

The problem of employment for women with multiple sclerosis

[Business](#), [Employment](#)



Multiple sclerosis (MS) is an immune-mediated disease affecting more than half a million Americans (Campbell et al., 2014). Symptoms of MS vary and can impact cognitive, physical, and/or emotional functioning (Murray, 2004). Changes in these and other areas of functioning may lead to significant difficulties, both socially and occupationally. Unemployment and loss of employment is prevalent in the MS population (Grytten et al., 2017). Unemployment in persons with MS has been associated with higher economic stress, poor self-efficacy and lower quality of life (McCabe & De Judicibus, 2003; Johnson et al. 2004; Miller & Dishon, 2006; Milo & Kahana, 2010).

The present study assessed the feasibility and acceptability of an intervention that addressed loss of employment for women with MS — a group that is significantly at risk. The present pilot study was part of a larger single-blinded, randomized control intervention that is currently underway at the MS Center at Holy Name Medical Center in Teaneck, NJ. Employed women at this center are screened based on major contributors to unemployment in persons with MS: measures of fatigue, cognitive impairment and depression. Women who meet established cut-off criteria on any one of the above risk measures have been randomly placed in either a control treatment group or an experimental treatment group. Both groups undergo neuropsychological testing and each patient is given an individualized action plan in the form of a written report with recommendations made to address specific problems related to maintenance of employment. For both groups, neurologists receive a copy of each patient's report. The usual care control group receives standard care:

each participant is given a copy of her report in the mail, and a phone call with feedback regarding test findings and recommendations. In the experimental group, each participant is given in a face-to-face feedback session and a copy of their report.

Furthermore, a care coordinator nurse follows up with participants in the experimental group at approximately one month and six months post-testing, to help coordinate the completion of the given recommendations. Women in both treatment groups are contacted at one year for follow up with regards to current functioning and to assess whether they completed recommendations and whether they found the intervention to be beneficial.

Background and Significance Overview of Multiple Sclerosis Multiple Sclerosis is a chronic neurological disorder affecting more than 500, 000 people in the United States (Campbell et al., 2014) and 2. 3 million people worldwide (Browne et al., 2014). Although its cause is unknown, MS is an immune-mediated, inflammatory disease of the central nervous system. The location of demyelinating plaques may vary, leading to a unique clinical picture for each individual (Malik et al., 2014). Typically, individuals with MS experience these inflammatory processes at unpredictable intervals (often referred to as “exacerbations” or “relapses”) which may last from days up to months and which predominantly impact the myelin sheaths surrounding nerve axons (Goodin, 2014). Symptoms of MS may include motor, visual, sensory, and cognitive deficits (Murray, 2004). Thus, people with multiple sclerosis (“pwMS”), face burdensome symptoms that impact many areas of functioning.

Since its initial description by Jean Martin Charcot in 1868, the diagnostic features of MS have continuously changed. The McDonald Criteria are used to identify individuals with different forms of MS. In its most common form, affecting 85-90% of individuals with MS (Goodin, 2014), relapse remitting type (RRMS) is diagnosed when a patient presents with symptoms and with objective clinical evidence of one or more demyelinating lesion, using the additional radiological or laboratory evidence if necessary (Thompson et al., 2018). Generally, these patients experience some level of remitting to normal neurologic functioning over the following days to months (Goodin, 2014). Progressive MS may be diagnosed when evidence suggest at least one year of progression using additional radiological and/or laboratory evidence (this may be primary progressive or secondary progressive) (Polman et al., 2011). The fourth and rarest form, progressive-relapsing MS, begins with a progressive course, however, at some point, these patients begin to experience relapses (similar to RRMS) in addition to their otherwise steadily progressing disease course (Goodin, 2014). Although MS is not considered to be a fatal disease, life expectancy is typically reduced in pwMS as compared to the general population. However, treatment with disease-modifying therapies (DMT) may alter this natural history with early treatment potentially improving survival rates (Goodin, 2014). Further, treatment and management of symptoms may improve quality of life as well as decrease the impact of disability (Toosy et al., 2014).

