

# Multiple Sclerosis Fatigue Self-Management: Strategies and Influencing Factors 5 Years After a Multimodal Intervention

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## ABSTRACT

**BACKGROUND:** Fatigue: Take Control (FTC) is a multimodal self-management program. Results of a previous clinical trial showed its effectiveness at improving fatigue related to multiple sclerosis (MS). The objectives of this study were to use the very long-term data from the FTC study to understand fatigue management strategies used 5 years after enrollment, identify facilitators and barriers to utilizing strategies, and explore the potential relationships between the strategy used and fatigue outcomes.

**METHODS:** This study adopted a cross-sectional survey design. A subset of the original FTC clinical trial participants was invited to complete the Modified Fatigue Impact Scale for fatigue severity measurement and a 17-item questionnaire about their fatigue management strategies 5 years after enrollment. Descriptive statistics and content analysis were used to analyze quantitative and qualitative data using the COM-B (capability, opportunity, motivation-behavior) model for behavior change as a framework.

**RESULTS:** Planning daily activities and prioritizing tasks were the fatigue management strategies most often reported. Facilitators to utilizing management strategies included access to enabling devices, paid professional help, companions, and maintaining a positive attitude. Barriers to implementing strategies included high cost, the presence of other health problems, and temperature sensitivity. Internal focused strategies showed a trend toward reducing fatigue impact when controlled for typology group assignment.

**CONCLUSIONS:** Future work may focus on promoting low-cost strategies to help people with MS manage fatigue. Internal factors (eg, motivation) play an important role in influencing the application of MS fatigue self-management strategies. Future clinical trials with larger sample sizes that assess the applicability of the COM-B model are warranted.

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Multiple sclerosis (MS) is a chronic inflammatory and degenerative disease of the central nervous system. MS-related symptoms may vary by person, but fatigue is experienced by over 80% of people with MS and is often perceived as the most debilitating symptom, substantially impacting quality of life.<sup>1</sup> MS-related fatigue is distinctive because it is unpredictable and fluctuates in association with heat and humidity. People with MS may experience fatigue symptoms that can manifest suddenly and worsen over time, which eventually negatively impacts their ability to participate in daily activities.<sup>2</sup> Previous literature shows that nonpharmacological interventions for MS fatigue are preferred over pharmaceutical therapies given the lower cost, fewer adverse effects, and better efficacy.<sup>3</sup>

Self-management programs for chronic conditions, including MS, are nonpharmacological interventions that educate people on how to actively manage the impact of their conditions through behavioral change.<sup>4-7</sup> Since publication of the 1998 international treatment guidelines<sup>8</sup> outlining recommendations for fatigue management, various self-management programs have been developed that are specific to MS fatigue management. Some focus on a single strategy, such as energy conservation,<sup>4,5</sup> while others recommend using multiple strategies, including medical treatment, physical exercises, and psychological support.<sup>6,7</sup> These programs have shown promising effects in improving MS fatigue and overall health outcomes. As an example of a multimodal behavior change intervention, the Fatigue: Take Control (FTC) program is an MS fatigue-specific education program that provides knowledge and skills to self-manage fatigue. A multisite randomized controlled trial (RCT) showed that the FTC was effective in reducing fatigue impact at the 12-month follow-up.<sup>9,10</sup> However, very few studies have been conducted to examine whether the program remains effective in the very long term (VLT; ie, 5 years post intervention). In a quantitative report, Norton et al<sup>11</sup> compared the VLT fatigue impact and behavior changes in individuals

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**TABLE 1.** FTC and MSTC Program Content

FTC	MSTC
6 weekly, in-person, 2-hour, small-group sessions (8-10 people/group)	6 weekly, in-person, 2-hour, small-group sessions (8-10 people/group)
Session titles	
Medical Management of Fatigue Making Proactive Energy Choices Adding Exercise to Your Life Modifying Your Environment Making Changes and Choices to Take Control of Fatigue Final Session	Food for Thought: MS and Nutrition Vitamins, Minerals, and Herbs in MS Taming Stress in MS MS and Your Emotions Solving Cognitive Problems Urinary Dysfunction and MS

