

Article

Combining Qualitative and Quantitative Data Collection and Analysis Methods in Understanding Multiple Sclerosis Fatigue Management

Merrill J. Turpin B.Occ.Thy, PhD
Senior Lecturer in Occupational Therapy
School of Health and Rehabilitation Sciences
The University of Queensland
Australia

Miho Asano PhD
Postdoctoral Research Fellow
School of Rehabilitation Therapy
Queens University
Kingston, Canada

Marcia Finlayson OTR, PhD
Vice-Dean (Health Sciences) and Director, School of Rehabilitation Therapy
Queens University
Kingston, Canada

© 2015 Turpin, Asano, Finlayson. This is an Open Access article distributed under the terms of the Creative Commons-Attribution-NonCommercial-ShareAlike License 4.0 International (<http://creativecommons.org/licenses/by-nc-sa/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly attributed, not used for commercial purposes, and if transformed, the resulting work is redistributed under the same or similar license to this one.

Abstract

Combining qualitative inquiry with quantitative frequency data in a mixed methods research approach was valuable in understanding the strategies that people with Multiple Sclerosis (MS) used to manage their fatigue. Understanding its management is important because fatigue is often described by people with MS as their most disabling symptom and can pervade all aspects of a person's life. This research aimed to identify how often people used particular fatigue management strategies and the factors that influenced their use in the context of daily life. The methodology was Qualitative Description with phenomenological overtones using convenience sampling, interviews with semi-structured and structured components, and frequencies combined with typology development. Thirty-one people with MS from Chicago, Ill and Brisbane, Queensland in Australia who experienced fatigue were interviewed and asked to sort 15 cards with common fatigue management strategies into 3 categories, indicating whether they used them regularly, sometimes or never. Frequency counts were used to identify the number of participants who placed a specific strategy in a particular category. Frequencies were used to develop a typology with which to code the qualitative data. The strategies placed most frequently in each category were: *Plan / organize the day* used regularly, *Ask someone for help* used sometimes, and *Use mobility devices* never used. Mixed methods research techniques enabled us to explore the participants' fatigue management in greater depth. Each data type (i.e., qualitative and quantitative data) complemented the other and led to a richer understanding than either could provide in isolation.

Keywords: mixed methods, embedded design, pragmatism, qualitative description, Multiple Sclerosis fatigue

Author Note: The authors wish to thank the Consortium of Multiple Sclerosis Centre, USA, for the funding support for this project and the participants who gave their of time and experiences.

Multiple Sclerosis (MS) is a neurological condition in which demyelination of the central nervous system occurs, producing a range of symptoms depending on the site of demyelination (Rodriguez, Kantarci, & Pirko, 2013). Therefore, symptoms vary from person to person, but commonly include problems with sight, balance, muscle strength, and bowel and bladder control, as well as heat sensitivity, sensory changes, and fatigue (both physical and cognitive) (Cameron, Finlayson, & Kesselring, 2013; Gelfand, 2014). The condition has four typical courses (Cameron et al., 2013) as follows: (a) Relapsing-Remitting MS (RRMS), the most common type affecting approximately 85% of people with MS, characterized by clearly defined relapses with full, or almost full, recovery of function and no progression of the condition between relapses, ; (b) Secondary Progressive MS (SPMS), whereby, after an initial relapsing-remitting course, the condition progresses over time (within 15 years of diagnosis 50% of people with RRMS will transition to this type); (c) Primary progressive MS (PPMS), which affects approximately 10% of people with MS and is characterized by a gradual and continuous worsening over time; and (d) Progressive Relapsing MS (PRMS), which affects only 5% and has a progressive course with distinct relapses and, unlike RRMS, progresses between relapses.

Fatigue is a common symptom of MS, experienced by 70% to 90% of people and is often described as their most disabling symptom (Finlayson, Johansson, & Kos, 2013). MS fatigue has been defined as “an overwhelming, debilitating, and sustained sense of exhaustion that decreases one’s ability to carry out daily activities, including the ability to work effectively and to function at one’s usual level in family and social roles” (Cook, Roddey, & Kim, 2013, p. 654). It is not the same as ordinary tiredness and can have physical and cognitive manifestations (Johnson, 2008).

Although people with MS acknowledge that some level of fatigue is always with them and that its severity can change quite suddenly and, often, unpredictably, they also undertake to manage its effects on their daily lives. Because MS fatigue can be so debilitating, providing accurate information on effective fatigue management is important. Two effective strategies for managing MS fatigue are exercise and energy management (Asano, Berg, Johnson, Turpin, & Finlayson, 2015; Asano & Finlayson, 2014). Taken together, these two types of intervention aim to increase capacity for activity by building strength and endurance, and by conserving energy to make it available for valued activities. Often, approaches to energy management are based on the program developed by Packer, Brink, and Sariol (1995). The majority of research on energy management has centered on evaluating programs (e.g., Finlayson, Preissner, Cho, & Plow 2011; Ghahari, Leigh Packer, & Passmore, 2010; Sauter, Zebenholzer, Hisakawa, Zeitlhofer, & Vass, 2008), rather than on exploring people’s actual use of energy management strategies in their daily lives. However, in one study (Holberg & Finlayson, 2007) that involved the evaluation of a course offered by teleconference, the participants were asked about the 14 strategies taught in the course and how easy or difficult they were to use. They identified three themes that related to participants’ use of strategies: (a) experience with the disease, (b) sense of self, and (c) environmental factors.