A multidisciplinary approach is often useful in treating the various symptoms pwMS experience and may include evaluation and treatment by

physiotherapists, occupational therapists, specialist nurses, and neurologists or rehabilitation physicians. Typical treatments for various physical symptoms such as spasticity, pain, vertigo, nystagmus, fatigue, and walking difficulty, include various medications, surgical options, and exercise regimens (Toosy et al., 2014). Employment and MS MS is most commonly diagnosed between the ages of 20 and 50, a critical time for education and career development (Julian et al., 2008; Milo & Kahana, 2010).

Unemployment and loss of employment are common in the MS population (Sweetland et al., 2012; Grytten et al., 2017). In fact, unemployment rates after approximately 20 years of diagnosed MS are quite high, ranging from 55% to 83% (Lunde et al., 2014; Grytten et al., 2017). However, a number of specific factors have been found to be associated with unemployment and loss of employment, including older age of disease onset, lower level of education, and greater symptom severity (Lunde et al., 2014). Fatigue and Employment in MS Fatigue is among the most commonly reported symptoms of MS, impacting approximately 80% of individuals (Charvet et al., 2014). While fatigue has no universal definition, it is often characterized as a state of “ exhaustion or tiredness (distinct from depression, weakness, or sleepiness) which renders an individual unable to either initiate or complete tasks or activities that he/she would otherwise be able to accomplish” (Charvet et al., 2014).

While fatigue remains somewhat illusive to objectively measure, a great many self-report fatigue scales exist that classify pwMS who experience significant fatigue symptoms. Further, objectively measuring “ fatiguability”

is sometimes possible through evaluating declines in motor and cognitive performance. Possible etiology may be primary in nature (i. e., relating directly to the MS disease process) or may be secondary in nature (i. e., comorbidity). Self-reported fatigue has been associated with disease severity, multiple relapses, increased disability, and loss of ambulation (Charvet et al., 2014) as well as pain and depressive symptoms (Patrick et al., 2009). One imaging study found an association between fatigue and regional atrophy of supratentorial brain parenchyma, involving the cerebral cortex, nearby white matter and the caudate head, (areas which are related to attentional control) (Andreasen et al., 2010). While lower education has been identified as a risk factor for fatigue in MS, disease duration, age and gender differences have not (Charver et al., 2014). = Fatigue in MS can be exacerbated by heat [10, 11] and may improve with cooling.[12, 13] It is simple to understand how fatigue might impact an individual's capacity to work. Notably, with the exception of physical disability, fatigue is the most commonly reported reason for leaving the workforce among pwMS and is highly associated with unemployment (Coyne et al., 2015; Sweetland et al., 2012). Fatigue has also been correlated to an aspect of cognition, slowed cognitive processing speed (Charvet et al., 2014), which may cause further problems for employed individuals. Cognition and Employment in MS In fact, as many as 50-70% of pwMS experience mild to severe cognitive deficits, (Benedict & Zivadinov, 2011; Julian, 2011; Campbell et al., 2014) especially in the areas of processing speed, memory, and/or executive functioning. These deficits often impact quality of life (Glanz et al., 2010).

Further, cognitive complaints such as memory and concentration difficulties have frequently been cited as a reason for unemployment (Sweetland et al., 2012). It is clear that limitations in cognitive abilities can impact work productivity and quality. Thus providing interventions to address cognitive problems for working pwMS is of primary importance. Depression and Employment in MS Depression impacts approximately half of all pwMS (Koch et al., 2015). Among psychological problems, depression is most often reported to be associated with work instability and unemployment (Sweetland et al., 2012; van der Hiele et al., 2015; Wicks et al., 2016). Additionally, depression may also cause or exacerbate fatigue symptoms (Charvet et al., 2014), and is associated with cognitive impairments (Simioni et al., 2007), indicating that the interplay between these symptoms is significant, thus yielding a more complex presentation and necessitating a multifocal treatment approach. Effects of Unemployment Loss of employment is clearly detrimental to pwMS and their families, and is associated with lower quality of life (Miller & Dishon, 2006; Milo & Kahana, 2010; Pack, et al., 2014), reduced social engagement, and poorer self-image (Johnson et al., 2004). Unemployment is also associated with economic stress (McCabe & De Judicibus, 2003). Even where pwMS obtain Social Security Disability Insurance (SSDI) due to their physical and cognitive deficits (Krupp & Christodoulou, 2001), this added support does not allow them to experience financial security (McCabe & De Judicibus, 2005).