FTC, Fatigue: Take Control; MS, multiple sclerosis; MSTC, MS: Take Control.

who received FTC with those who received a comparable program (MS: Take Control [MSTC]) and found no difference in the VLT benefits between the 2 programs after 5 years. They also reported that the most frequently endorsed strategies during these 5 years were prioritizing activities (76%), managing sleep quality (69%), managing weakness (66%), managing diet (65%), changing exercise routine (64%), and managing heat sensitivity (63%). However, little is known about how participants were using these strategies 5 years after enrollment and what factors may have influenced their endorsement of certain strategies. Therefore, the purpose of this study is to (1) understand how people with MS used the endorsed strategies to manage MS fatigue 5 years after enrollment, (2) identify facilitators and barriers to strategy utilization, and (3) explore potential relationships between strategy used and fatigue outcome.

### *Michie's Capability, Opportunity, and Motivation Behavior Model (COM-B)*

Previous studies have demonstrated the value of using the COM-B model and Theoretical Domains Framework (TDF) to understand factors contributing to physical activity among people with MS. Specifically, Riemann-Lorenz et al<sup>12</sup> and Silveira et al<sup>13</sup> reported long-term (12 months) adherence and determinants of physical activity among people with MS in Germany and the United States using the COM-B framework. Both studies developed survey questionnaires mapping to the TDF constructs and COM-B model. The COM-B model<sup>14</sup> assumes that behavior is influenced by 3 factors—the person's physical and psychological capability, the person's physical and social opportunity, and the person's reflective and automatic motivation—and that behavior change can only come about if 1 or more of these 3 components are modified. Capability and motivation are considered internal. Opportunity refers to physical and social factors outside of an individual's control; hence, they are external. The 14-item TDF<sup>15</sup> provides an explanation to the 3 primary sources of behavior in the COM-B model (eg, knowledge, skills, beliefs about capabilities) and especially aims to help with evaluating barriers and facilitators of the studied behavior. See [FIGURE S1](#) for details on the relationship between the COM-B model and TDF framework.

This study utilized COM-B and TDF as guiding frameworks to interpret data that had already been collected, as the

FTC program was developed before the COM-B model was available. It is important to note that the COM-B model and TDF are not study aims. Rather, they served as guides and tools for our analyses.

## METHODS

### *Parent Study Background*

The original multisite RCT (N = 204) compared the MS fatigue-specific intervention program, FTC, with a general MS education program, MSTC, on fatigue impact using the Modified Fatigue Impact Scale (MFIS).<sup>16</sup> [TABLE 1](#) shows the content of both interventions. Both programs demonstrated effects in fatigue impact reduction, but outcomes did not differ between the programs immediately following program completion or at 3- or 6-month follow-ups.<sup>9</sup> However, there was a clinically meaningful and statistically significant improvement in the FTC group relative to the MSTC group at the 12-month follow-up at 1 site (n = 74).<sup>10</sup> This led us to wonder whether there were long-term benefits of FTC that were not identified in the initial study. To that end, institutional review board approval was sought for a 5-year follow-up to retest the MFIS scores and develop a survey ([TABLE S1](#)) to assess participants' current experience of fatigue management. Additional details of the programs, approvals, consent, and trial design have been reported previously.<sup>9-11</sup>

### *Design and Sample*

The present study was a cross-sectional survey collecting quantitative and qualitative data. Convenience sampling<sup>17</sup> was used to recruit participants from the original RCT who completed the 12-month follow-up at 1 site (out of 4), regardless of their initial group assignment. At the original study's baseline, 74 ambulatory adults with MS of any subtype on any medications with moderate to severe fatigue (MFIS,  $\geq 25$ ) and without severe depression (Beck Depression Inventory-II,  $\leq 28$ ) participated.