The research presented here was conducted to expand knowledge of how people who experience MS fatigue manage it in their daily lives, regardless of whether they have participated in a fatigue management program. The intention was that knowledge informed by the perceptions of those who have direct experience of this phenomenon could contribute to the development of a tool to support the clinical reasoning of service providers by providing accurate and useful information on MS fatigue management. Specifically, the research questions used in this study were as follows:

1. What fatigue management strategies do people with MS use?
2. How often do they use those strategies (regularly, sometimes and never)?
3. What reasoning influenced their use of these strategies?

Method

Research Design

Qualitative description (Sandelowski, 2000, 2010) using criteria and convenience sampling (Collins, Onwuegbuzie, & Jiao, 2007), data collection through interviews with semi-structured and structured components (Robson, 2011), and the integration of frequency data with typology development for qualitative analysis (Bazeley, 2009; Caracelli & Greene, 1993) was used to address the research questions. As Sandelowski (2000) stated, “Qualitative description is especially amenable to obtaining straight and largely unadorned (i.e., minimally theorized or otherwise transformed or spun) answers to questions of special relevance to practitioners and policy makers.” (p. 337). In this research, we aimed for a description of how people managed MS fatigue in the context of their unique daily lives, exploring what they did and why, rather than taking a particular theoretical perspective towards the issue. Thus, we aimed for a “data-near” description of participants’ responses (Sandelowski, 2010, p. 78).

An important principle of qualitative description is naturalistic inquiry, research that “takes place within real-world settings and [in which] the researcher does not attempt to manipulate the phenomenon of interest” (Patton, 2002, p. 39). The phenomenological overtones of this research are reflected in the emphasis placed on the participants’ lived experience (Van Manen, 1997). In phenomenology, a distinction is made between phenomena and the experience of those phenomena. According to Van Manen, “lived experiences gather hermeneutic significance as we (reflectively) gather them by giving them memory” (p. 37). Guided by the perspective of Hermeneutic Phenomenology (Finlay, 2012), we aimed to understand the meaning participants made of MS fatigue and its effect on their daily lives and, consequently, how these meanings shaped the decisions they made regarding its management. Hermeneutic Phenomenology is based on the work of Heidegger, which assumes that all understanding is interpretive (Inwood, 1997). Therefore, in this research we acknowledged that both data collection and analysis are essentially interpretative and are always shaped by the perspective of the researcher.

The research was conducted in Chicago, IL and Brisbane, Queensland in Australia. Prior to undertaking the research, ethical clearance was obtained from the appropriate institutional review board and ethics committees. The research team comprised researchers with qualitative and quantitative expertise. The overall team leader was a specialist in MS rehabilitation and research, and the other two team members were specialists in qualitative and quantitative research, respectively. All three researchers undertook data collection and used their respective expertise to guide the analysis of each data type.

Participants

Thirty-one participants were recruited for the study: 18 from USA and 13 from Australia, all with direct experience of MS fatigue. The study was advertised through flyers and presentations, as well as direct letters to participants of previous research who had agreed to be contacted for further studies (in the U.S.) and a MS society Facebook site (in Australia). The sampling strategy was a convenience sample of those who voluntarily responded to the invitation to participate and met the inclusion criteria, which were: (a) self-reported diagnosis with MS, (b) aged 18 years and over, (c) being able to complete an interview in English, (d) used or attempted to use at least one type of fatigue management approach in the past two years, and (e) being able to tolerate an hour of discussion or being willing to complete the interview with breaks or to continue the interview on another day. The research participants all met these criteria and no exclusion criteria were applied.

Instruments

A mixed methods research approach was used to address the research questions. By combining qualitative and quantitative data, we were able to identify what strategies participants used and how frequently they used them, as well as exploring why they used them in their daily lives with that frequency. Using the expanded notation system outlined by Creswell and Plano Clark (2011), this research is conceptualized as QUANT + QUANT, or *equal status* (Johnson, Onwuegbuzie, & Turner, 2007, p. 123), because both methods occurred concurrently and neither was more dominant. In this research, we used an Embedded Design (Creswell & Plano Clark, 2011), with concurrent data collection, which reduced the imposition on participants, was practicable within the resources available, and allowed the researchers to use different types of data to inform and to develop a rich understanding.

Using Biesta's (2010) seven levels of mixed methods research, only the first two, data and methods, were mixed. Each of the other levels had a single approach as follows: at Level 3, a non-interventionist design; at Level 4, a pragmatist epistemology; at Level 5, a social ontology; at Level 6, the purpose of the research was to understand, rather than to explain; and, at Level 7, the practical role of the research was cultural, rather than technical.

All data were collected through single, in-depth interviews with a mean length of 85 minutes (range = 60-150, *SD* = 19). Prior to conducting the interviews a process of gaining written, informed consent from participants was undertaken, and participants were given a Participant Information Sheet to keep. The interview had three parts. The first part aimed to understand participants' experiences of MS fatigue in their daily lives. In order to contextualize their experiences of MS fatigue, the interview commenced by asking participants to describe their interests, circumstances, typical activities, and the effect of MS on their particular lives. The interview then turned to their MS fatigue. Participants were asked "How has MS fatigue changed your everyday routine and activities?" and were prompted to discuss their typical days and important and valued activities, as well as discussing how they managed their fatigue in that context.