Conversely, maintenance of employment has been associated with increased social participation, better quality of life, lower functional impairment (as

measured by the Expanded Disability Status Scale [EDSS]) and lower economic cost (Kwiatkowski et al., 2014). In fact, in Kwiatkowski et al.'s study, they found that quality of life was more related to social participation (and employment) than it was to functional impairments (EDSS). As such, creating interventions to address problematic symptoms and to prevent unemployment in pwMS is very worthwhile and important to improving the lives of pwMS. Further, given their prevalence, identifying problems relating to fatigue, depression and cognitive functioning is of primary importance when identifying pwMS who are at risk of unemployment and who may benefit from efficacious treatments available for these symptoms (Foley et al., 1989; Khan & Amatya, 2016). Women with MS and Employment Women are approximately three times more likely to develop MS as compared to men (Trojano et al., 2012) and are also more likely to be unemployed and to lose their employment status (Sweetland et al., 2012; Grytten et al., 2017). While women and men tend to experience cognitive impairment and fatigue at similar rates (Patti et al., 2009) women who are fatigued are more likely to experience depression (Dahl et al., 2009).

Additionally, women are more likely to experience severe depression as compared to men (Patti et al., 2009). Taken together these factors place women at a greater risk for work instability. Thus, although many pwMS have employment difficulties, women with MS have been found to be especially at risk of losing their jobs (LaRocca et al., 1985; Solari, & Radice, 2001; Sweetland et al., 2012; Grytten et al., 2017), and are therefore more likely to experience the detrimental effects described above. Interventions for

Employment Maintenance in MS To date, published research has mainly addressed the causes and correlates of unemployment in pwMS (Fantoni-Quinton et al., 2016; Johnson et al., 2004). There is a paucity of literature evaluating interventions to prevent unemployment. A study conducted in France which looked at factors causing pwMS to leave the work force, as well as job retention strategies, found that not only did few pwMS use vocational services, but most were unaware of such services despite their free access to an occupational medicine physician (Fantoni-Quinton et al., 2016). Given that many of the surveyed participants had decreased their hours or left the work force as a result of their MS symptoms, the authors emphasized the importance of early intervention for employment maintenance in this population. Research has also suggested that timely and early intervention is likely to be more helpful (Sweetland et al., 2012).

Despite the indication that employment interventions may be beneficial for pwMS, few studies have been published on such interventions and none have focused solely on women, despite their elevated risk of unemployment. A study led by Khan & Turner-Stokes (2009), attempted to identify whether vocational rehabilitation (VR) was effective in maintaining employment and found only two valid intervention studies to include in their literature review. The first of these studies, conducted by LaRocca et al. (1996), was a randomized intervention for participants (75.6% female) who considered themselves at risk of losing their jobs. These individuals either received a telephone call with limited input (control group) or, for the experimental group, received interviews with both a psychologist and an employment

specialist, as well as medical counseling geared towards job retention, with offers of free interventions. Unfortunately, the authors found no significant differences in employment outcomes. This was not particularly surprising to them, given that inclusion criteria were dependent on self-reported job risk, the small sample of this pilot study ($n = 43$) and the findings that pwMS were unlikely to follow recommendations. Thus their research importantly highlighted that for successful follow through of such an intervention, longer-term vocational support would be beneficial. In the second study described by Khan & Turner-Stokes (2009), 37 participants (78.4% female) who were already unemployed at the start of the study were given either a lower- or higher-intensity intervention (two telephone contacts and a packet of instructional information versus a telephone interview, a half-day “Accommodations Planning Team” (APT) seminar and follow up telephone and in-person support) (Rumrill et al., 1998). This study found significant return to the workforce, but no differences between the two intervention groups. Thus the authors support a ‘least intervention’ principle, suggesting that motivated unemployed pwMS may be able to seek and secure jobs on their own with only limited intervention.

A literature review examining VR studies conducted since 2009 yielded only one relevant article. This exploratory randomized control study of 76 participants (76% female) provided 38 individuals with an information sheet about sources of help available for people with a disability who were employed (control) and 38 individuals with an occupational therapist led intervention which involved the assessment of MS symptoms perceived to be

impacting work, and provided interventions or recommended services to address these concerns (e. g., neuropsychology referral, physiotherapy referral) (Sweetland, 2012). Given that their study was in preliminary stages, the authors were only able to conclude that the treatment group (N at completion of study = 29) reported greater ability to manage the demands of their work as compared to the control group (N at completion of study = 26) after six months. A qualitative study evaluated 19 participants from the original Sweetland (2012) study and also found that participants reported subjective benefit from the study (Jellie et al., 2014). At present this is the only outcome information available from this exploratory VR. Gaps in the Literature Thus, while there is minimal literature evaluating VR in MS, the few studies conducted have highlighted the benefit experienced by study participants. Further, these studies suggest that providing interventions to improve symptoms of MS may be an important step to helping pwMS maintain employment. Equally important, however, is ensuring follow through of recommendations and interventions offered by the VR. Finally, there have been no studies that specifically evaluated the feasibility of a VR in an MS population, necessitating a pilot study. As such, these are all important areas for continued research. Neuropsychological Testing as an Intervention Neuropsychological (NP) testing may be a useful intervention for employed pwMS.

NP testing in pwMS is often instrumental in diagnosing and making recommendations to address specific problems, such as those related to memory, concentration, attention, executive functioning or processing speed

(Amato et al., 2010; Ruet et al., 2013; Moghadasi et al., 2016). Additionally, neuropsychological testing also serves to evaluate other symptoms that may contribute to decreased cognitive abilities, such as mood and fatigue (Simioni et al., 2007; Charvet et al., 2014). Prior to testing, a clinical interview is typically conducted, which helps to evaluate past and present emotional, social, and cognitive difficulties. By identifying specific problems an individual faces, a neuropsychologist can make recommendations for useful services, such as fatigue consultation, cognitive rehabilitation, occupational therapy, or psychotherapy (Khan & Amatya, 2016). These interventions may address the very problems that pwMS have reported as reasons for leaving the workforce. For instance, a recommendation for cognitive remediation may improve aspects of memory or help the patient improve coping strategies, allowing an employed woman to function more effectively at her job. Similarly, a recommendation for fatigue management may decrease the amount of time that a pwMS must miss work or take breaks due to fatigue. Further, a referral for psychotherapy or psychopharmacology to address depression may alleviate mood symptoms, which can impact an individual's productivity and ability to work.

Unfortunately it is currently unknown whether busy employed women will be willing to complete NP testing given the time it takes to complete (approximately 2 hours), thus it is unknown whether this is a feasible intervention in this population. Problems Related to Adherence Adherence to medication, specifically disease modifying therapies (DMTs), among pwMS is well documented and is approximately 65-80% (Turner et al., 2007;

Treadaway et al., 2009; Devonshire et al., 2011). Adherence to non-medication recommendations made by physicians, such as for diet and exercise, is typically lower (31-67%), as seen in various other health populations (Aminzadeh, 2000; Alosco et al., 2012). In a study that evaluated individuals with a range of psychiatric and neurological disorders, seen in a general outpatient neuropsychology practice, adherence rate to treatment recommendations was 46% (Meth et al., 2016).