

Editorial: Navigating Life With Multiple Sclerosis From the Physical, Social and Neurocognitive Standpoints



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ABSTRACT

Multiple sclerosis (MS) is a life-long condition with a wide range of symptoms which can have a profound impact on all aspects of a patient’s life, including future plans, self- confidence, self-esteem, relationships, quality of life, and employment prospects. Living with MS can certainly be difficult and frustrating. Over time, however, most people find ways to adapt and come to terms with many changes that MS can bring and do manage to live fairly full lives.

1. Introduction

Living with a disease such as multiple Sclerosis (MS) can be understandably difficult, frustrating, and at times, frightening. Although the precise symptoms and course vary from one individual to another, one thing is clear that a lifelong disease with the prospect of progressive levels of disability can have a profound impact on almost every aspect of a patient’s life. The period before diagnosis, whilst symptoms are being investigated and the cause is uncertain, can be particularly stressful for patients. During this period, patients often have to live with illness without legitimacy, without health practitioner sanctioning of the ‘sick role,’ and are often misunderstood by others [1, 2].

ments with an assortment of specialists before physicians finally begin to link individual symptoms together and view them in a more holistic manner. In some cases, symptoms may not even be particularly indicative of MS and physicians may suspect other causes, such as psychological explanations. Some patients also find that their symptoms are not taken seriously, a situation that leaves them feeling bitter and angry [3].

People with MS often tend to become ‘experts’ in their condition and active participants in their own care. The areas of people’s life most affected by MS are occupational functioning, self-care/independent functioning and physical well-being [4].

Caring for someone with MS can be emotionally and physically demanding and can lead to considerable stress and fatigue. The quality of life of the caregiver often reflects that of the patient. People with MS often

Owing to the fact that symptoms can be so varied, patients may have to attend a series of different appoint-

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have different expectations of treatment. Patients tend to be skeptical about the benefits of disease-modifying treatments and do not like having to inject. Patients need to be informed about what they can expect from therapy over the short and long term. Some of the symptoms of MS, such as fatigue, ambulatory and cognitive problems, incontinence, and sexual problems are particularly difficult for individuals to deal with [5].

Fatigue is one of the most common and debilitating symptoms experienced by people with MS [6]. About 40% to 65% of people with MS will develop some form of cognitive impairments. The lifetime risk for depression amongst people with MS is around 50%. Depression is more common during relapses, and may exacerbate fatigue and cognitive impairment. Some people with MS may let bladder and bowel problems persist for years and may seek help only when these problems begin to significantly affect their daily lives. Many people with MS do not discuss sexual intimacy with their healthcare professional because they assume it to be a part of the disease or are too embarrassed to admit to such problems. Although muscle spasms can be uncomfortable and painful, they can be successfully managed. Pain in MS may be either neuropathic or musculoskeletal in origin [6-8].

There is a need for better recognition, assessment, and treatment of chronic MS symptoms, particularly fatigue. Today's 'expert MS patient' both requires and expects reliable and valid information on MS, a better understanding of MS treatments, and better communication with healthcare providers. Patient needs information at different stages of MS. People with moderate MS need better access to community services [4].

2. Specific Problem Areas

Some symptoms of MS such as fatigue, depression, and cognitive problems, as well as incontinence and sexual problems are particularly difficult for individuals to deal with. Many people with MS are also apprehensive about discussing certain topics with healthcare professionals. The emotional and relationship problems associated with MS, for instance, have not always been fully appreciated by healthcare professionals, who have tended to concentrate more on the physical aspects of the disease [4].

There is a common view that specialist physicians are 'authority figures' and as a result, people may feel intimidated by them. Such a viewpoint can make it difficult for patients to discuss any concerns they may have about their condition or treatment. In combination with the common misconception that nothing can be done, this

may lead to prolonged and unnecessary suffering in a patient with MS [3].

3. Life Planning and Independence

Many people with MS continue to work and retain their financial independence despite the symptoms and disabilities associated with their condition. However, doing so requires a combination of determination, knowledge of disability discrimination laws, and the help and support of colleagues, friends, family, and healthcare professionals [4].

Despite greater understanding of how and why MS develops, improvements in the reliability and timing of diagnosis, and the availability of new treatments, about 50% of people with MS still leave their jobs 10 years after disease onset because of debilitating symptoms. The psychological, cognitive, social, and financial burden on people with MS, their caregivers, and the community as a whole, is thus significant and needs to be refocused in areas such as neurology, cognitive psychology, clinical neuroscience clinics and reimbursement bodies [9].

Some people with MS will not require any change to be made to their job or working pattern, whilst others might gain immediate benefit from choosing a more suitable job or making appropriate adjustments. Fatigue and cognitive issues are the major reasons why people with MS leave work. Fatigue can be particularly challenging and can make some jobs that have high physical demands, such as travelling or standing all day, impossible. Nevertheless, flexible working, adequate rest periods, and practical aids mean that most jobs remain manageable.

Cognitive problems that affect attention, concentration and short-term memory can also be a problem. However, simple practical coping strategies can be implemented, such as a move to a quieter area of the office to minimize disruption. Cognitive rehabilitation services may potentially serve them with a more acceptable neurocognitive performance, mental health, quality of life, and activity of daily living [1, 2, 9].

4. Comment

Greater recognition and treatment of the comorbid and chronic symptoms that affect the quality of life for people with MS is warranted. In addition, more information, communication, and interaction between patients, caregivers and other medical staff need to be emphasized in clinical practice. Last but not least, a better access to

community services would be expected to lessen the overall disease burden.

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Conflict of Interest

The author declared no Conflict of Interests.

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