The second part of the interview comprised a card-sorting activity, in which participants were presented with 15 cards with common fatigue management strategies and asked to sort them according to whether they used each strategy regularly, sometimes, or never. These cards were developed from the literature on MS fatigue and included strategies used in energy conservation courses (e.g., Take rests during the day, Try to make activities simpler) and strategies that target exercise (e.g., Do exercises to build strength) (see Table 1). Blank cards also were provided so that participants could record other strategies they used and sort them. Once sorted, the cards in each category were laid out in turn and discussed.

Finally, participants were asked to provide specific demographic information and complete two standard MS measures. First, the Patient Determined Disease Steps (PDDS) (Hohol, Orav, & Weiner, 1995; Marrie & Goldman, 2007) required participants to indicate which of nine descriptors of level of disability applies to them (0=mild symptoms, 8=unable to sit in a wheelchair for more than 1 hour). Second, in the Modified Fatigue Impact Scale (MFIS), a shortened version of the Fatigue Impact Scale (Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994, and commonly used in MS research; e.g., Amtmann et al., 2012; Kos et al., 2005), participants rate on a 5-point scale, from never to almost always, 21 statements commencing with the stem "Because of my fatigue during the past 4 weeks...".

Data Analysis

Interview recordings were transcribed verbatim and the category into which each fatigue-management card was placed was recorded on an Excel spreadsheet. Data were analyzed

according to their form: whether numerical or words. The numerical data were analyzed using descriptive statistics such as frequency counts. Qualitative data were coded using a typology (Bazeley, 2009; Caracelli & Greene, 1993) developed from the frequency counts. Once the frequencies of strategies in each category were determined, the qualitative data were systematically searched for discussions of those strategies with the higher frequencies in each category. Quantitative data were used to address the first two research questions pertaining to the use of strategies and the qualitative data were used to identify the factors that influenced participants' use of strategies. Thus, the reasons for mixing research were complementarity (Greene, Caracelli, & Graham, 1989) and to address different research questions (Bryman, 2006).

Results

Of the 33 people who made contact, 31 participated in the study; one person was admitted to hospital and another believed that the study was not appropriate as a recent change in medication had addressed his problems with fatigue. Twenty-three of the participants were female and eight were male, this is consistent with the 70% to 75% of people with MS being women (Finlayson, Chitnis, & Hartman, 2013). The mean age was 51.3 years (range = 25-70, $SD = 12.4$). Twenty-one participants had RRMS, four had SPMS, four had PPMS, and two were unknown. Mean years since symptom commencement was 16.8 (range = 3-46, $SD = 10.6$) and mean years since diagnosis was 10.3 (range = 1-25, $SD = 7.3$). Nine people lived alone, 14 with a spouse, four with parents or siblings, three indicated 'other,' and one chose 'rather not say.' All except one participant completed the Patient Determined Disease Steps (PDDS), with the mean score being 3 (range = 0-7, $SD = 2.2$), described in the interview guide as: MS interferes with your activities, especially your walking. You can work a full day, but athletic or physically demanding activities are more difficult than they used to be. You usually don't need a cane or other assistance to walk, but you might need some assistance during a MS attack (relapse or exacerbation).

All participants completed the Modified Fatigue Impact Scale, with the median score of 45 ($IQR = 35-51$), which is significantly higher than reported for a sample of healthy adults (Tellez et al., 2005), where the median score was 11 ($IQR = 5.0-21.5$). Because there were no substantial differences between groups in terms of age, gender, and geographical location (except for the strategy of avoiding heat and humidity, which is commented upon), the results are presented as an aggregate of the whole cohort of participants.

Frequency of Strategy Use

Using descriptive statistics and counting the number of times that strategies were placed in each category, we addressed the first two research questions and determined what strategies participants used and how often they used them: regularly, sometimes, or never. Regarding overall use of the 15 strategies presented to participants: the mean number for 'used regularly' was 7 (range = 2-13, $SD = 3$), or approximately 50% of strategies; the mean for strategies 'used sometimes' was 5 (range = 0-10, $SD = 2$, 34%); and only a mean of 2 strategies (16%) were 'never used' (range = 0-7, $SD = 2$). Results show that the mean number of strategies placed in each category was higher for strategies used regularly than for those placed in the other categories, particularly those never used. Overall, 84% of the strategies were used regularly or sometimes. Very few participants added other strategies, but those recorded included maintaining good sleep hygiene and using medication.

Table 1 provides the frequency with which strategies were placed in each category of use. *Plan / organize the day* was placed in the 'used regularly' category by the highest number of people ($n = 26$, 83.8%), followed by *Avoid heat and humidity*, *Break up activities over the course of the day or over several days* and *Sit to do an activity, rather than stand* (all $n = 20$, 64.5%). The lowest frequency in this category was *Delegate an activity to someone else* ($n = 8$, 25.8%).

