7 (4–9)</td>
</tr>
<tr>
<td>Session 3*</td>
<td>5</td>
<td>9</td>
<td>6</td>
<td>7</td>
<td>7</td>
<td>–*</td>
<td>6</td>
<td>7</td>
<td>7 (5–9)</td>
</tr>
<tr>
<td>Session 4</td>
<td>7</td>
<td>9</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>5</td>
<td>5</td>
<td>6</td>
<td>6 (5–9)</td>
</tr>
<tr>
<td>Session 5</td>
<td>6</td>
<td>5</td>
<td>7</td>
<td>7</td>
<td>2</td>
<td>5</td>
<td>3</td>
<td>5</td>
<td>5 (2–7)</td>
</tr>
<tr>
<td>Session 6</td>
<td>8</td>
<td>9</td>
<td>6</td>
<td>4</td>
<td>8</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>6 (4–9)</td>
</tr>
<tr>
<td>Overall attendance</td>
<td>73.7%</td>
<td>87.7%</td>
<td>92.9%</td>
<td>79.2%</td>
<td>93.8%</td>
<td>80.0%</td>
<td>81.0%</td>
<td>75.0%</td>
<td>(20–50)</td>
</tr>
</tbody>
</table>

*Occupational therapist #6 (OT6) cancelled session 3 due to inclement weather and provided clients with session information by mail. Percentage of planned attendance is therefore based on five sessions for OT6 and for 7 sessions for Session 3.
therapists reported having support from their department to implement the programme, and believed the programme was cost-effective. Seven stated they would recommend the programme to a colleague, and that they would conduct the programme again.

Four main themes, each with subthemes, emerged from the analysis of focus group discussions with the occupational therapists. An overview of the results is described in Figure 1. Results are further described below, together with quotations that illustrate the discussions.

### A structured programme

**An occupational therapy intervention to manage fatigue**

The occupational therapists enjoyed having access to a structured MS-fatigue programme. Prior to the workshop, therapists typically introduced fatigue management strategies during one-on-one therapeutic encounters, without a manual or programme protocol. Furthermore, patient education sessions were primarily delivered in a lecture-style with limited emphasis on facilitating goal-setting, behaviour change processes, and provision of fatigue interventions in group formats was rare. Therapists reported being surprised at the significant impact that the session on “resting” had on MS participants’ ratings of fatigue, and how they seemed to reflect in more depth on their need to rest during the group programme, compared to during individual interventions.

The theoretical aspects of the programme, including psycho-educational group development principles and the role of dissatisfaction and resolution, were both new to the therapists. This information helped them to understand the reactions of individuals and the group, to pose reflective questions and direct group discussions, and to initiate reflections and individual development. Yet, they perceived the lack of a clear occupational therapy model or theory in the manual, something they were used to from other programmes. Being able to position the programme in context with other interventions they worked with also helped them integrate the programme into their current clinical practice.

### Table 4. Therapists’ ratings of the Managing Fatigue programme content (% 8).

<table>
<thead>
<tr>
<th></th>
<th>Session 1 (mean)</th>
<th>Session 2 (mean)</th>
<th>Session 3 (mean)</th>
<th>Session 4 (mean)</th>
<th>Session 5 (mean)</th>
<th>Session 6 (mean)</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relevant*</td>
<td>4.63</td>
<td>4.63</td>
<td>3.63</td>
<td>4.25</td>
<td>4.75</td>
<td>4.75</td>
<td>4.44</td>
</tr>
<tr>
<td>Important*</td>
<td>4.88</td>
<td>4.75</td>
<td>3.75</td>
<td>4.63</td>
<td>4.75</td>
<td>4.75</td>
<td>4.59</td>
</tr>
<tr>
<td>Understandable*</td>
<td>3.75</td>
<td>4.63</td>
<td>3.88</td>
<td>3.71</td>
<td>3.88</td>
<td>4.25</td>
<td>4.02</td>
</tr>
<tr>
<td>Culturally appropriate*</td>
<td>4.5</td>
<td>4.12</td>
<td>4.25</td>
<td>4.75</td>
<td>4.75</td>
<td>4.88</td>
<td>4.54</td>
</tr>
<tr>
<td>Overall Mean per Session</td>
<td>4.44</td>
<td>4.53</td>
<td>3.88</td>
<td>4.34</td>
<td>4.53</td>
<td>4.66</td>
<td></td>
</tr>
</tbody>
</table>

*Five-point rating scale, higher values are more positive.

