Factors Influencing the Use of Energy Conservation Strategies by Persons With Multiple Sclerosis

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OBJECTIVE. To examine the factors influencing the implementation and continued use of energy conservation strategies among persons with multiple sclerosis.

METHOD. A qualitative research design was used. Eight persons with multiple sclerosis who participated in a 6-week energy conservation educational course delivered by teleconference were interviewed using a semistructured, open-ended format. Participants were asked about their thoughts, feelings, and actions resulting from course participation. They also were engaged in a card-sort activity to promote discussion about using the energy conservation strategies. The data were analyzed thematically.

FINDINGS. Three themes directly addressed and interacted to enhance or hinder the use of energy conservation strategies: (1) experience with the disease, (2) sense of self, and (3) environmental factors. The fourth theme of education emphasized how participation in the educational course and use of the strategies afterward gave participants a new ability to manage their lives with multiple sclerosis.

PRACTICE IMPLICATIONS. The findings of this study demonstrated that the use of energy conservation strategies is not dependent on a single factor but rather on complex, interrelated contextual factors.


Introduction

Multiple sclerosis is a “chronic disease of the central nervous system (CNS), in which there is destruction of myelin and nerve axons within several regions of the brain and spinal cord at different times.” (Venes, 1997, p. 1854). The damage to the myelin and nerve axons impedes the nerves from sending their electrical impulses to and from the brain. The symptoms of multiple sclerosis are variable and unpredictable, depending on when and where the myelin is damaged. Multiple sclerosis affects approximately 400,000 persons in the United States and 2.5 million people worldwide (National Multiple Sclerosis Society, 2005). Persons affected by multiple sclerosis tend to be diagnosed between the ages of 20 and 50, to be of northern European ancestry, and to be female. The etiology of multiple sclerosis remains unknown; however, genetics, gender, and environmental triggers appear to play a role (National Multiple Sclerosis Society, 2005).

Fatigue is the most common symptom reported by people with multiple sclerosis, affecting 75% to 95% of individuals with the disease (Multiple Sclerosis Council for Clinical Practice Guidelines, 1998). Furthermore, 50%–60% of persons with multiple sclerosis report that fatigue is their most disabling symptom. The Panel of the Multiple Sclerosis Council (1998) for Clinical Practice Guidelines has defined fatigue as a “subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities” (p. 2). Most people with multiple sclerosis report that they experience fatigue on a daily basis, with the fatigue becoming more severe later in the day (Freal, Kraft, & Coryell, 1984). Fatigue prevents many people with multiple sclerosis from performing desired daily activities because of lack of efficiency and endurance (Vange, Gilbertson, & Mathiowetz, 2003). Not only does fatigue often lead to

KEY WORDS

- energy conservation
- fatigue
- multiple sclerosis
- telehealth
decline in occupational functioning, but it also is known to exacerbate other physical and mental symptoms of multiple sclerosis and to severely harm an individual’s sense of control over his or her illness (Schapiro & Schneider, 1999). Thus, the effect of fatigue on people’s lives is great and may seriously compromise a person’s quality of life (Ward & Winters, 2003).

To assist people in managing their fatigue, Packer, Brink, and Sauriol (1995) developed a therapeutic energy conservation course entitled “Managing Fatigue: A Six-Week Course for Energy Conservation,” which focuses on educating people about strategies that optimize energy management. This community-based group intervention shows persons with multiple sclerosis how to manage their fatigue by teaching the following energy conservation strategies: (a) the importance of rest, (b) budgeting and banking energy, (c) scheduling rest periods into the day, (d) communicating needs for assistance to others, (e) applying proper body mechanics, (f) organizing activity stations; (g) using assistive technology, (h) setting priorities and standards, (i) living a balanced life, and (j) creating short-term and long-term energy management goals. Recently, this program was modified for delivery by teleconference for persons with multiple sclerosis (Finlayson, 2005). Both the original and the teleconference versions of the course encourage participants to implement behavioral changes within their lives in an attempt to reduce fatigue-related disability in the areas of self-care, productivity, and leisure.

Studies of the original and teleconference versions of “Managing Fatigue” have found that the course decreases the effect of fatigue, increases self-efficacy for performing energy conservation strategies, and increases some aspects of quality of life for participants with mild to severe multiple sclerosis (Finlayson, 2005; Mathiowetz, Finlayson, Matuska, Chen, & Lou, 2005; Mathiowetz, Matuska, & Murphy, 2001; Packer and colleagues, 1995; Vanage et al., 2003). These studies also have demonstrated that participants use more energy conservation strategies as a result of taking the course. In the studies by Packer and colleagues (1995), Mathiowetz and colleagues (2001), and Vanage and colleagues (2003), 70% to 82% of participants used at least six energy conservation strategies as a result of participating in an energy conservation course. Together, the current research supports the effectiveness of the energy conservation course in helping individuals with multiple sclerosis manage fatigue and supports continued implementation of the course as an effective therapeutic intervention for persons with multiple sclerosis (Finlayson, 2005; Mathiowetz et al., 2001, 2005; Vanage et al., 2003).