Table 1

Frequency of Strategy Use (n = 31)

Strategy	Frequency: Regularly	Strategy	Frequency: Sometimes	Strategy	Frequency: Never
Plan / organize the day	26 (83.8%)	Ask someone else to help	20 (64.5%)	Use mobility devices	16 (51.6%)
Avoid heat & humidity	20 (64.5%)	Try to make activities simpler	17 (54.8%)	Use gadgets to make jobs easier	10 (32.3%)
Break up activities over the course of the day or over several days	20 (64.5%)	Choose not to do an activity in order to do something else	16 (51.6%)	Do exercise to build endurance	8 (25.8%)
Sit to do an activity, rather than stand	20 (64.5%)	Delegate an activity to someone else	16 (51.6%)	Delegate an activity to someone else	7 (22.6%)
Do exercises to build strength	18 (58.1%)	Do activities less often	13 (41.9%)	Reorganize workspaces so that items are convenient	7 (22.6%)
Do exercise to build endurance	17 (54.8%)	Reorganize workspaces so that items are convenient	13 (41.9%)	Break up activities over the course of the day or over several days	6 (19.4%)
Take rests during the day	17 (54.8%)	Take rests during the day	10 (32.3%)	Do exercises to build strength	5 (16.1%)
Do activities less often	16 (51.6%)	Use gadgets to make jobs easier	10 (32.3%)	Take rests during the day	4 (12.9%)
Choose not to do an activity in order to do something else	14 (45.2%)	Sit to do an activity, rather than stand	9 (29%)	Avoid heat & humidity	3 (9.7%)
Try to make activities simpler	13 (41.9%)	Avoid heat & humidity	8 (25.8%)	Do activities less often	2 (6.5%)
Reorganize workspaces so that items are convenient	11 (35.5%)	Do exercises to build strength	8 (25.8%)	Plan / organize the day	2 (6.5%)
Use gadgets to make jobs easier	11 (35.5%)	Do exercise to build endurance	6 (19.4%)	Sit to do an activity, rather than stand	2 (6.5%)
Ask someone else to help	10 (32.3%)	Use mobility devices	6 (19.4%)	Ask someone else to help	1 (3.2%)

Strategy	Frequency: Regularly	Strategy	Frequency: Sometimes	Strategy	Frequency: Never
Use mobility devices	9 (29%)	Break up activities over the course of the day or over several days	5 (16.1%)	Choose not to do an activity in order to do something else	1 (3.2%)
Delegate an activity to someone else	8 (25.8%)	Plan / organize the day	3 (9.7%)	Try to make activities simpler	1 (3.2%)

Ask someone for help was the strategy most frequently placed in the ‘used sometimes’ category ($n = 20$, 64.5%). This was followed by *Try to make activities simpler* ($n = 17$, 54.8%) and then *Delegate an activity to someone else* and *choose not to do an activity in order to do something else* (both $n = 16$, 51.6%). *Plan / organize the day* was placed in this category least frequently ($n = 3$, 9.7%).

Most frequently identified as never used was the strategy *Use mobility devices* ($n = 16$, 51.6%), which was followed by *Use gadgets to make jobs easier* ($n = 10$, 32.3%). Three strategies were placed in this category least often: *Ask someone else to help*, *choose not to do an activity in order to do something else*, and *Try to make activities simpler* (all $n = 1$, 3.2%).

Reasoning Behind Use of Strategies

To illustrate participants’ reasoning in their use or not of strategies and the contexts in which they used them, the three most frequently identified strategies in each category are presented. However, for strategies used regularly and sometimes, four strategies are provided, because more than one strategy was placed in those categories with equal frequency. For each, a description of the qualitative comments with example quotations is provided. Participant number (e.g., P1 = Participant #1), country, and gender are provided alongside each quotation. The three categories are discussed in the following sections.

Strategies most frequently categorized as “used regularly”. *Plan and organize the day* was the strategy most frequently identified as being used regularly (83.8%). This strategy was important because a sudden or unanticipated change in people’s plans for the day could accentuate their fatigue levels and have negative consequences for the remainder of their day and, at times, their week. By planning and organizing, people attempted to avoid situations where their fatigue prevented them from participating in or continuing an activity. Common examples included planning not to undertake too many activities in one day and planning their schedules to allow rest in between activities. Participants commonly reported planning to complete activities in the morning and to rest in the afternoon. Additionally, planning sufficient time to complete an activity was emphasized as important. By planning, people attempted to prevent ‘being caught’ in a position where they might be fatigued and could not use other strategies to manage it. For example, participants discussed driving themselves to social events, rather than carpooling with friends, because this allowed them to leave when they wanted to do so.

Participants described various methods that they used to organize their day, including preparing a to-do list and writing goals on Post-it notes. Technology such as iPads provided a sound to prompt them to complete or to change activities. In addition to planning and organizing their day, planning and organizing their week allowed them to conserve energy on some days in order to have it available on other days.

Planning and organizing was something many people had always undertaken and so they applied it to fatigue management, as illustrated by P12 (U.S. female), who explained:

Planning [your] day and prioritizing is just something you kind of need to do for a bunch of reasons. The focus of planning it based on fatigue is new; so, it's sort of using something that is a skill that one has and uses, but now for a much more specific focus.

Others believed that they were not natural planners. The disadvantage identified of planning was that it removed the opportunity to act spontaneously.

The next three strategies in this category were identified with equal frequency. These were *Avoid heat and humidity*, *Break up activities over the course of the day or over several days*, and *Sit to do an activity, rather than stand* (all 64.5%).

When discussing the strategy *Avoid heat and humidity*, participants reported using ice blocks, running hands and wrists under cold water, accessing air conditioning, and using neck wraps with ice inside. Also, they discussed choosing to undertake activities at certain times of the day, such as morning or late afternoon, when the air was cooler. One participant indicated that she managed heat when grocery shopping by standing in the freezer aisle. Another participant (P25, Australian, female) revealed: “[to] avoid heat and humidity, my favourite thing is to go to the movies or go to a shopping centre [both air conditioned] and just stay in the cool.” Eighty-one per cent of participants who used the strategy of avoiding heat and humidity regularly were Australians. This could be due to the time of year in which the interviews were undertaken (summer in Australia and winter in the United States) and also because very high humidity is a feature of summer in Brisbane.