![Figure 1. An overview of the three main themes and subthemes.](image-url)
Therapists revealed that even if the MF programme clearly is an occupational therapy intervention, the manual did not specifically suggest using outcome measures focusing on engagement in occupations. They argued that adding such tools could provide a better overview of how MS-fatigue influenced MS participants’ everyday occupations and occupational performance. They also believed knowledge gained from such tools could assist therapists to tailor programme components during the course, as well as help clients transfer knowledge learned during the programme to performance of occupations in their everyday life. A few, however, were more hesitant to add more assessment tools, not wanting to increase the paperwork and client burden. The different perspectives are illustrated in this discussion:

Participant 4: “It is crucial to put a lot of effort into the pre-group session… but it [the manual] misses getting deeper into [clients’] occupations and occupational history. The questions that were included [in the manual] focus on diagnosis and other aspects but there are no assessments specifically of occupations… Maybe the ADL-taxonomy, the COPM [Canadian Occupational Performance Measure] or the MSIS-29 [The Multiple Sclerosis Impact Scale-29] can be used…”

Participant 1: “I used the MSIS-29 with all my clients… and the FSS [Fatigue Severity Scale]. I also did the COPM with half of the group but it became awkward… I’m not familiar with using that tool. I decided to do an informal interview instead because it was too many papers to fill in.”

Participant 2: “I used the COPM with all my clients and tried to emphasise that they should focus on occupations that were important for them, and to select those that were influenced by their MS-fatigue. It gave me a solid foundation. They also had to fill in the different scales [fatigue]… It wasn’t too many forms. Well, some thought it was a bit tedious but afterwards, when we evaluated, they were pleased with having the results in black and white, not only experiencing an improvement… But yes, it does take time [to do the assessments].”

**Catalysing client awareness and process of change**

Therapists described the belief that the programme helped to initiate the process of change among participating MS clients. Therapists attributed this change to programme features such as its length and the homework assignments, which allowed MS clients to engage in the therapeutic process and implement newly-learned strategies into their lives. However, as some clients had barely started their process of change by the end of the programme, therapists suggested that follow-up, of at least 6 months, should be implemented after programme completion. Recognising that MS clients engaged in the change process at their own pace, therapists emphasised the importance of being able to address goals, homework, struggles, and questions with each MS client during the programme. To achieve this, they agreed that a maximum of eight MS clients should be included per group. Others, however, reported on their experience with two programme leaders per group, concluding this arrangement allowed for inclusion of more MS participants.

Therapists described how the programme provided their MS participants with an increased awareness of how available rehabilitation interventions could potentially contribute to a better quality of life, and some became more willing to explore interventions and strategies previously neglected or unknown. While some were occupational therapy interventions (such as learning alternative ways of performing occupations, having access to housing adaptations, or use of assistive technology), some were also interventions provided by other professions (for example social workers or physical therapists). Therapists attributed this to the group format which gave MS participants an opportunity to share experiences with others in the same situation. They also shared positive experiences of the programme with their referring physician and with others with MS-fatigue who had not attended a MF programme. This led to an increase in referrals to the programme, as well as to occupational therapy in general.