Despite the strength of the current evidence for the energy conservation course, gaps in knowledge still exist. In particular, it remains unclear what factors influence the actual behavioral changes observed as a consequence of the course. We know that not all participants use all of the strategies. Understanding the factors that ease or hinder the use of energy conservation strategies may enable occupational therapists to more effectively guide clients through various stages of change and enhance clients’ continued use and maintenance of specific strategies, as well as suggest strategies to promote the implementation of new strategies as multiple sclerosis–related fatigue changes over time. To date, no study has investigated the factors that influence a person’s ability to implement and continue using these energy conservation strategies. Therefore, this study aims to understand the factors that influence the use of energy conservation strategies (i.e., behavioral change) by persons with multiple sclerosis who participated in a teleconference version of “Managing Fatigue.” The specific questions addressed in this study are the following:

1. What factors enhance a person’s initial use of a selected energy conservation strategy?
2. What factors hinder a person’s initial use of a selected energy conservation strategy?
3. What factors enhance continued use of selected energy conservation strategies?
4. What factors hinder continued use of selected energy conservation strategies?

Guiding Theoretical Framework

The Transtheoretical Model of Change was used to examine the factors that influence a person’s ability to implement behavioral changes within their lives (Cancer Prevention Research Center, 1998; Prochaska, Norcross, & DiClemente, 1994). This behavioral change model describes how people move through various stages of change in an effort to modify a problem behavior or acquire a positive behavior. The model focuses on intentional change and the decision-making process of an individual as he or she progresses through five stages—precontemplation, contemplation, preparation, action, and maintenance. The model emphasizes that change occurs over time instead of being represented as an isolatable event (Cancer Prevention Research Center, 1998; Prochaska et al., 1994).

The transtheoretical approach is promising when applied to a variety of problems that require behavioral change (Hacker, Brown, Cabral, & Dodds, 2005; Zimmerman, Olsen, & Bosworth, 2000). Although multiple sclerosis–related fatigue is not a behavioral problem but rather a symptom of multiple sclerosis, the model was selected to guide this study because behavioral change by persons with multiple sclerosis is necessary to better manage...
their multiple sclerosis fatigue. The transtheoretical model was used to guide the selection and ordering of the interview questions, and the questions were ordered to correspond with the stages of the transtheoretical model. The transtheoretical model also was used to help frame the coding process during qualitative analysis.

Design and Methods

To address the research questions, a qualitative approach was used. Semistructured open-ended interviews were used to record participants’ thoughts, feelings, and actions resulting from participation within an energy conservation course. In addition, participants engaged in a card-sort activity to promote discussion about past, present, and future use of the 14 energy conservation strategies addressed in “Managing Fatigue.” The Human Subjects Review committee of the authors’ university approved the study.

Participants

This current study recruited participants from a previous pilot study that tested the teleconference version of “Managing Fatigue” with 29 persons with multiple sclerosis (Finlayson, 2005). These persons were ages 18 years or older, had functional English literacy (could read and understand written and spoken English), had a Fatigue Severity Score (FSS) of 4 or greater (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989), and had passed a cognitive screening using the Blessed Orientation Memory Concentration test (Katzman et al., 1983). Of the 29 pilot study participants, 12 had agreed to be contacted about future studies. These 12 persons were sent an invitation to participate in the current study. Eight responded and met the eligibility criteria. Criteria included having attended at least two of the six 90-minute energy conservation teleconference sessions and living within driving distance of the university. The basic demographic characteristics of the participants are provided in Table 1. Participants were middle age, well educated, primarily female, and primarily unable to work because of disability.

Data Collection Tools and Procedures

After establishing eligibility with each participant, an interview with the first author was arranged. All of the interviews occurred at a place of the participant’s choice. Six interviews occurred at the participants’ homes, and two occurred at a restaurant near one participant’s home. After consent was established, the first author asked each participant to complete the Stage of Change Questionnaire. This questionnaire was based on the transtheoretical model and was used to determine the participant’s stage of change in relation to the use of energy conservation strategies.

An in-depth qualitative interview was conducted using a guide that was designed to facilitate the discovery of factors that influenced the participant’s use of energy conservation strategies. The interview progressed chronologically, focusing first on the strategies participants used before taking the energy conservation course and then moving to a discussion of the strategies the participants had used since the course ended. Participants also were asked about the strategies that they were using at the time of the interview, as well as about the ones that they expected to use in the future. Embedded in the interview process was a card-sort activity. Each card identified one of the 14 energy conservation strategies taught within the teleconference course (Table 2). At different points in the interview, participants were asked to sort the cards using different criteria; for example, the easiest strategies to use, hardest strategies to use, and strategies they planned to use in the future. After each sort, the interviewer asked questions to gather in-depth information about the participant’s particular choices. On completion of the interview, participants were asked to complete a background questionnaire to gather information such as age, gender, education, and ethnicity. The entire contact took approximately 2 hours and was tape-recorded with the participants’ permission.

Table 1. Demographics of Participants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Gender</th>
<th>Years With Multiple Sclerosis</th>
<th>Symptoms</th>
<th>Racial Group</th>
<th>Years of School</th>
<th>Employment Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Angie</td>
<td>40</td>
<td>F</td>
<td>5</td>
<td>5</td>
<td>Caucasian</td>
<td>More than 15</td>
<td>UE disability</td>
</tr>
<tr>
<td>Beth</td>
<td>41</td>
<td>F</td>
<td>14</td>
<td>14</td>
<td>African American</td>
<td>More than 15</td>
<td>UE disability</td>
</tr>
<tr>
<td>Denis</td>
<td>54</td>
<td>M</td>
<td>18</td>
<td>18</td>
<td>Caucasian</td>
<td>More than 15</td>
<td>Retired</td>
</tr>
<tr>
<td>Erica</td>
<td>49</td>
<td>F</td>
<td>25</td>
<td>25</td>
<td>Caucasian</td>
<td>12–15</td>
<td>UE disability</td>
</tr>
<tr>
<td>Fran</td>
<td>47</td>
<td>F</td>
<td>5</td>
<td>5</td>
<td>Other</td>
<td>12–15</td>
<td>UE disability</td>
</tr>
<tr>
<td>Gail</td>
<td>43</td>
<td>F</td>
<td>4</td>
<td>4</td>
<td>African American</td>
<td>More than 15</td>
<td>UE disability</td>
</tr>
<tr>
<td>Ingrid</td>
<td>46</td>
<td>F</td>
<td>22</td>
<td>22</td>
<td>African American</td>
<td>12–15</td>
<td>Part-time</td>
</tr>
<tr>
<td>Kim</td>
<td>50</td>
<td>F</td>
<td>6</td>
<td>6</td>
<td>Caucasian</td>
<td>12–15</td>
<td>UE disability</td>
</tr>
</tbody>
</table>

Note. UE = Unemployed (unable to work—disability).
Table 2. Energy Conservation Strategies Taught Within the Teleconference Energy Conservation Course

<table>
<thead>
<tr>
<th>Number</th>
<th>Energy Conservation Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Changing work heights</td>
</tr>
<tr>
<td>2</td>
<td>Changing the location of equipment, furniture, or supplies</td>
</tr>
<tr>
<td>3</td>
<td>Using adaptive equipment, gadgets, or energy-saving devices</td>
</tr>
<tr>
<td>4</td>
<td>Changing the way the body is positioned while doing an activity</td>
</tr>
<tr>
<td>5</td>
<td>Eliminating part or all of an activity</td>
</tr>
<tr>
<td>6</td>
<td>Delegating part or all of an activity</td>
</tr>
<tr>
<td>7</td>
<td>Asking for help from family or friends because of fatigue</td>
</tr>
<tr>
<td>8</td>
<td>Reducing standards for an activity</td>
</tr>
<tr>
<td>9</td>
<td>Adjusting priorities</td>
</tr>
<tr>
<td>10</td>
<td>Simplifying activities</td>
</tr>
<tr>
<td>11</td>
<td>Planning the day to balance work and rest times</td>
</tr>
<tr>
<td>12</td>
<td>Changing the time of day that an activity is done</td>
</tr>
<tr>
<td>13</td>
<td>Including rest periods in the day</td>
</tr>
<tr>
<td>14</td>
<td>Stopping to take a rest in the middle of a long activity</td>
</tr>
</tbody>
</table>

On completion of the interview, a 2-page summary was prepared by the first author and shared with the participant for member-checking. The summaries were sent to the participants either by mail or e-mail, depending on the participant’s preference, 1 week after the interview. If feedback was not received 2 weeks after the summaries were sent, the participants were contacted by the first author. All participants provided feedback, and none of them disagreed with the written summaries. A number of participants took the opportunity of the member-checking process to further elaborate on topics that were discussed during the interviews.

Data Management and Analysis

The interview tapes were transcribed verbatim and then checked against the tapes for accuracy. To analyze the data, the first and second authors each read through the transcripts and independently labeled common words, phrases, or themes. This open coding process was used to identify commonalities among the participants that influenced the use of energy conservation strategies, as well as any other repeating ideas expressed by the participants. Consensus meetings were then held to talk about the coding process, as well as the relationships between the ideas expressed. After three consensus meetings, a master list of codes was established and axial coding began. Both authors engaged in axial coding, noting commonalities between coded categories to form broader categories or themes. The themes were used to understand the participants’ experiences regarding use of energy conservation strategies. A code–recode procedure was included as the interpretations transformed. Consistent with the recommendations of Morse and Field (1995), a computerized and written log was kept by the first author as a record of the interviews, analysis procedures and decisions, and reflections about emerging themes in the data. The computerized and written log served as an audit trail to allow people unfamiliar with the study to understand the authors’ logic and decision-making process while analyzing the data.

Results

Based on the interview and card-sort data gathered, four broad themes were identified. In addition, nuances of these themes became apparent when the participants’ responses to the Stage of Change Questionnaire were examined. Findings from this questionnaire indicated that 4 participants (with the pseudonyms of Angie, Erica, Gail, and Kim) were in the action stage of the Transtheoretical Model of Behavioral Change, whereas the other 4 participants (with the pseudonyms of Beth, Denis, Fran, and Ingrid) were in the maintenance stage. Participants’ narrative data, however, made it clear that change occurs at a global level as well as in relation to individual energy conservation strategies.

Three themes directly addressed the factors that enhanced and hindered use of energy conservation strategies: Experience With the Disease, Sense of Self, and Environmental Factors. The fourth theme was labeled Value of Education and captures how participation in the course gave participants a new ability to manage their lives with multiple sclerosis. Themes are described in detail in the following section and depicted in Figure 1.

Experience With the Disease

The energy conservation strategies that participants found easier or more difficult to implement in their everyday lives were dramatically influenced by their experience with the disease. These experiences were multilayered and included the variability of disease progression, the variability of the fatigue itself, and the physical and cognitive aspects of their fatigue. Participants’ experiences with multiple sclerosis captured the unpredictable nature and consequences of the disease and how it influenced their lives and ability to implement the energy conservation strategies taught in the course.

Variability in Disease Progression and Level of Disability

Participants’ experiences of disease progression and their level of multiple sclerosis disability played a major role in determining which strategies were used and how they were used. Persons who were experiencing significant physical impairment, disability, and cognitive changes explained how certain energy conservation strategies were more difficult to use than others. For example, changing the location of equipment, furniture, and supplies was a strategy that was difficult for Denis. He never used this strategy because
of his “lack of strength” and difficulty “conceptualizing” how to use it to better manage his multiple sclerosis fatigue. Simplifying activities also was difficult for Denis because he felt that he could not “simplify anymore.”

In comparison, participants whose disease had not progressed to the same degree often were able to implement a strategy but didn’t feel the need to do so. As Ingrid explained, “Sometimes I am not necessarily at a point where I need to do a whole lot of changing of things.” For her, the strategies that were least beneficial were ones that she did not feel she needed to use because of her relatively low level of disability. Consistent with the Transtheoretical Model of Change, some of these participants reported that they were preparing themselves to implement some of the strategies in the future. Angie said, “I plan on moving . . . [but] I have not really gotten to the stage yet where I am ready to go.”

Variability of Fatigue Experiences

Variability in participants’ experiences of fatigue also played an important role in their choice of energy conservation strategies. Multiple sclerosis fatigue was described by participants as “immobilizing,” “exhausting,” and “frustrating.” A few participants stressed that the word fatigue did not fully capture the magnitude and uniqueness of their experience. As Ingrid said,

MS [i.e., multiple sclerosis] fatigue is very different from anything I ever experienced. It is a tiredness, an exhausted tiredness . . . you are to the point of just total exhaustion, you know, versus being tired for any other reason, from actually doing something physical.

She went on to explain the variability of this symptom, how it was “either hot or cold,” and how one minute she could be feeling good and the next minute she could be feeling “wiped out where I need to lie down for a while.” Because of the variability in their fatigue, many participants had difficulty using the strategy of planning their days to balance work and rest time. As Angie said, “If I plan and I do not succeed in the plan, it gets me more frustrated than not to plan at all.” Denis had a similar point of view:

I don’t know how much strength I would have and I would be more frustrated . . . planning something I want to do and not being strong enough to do it. In my mind that is like shooting yourself in the foot. So, I don’t plan, and I am doing much better.

For this reason, Erica only plans day-by-day, depending on how she feels that day. Similarly, Kim makes very loose, tentative plans and tries to plan just one activity a day.

Variability of multiple sclerosis fatigue also made the strategy of stopping to take a rest in the middle of a long activity difficult. As 4 participants in the study explained, when they felt good, they wanted to keep going and not rest, for fear that they would not finish a task or that they would lose their train of thought. Nevertheless, all 8 participants reported using this strategy. Furthermore, 3 out of 8 identified this strategy as one of the most beneficial ones that they used. Ingrid explained the importance of taking a
rest “because when I feel good, I want to keep working, and I don’t necessarily get tired when I am working. It is when I go and overextend that all of a sudden I get exhausted.”

Some of the strategies were more useful to the participants who were able to more consistently predict or anticipate their energy levels. Gail explained,

“Well, for me, I am not a morning person. So changing the time of the day that I do anything to afternoons really helped me a lot because then I don’t stress myself waking up early and trying to do stuff when I know I [don’t] have the energy or clarity of mind.

Physical Aspects of Multiple Sclerosis Fatigue

Participants described how multiple sclerosis fatigue reduced their limited physical strength, made mobility more difficult, and compromised their balance. Participants also gave examples of how other multiple sclerosis symptoms were exacerbated when they were experiencing fatigue; for example, Kim described how her urinary incontinence was intensified when she was fatigued.

Level of physical fatigue influenced participants’ choices of energy conservation strategies, particularly when they also experienced greater levels of physical impairment and disability. These participants tended to have a more difficult time using strategies based on environmental modification (e.g., changing the location of furniture, adjusting work heights) because they needed the assistance of another person to make the changes. Fran rated changing the location of furniture and supplies as one of the hardest strategies to use because, she said, “if there is no one here, I can’t lift those things and put [them] in another place.” Some strategies, however, were actually easier for these participants to use because they were consistent with existing habits for managing their physical disabilities. For example, Fran found that using adaptive equipment was one of the easiest strategies because she already was using a wheelchair and reacher, and she felt comfortable adding other adaptive devices.

Cognitive Aspect of Fatigue

Cognitive fatigue played an important role in participants’ use of energy conservation strategies, particularly when they also experienced cognitive symptoms of multiple sclerosis (e.g., problems with memory, poor concentration, reduced problem solving). Cognitive fatigue plus cognitive symptoms made it difficult for some participants to figure out how to use certain strategies within their daily lives. Angie realized that the strategies she identified as the hardest ones to implement were all strategies that were “abstract.” She explained how sometimes it was hard for her to “see the big picture.”

Simplifying activities was a particularly difficult strategy for these participants to apply in their lives. They had difficulty explaining this strategy during the interview and depended on examples that had been discussed during the course. Gail thought that simplifying activities was one of the five hardest strategies to implement because it is “not necessarily that clear as far as putting your arms around the concept. . . . Simplifying activities, that is kind of what everything is.”

Sense of Self

A second predominant theme across the interviews was participants’ sense of self. Their view of themselves as persons with multiple sclerosis influenced their use of strategies. Denis explained how multiple sclerosis fatigue was no longer a problem for him because he was learning to “accept.” When asked if he would explain this idea further, he said,

“I have a very positive attitude at this point . . . I have seen the bottom of the barrel. I was wallowing in self-doubt. Lived in it for a while, and now I am coming up out of the closet. Early stage, you get very angry and depressed and if you can go through it you do much better . . . you will ultimately get where you want to go, but you have to go a little slower and not start out so fast. It takes a little longer.

At the time of the interview, Denis’s responses on the Stages of Change questionnaire indicated that he was at the maintenance level. He believed that he had successfully managed his fatigue by consistently practicing energy conservation strategies for more than 6 months. He said that it took him a very long time to accept his multiple sclerosis, and during parts of his interview the process appeared to be ongoing.

Erica, Gail, and Ingrid dealt with multiple sclerosis in their lives by fostering a “no worries” attitude and setting limits and boundaries. Gail reported that when she was unable to finish a task, she would no longer “beat herself up” about it afterward. After the course, Angie was able to turn down activities. She said, “I used to be up for anything . . . or willing to do anything before, but now I am just starting to say no.” Erica regretted how in the past she would push herself to do a task despite her high level of multiple sclerosis fatigue “because that is the way I always done that, you know, that was when I was really mentally . . . fooling my psyche.”

In dealing with multiple sclerosis and its influence on their sense of self, participants struggled with some strategies more than others. Asking for help, simplifying activities, and reducing standards were particularly difficult strategies to implement. Six participants rated asking for
help as a hard strategy to implement. In comparison, only three persons indicated that delegating was a difficult strategy to use. Although participants tended to rate both of these strategies as beneficial, they found delegating easier than asking for help. Erica tried to explain this difference:

Delegating is giving part of a task to someone else, but you are still in control of it. Whereas asking for help is just hard. Asking for help is like infringing on another.

Delegating allowed participants to retain control, whereas asking for help made them feel like a burden on others. Asking for help also placed some participants in situations of role reversal, which threatened their view of themselves as the caregiver in their relationships.

Another strategy that was strongly influenced by participants’ view of themselves was reducing standards. Five of the 8 participants rated this strategy as one of the five least beneficial ones, more than any other. Erica explained,

I have always had it in mind that [you] never reduce your standards . . . I think you have to maintain a certain level of standards . . . I don’t want to reduce what my ideas of my standards are.

Denis explained that reducing your standards was like “quitting.” Two participants explained that the wording of the strategy reducing your standards was upsetting and unappealing. Ingrid explained that “[it] kind of tells me that I can’t do something, and I don’t like that.” Erica agreed. She thought that reevaluating your standards would be a better choice of wording because “you feel like so much is just taken away from you all the time that . . . you don’t want to reduce anything.”

To some degree, all participants believed that they were compromising themselves by using energy conservation strategies, yet those individuals who projected a sense of self as a person with multiple sclerosis seemed able to implement a wider range of strategies. None of the participants, however, wanted to be portrayed as needy; they wanted to be respected by being given control over their situation. Two participants mentioned that, if society was more accepting of people with disabilities and did not place so much emphasis on independence, it would be easier to receive assistance, live openly with a disability, and use energy conservation strategies.

Environmental Factors

In addition to the themes Experiences With the Disease and Sense of Self, factors within the environment had a major effect on participants’ abilities to use the energy conservation strategies. This theme had a physical and a social dimension.

Physical Surroundings

All of the participants mentioned that they used a variety of means to complete an activity to save energy. The environment affected what alternatives were available. For example, Angie and Erica mentioned using motorized carts when grocery shopping. Fran and Gail reported using teachers in order to remain seated. Ingrid discussed the importance of having options in how activities were conducted: “I can use the cash station vs. going to the bank, or I may call the bill in and pay it over the phone . . . vs. going to the facility and actually paying the bill.”

Three of the 8 participants talked about how their ability to successfully include rest periods in their days and to rest in the middle of a long activity was dependent on their access to a restful place. Erica changed the location of her comfortable chair from her living room to her bedroom, so that she was “not sitting and sleeping in front of everybody else.” When entering a new environment, Gail reported being “the first person to look for a chair . . . and if there is not a chair . . . a ledge.” When Ingrid went to take a break at work, she said, “I will leave the desk and sit somewhere” because her desk was “not restful.”

Only 1 participant, Ingrid, was working at the time of the interview. Two others had worked in the recent past but were currently on disability. Their stories suggested that rigid work environments often hindered or prevented the use of energy conservation strategies. Other work settings were more accommodating and facilitated the use of strategies, depending on the types of reasonable accommodations provided. For example, Ingrid said that her employer “asked me what accommodations I needed [when she was diagnosed with multiple sclerosis]. At the time I didn’t know, and it is still a work in progress, because as we go along, you know, this may relate.” She said that when she was not feeling well, “I will let them know, alert them I need to take a break here . . . that is an accommodation for me.”

Beth’s and Gail’s experiences were different from Ingrid’s. Gail explained,

[I] would ask for easier projects or less projects and they would look at me like, you know, you are handling this, why should we do that? And then my doctor said, OK, fine, she is on disability. Then, it is like, Rest, if all you needed was a couple of days off. That was not what I needed.

In Gail’s situation, her work environment was not supportive, and her coworkers did not understand the impact of her multiple sclerosis; therefore, Gail had to go on disability. Beth also believed that her fatigue was misunderstood at work. She thought that “if I delegated a lot of stuff from my job to the part-timers, my boss would think that I wasn’t doing my job. So I would try to do basically all of it myself.”
Beth reported trying to hide her disability from her boss, which was very stressful. These women wanted to work, but thought that they could not return to the same environment because it was not conducive to their well-being.

Despite the support that Ingrid received in her work environment, some accommodations were more difficult for her to request and use than others. Ingrid could not always plan her days to balance work and rest times because "if he [i.e., the boss] wants something done right away then I can't change that, you know, that is when I have to do it.”