Regarding the strategy *Break up activities over the course of the day or over several days*, reference was made particularly to household activities. The body heat accumulated while completing certain tasks, which made them feel physically drained, was a major reason for using this strategy. Sometimes breaking up activities was planned. At other times, it was used in response to the situation. For instance, P21 (Australian female) explained:

I do that quite often, but not consciously. As in, I start something and I think, no this is taking too much out of me, I'll finish it tomorrow and then I'll just leave it. But it happens more and more often because I get more and more tired easily—which is annoying.

Most frequently, those who used this strategy had begun in a trial-and-error way and used it because they had to do so. As P11 (U.S. female) described:

I would try to just do things around the house like I normally did, but I just would get too exhausted. So, then I started taking little breaks. But I still couldn't do a whole lot in a day. So that's when I started breaking it down into do a little bit here, a little bit there. So it was definitely out of necessity. I had no choice.

A reason given for not using this strategy was that it was not consistent with their type of personality. Instead, they preferred to get tasks accomplished, rather than leaving them to complete at a later time.

Sit to do an activity, rather than stand was the third strategy equally-commonly identified as being regularly used. Apart from activities that would commonly involve sitting, people might choose to sit for other activities such as setting the table or cutting vegetables. Often, the use of this strategy depended on the physical environment and whether it was easier or possible to undertake the activity in a seated position, for example, if there was a bar stool at the kitchen bench or whether the type of work in which the person was involved allowed for sitting. A few participants indicated that they preferred to stand rather than to sit to perform an activity because it helped with their fatigue by keeping them alert.

Strategies most frequently categorized as ‘used sometimes’. When discussing why they used some strategies only sometimes, participants generally stated that their use of strategies depended

on three factors: (a) circumstances, (b) the activity that they were performing, and (c) their fluctuating fatigue levels. For example, they were able to use a particular strategy in some situations, but not in others; they did not need to use a strategy for activities that were easy, but they would need to use it for other activities; they might use a strategy for those activities that they believed important to have completed, but not for other activities; and a particular strategy might only be needed when they were feeling fatigued and, therefore, would not be needed all the time.

Ask someone for help was the strategy most frequently identified in this category (64.5%).

Although participants indicated they asked close family members such as their spouse/partner or children for help, often they appeared to be more reluctant to ask others outside close family for assistance. In general, people did not like asking for help, often declaring that they valued their independence. P5 (U.S female) explained:

Sometimes, I guess, I ask someone to help when I don't know what else to do, and there seems like there's no other option, and you just sometimes have to ask others for help, even though you may not want to... if you're just too overloaded and worn down.

A few participants identified this strategy as one they never used. Reasons for not using it included that they believed others did not always receive it well, they did not have someone to ask, or, in the case of formal help, that it would cost money.

Try to make activities simpler was the strategy second most frequently placed in this category (54.8%). Most participants reported that it was a strategy that they ordinarily used in their life; therefore, they automatically used it to manage their fatigue. Others said that they had already made activities simple in their lives, and, consequently, did not need to use it as a strategy to manage their fatigue. A common way to make activities simpler was to skip steps. For example, P21 (Australian female) stated:

Yes, I skip steps. I used to, for instance, bake everything from scratch. Now I just use packet mixes and make them easier. I used to mop the floors and stuff – [now] I use one of the little Swiffer things you just swivel round with. [I] just ignore that there is dust under things and just don't see it... I don't iron as much, I just fold things or tell everybody else that they can do their own; it's much easier on me.

Participants discussed the challenges associated with using this strategy. Some people explained that, in order to make activities simpler, they might have to change the standards that they would accept and expect. Another challenge with using the strategy was that there might conflict with their other beliefs or values. For instance, one participant talked about using a clothes dryer instead of hanging washing. Although she was too fatigued to hang the washing, she did not like using the dryer because of the impact that it had on the environment.

Sixteen participants placed *Delegate an activity to someone else* in the 'Used Sometimes' category (51.6%). The advantage of using this strategy was that it would prevent them from becoming fatigued while ensuring that the task was completed. Whether people used this strategy seemed to depend on the activity and the circumstances. For instance, people would only delegate at work if it was appropriate to their position. It would also depend on the availability of people to whom to delegate and, often, people would attempt to make it easy for people by timing the request with what others were doing. For example, P19 (U.S. male) concluded: "I don't usually delegate all the time. I delegate it when it's convenient for them to do [it]. If you're delegating [to] somebody, 'Hey, man, while you're coming home, will you go to downtown?'" One participant reported that she would delegate more often if she had more family members and friends around to whom to delegate, but did not feel the same regarding delegating to support workers. A challenge reported in using this strategy was that people did not want to burden others.

Choose not to do an activity in order to do something else also was placed in the 'Sometimes' category by 16 people (51.6%). Participants linked this strategy to determining what was important to them and prioritizing some tasks over others. Its use depended on circumstances. P31 (Australian female) discussed her priorities:

Well, I choose to function and do the things I need to do at home, mostly, you know, shopping and washing and that sort of stuff. To have the energy to do that rather than go out with friends to the movies or go on a – you know, for exercise, go on a hike, or do any of that stuff. I just sort of think “no, I’ll just not do any of that.” At least then I can function and do what I need to do at home.

Strategies most frequently categorized as ‘never used’. Participants also were asked to identify those strategies that they never used. *Use mobility devices* was placed most frequently in the 'never' category (51.6%). Whether people used a mobility device was dependent on their need, in that, many people indicated that their mobility was not affected and they did not need such a device. Although some participants did not need a mobility device at the time, they were receptive to the prospect of using one if required. P5 (U.S. female) stated:

And the same thing with the mobility devices, I mean, again, I feel like I’m lucky and thank God that I’m not to the point where I would need some sort of cane or walker or scooter device that would help me. But, I mean, I guess if the need arose it’s not like I would say, “Oh, I’m never gonna use that kinda thing” - but I just haven’t had to.

Some participants made it clear that they believed there was stigma attached to mobility devices and indicated that they never used them for this reason. Participants commonly associated using a mobility device with loss of independence and strength, which they wanted to maintain, or not wanting to be different:

It makes me feel – I’ll tell you – this I’ll say – I always say anybody who has MS, or some disability that’s noticeable or that affects your life, I think, can understand that you just want to be like everybody else. I just don’t want to be with a walker. I don’t want to be with a cane. I want to be like everybody – you don’t want to be different. That’s just me, although I know there’s other people that feel that way, I’m sure. (P2, U.S. female)

Participants who did use them explained that it was due to the progression of their disability. One participant reported that she noticed her feet would drag and another participant indicated he would fatigue faster if he did not have the aid of a mobility device. Other participants stressed that they only used a mobility device if required during outings. One participant described using her mobility device as a security measure, in that she worried less about falling if she was in a crowded place or near children.

Visual impairment, a common symptom in MS, also influenced participants’ use of mobility devices. One participant, who was legally blind, commented that her mobility device was her guide dog. She did not have problems with balance, but discussed how difficult it would be if she did. Another participant with visual impairment explained that any mobility device would be a nuisance to her because she would need to be cautious of not tripping over it, as well as it being another aspect of which to “keep track.”

The second strategy most frequently placed in the never used category was *Use gadgets to make jobs easier* (32.3%). This particular strategy highlights the low frequency of strategies placed in the 'never used' category. Although it was one of the highest frequencies in this category, it was placed in all three categories quite evenly. That is, approximately one third of participants each indicated that they used the strategy either regularly, sometimes, or never. Many people mentioned the gadgets that they used, but did not link their use to fatigue, specifically because they were just devices that they would ordinarily use. When participants stated that they never

used gadgets, they gave a range of explanations, which included that they were not able to use them due to impairments such as poor hand function, that they were not a “gadget person,” and that they would choose to obtain assistance rather than use a gadget. The most commonly mentioned gadget was a Swiffer. As P11 (U.S. female) stated: “I don't use a lot of different gadgets. I do like the Swiffer. It's easier than lugging the big vacuum cleaner all over the place.” Often people noted that they started using this strategy to manage fatigue because it was suggested in energy management programs.

The third strategy most commonly identified as ‘never used’ was *Do exercise to build endurance* (25.8%). This strategy was placed in this category more commonly than *Exercises to build strength*. Participants often cited raised body temperature as a barrier to exercising for endurance, as this added to fatigue. Although air conditioned gymnasiums could be promoted as a way of dealing with this problem, their cost often was identified as a barrier. Discussing exercise more generally, participants indicated that they found it useful to attend sessions with a neurological physiotherapist, who would have an appropriate environment for exercising and also adapt exercises to suit their capabilities. The Australian participants also indicated that they did Pilates for their exercise.

Discussion

We aimed to study events in the real world and discover how people who experienced MS fatigue managed it in the context of their lives. The purpose of this research was to provide a foundation of knowledge upon which tools to assist clinical reasoning and rehabilitation interventions could be developed and their effectiveness tested.

Combining quantitative and qualitative data (i.e., information about quantity and quality) enabled us to develop a fuller understanding of participants’ use of strategies to manage their MS fatigue than either data type alone could have revealed. We were able to identify which strategies were used more and less often and to gain an appreciation of the reasons why and circumstances in which participants chose to use particular strategies or not.

The wide range in the number of strategies placed in each category (e.g., 2-13 out of 15 strategies for frequently used) suggests a substantial variation in strategy use. Discussing their strategy use with participants assisted in understanding some of this variation. Of the strategies used regularly, planning one’s day and avoiding heat and humidity seemed to have a habitual element, as did sitting rather than standing (or standing rather than sitting). In contrast, breaking up activities over time seemed to be a strategy that people developed when they found it necessary. However, once people accepted that a strategy was needed, they would then use it habitually.

Strategies delineated as used sometimes appeared to be contingent on factors such as fluctuations in fatigue level, circumstances, and the activity being undertaken. The Person-Environment-Occupation (PEO) model (Law et al., 1996) provides a useful framework for understanding the complexity of interactions among these factors. This model proposes that achieving what people want and need to do results from the degree of ‘fit’ among: a person’s capacities (person), the circumstances and situation in which something occurs (environment) and what is being performed (occupation). Examples include: someone might use a strategy when feeling fatigued but not at other times (variations in the person’s capacities); the person might use a strategy when it is the only way he/she can achieve task completion (i.e., using the strategy makes the fit sufficient among the person’s capacities—even if it is another person, the demands of the task and the nature of the environment); the person might use a strategy for some tasks and not others (the person’s capacity fits with the demands of some tasks and not others); there might be particular times or places when it is or is not possible to use a particular strategy (the nature of the environment).