### *Measures Survey*

The 17-item survey in [Table S1](#) was developed by the experts who helped develop FTC. This survey asked about the self-management strategies used by study participants 5 years

**TABLE 2.** MFIS Scores by Survey Response Typology

FTC		MSTC			
MFIS: baseline	5-6 year follow-up	MFIS: baseline	5-6 year follow-up		
Internal focused	43	<b>33*</b>	43	<b>31*</b>	
	56	<b>35*</b>	30	47	
	81	<b>66*</b>	Internal focused	44	<b>29*</b>
	50	53		34	<b>20*</b>
			54	<b>37*</b>	
Lack of control	82	<b>73*</b>		54	62
	53	<b>43*</b>		81	<b>51*</b>
	38	44	Lack of control	39	45
	37	40		40	50
	44	46			
External focused	57	67		50	61
	36	57	External focused	46	<b>36*</b>
				51	46
			36	50	
Combined	57	<b>44*</b>		33	<b>24*</b>
	41	<b>39</b>		49	58
	35	<b>34</b>	Combined	34	30
	28	<b>21*</b>		54	<b>40*</b>
			41	57	
			<b>71</b>	<b>72</b>	
Limited response				34	34
			Limited response	42	53
			27	28	

FTC, Fatigue: Take Control; MFIS, Modified Fatigue Impact Score; MSTC, MS: Take Control; VLT, very long-term.

Note: Bold type means reduction in MFIS score at VLT follow-up.

\*Clinically meaningful reduction of MFIS score ≥ 7 points difference from baseline to VLT.

after enrollment in the initial RCT. More specifically, 15 questions were asked about participants' current use of FTC strategies for managing MS fatigue. The last 2 questions asked participants what they recalled of the RCT interventions and what additional strategies they were currently using for fatigue management. Each question allowed yes and no answers and free responses.

**MFIS**

The MFIS<sup>16</sup> is a validated, self-reported outcome measure assessing the impact of MS fatigue on individuals' physical, cognitive, and psychosocial functioning over the past 4 weeks. The 21-item MFIS asks participants to rate their perceived frequency of certain fatigue-related situations. Each item is scored from 0 to 4, with 0 indicating *never*; 1 *rarely*; 2 *sometimes*; 3 *often*; and 4 *almost always*. A higher total score indicates a higher level of impact on functioning, which reflects a higher fatigue severity.

**Procedure**

Surveys were sent via the mail. Participants' demographic data, such as age, sex, and income, were retrieved from the parent study.

All participants signed a Veterans Administration Portland Healthcare System Institutional Review Board-approved consent form at parent-study enrollment and again 5 years later. Participants provided verbal consent prior to receiving the mailed questionnaires for the follow-up survey.

**Analysis**

**Quantitative Data Analysis**

The descriptive statistics method was used to report participant characteristics and the most endorsed strategies.

**Qualitative Data Analysis**

Content analysis<sup>18</sup> with a combination of deductive and inductive coding approaches was used to analyze the free responses

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that were stored in Microsoft Excel. Initial coding was guided by the FTC program. Following this, a codebook was developed using an iterative process. Themes were generated with the guidance of the COM-B model and finalized with consensus among research team members.

To explore the potential relationship between strategy uses and fatigue outcomes, we created a summary for each participant in 3 areas reflected by survey responses: (1) expressed emotion, (2) number of strategies, and (3) use of external aids in managing MS fatigue (TABLE S2). We then classified these characteristics into 5 categories: internal focused, combined, lack of control, external focused, and limited response. Internal-focused answers centered on mindfulness, determination, knowledge, and skills corresponding to *being in control* or *willing to try*. A combination of strong internal-focused answers with the use of multiple external aids, including devices and help from others, would be classified as *combined*. Lack of control answers exhibited the sentiment of *not being in control*. Those who relied almost exclusively on external aids/help were grouped under *external focused*. *Limited response* included 3 participants who responded to limited items or with limited words and hence were impossible to categorize in any of the 4 other subgroups. Once typology subgroup was assigned, individuals were divided, based on their group assignment in the original trial, as FTC or MSTC.

The person's MFIS scores at baseline and 5-year follow-up were also compared.

### Positionality Statement

The authors do not self-identify as people with MS or other disabilities. While all of us have either clinical and/or research experiences working with people with MS and other chronic conditions, we do not have insider perspectives or lived experience in managing chronic disabling symptoms (eg, fatigue) on a daily basis. We appreciate participants' firsthand perspectives that enabled us to better understand their experiences of fatigue management.

## RESULTS

### Participant Characteristics and Descriptive Statistics

Thirty-eight of 74 participants from the 12-month follow-up responded to the VLT follow-up survey. One was removed from this report due to no free responses, so the final sample included a total of 37 participants. Of the 37, 31 were women and the average age at baseline was 55 years (range, 31-73). Thirteen participants reported less than \$30,000 in annual income. Fifteen were from the FTC group and 22 were from the MSTC group. Twenty-two participants were diagnosed with relapsing-remitting MS and 15 had progressive MS. Additionally, previously reported quantitative data from the VLT survey showed no significant differences in the baseline demographic characteristics and MFIS scores among participants ( $n = 37$ ) and nonparticipants ( $n = 36$ ) of the current study.

On average, participants endorsed an average of 8 strategies (range, 1-14). Thirty-two participants reported using 4 or more strategies, 3 participants reported using 3, and

2 reported using only 1 strategy. Of the 15 strategies listed, the 7 most endorsed were: planning daily activities ( $n = 28$ ), prioritizing tasks ( $n = 28$ ), managing sleep habits ( $n = 25$ ), managing eating habits ( $n = 24$ ), managing weakness ( $n = 23$ ), managing heat sensitivity ( $n = 22$ ), and resting/napping ( $n = 22$ ).

### Qualitative Findings

With guidance from the COM-B model, 2 themes were generated from the free responses to the survey. Theme 1 presented the most frequently used strategies for MS fatigue management as well as how they were used among participants, representing the *capability* construct in COM-B. Theme 2 aligns with COM-B's *opportunity* and *motivation*, revealing internal and external facilitators and barriers to implementing useful strategies. Example quotes for theme and subtheme are presented in TABLE S3.

#### Theme 1: Frequently Used Strategies for MS Fatigue Management

**Improve efficiency and productivity by strategic planning.** Most participants shared that strategically planning their day according to their energy level and the importance of tasks was an effective way to minimize the impact of fatigue on their daily functioning and maximize productivity. For example, participants who are aware that their fatigue typically progressed as the day went on would try to arrange most activities during the time when they had higher energy levels. As one stated, "Anything that uses extra energy is done in the morning." They also scheduled activities based on their priority. For things that are less time sensitive, participants shared the mindset that not everything has to be completed on the same day, as this would probably worsen the fatigue.

**Energy conservation: pacing, resting, using assistive devices or services.** Energy conservation by pacing activities, resting, and using external aids was another common strategy shared by participants. Knowing that fatigue is a physical and mental state where energy is lacking, participants shared that energy conservation was a great help to prevent fatigue or slow down fatigue progression. Participants described various ways they save energy daily. Examples included taking more breaks during physical activities, using mobility aids like walkers and scooters for longer travel, using assistive tools like reachers/grabbers, and delegating tasks like cooking and cleaning to others.

**Improve sleep quality.** Many participants recognized the relationship between sleep quality and fatigue; therefore, taking steps to improve sleep quality was key to managing fatigue. However, participants expressed that improving sleep quality was challenging due to other sleep-disrupting symptoms such as muscle spasms, bladder problems, and heat sensitivity. Hence, in addition to making modifications specific to sleep hygiene (eg, avoiding blue light before bedtime and adjusting the bedroom temperature for comfort), participants also attempted to improve sleep quality through management of other symptoms, including making



nighttime bathroom trips more convenient with a commode in the bedroom and investing in sleep-enhancing products like cooling pillows and lightweight blankets.

**Stay physically active without overexertion.** Although acknowledging the benefits of physical activity and the importance of staying physically active, our participants were keen to avoid the overexertion and overheating that could exacerbate their fatigue. They implied that knowing which type of exercise was beneficial, limiting the time spent on physical activities, and using tools to prevent overheating were crucial to prevent increased fatigue due to overexertion. To achieve these goals, participants shared that they learned to become knowledgeable about the amount of exercise that worked best for them, utilized fitness tracking devices to monitor the amount of exercise, and carried “cooling wraps and a small backpack that is an insulated cooler for extra ice packs” when the temperature was hot.

**Maintain a healthy diet.** When the original program interventions were delivered in 2013 and 2014, the American Heart Association guidelines for healthy eating were used in both the FTC and the MSTC. Many participants said they endorsed dietary adjustments and mindful eating habits to manage symptoms such as overheating, appetite changes, and hot flashes, all of which could aggravate fatigue. For example, a participant shared, “I try to limit myself to 2 cups of coffee per day, since I noticed too much caffeine makes me overheated.” Some participants also shared that they felt better after switching to a plant-based diet.

## Theme 2: Facilitators and Barriers Influencing the Implementation of Fatigue Management Strategies

This theme identified external and internal factors that supported or interfered with the implementation of strategies for MS fatigue management. Participants reported that availability and access to needed devices and services, the presence of a companion, and support from family were external factors that enabled them to use fatigue management strategies. These factors reflect the *opportunity* construct of COM-B. Internally, their mindset and desires, parallel with COM-B *motivation*, also influenced the results of whether they could and how they could manage fatigue.

**Availability of and access to needed devices and services.** As in theme 1, our participants utilized various devices to make their lives easier, including mobility assistance, cooling devices, sleeping aids, bathroom aids, activity trackers, and postural awareness equipment. Several participants also shared that they had access to health care and housekeeping services, including physical therapy, acupuncture, counseling, chiropractic care, and a house cleaner, which was crucial to maintain their physical, mental, and emotional health.

**Companions for exercise.** As in theme 1, participants acknowledged the importance of proper exercise to help them maintain their energy. They also endorsed that having exercise companions facilitated their ability to exercise, which speaks to TDF’s social influence under COM-B’s *opportunity*. These

companions were often pets, such as a dog, a horse, and even a turtle. On the other hand, losing a companion could be a blow to being active; as a participant shared, “After my dog died and I stopped taking him on daily walks, I walked less and less. Now I walk much less.” This contingency or dependent relationship speaks to reinforcement in TDF under *motivation* in COM-B.

**Family influence.** Participants stated that their family members (eg, spouse, daughter, or ex-husband) influenced their lifestyles and, therefore, their ability to manage fatigue. Family support helped reduce the physical and mental burdens of people with MS. For example, a supportive spouse helped modify their home to make the environment more accessible. However, some participants indicated that they had the opposite experience; for example, they shared that it was difficult for them to eat healthier and/or improve sleep quality because of their spouses.

**Personal factors: intention, emotions, beliefs.** Many participants described compassion for themselves, acknowledging and accepting their daily limitations or expressing the importance of not badgering themselves or feeling guilty. One participant highlighted the importance of not feeling guilty about napping and resting, a fatigue management strategy that may be perceived negatively. They implied that how they managed fatigue was also inherently related to their own desire and mood, which reflects the *motivation* component of the COM-B model.

## Mixed-Methods Comparison of MFIS by Typology

In Table 2, all 4 participants in the combined typology assignment on the left (the FTC intervention group) had lower or improved MFIS scores at VLT follow-up. In contrast, no fatigue improvement was found in the external subgroup.

On the right side of Table 2, the most fatigue improvement was found in the internal-focused typology subgroup for the MSTC intervention group (except for 1 participant who had a worse MFIS score), but to a lesser degree in all other subgroups. Finally, 2 of 3 in the limited response subgroup had worse fatigue scores.

## DISCUSSION

Few studies evaluating MS fatigue self-management programs have gone 12 months post intervention or beyond.<sup>11-13</sup> In this study, we report on the VLT follow-up of 37 individuals and apply the COM-B model to free response survey results to identify barriers and facilitators to implementing fatigue management strategies. This also demonstrated the applicability of COM-B to evaluate MS self-management programs retrospectively. Furthermore, the trend revealed in our mixed-methods analysis showed the value in applying COM-B and TDF to analyze MS fatigue self-management outcomes, as well as the importance of looking at internal vs external individual management styles.

In the context of this study, if a person with MS has the ability and desire to utilize a tool, has access to the tool, and has support from others to use the tool, they are more likely to successfully use the tool for fatigue management, as



Planning daily activities and prioritizing tasks are low-cost strategies to help individuals with multiple sclerosis manage their fatigue.

Clinicians should be prepared to connect individuals with resources if financial limitations prohibit them from acquiring devices or aids to manage fatigue. ■

shown in the mixed-methods section comparing MFIS scores after typology group assignment. Notably, our study also indicates that capability and motivation can be impacted by opportunity. For example, if the person does not have access to the device they needed, even though they have the ability and high motivation, they would still face significant challenges utilizing the device. This seems obvious, but it has never been noted before.

Planning daily activities and prioritizing tasks were the top 2 strategies used 5 years after study enrollment. Engaging these 2 strategies requires physical and mental capability, mental commitment, and confidence. The Thomas et al<sup>6</sup> evaluation of an MS fatigue intervention program incorporating cognitive behavioral and energy effectiveness techniques found prioritization to be the most used strategy at 4 months after program completion. Similarly, the mixed-methods study by Turpin et al<sup>19</sup> reported planning/organizing the day to be the most utilized strategy by 37 people with MS. Participants in Turpin et al, however, did not use mobility devices. On the contrary, our participants reported extensive use of mobility devices. This might be because our sample endorsed higher MS fatigue severity than the participants of Turpin et al. Specifically, their sample reported a Patient Determined Disease Steps average of 3, whereas ours was approximately 5.

Our second question regarding facilitators and barriers to strategy utilization was answered by uncovering an extensive list, in addition to learning different types of strategies people with MS incorporated in the VLT. Two of the facilitating factors, use of enabling devices and paid professional help, require financial means. With more than a third (13 of 37) of our participants reporting an annual income of less than \$30,000, those strategies may not be possible for everyone. Moreover, positive and/or negative impacts of living arrangements and pets varied in our data. These results suggest that providers should take a multifaceted approach to assessing social support, specifically

whether a spouse or housemate is a barrier or facilitator to fatigue management.

Other studies<sup>6,20</sup> of self-management interventions for MS fatigue have pointed out the importance of psychological traits or attitude in maintaining strategies. Table 2 shows that our data concur with those findings. First, the internal-focused subgroup showed the most fatigue improvement within the MSTC group. Furthermore, the combined subgroup had the highest improvement in MFIS scores in the FTC group. Participants in the combined subgroup exhibited internal strength (ie, expressed strong capability and motivation) and utilized external facilitators. This is consistent with the finding of Silveira et al,<sup>13</sup> who identified internal factors as the primary predictors of long-term physical exercise adherence in people with MS.

## CONCLUSIONS

In conclusion, this study benefited from the TDF and COM-B frameworks. Taking the coded data 1 step further to analyze VLT MS fatigue management strategies and creating typology is a novel approach. We encourage future studies to replicate and use instruments specifically measuring COM-B framework components.<sup>13</sup>

Limitations of this study included the self-reported nature of all questionnaires and bias in assigning typology based on survey response style and length of expression. Interpretation of the MFIS scores and strategies cannot be directly related to program comparison. Also, the VLT data were not part of the original multisite RCT design.

We recommend that future research include VLT findings beyond 12 months; researchers should conduct a follow-up of the initial study design and instruments to assess capability, opportunity, and motivation to evaluate behavior change interventions. ■

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