One year ago, when my doctor first told me that my fatigue was a symptom of multiple sclerosis (MS), I was at a loss as to how my life would continue. How could I continue my job? How could I manage my fatigue? How could I pursue my dreams? Since receiving my diagnosis, my MS has gone into remission and I am continuing in my line of work as an air traffic controller. I have gained control over my fatigue and raised over $4000 for the MS Society. I am also participating in the annual MS walk for charity and am planning to go to Europe with my best friend this summer. Life is looking up. – Hannah, 24 years old

What is multiple sclerosis?

Multiple sclerosis (MS) is a slow progressive disease of the central nervous system that affects 55,000-70,000 Canadians. Symptoms of MS include fatigue, balance issues, and weakness, which interfere with an individual’s ability to perform their activities of daily living. There are four categories of MS including relapse-remitting, secondary-progressive, primary-progressive, and progressive relapsing. The most common type of MS is relapse-remitting, which affects approximately 70% of individuals. It is identified by its clearly defined relapses which may or may not result in permanent deficits. The average age of onset is between 15-40 years of age, affecting individuals in the prime of their lives while they hold a variety of roles which contribute to formation of their self-identity, or sense of self.

One of the most disabling symptoms of MS is MS-related fatigue. Daily fatigue levels in those with MS have been found to be 125% greater than those of healthy individuals. MS-related fatigue is described as a subjective lack of physical and/or mental energy that interferes with an individual’s activities, including employment (Crayton & Rossman, 2006; Mathiowetz et al., 2007). Unfortunately, MS-related fatigue occurs in 65-97% of persons with MS, of whom approximately one third report fatigue as their most disabling symptom.

There are four main components of MS-related fatigue – physical, emotional, behavioural, and cognitive. When individuals with MS are unable to cope physically, they express emotional perceptions of worthlessness, despair, sadness and sorrow (Crayton & Rossman, 2006). Fatigue is exacerbated by sleep disturbances, depression, and physical disabilities that frequently accompany MS. In the past, individuals with fatigue were generally advised to rest and avoid physical activity, a behaviour which is now known to reduce cardiovascular fitness, promote poor muscle conditioning, and consequently contribute to the fatigue experience (Smith, 2006).

Keeping in mind the disabling symptoms of MS, how can occupational therapists ease the transition of newly diagnosed individuals through the application of theory and evidence-based practice to aid clients in contributing to their own rehabilitation efforts? Focusing on early intervention, we aim to outline and describe various techniques employed by occupational therapists to support those newly diagnosed with MS. Techniques include, but are not limited to, education, compensation, and focus on aiding clients in managing their symptoms and participating in occupations to support future engagement.

What is the occupational therapy role?

Occupational therapists use three therapeutic strategies to produce changes in occupation – remediation, compensation, and advocacy (Chisholm, Dolhi, & Schreiber, 2004). Because MS is a degenerative disease, the focus of occupational therapy intervention will be on compensation and advocacy.

About the authors –

All of the authors are in the MScOT program at Queen’s University in Kingston, Ontario and are scheduled to graduate this year.
The fatigue affected me in many areas of my life. I had difficulties in completing most of my regular tasks (including showering, cooking, and shopping), as the fatigue was so severe. Additionally, the stress upon receiving the diagnosis caused me grief and eventually I broke up with my long-term boyfriend. I started seeing a psychologist to help me cope with my new diagnosis and my grief, and return to work was our main topic of discussion. – Hannah

As compensation entails identifying ways to overcome performance deficits, educating Hannah on energy conservation techniques can significantly reduce the impact of fatigue on her occupational performance. Energy conservation is defined as “common sense ideas to improve task efficiency and reduce energy expenditure during all occupational performance tasks” (Fasoli, 2002, p.p. 696). The occupational therapist, with his/her focus on the person, environment, and occupation, plays an important role in employing beneficial strategies for energy conservation, such as planning each day according to fatigue levels, incorporating frequent rest periods, using adaptive equipment, altering work heights, simplifying activities, and delegating part or all of an activity to others (Packer et al., 1995).