**Building on previous expertise**

**Preparing and becoming familiar with programme content**

The occupational therapists described the need to thoroughly prepare themselves to become familiar with the materials, sessions, and terminology in order to explain aspects to their MS participants. Some struggled to learn the materials. For instance, the difference between the terms budgeting and banking was difficult to comprehend. One participant said she changed the analogy from one based on economic terms, instead using electrical terms, e.g. battery, charging etc. Other therapists preferred to use the term occupational balance, a term they found more familiar. “Norms” was another challenging term, also difficult for some MS participants to comprehend. Nevertheless, therapists emphasised that as long as the main message was understood and stimulated a reflective process among the MS participants that was in line with the manual, the terms used may be of minor importance.
Therapists also valued the 2-day training workshop they participated in prior to delivering the MF programme. They specifically emphasised the importance of offering new programme leaders at least a 1-day course focusing, in particular, on learning the basic theories and concepts such as the theory of readiness to change and the different phases of group development, as illustrated by this discussion:

 Participant 4: “…The steps in the model [readiness for change] were very useful for me when some clients wanted to change whereas others did not… it’s a great model to lean on when one is leading this course.”

 Participant 1: “Yes, I agree. One of my clients was very angry… it became very emotional for her when she realised she had to go through a change to have a better life situation. I could use the knowledge I learned [during the workshop] that people can react with anger… it’s mixed feelings for clients when they understand and try to act based on their new knowledge. It happened several times [during the course].”

 Participant 4: “The questionnaire with different colors [decision matrix] is something I showed my team members and now all of us use that. It’s a very useful tool to identify how motivated our clients are.”

 Participant 2: “If I had only received the manual, I don’t think I would have dared to [lead the MF programme]… it’s much better to have the opportunity to go through the different steps [in the manual].”

 Participant 2: “…All course leaders should take it. To receive a workshop or something where you can discuss how to go through the different parts in the manual, preferably a workshop that goes through the process of change and motivation to change.”

 Participant 3: “Participating in a workshop also gives you the opportunity to meet others [colleagues]… maybe from the same region that you can continue discussion with if needed.”

Building on previous knowledge, experience and expertise

The occupational therapists agreed on the importance of having previous experience working with MS clients, specifically an understanding of how MS-fatigue can affect clients’ everyday occupations. This included therapists with knowledge of solutions successful to other clients with MS-fatigue.

Overall, the occupational therapists reported that the programme was well suited for occupational therapy practice and emphasised the need to inform occupational therapy colleagues, in order to increase the number of occupational therapists offering this intervention.

Recruiting clients for groups

Selecting suitable clients

Therapists agreed that selection of suitable participants for the MF programme had to be decided based on individual client needs, and noticed how symptoms such as cognitive impairments or depression could be a barrier to group participation. While some therapists were reluctant to include any clients with these symptoms, others suggested including only those for whom the symptoms were less severe. There was greater agreement regarding suitability of clients thought to lack motivation to participate. Instead of participating in the MF programme, therapists suggested these clients should receive treatment for their symptoms, and other interventions that potentially could motivate them to participate in the programme in the future. Therapists also believed that including clients who had been unsuccessful with other programmes, could negatively influence group collaboration and other participants’ experiences.

Finally, therapists described how collaboration with other professionals was important during the selection process. They agreed that information about the programme should be communicated to other health professionals to ensure programme suitability for clients who were referred and recruited.

Forming a collaborative group of clients

During the selection procedure, the occupational therapists considered the diversity between, similarity among, and motivation of potential MS participants. They discussed how they had selected people who were both similar but also different in terms of their impairments and age, as it enabled MS participants to find role models within the group. Potential participants’ understanding of the programme also influenced selection. Therapists reported how some clients accepted participation only because they were offered a rehabilitation intervention, and not because it specifically focused on managing fatigue. Others agreed to participate due to its specific focus on fatigue, and because they expected it to be less intensive than inpatient rehabilitation programmes.
Integrating programme into current practice

Adapting programme content to fit participant needs

The occupational therapists shared different ways they had adapted programme components for their group participants. For instance, parts of the biomechanics session included standing positions, and therefore needed to be augmented and adapted for wheelchair users. Sometimes discussions also had to embrace topics the group specifically wanted to focus on, something the manual was flexible enough to allow.

Assignments were appreciated, and considered important, but at the same time some MS participants reacted negatively because they thought they were too extensive. To enable them to get started, and complete the home assignments, therapists tried to allocate plenty of time to initiate the assignments during the sessions. They also adapted them according to individual needs. For example, they prepared completed handouts as examples when some MS participants had difficulty understanding the assignment or its relevance. Others adapted the style of the home assignments. For example, for clients with vision problems, therapists used symbols or enlarged the charts; if clients were not able to read material presented on the screen, paper copies of the session material were provided. In some cases, MS participants asked for electronic handouts.

