Exercise: 'Friend or Foe' for people with multiple sclerosis who experience fatigue?

Catherine Smith, PhD

Research Fellow, Centre for Physiotherapy Research, University of Otago

ABSTRACT

Self-reported fatigue is a complex, multifactorial symptom frequently experienced by people with multiple sclerosis (MS). There is growing evidence that regular participation in exercise activities might result in better physiological fitness and perceived health in this population; however, many people with MS-related fatigue are anxious about exercising. Measurement of self-efficacy coupled with intervention strategies to increase levels of self-efficacy might help to lessen anxiety and improve exercise confidence for people with MS.

Smith C (2012): Exercise: 'Friend or Foe' New Zealand Journal of Physiotherapy 40(1) 29-32.

Key words: Multiple sclerosis, fatigue, exercise, self-efficacy, confidence

Self-reported fatigue is a complex and multifactorial symptom; poorly understood, yet frequently experienced as a disabling symptom in many chronic conditions including multiple sclerosis (MS) (Braley and Chervin 2010). For people with MS, self-reported fatigue is described 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" (Multiple Sclerosis Council for Clinical Practice Guidelines 1998, p2). It is thought that many chronic conditions such as Parkinson's disease, rheumatoid arthritis and MS share some of the contributory causes of self-reported fatigue (such as poor sleep quality and mood disorders); however, it appears that each condition might have a unique pathophysiological trigger (Smith and Hale 2007). In MS, this trigger is thought to be a compensatory increase in central nervous system activity in response to delayed axonal conduction (Braley and Chervin 2010). The energy demands of this process cannot easily be met as the MS brain demonstrates a reduced ability to utilise glucose (Roelcke et al 1997). This energy imbalance coupled with slowing of damaged axonal conduction in response to heat have, in the past, given rise to the seemingly sensible solution of 'doing less' and 'resting more'(Petajan and White 1999). Unfortunately, this well-meaning advice became widespread before research categorically demonstrated that people with relapsing remitting MS could expect a reasonably normal lifespan and that inactivity over a lifetime with MS could result in the development of other chronic conditions such as type II diabetes and cardiovascular disease (Slawta et al 2003).

The aim of this commentary is to briefly summarise both quantitative and qualitative evidence for the effects of exercise on fatigue in MS and to propose that evaluation, measurement, and intervention strategies for self-efficacy might assist both the person with MS considering exercise and the health care provider in the facilitation of exercise-related behaviour changes.

In 1996, Jack Petajan and colleagues published a seminal randomised controlled trial (RCT) which demonstrated that people with MS who exercised on stationary cycles several times per week became fitter without any significant increase in self-reported fatigue compared to a non-exercising control group. Furthermore, although non-significant, the authors reported a trend towards reduced fatigue in the exercising group (Petajan et al 1996). Several studies over the last 25 years have demonstrated similar results and subsequent reviews have made cautious recommendations about the potential health benefits of exercise such as increased strength and cardiovascular fitness, reduced fatigue, and increased quality of life for people with MS (Andreasen et al 2011, Rietberg et al 2005). These reviews also recommend further research to establish optimal exercise dose for this population.

In addition to the regular health benefits to be gained from exercise participation, exciting preliminary evidence from recent animal-based studies suggests that exercise might also play a crucial role in the brain health of MS including neuro-regenerative, neuro-protective and neuro-adaptive contributions (White and Castellano 2008). Furthermore, a recent review tentatively suggested that people with MS who are physically fit might perform better cognitively than those who are not physically fit (Motl 2011). There is currently no evidence that exercise induces relapse in the remitting relapsing form of MS. However, despite mounting evidence for the benefits of regular exercise for this population with no adverse effect on self-reported fatigue, people with MS continue to find exercise participation daunting, in no small part due to their fatigue experiences and fear of what fatigue might mean in terms of disease progression (Kayes et al 2010). In order to answer the question of how fatigue influences exercise participation, it is necessary to take an in-depth look at fatigue and exercise experiences for people with MS.

Research investigating the lived experiences of fatigue in people with MS has described how the complex, individualistic, invisible and unpredictable nature of perceived fatigue can easily overwhelm the person with MS (Flensner et al 2003). In a more recent study, more specifically exploring fatigue and exercise experiences in this population, participants have described fatigue experiences as 'possession', a state in which they feel that fatigue has total control over the individual (Smith et al 2009). On a theoretical continuum of perceived control, these authors associated 'possession' with individuals having a low or 'no' sense of perceived control over fatigue. Participants who perceived a low sense of control over fatigue appeared to experience more negative exercise outcomes than those who experienced a strong sense of perceived control. It was hypothesised that a sense of perceived control played an important role in perceived exercise outcomes and that heath care providers should possibly employ strategies to improve or maintain this sense of control when recommending or facilitating exercise participation.

Strategies which might foster an improvement in perceived control over fatigue include recognition and facilitation of the complex choices involved in exercise participation and active listening and observational skills during assessment and intervention. Research in this area found that choice influenced the level of perceived control in women who participated in a variety of community-based exercise activities (Smith et al 2011). Furthermore, those choices were complex, involving type, frequency, intensity, and meaning of exercise. The more that these exercise choices resulted in positive outcomes, the more the women felt in control of their fatigue. For example, most participants recognised that there would be both 'costs' and 'benefits' of every exercise choice. If they were 'satisfied with trade-offs' between the costs and benefits, then they experienced more perceived control over fatigue.

In the latter two studies, participants frequently referred to health care provider attitudes and encounters which influenced confidence in their ability to safely exercise with fatigue, a finding supported strongly in other literature investigating the experiences of people living with chronic conditions (Thorne et al 2004). Subsequent research into the beliefs and opinions of health care providers revealed that the poorly understood nature of MS-related fatigue could lead to feelings of interdisciplinary conflict particularly between health care providers who focused on holistic energy management and those who prioritised physical fitness as a key management strategy for this population (Smith et al 2010). Several health care provider participants in this study suggested that patients were able to detect this conflict resulting in loss of confidence in behaviour change (such as taking up a new exercise activity). A second finding from this study was that confidence to recommend and prescribe exercise was low amongst health professionals, particularly with lack of scientific understanding of fatigue. Several health care provider participants found that careful observation of patients during exercise, and active listening to fatigue descriptions guided more successful exercise prescription experiences. Occasionally, health care provider recommendations based on these 'subjective' strategies did not reflect recommendations based on experimental research findings, for example, health professionals described patients who experienced greater perceived health benefits when exercising only once per week instead of most days week (as recommended by the American College of Sports Medicine (Haskell et al 2007). In order to facilitate on going exercise participation, it might be necessary initially for health care providers to foster enjoyment and confidence with shorter, less frequent exercise sessions rather than to aim for a regime based on current recommendations. As the person with MS gains more confidence it might be possible to focus more on frequency and intensity of exercise required to increase physiological fitness.

From this series of studies it appeared that control, choice, and confidence (for both people with MS and health care providers) were three constructs that might influence perceived enjoyment of exercise and might possibly therefore also influence long term engagement in higher levels of physical activity. Sustained physical activity is important to prevent the onset of other long term conditions associated with inactivity.

It seems sensible to suggest that control, choice and confidence are related to the concept of self-efficacy: "beliefs in ones capabilities to organize and execute the courses of action required to produce given attainments" (Bandura 1997, p3), in other words, confidence in your ability to achieve a particular goal. Bandura proposed four sources of self-efficacy: mastery experiences, vicarious experience (modelling), physiological feedback, and verbal persuasion (Jones and Riazi 2011).

Physiotherapists will recognise examples of all these sources of self-efficacy in clinical practice. For example, mastery of a certain activity such as treadmill training could be achieved through a series of small tasks which might start with the use of a harness with minimal body weight support and gradually be reduced to treadmill walking with handrail support only. Achievable, incremental steps were described as important factors for people with MS attempting to take up new forms of exercise (Smith et al 2011 under review). Vicarious experience involves comparison and 'modelling' to persons perceived as being at a similar level or experiencing the same problems. This suggests that peer support might be useful for PwMS considering exercise; however, physiotherapists should carefully consider group dynamics if providing group exercise classes for the following reasons: firstly because a "one size fits all" approach has been described as a negative aspect of encounters with health care providers (Smith et al 2011), and secondly, because verbal persuasion, another source of self-efficacy, might influence self-efficacy both negatively and positively. It has been suggested that supportive family members are a potential source of self-efficacy through verbal persuasion as long as the patient perceives that they have been successful in a given task (Jones and Riazi 2011); however, Bandura cautions that persuasion pertaining to unrealistic goals can further undermine the confidence of an individual (Bandura 1997).

Physiological feedback influences self-efficacy when individuals form beliefs about how certain tasks make them feel both physically and emotionally. This has been demonstrated in a study when participants with MS-related fatigue exercised in eight-week physiotherapy led exercise programme. Those participants who felt a strong sense of perceived control over their fatigue experienced better psychological and physical feelings following exercise than those participants who did not feel in control of their fatigue. These feelings in turn reinforced level of perceived control (Smith et al 2009).

Preliminary evidence supports the link between self-efficacy and level of engagement in physical activity. Individuals who received a efficacy-enhanced exercise programme (n=13) showed significantly higher levels of enjoyment and adherence to exercise than the control group who received the same exercise programme but without an efficacy enhanced approach (n=13) (McAuley et al 2007). Furthermore, in a study which examined links between participation in physical activity and quality of life in people with MS (n=292), Motl et al (2009) demonstrated that physical activity participation had a stronger link with better perceived quality of life in people with MS who had higher self-efficacy and lower levels of fatigue (Motl et al 2009).

In view of these findings, physiotherapists might consider using measurement tools to assess self-efficacy and if low self-efficacy is identified, introduce strategies to promote higher levels of self-efficacy in patients with MS wishing to increase their physical activity. Measures of self-efficacy can be roughly divided into condition-specific and task-specific scales. Two condition-specific measures have been developed for people with MS: the Multiple Sclerosis Self-efficacy Scale (MSSS) (Rigby et al 2003) and the Multiple Sclerosis Self-Efficacy Scale (MSSE) (Schwartz et al 1996). It could be argued that the MSSS is the most applicable self-efficacy scale for people with MS as it was developed from 'the ground up' following in-depth consultation with individuals who have MS whereas the MSSE was modified from an earlier arthritis self-efficacy scale. However, in a recent study designed to promote increased levels physical activity, MS participants found that items on the MSSS (condition-based) did not necessarily reflect the increase in confidence to exercise that they experienced following the intervention (Smith et al 2011 under review). As this study focused upon exercise participation and, as levels of self-efficacy are task specific, self-efficacy results might have reached significance if an exercise specific scale such as the Self-Efficacy Exercise scale (Resnick and Jenkins 2000) rather than a condition-based self-efficacy measure had been used.

The Self-Efficacy Exercise scale (SEE) is a task-related self-efficacy scale (the task being exercise) (Resnick and Jenkins 2000). Originally developed in sedentary adult and older populations, this scale has been used recently to explore relationships between physical activity, self-efficacy and quality of life in people with MS (Motl et al 2009). The SEE has been further adapted in order to increase relevance in a spinal cord injury population (Spinal Cord Injury Self Efficacy Scale–ESES) (Kroll et al 2007). The ESES has been used to determine correlations between exercising and non-exercising participants (n=93) and exercise self-efficacy. In this postal survey, participants who were classified as exercising scored significantly higher on the ESES than those classified as non-exercising (Stroud et al 2009). This scale however may require further modification for people with MS. For example, in order to increase the relevance of this measure, items that recognise the impact of heat sensitivity, a potential barrier to exercise in this population might be warranted. In summary, no current self-efficacy scale will capture all dimensions of self-efficacy and physiotherapists need to choose judiciously with regards to the context of self-efficacy under examination.

One strategy purported to increase levels of self-efficacy is motivational interviewing (MI). Originally developed as a counselling strategy for drug and alcohol rehabilitation, a modified form of this approach is increasingly being employed in many areas of health care in order to facilitate behavioural changes such as lifestyle changes and symptom management (Rollnick et al 2008). Motivational interviewing comprises a range of communication techniques designed to elicit an individual's intrinsic motivation to change health behaviours. Currently, there is little robust evidence for this intervention predominantly due to the wide variations in populations, contexts, and outcome measures employed in research to date (Knight et al 2006). Despite lack of strong evidence, health care providers are finding MI a useful tool to promote increased levels of engagement in physical activity. Shandon and Hillsdon (2007) provide an insightful hypothetical example of how MI can be used in a musculoskeletal setting. They illustrate particularly how MI might elicit intrinsic (the patient's own) facilitators for overcoming fear of chronic low back pain in order to exercise (Shannon and Hillsdon 2007). People with MS experience fatigue, amongst other multiple symptoms and perceptions, as a major barrier to exercise (Stroud et al 2009) and it is possible that MI might assist in overcoming fear of fatigue and increasing confidence to exercise in this population.

In conclusion, there is now compelling evidence that regular exercise participation will result in better strength, cardiovascular fitness, perceived health-related quality of life and reduced levels of fatigue for people with MS. There is no doubt that in terms of proven health benefits, exercise is a friend to people living with MS-related fatigue. Furthermore, neurophysiological studies are demonstrating exciting possibilities regarding the role of exercise in brain repair and health. Exercise however is still perceived by many living with MS as something to be feared. Engaging people in enjoyable, health-promoting and sustainable exercise habits is an on-going challenge for most health care providers. Evaluation of self-efficacy and, strategies to promote self-efficacy might prove rewarding tools for both patient and therapist and change perceptions of exercise from foe to friend.

KEY POINTS

- Despite proven perceived and physiological health benefits of exercise for people with MS, many individuals with this condition are anxious about exercising predominantly because of fatigue.
- Perceived control over fatigue appears to result in more positive exercise experiences.
- For exercise-related interventions and research, physiotherapists might consider self-efficacy scales related to exercise more useful than condition based self efficacy scales.
- Motivational Interviewing might be a useful intervention for increasing levels of self-efficacy in people with MS-related fatigue; however, there is currently little evidence for the effectiveness of this strategy.

ADDRESS FOR CORRESPONDENCE

Dr Cath Smith, School of Physiotherapy, University of Otago, PO Box 56, Dunedin, New Zealand, 9054.

REFERENCES

Andreasen A, Stenager E and Dalgas U (2011): The effect of exercise therapy on fatigue in multiple sclerosis. *Multiple Sclerosis* 17: 1041-1054.

Bandura A (1997): Self-efficacy: The exercise of control. New York: W. H. Freeman & Co.

Braley T and Chervin R (2010): Fatigue in multiple sclerosis. *Sleep* 33: 1061-1067.

Flensner G, Ek A and Soderhamn O (2003): Lived experience of MS-related fatigue -- a phenomenological interview study. *International Journal of Nursing Studies* 40: 707-717.

Haskell W, Lee I, Pate R, Powell K, Blair S, Franklin B, Macera C, Heath G, Thompson P and Bauman A (2007): Physical activity and public health:updated recommendations for adults from the American College of Sports Medicine and the American Heart Association. *Circulation* 116: 1081-1093.

Jones F and Riazi A (2011): Self efficacy and self management after stroke: a systematic review. *Disability and Rehabilitation* 33: 797-810.

Kayes NM, Macpherson KM, Taylor D, Schluter P and Kolt GS (2010): Facilitators and barriers to engagement in physical activity for people with multiple sclerosis: a qualitative study. *Disability and Rehabilitation* 33: 625-642.

Knight K, McGowan L, Dickens C and Bundy C (2006): A systematic review of motivational interviewing in physical health care settings. *Journal of Health Psychology* 11: 319-332.

Kroll T, Kehn M, Ho P and Groah S (2007): The SCI Exercise Self-Efficacy Scale (ESES): development and psychometric properties. *International Journal of Behavioral Nutrition and Physical Activity* 4.

McAuley E, Motll RW, Morris KS, Hu L, Doerksen SE, Elavsky S and Konopack JF (2007): Enhancing physical activity adherence and well-being in multiple sclerosis: a randomised controlled trial. *Multiple Sclerosis* 13: 652-659.

Motl R (2011): Cognitive dysfunction and multiple sclerosis: developing a rationale for considering the efficacy of exercise training. *Multiple Sclerosis* 17: 1034-1040.

Motl R, McAuley E, Snook E and Gliottoni R (2009): Physical activity and quality of life in multiple sclerosis: intermediary roles of disability, fatigue, mood, pain, self-efficacy and social support. *Psychology, Health and Medicine* 14: 111-124.

Multiple Sclerosis Council for Clinical Practice Guidelines (1998). Fatigue and multiple sclerosis: evidence-based management strategies for fatigue in multiple sclerosis, Paralyzed War Veterans of America.

Petajan JH, Gappmaier E, White AT, Spencer MK, Mino L and Hicks RW (1996): Impact of aerobic training on fitness and quality of life in multiple sclerosis. *Annals of Neurology* 39: 432-441.

Petajan JH and White AT (1999): Recommendations for physical activity in patients with multiple sclerosis. *Sports Medicine* 27: 179-191.

Resnick B and Jenkins L (2000): Testing the reliability and validity of the Self-Efficacy for Exercise Scale. *Nursing Research* 49: 154-159.

Rietberg MB, Brooks D, Uitdehaag BM and Kwakkel G (2005): Exercise therapy for multiple sclerosis. *Cochrane database of systematic reviews* 1.

Rigby S, Domenech C, Thornton E, Tedman S and Young C (2003): Development and validation of a self-efficacy measure for people with multiple sclerosis: the Multiple Sclerosis Self-efficacy Scale *Multiple Sclerosis* 9: 73-81.

Roelcke U, Kappos L, Lechner-Scott J, Brunnschweiler H, Huber S, Ammann W, Plohmann A, Dellas S, Maguire RP, Missimer J, Radu EW, Steck A and Leenders KL (1997): Reduced glucose metabolism in the frontal cortex and basal ganglia of multiple sclerosis patients with fatigue: a 18F-fluorodeoxyglucose positron emission tomography study. *Neurology* 48: 1566-1571.

Rollnick S, Miller W and Butler C (2008): Motivational interviewing in health care: helping patients change behavior. New York: The Guildford Press

Schwartz C, Coulthard-Morris L, Zeng Q and Retzlaff P (1996): Measuring self-efficacy in people with multiple sclerosis: a validation study. *Archives of Physical Medicine and Rehabilitation* 77: 394-398.

Shannon R and Hillsdon M (2007): Motivational Interviewing in musculoskeletal care. *Musculoskeletal Care* 5: 206-215.

Slawta JN, Wilcox AR, McCubbin JA, Nalle DJ, Fox SD and Anderson G (2003): Health behaviors, body composition, and coronary heart disease risk in women with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation* 84: 1823-1830.

Smith C and Hale L (2007): The unique nature of fatigue in multiple sclerosis: prevalence, pathophysiology, contributing factors and subjective experience *Physical Therapy Reviews* 11: 43-51.

Smith C, Hale L, Mulligan H and Treharne G (2011 under review): participant perceptions of a novel physiotherapy approach for increasing levels of physical activity in people with multiple sclerosis: a qualitative study following intervention. *Disability and Rehabilitation*.

Smith C, Hale L, Olson K, Baxter G and A S (2010). How do health care providers perceive exercise as an intervention for fatigue in people with multiple sclerosis? Stepping Forward: Physiotherapy New Zealand Neurology Group Neurosymposium. Dunedin, New Zealand.

Smith C, Hale L, Olson K and Schneiders AG (2009): How does exercise influence fatigue in people with multiple sclerosis?. *Disability & Rehabilitation* 31: 685-692.

Smith C, Olson K, Hale LA, Baxter GD and Schneiders AG (2011): How does fatigue influence community-based exercise participation in people with multiple sclerosis? *Disability & Rehabilitation* Early online: 1-10.

Stroud N, Minahan C and Surendran S (2009): The perceived benefits and barriers to exercise participation in persons with multiple sclerosis. *Disability & Rehabilitation* 31: 2216-2222.

Thorne S, Con A, McGuinness L, McPherson G and Harris SR (2004): Health care communication issues in multiple sclerosis: an interpretive description. *Qualitative Health Research* 14: 5-22

White L and Castellano V (2008): Exercise and brain health - implications for multiple sclerosis. *Sports Medicine* 38: 91-100.

The Honorary Editorial Committee thanks the people listed below for their willingness and dedication in reviewing manuscripts submitted to the New Zealand Journal of Physiotherapy in 2011:

Dave Nicholls
William Levack
Steve Tumilty
Erik Dombroski
Peter Larmer
Janet Copeland
Stephanie Woodley
Leica Clayton
Bridget Dickson
Richard Ellis
Liz Binns
Lynley Anderson
Gill Johnson
Julie Reeves
Margot Skinner
Kim Donovan
Verna Stavric
Anna Mackey
Peter Larmer
Brett Woodley
Anthony Schache