Social Support

The social environment also played an important role in participants’ ability to use energy conservation strategies. This role was particularly apparent when participants discussed the strategies of asking for help and delegating. Participants tended to feel more comfortable asking for help and delegating activities to another person when that person had a well-defined role, such as coworker or personal assistant, because the provision of assistance was part of that person’s job. For example, Beth said adamantly that she would ask her coworkers for help, “but not my family, cause I don’t want to be that [type of] person. . . . If I am bogged down in work and [my coworkers have] finished what they have to do . . . that [asking for help] is no problem.”

Beth was willing to ask for help at work because her coworkers were being compensated for their services. She was unwilling to ask for help from family or friends because they were not paid. Denis also reported delegating part or all of an activity to another person when that person had a well-defined role, such as coworker or personal assistant, because the provision of assistance was part of that person’s job. For example, Beth said adamantly that she would ask her coworkers for help, “but not my family, cause I don’t want to be that [type of] person. . . . If I am bogged down in work and [my coworkers have] finished what they have to do . . . that [asking for help] is no problem.”

Communication played an important role in whether participants were able to use these strategies at home. Angie emphasized how difficult it was to communicate to others her need for assistance:

"I can’t change that, you know, that is when I have to do it.”

Social Support

The social environment also played an important role in participants’ ability to use energy conservation strategies. This role was particularly apparent when participants discussed the strategies of asking for help and delegating. Participants tended to feel more comfortable asking for help and delegating activities to another person when that person had a well-defined role, such as coworker or personal assistant, because the provision of assistance was part of that person’s job. For example, Beth said adamantly that she would ask her coworkers for help, “but not my family, cause I don’t want to be that [type of] person. . . . If I am bogged down in work and [my coworkers have] finished what they have to do . . . that [asking for help] is no problem.”

Beth was willing to ask for help at work because her coworkers were being compensated for their services. She was unwilling to ask for help from family or friends because they were not paid. Denis also reported delegating part or all of an activity to another person when that person had a well-defined role, such as coworker or personal assistant, because the provision of assistance was part of that person’s job. For example, Beth said adamantly that she would ask her coworkers for help, “but not my family, cause I don’t want to be that [type of] person. . . . If I am bogged down in work and [my coworkers have] finished what they have to do . . . that [asking for help] is no problem.”

Communication played an important role in whether participants were able to use these strategies at home. Angie emphasized how difficult it was to communicate to others her need for assistance:

The problem, I think, with MS is that when you are first diagnosed, people come out of the woodwork and they are like, “How can I help you, oh my God, this is horrible, blah blah blah,” and then I find 3 or 4 years later, you know, when you really need the help, you know, when you find out that you can’t do things anymore . . . everybody is used to you being self-sufficient . . . how can I ask for help and how can they offer it when, you know, when I was fine for the last 3 or 4 years?

Angie would have had an easier time asking for help if the people around her had greater awareness of her disability and were offering her their assistance.

One way Gail solved the problem of communicating her need for assistance to others was by . . . constantly telling them [i.e., her family] what I know about MS. You know, constantly telling them my limitations for that day or what could be a limitation. . . . I had to learn how to ask, and my family has to learn how to respond.

By constant, open communication, Gail was able to foster a very strong support system within her family. The way the family and friends responded to the person with multiple sclerosis made a big difference on how easy or difficult it was for the participants to use many of the energy conservation strategies.

Value of Education

The final theme identified in the interview transcripts was that participation in the course changed participants’ perspectives on fatigue, their willingness to try strategies, and their awareness of what worked and what did not. The course enhanced participants’ abilities to manage their life with multiple sclerosis and feel part of a community of people with the disease.

As a consequence of their participation in the teleconference course, 7 of the 8 persons reported changing their perspectives about fatigue. These participants found the course and discussions with others to be comforting because their own experiences were confirmed and validated. Both their feelings about fatigue and their tolerance for it changed. Many participants explained that, before taking the course, they had feelings of guilt or believed that they were lazy, bad, slow, or weak because they could not do as much as they or others would have liked. The energy conservation course transferred the blame away from the individual and shifted it to the disease. Kim explained,

It was like, oh my goodness, this is not all my fault. You know, I sort of blamed myself. That I was just losing it or getting Alzheimer’s or something . . . but when I got involved with that [the course], I found out a lot of things were related to the fatigue.

Erica explained how the course made her more tolerant of multiple sclerosis fatigue:

You know that book [i.e., energy conservation manual] gave me freedom. . . . It was an eye opening; it was the best thing that has happened to me. And it was just kind of like a mother comforting, saying, “It is OK to rest, it is OK, this is what you should do.” So you are doing a good thing.

The course provided relief not only by reaffirming that fatigue was a common and normal part of multiple sclerosis but also by giving people strategies to better manage their multiple sclerosis–related fatigue. Before the course,
most of the participants felt helpless in their ability to manage their multiple sclerosis fatigue. The course liberated them and gave them better control. As Beth said,

I started practicing those [energy conservation strategies] and I found that I could bank more energy and do stuff when I felt like doing it; if I didn’t feel like doing it, it [i.e., things she needed to do] would be there, and this [strategy] is what I been doing, so my fatigue has gotten a little better, ’cause I get up, I wake up now like I have to go to work.

The course empowered people to take greater control over their available energy by optimizing their energy expenditure within their daily lives. As Gail exclaimed, “I wouldn’t say it [the strategies] reduced the fatigue, it allowed me to be able to do more things, be prepared, you know, rest before I do something.”

Both before and after the energy conservation course, participants used energy conservation strategies out of necessity; however, the way they selected and used the strategies changed. Before taking the course, participants managed their fatigue by instinct and by trial and error. They rested when they were exhausted rather than alternating work and rest. Most expressed that they did not realize the benefit of rest until it was explicitly taught to them within the course. After the course, participants had a different view of managing their energy. As Gail and Ingrid explained, it was not until after the course that they realized they could consciously use specific strategies to help them manage their multiple sclerosis-related fatigue. Gail explained,

They [i.e., the strategies] are definitely more conscious . . . some of them, I guess I was doing all along, but I didn’t know that they were helping me. And I didn’t know to use them more often . . . now that’s definitely something I realized [during the course] because I didn’t have a clue before.

After the course, participants consciously implemented the strategies, and actively problem solved how to save energy and do activities more efficiently. These actions allowed them to take more control of their multiple sclerosis fatigue and become more accommodating toward it. They wished other people would be educated about multiple sclerosis fatigue and energy conservation. Erica mentioned how education on multiple sclerosis could help, “get people to accept it . . . I think it is just a total understanding of the disease.”

Another aspect of the Value of Education theme was how the course and the interactions stemming from it facilitated participants’ willingness to try strategies. Angie thought that the teleconference course was “a great way to converse with people who have the disease, to compare notes,” and “there is nothing like talking to your peers.” Gail explained,

It was nice just to talk to other people that had the same problems that you had at different levels because not all of us were in the same stages. So that was kind of nice. Um, and other people had ideas that we, you know, haven’t thought of.

Through interactions with peers, Erica “realized that [she] was not alone.” Three participants mentioned how the course provided a support network in which they could relate and share experiences with one another. During the interviews, a few participants expressed trying energy conservation strategies that were endorsed by other participants. For example, Kim mentioned that one of the other participants had explained how she hung her pots and pans on the wall (changing the location of equipment, furniture, or supplies) to save energy rather than taking them out and putting them away. Kim reported trying this strategy at home and found a solution that worked similarly well for her.

Discussion

Findings from the interviews indicated that participants’ experience with the disease, sense of self, and their environment all influenced their use of energy conservation strategies. In particular, the progressiveness of the disease, the effect of multiple sclerosis fatigue on everyday life, and strong social supports enhanced the use of many strategies. In comparison, variability of the disease, struggles with sense of self, and rigid environments with limited social supports all hindered strategy use. Overall, the educational experience was valuable, and enhanced participants’ willingness and ability to work to combat the effects of multiple sclerosis fatigue.

Participants in this study reported using many energy conservation strategies after attending the teleconference program, with all of them reporting the use of at least 7 strategies 5 months after the course had ended. This percentage of use is significantly higher than that found in previous studies. Packer and colleagues (1995) reported that 80% of their participants were using at least six strategies at the end of the 6-week course, whereas Mathiowetz and colleagues (2001) reported 82%, and Vanage and colleagues (2003) reported 70% for the same number of strategies at the end of their programs. The high rate of energy conservation strategy use in the current study may represent a sampling bias in that persons who were using the strategies may have been more likely to volunteer for follow-up interviews. Although the participants of the Mathiowetz and associates (2001) study reported that planning their days was one of the most helpful strategies, the participants of the current study said that it was a difficult strategy to use and
was not beneficial for half of the participants. For those participants for whom this strategy was not beneficial, multiple sclerosis fatigue was variable and unpredictable, which made planning frustrating. For these participants, being flexible and making loose, tentative plans was more beneficial for them than expending energy planning activities that they could not fulfill.

The least helpful strategy mentioned by participants in the Mathiowetz and colleagues (2001) study was changing the way one positioned the body to do an activity. In the current study, however, the strategy rated as least beneficial by most of the participants was reducing one’s standards. Although several participants said they used it out of necessity, participants vocalized dislike for the wording of this strategy. They found the wording insulting, explaining that “reducing standards for an activity” made them feel as though they were not capable of being fully functioning adults. Changing the wording to “reevaluating your standards or setting limits” was suggested by two participants as a way of reframing the strategy to promote a sense of control. With the exception of this one strategy and its wording, participants generally thought that the energy conservation strategies provided them with increased control to better manage their multiple sclerosis fatigue.

In the Vanage and colleagues (2003) study, it was hypothesized that participants with greater disability were using fewer energy conservation strategies after the course because of a combination of prior education and lifestyle necessity. In addition, Vanage and colleagues hypothesized that participants’ decreased use of energy conservation strategies after the course might be due to the participants’ greater physical dependency on other people for assistance, including the implementation of some specific strategies. The current study supports these hypotheses. Participants whose multiple sclerosis or multiple sclerosis fatigue was more progressed often reported needing assistance and support within their immediate environment to implement some of the energy conservation strategies.

A key difference between the participants in the current study and those from previous ones is that the current participants received their energy conservation education via teleconference. In previous studies, participants took the course in person at a community center. A review of telehealth research by Liss, Glueckauf, and Ecklund-Johnson (2002) found that telehealth delivery can be at least as effective as face-to-face delivery for many health outcomes. Further research is required to determine whether differences exist between the two delivery modes in terms of the factors that enhance or hinder energy conservation strategy use.

This study is unique in its focus on the specific factors shaping use of energy conservation strategies in participants’ daily lives. The card-sort activity that was used to elicit discussion about the strategies seemed to enhance participants’ ability to compare various strategies with one another. It also appeared to serve as a visual cue to participants who experienced difficulty maintaining their train of thought during the interview.

A major finding of this study is that persons with multiple sclerosis might not implement a strategy until it is necessary for them to do so because of the severity of their disease and their multiple sclerosis fatigue. If a person with multiple sclerosis waits too long to implement a strategy, however, the cognitive or physical progressiveness of the disease may hinder the person from being able to do so. Findings suggest that more diverse and concrete examples to illustrate the energy conservation strategies, particularly activity simplification, would likely benefit persons who are experiencing cognitive symptoms. This approach may help participants to make clearer connections and translations of the materials to their own situations. Additionally, as the disease becomes more severe, the importance of having helping relationships or access to assistive devices becomes more important and necessary.

Study findings suggested that the implementation and use of energy conservation strategies had broad implications for the person’s sense of self that may not be obvious to an outside observer. During the interviews, participants talked about their struggles to change the way they viewed themselves in relation to the disease and to make the lifestyle changes necessary to better manage their multiple sclerosis and fatigue. Participants who had worked through some of these struggles and were more accepting of their disease seemed to have an easier time incorporating energy conservation strategies into their lives. From the interviews, however, it was apparent that participants’ level of acceptance was an evolving phenomenon. Many participants saw themselves as more accommodating of multiple sclerosis now than previously, but there were still many aspects of having multiple sclerosis that they were not comfortable acknowledging. Consequently, participants often were conflicted about whether to use strategies or not, because using them seemed to threaten their sense of self.

Use of energy conservation strategies requires the person with multiple sclerosis to make changes that involve a great deal of recognition and understanding, not only for the person with the disease but also for the people in their environment, and society as a whole. The energy conservation course offered participants the opportunity to talk with other persons with multiple sclerosis who experienced similar challenges. For some participants, this support and the contents of the course enabled them to communicate their experiences with fatigue more effectively with their loved ones and others in their social environment.
Most participants reported that delegating to others was a beneficial strategy, although one of the hardest strategies for the participants to implement was asking for help. To make asking for help easier for people with multiple sclerosis, future energy conservation educational programs may benefit from the inclusion of family members and friends. Alternatively, simultaneous programs for the different groups could be considered. This approach has the potential to facilitate communication between people with multiple sclerosis and members of their support network and place the individuals who provide support in a better position to do so while allowing the person with multiple sclerosis to retain control over the situation.

To address the environmental issues surrounding the workplace and disability rights, it would be beneficial for the energy conservation course to include a session on what constitutes reasonable accommodations, as required of employers under the Americans with Disabilities Act of 1990. Also, with time and finances permitting, participants in the course may benefit from a home visit from the course instructor, an occupational therapist, to assist with strategies that are difficult for participants to conceptualize and implement on their own (e.g., changing the location of equipment, furniture, or supplies; changing work heights).

A striking finding from this study was the way participation in the course not only helped participants to better manage their multiple sclerosis fatigue but also had a ripple effect in their lives. Several participants found that the use of energy conservation strategies decreased stress, aided cognitive functioning, and improved psychological well-being. This study not only supports the use of energy conservation strategies to manage multiple sclerosis fatigue but also suggests that energy conservation strategies can be a supplement in managing other multiple sclerosis symptoms.

Limitations of this study included using a small convenience sample of participants who were all well educated and willing to participate in the study. Additionally, all participants in the study were currently in the action and maintenance stages of change according to the Transtheoretical Model of Change (Cancer Prevention Research Center, 1998), whereas the wording and presentation of energy conservation strategies influenced participants’ willingness to use them, which suggests that therapists need to be sensitive to the way information is presented during this type of education. Materials that empower clients may increase their willingness to use them. Third, peer interaction was valued by participants and suggests that occupational therapists may want to build this approach into their treatment or, at minimum, ensure that they are recommending activities such as support groups for their clients. Finally, comments from participants suggested that other people did not understand multiple sclerosis fatigue, and therefore, it might be beneficial.

The purpose of this study was to examine the factors influencing the implementation and continued use of energy conservation strategies by persons with multiple sclerosis who received energy conservation education by teleconference. Findings showed that participants’ strategy use varied depending on their personal experience with the disease, their sense of self, and environmental factors. The educational process was found to be valuable in and of itself through peer interaction and support.

The findings from this study have several clinical implications. First, findings supported the use of the teleconference version of the “Managing Fatigue” program. Second, the wording and presentation of energy conservation strategies influenced participants’ willingness to use them, which suggests that therapists need to be sensitive to the way information is presented during this type of education. Materials that empower clients may increase their willingness to use them. Third, peer interaction was valued by participants and suggests that occupational therapists may want to build this approach into their treatment or, at minimum, ensure that they are recommending activities such as support groups for their clients. Finally, comments from participants suggested that other people did not understand multiple sclerosis fatigue, and therefore, it might be beneficial.

Conclusions

The findings from this study have several clinical implications. First, findings supported the use of the teleconference version of the “Managing Fatigue” program. Second, the wording and presentation of energy conservation strategies influenced participants’ willingness to use them, which suggests that therapists need to be sensitive to the way information is presented during this type of education. Materials that empower clients may increase their willingness to use them. Third, peer interaction was valued by participants and suggests that occupational therapists may want to build this approach into their treatment or, at minimum, ensure that they are recommending activities such as support groups for their clients. Finally, comments from participants suggested that other people did not understand multiple sclerosis fatigue, and therefore, it might be beneficial.
to have an energy conservation educational course geared toward the caregivers or loved ones of people with multiple sclerosis.

This study illustrates the complexity of the implementation and continued use of energy conservation strategies taught through a group telehealth format. Energy conservation use is not dependent on a single factor but rather is contextually dependent. Having a solid contextual understanding of the client is likely to enable occupational therapists to target educational efforts that will assist clients with multiple sclerosis to use energy conservation strategies that will benefit them within their own environments and situations. ▲

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References