Substantial increases in adoption of energy conservation behaviours have been found following participation in energy conservation education (Mathiowetz et al., 2007). This suggests the benefits of energy conservation interventions in managing MS-related fatigue and improving daily occupation participation. However, such an intervention needs to be more than just providing information; an occupational therapist must induce a change in current behaviours and target individuals who are more likely to adopt these new behaviours (Matuska et al., 2007).

I was just starting off in my career as an air traffic controller when I received my diagnosis of MS. As my most severe symptom was fatigue, I feared meeting my job requirements of focused attention. I disclosed my diagnosis to my employer and was put on an indefinite leave of absence. During this time, I received testing by a neurologist from the MS clinic to determine my capabilities to continue in this line of employment. Luckily, I passed the tests and returned to my job three months later. However, throughout my career I will require similar job-testing annually to ensure that I am capable of meeting the demands of my job. – Hannah

In addition to educating about energy conservation techniques, the occupational therapist can also support Hannah in changing her work environment, such as reducing distractions to help her maintain attention. Increasing social support through educating family and friends about MS can positively impact Hannah’s social environment. The occupational therapist can also enhance occupational performance by recommending assistive devices and modifying the task (e.g., showering in sitting to reduce the amount of energy required). Advocacy addresses system-level barriers to independence (Chisholm et al., 2004). The occupational therapist can advocate for Hannah with her employer for work-related compensations, such as regular breaks and modified tasks. The occupational therapist can also teach self-advocacy skills to Hannah and her family so they can self-advocate when further compensation is required in the future.

When the doctor first told me I had MS I did not know what it was, I did not know how to proceed, I thought my life was over. – Hannah

Occupational therapists are well informed and connected with community resources and can act in a mediatory role with the client, linking them with various resources in the community for support. The occupational therapist working with Hannah could provide her with basic education, as well as link her with her local MS Society branch, MS support groups, and non-profit organizations that provide support to individuals with MS.

In a multi-disciplinary rehabilitation approach, the role of occupational therapy on the MS care team is well recognized (Feigenson, 1981; Freeman, 1997). One meta-analysis article suggested that occupational therapy-related interventions have positive outcomes on clients’ capacity/ability (e.g., muscle strength, range of motion) and task/activity level (e.g., dressing, bathing) (Baker and Tickle-Degnen, 2000). However,
there is insufficient evidence to support the effectiveness of mono-disciplinary occupational therapy intervention, because a systematic review conducted in 2003 identified only three studies satisfying inclusion criteria with inconclusive results (Steultjens et al., 2003).

More studies are being published to support the effectiveness of occupational therapy intervention. Because MS-related fatigue is regarded as one of the most disabling symptoms, many studies point to the importance of education on energy conservation. A recent randomized control trial of an occupational therapy-delivered energy conservation course supported occupational therapy efficacy, because it demonstrated significant reductions on fatigue impact, increased self-efficacy, and increase in some aspects of quality of life (Mathiowetz et al., 2005).

Occupational therapy is one of the leading disciplines to practice with a client-centered philosophy. However, clients' satisfaction with occupational therapy services in MS care, ironically, receives little attention. A recent study reported a low occupational therapy service utilization rate of 38% (Finlayson et al., 2008). More importantly, of those using occupational therapy services, almost all indicated that these services were very important to their health and well-being (Finlayson et al., 2008). Many people with MS were found to discontinue occupational therapy services after initial contact, which could be an indicator of effective early occupational therapy interventions. Early occupational therapy interventions and education are suspected to enable clients to better handle ongoing challenges with less reliance on future professional input (Finlayson et al., 2008).

The future outlook:
The World Health Organization (2001) focuses on activity participation, which sets the stage for occupational therapists working with individuals with MS. Through early intervention and the use of education, compensation, and advocacy techniques, occupational therapists support individuals with MS in regaining roles, participating in activities, and incorporating symptom-management into their daily lives (Mathiowetz et al., 2001, 2005; Steultjens et al., 2003). Occupational therapy should be utilized early in the disease process to prevent disengagement in activities and life roles, influencing overall quality of life.

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References:


