Use and Perceived Effectiveness of Energy Conservation Strategies for Managing Multiple Sclerosis Fatigue

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KEY WORDS
- energy conservation
- fatigue
- multiple sclerosis

OBJECTIVE. This study describes the use and perceived effectiveness of energy conservation strategies by persons with multiple sclerosis after participation in an energy conservation course.

METHOD. One hundred twenty-three participants completed a survey about their use of energy conservation strategies.

RESULTS. All strategies were newly used by at least 50% of the participants and rated as effective. Strategies that involved rest and delegation were used most and rated most effective, followed by modifying priorities and standards. The most common reason for not implementing strategies was that participants were already using them.

CONCLUSION. Persons with multiple sclerosis who participated in an energy conservation course implemented a number of new energy conservation strategies and reported them as effective.

Matuska, K., Mathiowetz, V., & Finlayson, M. (2007). Use and perceived effectiveness of energy conservation strategies for managing multiple sclerosis fatigue. *American Journal of Occupational Therapy, 61,* 62–69.

Multiple sclerosis is a chronic, unpredictable autoimmune disease of the central nervous system characterized by demyelinization of nerve cells with resultant scarring known as plaques. Approximately 2.5 million persons worldwide have multiple sclerosis, and every week about 200 persons are diagnosed with the disease (National Multiple Sclerosis Society, 2004a). Multiple sclerosis symptoms vary depending on the areas of the central nervous system that are affected, but common symptoms include vision problems, loss of balance and muscle coordination, slurred speech, tremors, stiffness, bladder problems, cognitive deficits, and fatigue.

Medical treatment aims to suppress or modulate the immune system, and other treatments seek to manage the symptoms of the disease (Schapiro, 1991). Occupational therapy provides important nonpharmacological services to persons with multiple sclerosis, such as energy conservation training to help them manage the effects of fatigue in their daily lives. Energy conservation training usually involves teaching individuals specific behavioral strategies for managing fatigue, such as spreading heavy work throughout the day or taking several rest periods. Although energy conservation strategies make intuitive sense and have been implemented by participants in other studies after an educational program (Mathiowetz, Matuska, & Murphy, 2001; Packer, Brink, & Sauriol, 1995), little information exists on reasons for nonuse or perceived effectiveness. This study explores the use, reasons for nonuse, and participant report of effectiveness for 14 energy conservation strategies designed to manage fatigue that were taught in a 6-week course (Packer et al., 1995) to persons with multiple sclerosis.

Literature Review

Fatigue is a common and very disabling symptom for persons with multiple sclerosis, with approximately 75% to 90% of persons with multiple sclerosis reporting that they have fatigue (Finlayson, Impey, Nicolle, & Edwards, 1998; Fisk,

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Pontefract, Ritvo, Archibald, & Murray, 1994; Freal, Kraft, & Coryell, 1984). Fatigue has been described as their most frustrating, overwhelming, and disabling symptom that interferes with daily activities, role performance, and overall quality of life (Krupp, Alvarez, LaRocca, & Scheinberg, 1988; McLaughlin & Zeeberg, 1993). Multiple sclerosis fatigue is chronic, occurs more frequently, and is more severe than other types of fatigue; prevents sustained physical functioning; and comes on quickly. Recovery from this type of fatigue takes much longer than fatigue from other sources, exacerbates other multiple sclerosis symptoms, and is worsened by heat (Krupp et al., 1988). Fatigue also can affect a person emotionally or cognitively, making it difficult for him or her to effectively cope with the stressors of daily life (Streeter & May, 2000).

Multiple sclerosis fatigue is very difficult to treat because of the multiple known and unknown factors influencing it and the unique and subjective ways that each person is affected by it. The causes of fatigue have been classified as either primary, indicating disease-related, or secondary, indicating conditions that could increase primary fatigue. The pathophysiology of the primary causes for fatigue remains unclear (Multiple Sclerosis Council for Clinical Practice Guidelines, 1998). The National Multiple Sclerosis Society (2004b), however, identified eight secondary causes that contribute to fatigue severity: heat sensitivity, weakness, poor nutrition, depression, imbalanced rest–activity cycle, sleeping problems, inactivity, and medication side effects. These underlying causes of fatigue can be identified and managed with specific behavioral or medical interventions, such as medication or counseling for depression, the use of cooling strategies or devices for heat sensitivity, improved dietary intake and exercise regimes, treatment for sleep-related and weakness problems, and use of energy conservation strategies for managing daily activity demands. This study will explore how participants use and perceive the effectiveness of energy conservation strategies for managing their daily demands.

The Multiple Sclerosis Council for Clinical Practice Guidelines (1998) refers to energy conservation as *energy effectiveness* and defines it as "the identification and development of activity modifications to reduce fatigue through a systematic analysis of daily work, home, and leisure activities in all relevant environments" (p. 17). Common energy conservation strategies include analyzing and modifying activities to reduce energy expenditure, balancing work and rest, delegating some activities, examining and modifying standards and priorities, using the body efficiently, organizing workspaces, and using assistive technologies to conserve energy (Mathiowetz et al., 2001; Mathiowetz, Finlayson, Matuska, Chen, & Luo, 2005). Occupational therapists have traditionally used energy conservation education for their clients with multiple sclerosis who experience fatigue. Practitioners, however, have little evidence about whether the strategies taught are actually implemented or considered by users as effective.

Teaching energy conservation strategies as an intervention to manage fatigue is challenging because, for the strategies to be effective, people need to use them in everyday life. That adjustment requires learning and remembering the strategies for use throughout life and making the behavior changes to implement them in daily routines. Health behavior models show that long-standing habits or behaviors are deeply ingrained and influenced by social, psychological, and environmental conditions and can be resistant to change. These models emphasize the complexity of changing health behaviors and suggest that readiness to change occurs through various stages (Prochaska & Velicer, 1997), is influenced by perceptions and beliefs about the health condition and recommended behavior change (Rosenstock, Strecher, & Becker, 1998), and is highly influenced by the environment and self-efficacy (Bandura, 1977). Therefore, effective energy conservation education must be more than just providing information about basic energy conservation principles, and needs to be delivered using methods that compel behavior change, at times when people are most receptive to change and in ways that increase confidence in their ability to change.

Although recent research has supported the efficacy of the 6-week, community-based energy conservation course using the protocol developed by Packer and colleagues (1995) in reducing the effect of fatigue and improving quality of life (Mathiowetz et al., 2001, 2005; Vanage, Gilbertson, & Mathiowetz, 2003), less is known about the participants' use and perceived effectiveness of specific energy conservation strategies. In previous studies using the same 6-week energy conservation course, participants increased implementation of energy conservation behaviors with 80% or more of the participants continuing to use 6 or more of the energy conservation strategies after the course (Mathiowetz et al., 2001; Packer et al., 1995). Of the strategies used, the Mathiowetz and colleagues (2001) study found that planning rest breaks was the most commonly used strategy, followed by planning the day (e.g., spacing out activities over the day). They also determined that participants had been using some energy conservation principles before taking the course but implemented many more strategies after the course. When the same 6-week course was delivered by teleconference to persons with multiple sclerosis at home, preliminary data showed that participants most frequently increased the use of the strategy *adding rest*

periods in the day (Finlayson, Holberg, Van Denend, & Frakes, 2004).

In a small study using interviews, Sears and Hubsky (1993) reported that when given a list of 17 fatigue management strategies, patients with either remitting/relapsing or chronic progressive multiple sclerosis ranked delegating tasks, naps, rest, and avoiding stress as the most effective strategies for managing fatigue. McLaughlin and Zeeberg (1993) compared perceived effectiveness of fatigue management strategies between persons with multiple sclerosis in the United States and Denmark and determined that the most frequent strategies used were similar between the groups (planning, resting, home modification), but that the Danish used fewer strategies overall. These studies showed that participants did use energy conservation strategies but did not provide information about the frequency of use, reasons for not using them, or the perceived effectiveness of the strategies.

Research Questions

The current study answered the following questions: What new energy conservation strategies did participants use after attending a 6-week energy conservation course? What were reasons given for not using some strategies? And, what was the perceived effectiveness of the strategies?

Methods

Design

This study was part of a larger randomized controlled trial (Mathiowetz et al., 2005) of 169 persons with multiple sclerosis to assess the efficacy and effectiveness of a 6-week energy conservation course (Packer et al., 1995) on fatigue impact, quality of life, and self-efficacy. All of the participants who completed the course were included in this study, because they all eventually received the same course and reported their perceptions of the effectiveness of the energy conservation strategies taught. The primary dependent variable for the study reported in this article was energy conservation strategy use, which was assessed 6 weeks after participation in the course.

Participants

Participants were recruited through mail from a mailing list of persons belonging to the Minnesota and Illinois chapters of the National Multiple Sclerosis Society between January 2002 and February 2003. Interested persons contacted the project directors at each site, and were screened over the phone. The inclusion criteria were the person had a diagnosis of multiple sclerosis, was ages 18 years or older, reported being functionally literate in English (i.e., able to read course materials), had a Fatigue Severity Scale (FSS) (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989) score of 4 or greater, lived independently in the community, and agreed to attend at least five out of six energy conservation sessions.

Persons who met all of these criteria were invited for an in-person screening session by occupational therapists for evaluation of cognitive abilities using four subtests of the Neuropsychological Screening Battery for Multiple Sclerosis (Rao, 1992), and collection of demographic information. Potential participants with moderate to severe cognitive deficits were excluded because they would be less likely to benefit from the group format of the course. The cut-off criterion for mild cognitive impairment was failing more than one cognitive subtest, as recommended by Rao (1992). The participants who met the inclusion criteria provided medical information, completed the Multiple Sclerosis Functional Composite (MSFC) (Fischer, Jak, Kniker, Rudick, & Cutter, 1999), and filled out the initial assessments for the larger study. Ethical clearance to conduct the study was obtained from the relevant universities' IRB committees and all participants signed a written informed consent.

Energy Conservation Course

The 6-week, community-based energy conservation course for adults experiencing fatigue secondary to chronic illnesses was developed by Packer and associates (1995). Each course consisted of 6 weekly, 2-hour, very structured classes as described in detail in an accompanying manual. A total of 20 groups with 7–10 participants per group were taught by a total of 12 certified occupational therapists in community settings such as National Multiple Sclerosis Society chapter offices, churches, and public libraries. The energy conservation course used a range of pedagogical techniques based on the theory of psychoeducational group development. The courses consisted of lectures, discussions, long-term and short-term goal setting, activity stations, and homework activities to assist participants' integration of energy conservation principles with their performance of everyday tasks. The 6 sessions addressed the importance of rest throughout the day, positive and effective communication, proper body mechanics, ergonomic principles, modification of the environment, priority setting, activity analysis and modification, and a balanced lifestyle (Mathiowetz et al., 2005; Packer et al., 1995).

Energy Conservation Strategies Survey

The Energy Conservation Strategies Survey (ECSS), developed by the authors of this article, assessed participants' use

of the 14 suggested energy conservation strategies that were emphasized in the course (Appendix A). Each of the 14 strategies was listed on the survey and, 6 weeks after the course, participants identified whether or not they used each suggested strategy as a direct result of the course. Participants also recorded the frequency of use and the perceived effectiveness of the strategy on a scale of 1 (*not effective*) to 10 (*very effective*). If they did not use the strategy, they indicated the reason by choosing from a list of common explanations such as "forgot to try it," "already doing this before the course," or "didn't think it would make a difference," or by writing in their reason. Test–retest reliability of the ECSS was determined with a sample of 53 participants with an acceptable interclass correlation of .79. Internal consistency was α = .92, indicating that all items represent the same underlying construct of behaviors that persons are supposed to change as a function of the training (Mallik, Finlayson, Mathiowetz, & Fogg, 2005).

Data Analysis

Results of the ECSS were analyzed descriptively. Frequencies and percentages were calculated for energy conservation strategy use and nonuse, and means were calculated for perceived effectiveness ratings.

Results

A total of 169 participants were assigned to the energy conservation education groups in the larger randomized controlled study to determine the effectiveness of the course on fatigue impact, self-efficacy, and quality of life. Of those assigned, 131 persons with multiple sclerosis participated in 5 or 6 sessions of the course, and 123 of them fully completed the ECSS used in the final data analysis for this study. When we compared participants who completed 5 or more sessions and had complete ECSS data (n = 123) against those who attended fewer than 5 sessions or had incomplete ECSS data (n = 46), we found no significant differences between groups on age, gender, racial distribution, years since diagnosis, FSS screening, and MSFC scores (p < .01 adjusting for multiple comparisons). Characteristics of participants who completed the ECSS are described in Table 1.