Three main reasons were evident in discussions of strategies categorized as ‘never used’. First, they did not need it (e.g., when people’s symptoms did not impede their mobility). Second, frequently, their circumstances did not allow for its use (e.g., there was nobody to ask for help or it would cost extra when being provided by a formal carer, they were not able to use that strategy in their workplace). Third, they associated its use with stigma and decline in their abilities.

These findings can inform the design of fatigue management interventions and provide a knowledge base from which to make recommendations for practice. For example, understanding their frequency of use helps to identify which strategies to prioritize when teaching fatigue management strategies that are new for people and reinforcing, refining, and helping people to recognize what they are already doing. Understanding when and why people do or do not use particular strategies can be used to inform rehabilitation therapists about the issues that they might need to consider (e.g., from whom a person might feel comfortable asking for help) and the need to explore individual circumstances, attitudes, and the activities that are important to the person.

The card sorting process was valuable in prompting people to reflect on their daily lives in a way that they otherwise might not have reflected. It appeared to make them think about their concrete experiences (an important strategy in phenomenology; Finlay, 2012), with one participant commenting that the process had given her a lot to think about. The Activity Card Sort (Baum & Edwards, 2008) is a well-accepted clinical tool. The sorting of MS fatigue strategy cards might have important value as a rehabilitation tool.

Reflections on Method

Johnson et al. (2007) stated, “Today, the primary philosophy of mixed research is that of pragmatism” (p. 113). In pragmatism, experience is conceptualized as “the transactions of *living organisms* and their environments” (Biesta, 2010, p. 106, italics in original). The notion of action is key to pragmatism, whereby a person’s actions both influence the environment and are affected by it. Upon reflection, the basis in pragmatism of mixed methods research was evident in the results, which elicited information regarding the transaction between the person and her/his environment. In addition, the PEO model (Law et al., 1996), described by the authors as a transactive model, highlighted the importance of the activities being undertaken in understanding this transaction. By adopting a mixed methods research approach, we were able to address all three research questions and to understand both the action participants took (or did not take) to manage their MS fatigue and the reasoning behind their choices of action.

Limitations and Further Research

When considering the transferability of these results, a number of issues need to be considered. First, this research used a convenience sampling strategy, rather than probability sampling. Teddlie and Tashakkori (2009) stated that purposeful sampling typically uses small sample sizes of 30 or less, whereas probability sampling aims to recruit a sufficiently large sample (e.g., 50 or more) to establish representativeness. Consequently, the results presented here aimed to contribute to an understanding of the phenomenon of managing MS fatigue, rather than claim to be representative of the population of people who manage MS fatigue. To establish representativeness, further research using a representative sample would be required.

Second, these results were obtained from adults with self-reported MS who experienced and used at least one strategy to manage it and could tolerate an interview in English for the required length (because all participants chose to complete the interview in a single session). In order to facilitate decisions about the potential relevance of these findings, we have provided a detailed description of this sample. The transferability of these findings to other groups would need to be established through further research.

Third, the frequency data obtained gave a description of participants' use of fatigue management strategies, but we did not gain an understanding of whether there is an optimal number or way to use strategies. Further research would be required to establish whether such a phenomenon exists or whether what is required is establishing what is optimal for each person in the context of his or her life and the best way to achieve this.

References

- Amtmann, D., Bamer, A. M., Noonan, V., Lang, N., Kim, J., & Cook, K. F. (2012). Comparison of the psychometric properties of two fatigue scales in multiple sclerosis. *Rehabilitation Psychology, 57*, 159-166. doi:10.1037/a0027890
- Asano, M., Berg, E., Johnson, K., Turpin, M., & Finlayson, M. (2015). A scoping review of rehabilitation interventions that reduce fatigue among adults with multiple sclerosis. *Disability and Rehabilitation, 37*, 729-736. doi:10.3109/09638288.2014.944996
- Asano M., & Finlayson M. L. (2014). Meta-analysis of three different types of fatigue management interventions for people with multiple sclerosis: Exercise, education, and medication. *Multiple Sclerosis International*. doi:10.1155/2014/798285. Retrieved from <http://www.hindawi.com/journals/msi/2014/798285/>
- Baum C. M., & Edwards, D. (2008). *Activity card sort: Test manual* (2nd ed.). St. Louis, MO: Washington University School of Medicine.
- Bazeley, P. (2009). Integrating data analyses in mixed methods research [Editorial]. *Journal of Mixed Methods Research, 3*, 203-207. doi:10.1177/155868980933443
- Biesta, G. (2010). Pragmatism and the philosophical foundations of mixed methods research. In A. Tashakkori & C. Teddlie (Eds.). *SAGE handbook of mixed methods in social and behavioural research* (2nd ed., pp. 95-117). Thousand Oaks, CA: Sage.
- Bryman, A. (2006). Integrating quantitative and qualitative research: How is it done? *Journal of Mixed Methods Research, 6*, 97-113. doi:10.1177/1468794106058877
- Cameron, M., Finlayson, M., & Kesselring, J. (2013). Multiple sclerosis basics. In M. Finlayson (Ed.). *Multiple sclerosis rehabilitation: From impairment to participation* (pp. 9-34). Boca Raton, FL: CRC Press.
- Caracelli, V. J., & Greene, J. C. (1993). Data analysis strategies for mixed-method evaluation designs. *Education Evaluation and Policy Analysis, 15*, 195-207. doi:10.2307/1164421
- Collins, K. M. T., Onwuegbuzie, A. J., & Jiao, Q. G. (2007). A mixed methods investigation of mixed methods sampling designs in social and health science research. *Journal of Mixed Methods Research, 1*, 267-294. doi:10.1177/1558689807299526
- Cook, K. F., Roddey, T. S., & Kim, J. (2013). Multiple sclerosis and fatigue: Understanding the patient's needs. *Physical Medicine and Rehabilitation Clinics in North America, 24*, 653-661.
- Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research*. Thousand Oaks, CA: Sage.
- Finlay, L. (2012). Debating phenomenological methods. In N. Friesen, C. Henriksson, & T. Saevi (Eds.) *Hermeneutic phenomenology in education: Method and practice*. Rotterdam, The Netherlands: Sense.
- Finlayson, M., Chitnis, T., & Hartman, E. A. (2013). Influences of age and sex. In M. Finlayson (Ed.). *Multiple sclerosis rehabilitation: From impairment to participation* (pp. 417-434). Boca Raton, FL: CRC Press.