Several therapists reported insufficient time for the group to discuss ways they communicated their MS-fatigue to others, during session 2. This topic was emotionally charged and many MS participants were eager to discuss it, and in some of the groups, this topic filled an entire session. In these cases, the programme material had to be re-arranged. The therapists discussed how communicating fatigue is not commonly included in individual occupational therapy interventions, and several therapists were surprised at how important it was to their MS participants. Some therapists questioned the sequence of programme material, finding it awkward that communication skills shared a session with, and was discussed prior to, body mechanics. They questioned the inclusion of two very different topics in a single session. Other therapists were more positive, arguing that pairing these topics improved the programme structure, and facilitated the discussions by allowing for both the less emotional topic of body mechanics, with the more emotional topic of communication.

Therapists discussed how to handle the situation when MS participants were absent. Since the sessions were thoroughly described in the manual, they found that the summary from each session provided a useful tool to review missed content with individual clients; others sent programme material directly to absent clients. A few times, sessions were postponed or canceled. One occupational therapist shared how she had had to postpone Session 3 due to a snowstorm and was unable to add another session. Instead, clients worked with the material on their own, which had been a successful alternative.

Integrating into an inter-professional clinical environment

Negotiating the place of the MF programme within an inter-professional work environment where a variety of fatigue interventions were already offered, was required of some of the therapists. Once team members understood how the MF programme could complement other interventions, many were positive. Some therapists had replaced recommended fatigue assessments with the ones already used by their department. Another therapist shared how adapting the programme to the department meant the 6-week programme had to be completed in the 4 weeks when clients were present. Without this adaptation, MS clients would have been unable to attend the programme.

Therapists discussed practical aspects of implementing the MF programme in clinical practice. For instance, documenting participation in the programme in clients’ medical records was a challenge in some settings since each county in Sweden sets its own process and standards regarding documentation of educational programmes. Therapists also emphasised the importance of being able to register client participation in MF programmes in the Swedish National MS-register in the future. Otherwise it will not be possible to track how many clients have been offered the programme, and if there are differences within the country. Another challenge was related to clients who were working and needed to be on sick-leave in order to participate in the programme. Sick-leave had to be approved by the Swedish Social Insurance Agency, who normally require MS clients to attend a rehabilitation programme lasting full days for several consecutive weeks. Because the MF programme only lasted 2-h per day, it was challenging to communicate this alternative pattern of sick-leave to authorities.
Updating the manual to fit current needs

Therapists felt certain topics could be updated to better reflect MS clients’ current needs within the Swedish context. The importance of including ergonomics was discussed, and some therapists said they spent no or only little time discussing the importance of having elevating chairs and desks at workplaces, since they argued this is common knowledge and every workplace has to actively prevent work-related hazards. Others said they did spend time discussing these matters. Some MS clients prioritised discussing ergonomics in relation to the occupations they did in their home environment, instead of those at work. Therapists also emphasised the importance of including more information about cognitive fatigue, and how it can influence MS clients’ everyday life, especially their working conditions. Therapists desired material to open and facilitate discussions regarding fatigue related to working in an open office space, and many MS participants requested more information about stress and its relation to fatigue. Some therapists included discussions on these topics and argued the programme needed to include strategies to manage cognitive fatigue:

Participant 8: “The manual is rather focused on physical rather than cognitive fatigue. This became evident from the group discussions when communicating fatigue in relation to cognition was more important to focus on.”

Participant 6: “I agree, but we didn’t have the time. We rushed through those parts to also find the time to discuss chairs and such [body mechanics].”

Participant 7: “You mentioned the [session Activity stations] ... when body mechanics and environments [were discussed], it was very focused on physical aspects. My clients said they experience cognitive impairments ... dealing with, for instance, how to organise their workspace, how to manage when they lose their train of thought when people call. We talked about [using] headsets, getting rest and recuperation, and actions to avoid getting disturbed. It’s much more cognition, hidden impairments and consequences for their working environment. I didn’t talk much about chairs and such, more about shutting out outer stimuli to handle everyday tasks during a work day. That was my clients’ concerns.”

The potential to include supplementary or optional material was raised. Therapists argued this would allow programme leaders to choose information relevant to their current group of participants. Other aspects raised were related to outdated quotations in the PowerPoints, not applicable to people with disability today. A few also felt the crossword could be taken out, since it did not add extra value to the MF programme.

Therapists expressed surprise that no family or caregivers were involved in the programme, something they were used to from their clinical practice. Potentially, it could increase their knowledge of MS-fatigue, and perhaps also facilitate communication of MS-fatigue related problems. A few of the MS participants stated they would have liked to have a family member with them during the programme.

Discussion

The results of this study show that the Swedish translation of the MF programme is feasible, and highly relevant in a Swedish context. All occupational therapists who participated in the study successfully recruited MS clients and ran the Swedish version of the MF programme; therapist ratings of the relevance, importance, understandability and cultural appropriateness of the sessions had mean scores of greater than 4/5. Still, there are aspects that can be further developed in order to better fit current MS clients’ needs and facilitate the delivery of the programme in a Swedish, and perhaps other contexts.

Many of the therapists reported having worked with their MS clients to manage their fatigue prior to using the MF programme, but mainly on an individual basis. Despite their previous expertise, most reported that their knowledge of fatigue and the way they implement fatigue programmes had changed since being introduced to the programme. This is not surprising since they also revealed being unfamiliar with running self-management programmes. Self-management programmes promote a client-professional collaboration where clients learn problem-solving skills to generalise and use in their everyday life [37]. This is in contrast to other educational programmes where clients passively receive professionals’ ready-made solutions often resulting in clients being less involved in their own rehabilitation process. In Sweden, the importance of implementing person-centred care [38] has been emphasised. Similar to self-management interventions, person-centered care also emphasises a collaborative approach where clients and professionals mutually develop an individual health plan, focusing on goals and needs each client identifies as important [39]. Still, the Swedish Agency for Health and Care Services Analysis [40] has reported that Swedish people with chronic conditions are less involved in their health care compared with peers in other countries. Only four out of ten stated that they
discussed goal setting or priorities in relation to possible interventions. This implies that health care professionals in Sweden are less used to collaborative care initiatives and may explain why the therapists in our study were not used to self-management interventions. Yet, they were very excited to learn how to implement self-management interventions in their practice, and said it fit well with the underlying principles of occupational therapy, and client-centered practice. Because they felt they did not have the knowledge and skills to implement self-management interventions, they valued the pre-workshop training they received, noting the additional knowledge gained regarding psychoeducational group facilitation, self-management, and readiness for change. In fact, they believed this knowledge was necessary to successfully deliver the programme; knowledge that could be acquired in a 1-day training workshop.

Even though therapists clearly identified the programme’s client-centred approach [11], in their opinion, the programme lacked a clear occupational theory, compared to other Swedish intervention programmes they were used to working with. This may be explained by the fact that in 1995, when the MF programme was first developed and published, coherent theories of occupation were in their infancy. Still, they acknowledged the client-centered approach that enabled them to adapt programme content to the needs of their clients while still maintaining fidelity and dose delivery. Six of the seven therapists reported they had added optional or supplementary content beyond that included in the programme manual, mainly in relation to how to deal with cognitive fatigue, and stress. They argued addressing these aspects was much more important than discussing ergonomics in relation to elevating chairs and desks at workplaces. Even if this is common knowledge it does not mean people use workplace ergonomic strategies or that they link them to managing fatigue. Consequently, it is important to update the programme with new knowledge without taking out previous information. Adding content about cognitive fatigue also reflects the fact that, despite the new medical treatment options, fatigue and cognition are related impairments that continue to be very common among people with MS, and have a large impact in their lives [41]. Updating the programme content could potentially alter the evidence base of the programme. Because the updates mainly concerned addition of content related to aspects already addressed, and without altering programme structure or delivery, this risk is low. In addition, the self-management principles [10,37] upon which the programme draws, encourage participants to focus on topics of most importance and to select strategies of most relevance to their own lives. Adding a small amount of additional material improves participant options.