Table 1. Demographic Characteristics of Participants (N = 123)

	Mean	*SD*
Characteristics of Participants		
Age (in years)	49.2	8.1
FSS score	5.9	0.7
Years since symptoms started	15.1	10.0
Years since diagnosis	9.3	7.4
MSFC score	–0.95	1.17
	N	%
Gender		
Women	101	82.1
Men	22	17.9
Ethnicity		
White	114	92.7
African American	6	4.9
Hispanic	1	0.8
Other	1	0.8
No response	1	0.8
Type of multiple sclerosis		
Relapsing/Remitting	80	65.0
Secondary progressive	21	17.1
Primary progressive	6	4.9
Progressive relapsing	1	0.8
Unknown	15	12.2
Education		
>15 years	71	57.7
12–15 years	46	37.4
<12 years	6	4.9
Employment status		
Full-time (≥ 40 hrs/wk)	35	28.5
Part-time (20–39 hrs/wk)	18	14.6
Part-time (1–19 hrs/wk)	10	8.1
Retired	9	7.3
Unemployed (chose not to work)	7	5.7
Unemployed (unable to work)	3	2.4
Disability	41	33.3
Other factors affecting fatigue	29	23

Note. FSS = Fatigue Severity Scale (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989), MSFC = Multiple Sclerosis Functional Composite (Fischer, Jak, Kniker, Rudick, & Cutter, 1999), *SD* = standard deviation.

Table 2 describes the frequency of use and perceived effectiveness ratings of the 14 energy conservation strategies that were implemented as a result of the energy conservation course. The strategies implemented by more than 70% of the participants included the following: *changed body position for certain activities, planned the day to balance rest and work, modified the frequency or outcome standards of activities, included rest periods in the day or at least 1 hour, adjusted priorities, simplified activities, communicated need for assistance,* and *rested during longer activities*. Of those who reported not using these strategies, the primary reason was because they were *already doing it before the course* (range of 58%–81%).

The energy conservation strategies implemented the least (51% or fewer of the participants) were *changed the time of day of an activity* and *started using adapted equipment or devices*. Of the participants who reported not using the strategies, the primary reason was because they were already doing it before the course (range of 55%–62%). Additionally, 13% who did not use adapted equipment reported that they were unsure about what equipment to use or were unable to use it.

Although the most frequent reason for not implementing the energy conservation strategies was because they were already using them before the course (Appendix B), some

Table 2. Use and Perceived Effectiveness of Energy Conservation Strategies Implemented as a Result of the Course (*N* = 123)

	Implemented Strategy		Perceived Effectiveness Rating	
Energy Conservation Behaviors	*N*	%	*X*	SD
Changed body position for certain activities*	102	(83)	7.0	2.2
Planned the day to balance rest and work*	98	(80)	7.8	2.0
Modified frequency or outcome standards*	97	(79)	7.2	2.1
Included rest periods in the day or at least 1 hour*	94	(76)	8.2	1.8
Adjusted priorities*	92	(75)	7.4	2.1
Simplified activities*	91	(74)	7.3	2.2
Communicated needs for assistance*	90	(73)	7.1	2.4
Rested during longer activities*	88	(71)	7.9	1.7
Changed location of equipment/supplies	85	(69)	7.2	2.3
Delegated part or all of an activity	82	(67)	7.7	2.1
Eliminated part or all of an activity*	79	(64)	7.3	2.1
Identified and changed incorrect work heights*	70	(57)	7.1	2.0
Changed the time of day of an activity*	63	(51)	7.4	1.8
Started using adapted equipment	60	(49)	7.4	2.2

Note. Effectiveness rating is from 1–10: 1 = *not effective,* 10 = *very effective.*

* indicates missing data (frequency range from 1–4, .8%–3.3%).

strategies were not implemented because of other personal or environmental barriers. Twenty-one percent of reasons for not changing the location of equipment or supplies, and 15% of the reasons for not identifying and changing incorrect work heights were because they were unable to do so. Thirty-two percent of the reasons for not delegating activities was because there was no one to whom to delegate. Thirty-six percent did not plan the day to balance rest and work, and 24% percent did not include rest periods in the day for reasons related to external demands such as job schedules.

All of the energy conservation strategies were rated as effective (range of 7.0–8.2 on a rating scale of 1–10 with 10 being most effective). The energy conservation strategies rated as most effective (7.5 or higher) were *delegated tasks to other people, planned the day to include a balance of rest and work,* and *rested during longer activities*. The energy conservation strategy rated least effective (7.0) was *changed body position for certain activities*. Appendix C lists the tasks most frequently delegated, and Appendix D lists energy saving devices or adapted equipment used most as a result of the course.

Discussion

The primary purpose of teaching energy conservation principles and strategies to persons who have multiple sclerosis is to encourage behavioral and environmental changes that conserve energy and improve everyday performance and life quality. The underlying assumptions associated with energy conservation training are that people can learn energy conservation strategies, that they will use the strategies learned, and that use of the strategies will reduce fatigue, leading to a better quality of life. This study was part of a larger study that found a 6-week energy conservation course effective in reducing fatigue impact and improving some aspects of quality of life, especially vitality (Mathiowetz et al., 2005). This study explored the use of energy conservation strategies learned in the 6-week course and the perceived effectiveness of each strategy.

The results of this study showed that the participants learned the energy conservation strategies taught in the 6-week course, implemented many new energy conservation strategies in their everyday lives, and reported them to be very effective. Similar to previous studies, strategies that included rest appeared to be the most used and most effective, particularly planning the day to include a balance of work and rest (Finlayson et al., 2004; Mathiowetz et al., 2001; Sears & Hubsky, 1993). In this study, modifying standards and adjusting priorities also were used frequently but were rated slightly less effective than resting strategies. This result seems intuitive because even though a person tries to lower outcome standards or adjust priorities, the outcome may be more difficult to accept when things aren't being done at one's preferred standard. Similarly, changing one's body positions for certain activities was the newly used strategy that was most implemented. Although this strategy had a relatively high perceived-effectiveness rating, it was implemented less often than the other strategies. This high rate of first-time usage might mean that the body mechanics unit in the course was new to the participants, they were interested in trying it, and it is relatively easy to implement at least a few times. This strategy requires vigilance and adaptation of body posture multiple times throughout a day as well as environmental supports such as properly fitting chairs, and participants may need more time and feedback to use this strategy effectively throughout their day.

The most common reason for not using a strategy as a result of the course was because they were already using it. In other words, many participants had learned from someone else or figured out on their own some of the energy conservation strategies that were taught in the course. Certain strategies can be used many times throughout a day. Others are more limited, however, and, if already being used, there is less need to make additional changes. For example, once work heights are modified, they don't need to be changed again. The strategies with the lowest frequency of use—such as delegating or eliminating activities,

changing the time of day for activities, or changing work heights—can be used only a few times and depend on environmental or social support, such as family members who can be delegated to and jobs that allow flexible scheduling. The lack of such resources was the next major reason for not using particular strategies. "I have no one to delegate to," "it's just me," or "it's not possible because of my job" were explanations citing limited support for making changes. Fifty-two percent of the participants were employed either full-time or part-time, which may have influenced their ability to do some things at different times of the day. Employment policies or practices that allow flexible scheduling would be a useful support for some persons with multiple sclerosis fatigue. Because delegating, simplifying, eliminating, or changing the time for activities are considered highly effective strategies, supportive social contexts such as families, employers, neighborhoods, communities, and health and human services providers may be crucial for optimal fatigue management.

The idea that even with chronic fatigue a person can improve daily performance by effectively managing energy can be empowering because each individual becomes the gatekeeper of his or her own energy, reserving and using it for activities deemed most important. Energy conservation training may be a useful alternative or supplement to a pharmaceutical approach to fatigue management. To be most effective, however, the environment needs to support persons using the strategies. Energy conservation education is effective for the individuals experiencing fatigue and may be equally as valuable for their families and employers. The families and employers could be more supportive if they understood the extent and types of modifications needed for implementation of energy conservation strategies. Simple supports such as employers providing ergonomically correct workspaces and flexible schedules to allow rest periods could make a big difference. Family members could support adjusted priorities and modified standards if they fully understood the importance of such changes.

This study showed that participants in a 6-week community-based energy conservation education program reported use of energy conservation strategies and considered them effective. It cannot be concluded that energy conservation education delivered in another format would have similar results, however. The group format of the energy conservation course was useful because participants shared ideas that were helpful to them and were able to give and receive support and feedback to the other members. Several participants mentioned that they received the most benefit from the interactions with group members, and many of the groups continued to meet on their own after the course was completed. Additionally, the 6 sessions were 1 week apart, allowing participants time to try out some of the ideas learned, to discuss the failures or successes, and to generate new ideas.

Limitations

The ECSS is a self-report instrument; thus, it is unknown whether participants were accurate reporters of their behavioral change. In future studies, it would be useful to gather information from significant others about the behavior changes that they observed and compare it to participants' responses. In addition, the instrument's psychometric properties should be tested further because it was developed specifically for the 6-week course. Additional reliability and validity testing would strengthen the results.

The participants who did not complete the study (attending fewer than 5 out of the 6 sessions) did not complete the energy conservation survey and were not included in the results. The data analysis reflects only those participants who were able to attend the sessions and perhaps were more motivated to learn the strategies. Thus, the results may be generalized only to people who are highly motivated (such as the participants willing to attend all of the classes) and willing to try new strategies.

Implications for Practice

This study shows that persons with multiple sclerosis who participated in a 6-week community-based energy conservation course increased their use of energy conservation strategies and perceived them to be effective. Occupational therapists traditionally teach energy conservation strategies to their clients who report fatigue but often in a one-to-one situation. The group format used in this study appeared to be a good venue for this type of education and may be a useful alternative delivery model. Additionally, to be most effective, occupational therapists may need to expand their education of energy conservation strategies to their clients' families and employers. As the results showed, some strategies were not used because the participants didn't have the external support to use them, such as flexible work hours. Additional research is needed to determine the impact of including families and employers in the 6-week educational program. Additionally, it would be useful to study the long-term results of energy conservation strategies by following a group out a year or more and assessing their energy conservation use and its perceived effectiveness. ▲

Appendix A. List of Strategies in the Energy Conservation Strategies Survey

1. Identified and changed incorrect work heights at home or at work
2. Changed location of equipment, furniture, or supplies at home or at work
3. Started using adapted equipment, gadgets, or energy-saving devices
4. Changed the way you positioned your body to do an activity
5. Eliminated part or all of an activity
6. Delegated part or all of an activity to another person
7. Communicated your needs for assistance to family members or others
8. Modified your standards by changing the frequency or expected outcome of an activity
9. Adjusted your priorities by choosing how to spend your energy
10. Simplified activities so they required less energy
11. Planned your day to balance work and rest times
12. Changed the time of day to do an activity
13. Included rest periods in the day, or rested at least an hour
14. Rested during fatiguing activities that took 30 min or longer

Appendix B. Primary Reasons for Not Using Energy Conservation Strategies (in Order of Highest Frequency)

1. Have been doing it before the course
2. *Unable to because of context (work demands, family not available)
3. Didn't think it would make a difference
4. Not enough time to try it
5. Forgot to try it
6. *Unwilling to try it due to preferred habits
7. Too many priorities

*Indicates a general summary of comments

Appendix C. Tasks Most Frequently Delegated

1. Carrying/moving things (up/down stairs, laundry, carrying in purchases)
2. Yard work, mowing lawn, gardening, heavy outside work
3. Meal preparation, cooking
4. Employment activities
5. Driving, parking, getting gas
6. Shopping
7. Vacuuming
8. Errands/trips
9. House cleaning, household chores (general)
10. Child care
11. Taking out the garbage

Appendix D. Energy-Saving Devices and Equipment Used Most Frequently as a Result of the Course

Electric kitchen devices
Reacher
Scooter
Carts
Cane
Kitchen stool
Walker
Shower chair

Acknowledgments

This research was supported by a research grant from the National Multiple Sclerosis Society.

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