- Finlayson, M., Johansson, S., & Kos, D. (2013). Fatigue. In M. Finlayson (Ed.), *Multiple sclerosis rehabilitation: From impairment to participation* (pp. 69-99). Boca Raton, FL: CRC Press.
- Finlayson, M., Preissner, K., Cho, C., & Plow, M. (2011). Randomized trial of a teleconference-delivered fatigue management program for people with multiple sclerosis. *Multiple Sclerosis, 17*, 1130–1140. doi:10.1177/1352458511404272
- Fisk, J. D., Pontefract, A., Ritvo, P. G., Archibald, C. J., & Murray, T. J. (1994). The impact of fatigue on patients with multiple sclerosis. *Canadian Journal of Neurological Science, 21*, 9-14.
- Gelfand, J. M. (2014). Multiple sclerosis: Diagnosis, differential diagnosis, and clinical presentation. In D. S. Goodin (Ed.), *Multiple sclerosis and related disorders*, Vol. 122 (3rd series): *Handbook of clinical neurology* (pp. 269-290). Edinburgh, Scotland: Elsevier.
- Ghahari, S., Leigh Packer, T., & Passmore, A. E. (2010). Effectiveness of an online fatigue self-management programme for people with chronic neurological conditions: A randomized controlled trial. *Clinical Rehabilitation, 24*, 727-744. doi:10.1177/0269215509360648
- Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis, 11*, 255-274. doi:10.2307/1163620
- Hohol, M. J., Orav, E. J., & Weiner, H. L. (1995). Disease steps in multiple sclerosis: A simple approach to evaluate disease progression. *Neurology, 45*, 251-255. doi:10.1212/WNL.45.2.251
- Holberg, C., & Finlayson, M. (2007). Factors influencing the use of energy conservation strategies by persons with multiple sclerosis. *American Journal of Occupational Therapy, 61*, 96-107. doi:10.5014/ajot.61.1.96
- Inwood, M. (1997). *Heidegger: A very short introduction*. Oxford, England: Oxford Press.
- Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research, 1*, 112-133. doi:10.1525/sp.1960.8.2.03a00030
- Johnson, S. L. (2008). The concept of fatigue in multiple sclerosis. *Journal of Neuroscience Nursing, 40*, 72-77. doi:10.1097/01376517-2008040005
- Kos, D., Kerckhofs, E., Carrea, I., Verza, R., Ramos, M., & Jansa, J. (2005). Evaluation of the Modified Fatigue Impact Scale in four different European countries. *Multiple Sclerosis, 11*, 76-80. doi:10.1191/135245850ms1117oa
- Law, M. Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The Person-Environment-Occupation Model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy, 63*(1), 9-23. doi:10.1177/000841749606300103

- Marrie, R. A., & Goldman, M. (2007). Validity of performance scales for disability assessment in multiple sclerosis. *Multiple Sclerosis, 13*, 1176-1182. doi:10.1177/1352458507078388
- Packer, T. L., Brink, N., & Sariol, A. (1995). *Managing fatigue: A six week course for energy conservation*. Tucson, AZ: Therapy Skill Builders.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Robson, C (2011). *Real world research: A resource for users of social research methods in applied settings* (3rd ed.). Hoboken, NJ: Wiley-Blackwell.
- Rodriguez, M., Kantarci, O. H. & Pirko, I. (2013). *Multiple sclerosis* (Contemporary Neurology Series). New York, NY: Oxford University Press
- Sandelowski, M. (2000). Focus on research methods – What ever happened to qualitative description? *Research in Nursing & Health, 23*, 334-340.
- Sandelowski, M. (2010). What's in a name: Qualitative description revisited. *Research in Nursing & Health, 33*, 77-84.
- Sauter C., Zebenholzer K., Hisakawa J., Zeitlhofer, J., & Vass, K. (2008). A longitudinal study on effects of a six-week course for energy conservation for multiple sclerosis patients. *Multiple Sclerosis, 14*, 500-505. doi:10.1177/1352458507084649
- Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioural sciences*. Thousand Oaks, CA: Sage.
- Tellez, N., Rio, J., Tintoré, M., Nos, C., Galán, I., & Montalban, X. (2005). Does the Modified Fatigue Impact Scale offer a more comprehensive assessment of fatigue in MS? *Multiple Sclerosis, 11*, 198-202. doi.10.1191/1352458505ms1148oa
- Van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy*. London, Ontario, Canada: Althouse Press.