Some therapists altered aspects of delivery to tailor the programme to their clients’ needs. For instance, they used electronic handouts, made summaries for missed sessions, and altered the time frame to meet the needs of inpatients. In relation to this discussion, therapists also raised some concerns regarding recruitment of clients to different groups. They were especially concerned with how to deal with the inclusion of clients who were not motivated or those who have cognitive difficulties. Finlayson et al. [42] described how the MF programme can be used with people with cognitive difficulties, and other articles have shown it is effective in different formats [19,20]. Adding additional occupation-based assessment tools, e.g. the COPM, were also suggested by some therapists who argued these tools could help clients identify activities that are affected by their fatigue and that they wanted to be able to perform or participate in, in the future. This has been described in previous studies, showing that using the COPM can help clients identify personally meaningful activities to focus on, at the same time becoming more actively involved in the goal setting procedure [43]. In the present study, therapists argued that results from the COPM could potentially help clients transfer knowledge gained during the MF programme into their daily lives, thereby facilitating the process of change, in line with a previous study by Kos et al. [44]. This is also similar to previous research reinforcing a focus on clients’ meaningful occupations during rehabilitation interventions, in order to support adaptation [45]. Therapists specifically said the homework assignments were a crucial mediator in this respect, but at the same time they described how clients often struggled to understand and finish the homework. Still, therapists reported all programme components, including homework assignments, were delivered 75% or more of the planned times.

Overall, therapists were positive about the MF programme, and believed MS participants appreciated both the content and the group format, believing these to support participation in their own rehabilitation. This confirms previous research where participants in the MF programme have confirmed the key features of the programme as opportunities to share stories and learn from each other, activities to test out new strategies, opportunities to learn and problem-
solve, try new strategies, and facilitation by a know-
ledgeable health professional [46]. All therapists also
reported having support from their department to
implement the programme again in the future. At the
same time, they raised a number of aspects that need
to be addressed to support implementation of the
programme on a more regular basis. For instance,
how to ensure documentation is filed in medical
records and logged in the national MS-register, and
to justify sick-leave insurance entitlement needs
consideration. Furthermore, to implement the pro-
grame within an inter-professional work environ-
ment requires collaboration with other health care
professionals. It should also be noted that there are
other programmes that address managing fatigue
from different health professionals’ perspectives [27],
as well as from an inter-professional perspective [47].

Turning to methodological considerations, the
sample size in our study was small, and therapists
were recruited through self-selected participation.
Even though the included therapists had different
backgrounds, and represented different parts of
Sweden, many worked in similar settings, i.e. neuro-
logical clinics. It is therefore possible that therapists
from other areas, e.g. primary health care, may have
different experiences providing the programme, and
delivering it as intended. Data were collected from
therapists only, and not from MS clients who partici-
pated in the programme, meaning that true receipt
fidelity could not be measured. Instead therapists
were asked about their impressions of MS clients’
engagement with the programme. Consequently, there
is a need for future studies to capture feasibility di-
rectly from the perspectives of MS clients who partici-
pate in the programme. Further, therapists’ self-report
of delivery fidelity may have been subject to bias.
Future studies of effectiveness may benefit from more
rigorous measures of fidelity. Finally, as the first
Swedish study, the authors were involved in both the
development of the Swedish version and its testing.
While this may be interpreted as a positive bias,
intimate knowledge of the programme was considered
an asset, rather than a limitation.

In conclusion, this study shows that the Swedish
translation of the MF programme is feasible, and
highly relevant in a Swedish context. The client-cen-
tred and occupation focused nature of the programme
is consistent with occupational therapists’ scope of
practice. To facilitate the MF programme’s implemen-
tation in Sweden, a short professional development
workshop is recommended before delivering the
intervention. This study provides important

information of an intervention that Swedish occupa-
tional therapists can offer to clients with MS-fatigue,
and at the same time help therapists become evi-
dence-based practitioners.

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