The lived experience of multiple sclerosis

Patient insights to guide general practitioner care

CPD

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Background
Multiple sclerosis (MS) is a neurodegenerative disease with symptoms that are varied and unpredictable, and although there are effective medications to treat some forms of MS, there is no cure. For many, an MS diagnosis means decades living with a chronic illness and disability.

Objective
Providing medical and support care to people with MS can be a long and complex partnership between the patient and the general practitioner (GP). The aim of this article is to provide knowledge of the lived experience of MS and the factors leading to a reduced quality of life.

Discussion
Often alongside the considerable threats to physical health and neurological function that MS poses, there are also significant mental health burdens. This article uses lived experience to outline some of the crucial trigger points where support from the GP, and the wider general practice team, can have a significant impact on a positive path forward for the patient.

DESPITE MANY RECENT ADVANCES in understanding and modifying the course of multiple sclerosis (MS),[1] significant symptoms often remain difficult to manage, which can greatly reduce quality of life for people living with all types of MS. These symptoms include issues with cognition, fatigue, pain, mental health, bladder and bowel, sensory and motor function, vision, spasticity and sexual function.[2] As a result of the innate unpredictability and uncertainty of the disease,[3] unique challenges present for the general practitioner (GP) to consider in caring for people with MS.

As GPs are central to coordinating medical care and referrals in the community; they form a central lynchpin to managing MS well and providing consistent support. The aim of this article is to introduce elements of the lived experience so that GPs can have a deeper understanding of how MS may affect individuals and target potential pathways of support for patients living with MS.

The lived experience of MS

For many people, particularly in the lead-up to and confirmation of a new diagnosis, the sudden, variable symptoms experienced when living with MS can be frustrating and frightening.[4] Key points about MS are listed in Box 1, highlighting that each patient's experience is unique. There are identified trigger points of fear throughout a person's trajectory with MS (Box 2), and these are pivotal opportunities to provide counselling and support to alter the lifepath in a positive, meaningful way. Understanding elements of the lived experience can provide awareness of the factors reducing quality of life, which can then be managed. This article draws on lived experience discussions of the authors with people living with MS in the course of clinical care and advocacy (TB, EB), lived experience research by the primary author in a doctoral dissertation (TB) and lived experience presented in the medical literature from other qualitative research in MS.

The diagnosis of MS

The lead-up to a diagnosis can be an overwhelming time, and often the GP

Box 1. Key points about multiple sclerosis (MS)

- There are different types of MS.
- Within each type of MS, there are many potential individual pathways.
- MS is characterised by uncertainty and unpredictability.
- MS has complex and varied symptoms.
- MS has effects on both physical and mental health.

is the key healthcare provider (HCP) at this time of unusual symptoms before an MS diagnosis. Adding to the complexity for GPs is that it can be hard for patients to differentiate some MS symptoms from more common conditions.[5] Motor symptoms can be more obvious, but many symptoms of MS can be intermittent, invisible and sensory in nature and more difficult to localise.[6] Diagnosis can be a devastating blow or a relief, depending on what other potential diagnoses are being considered and the type of MS diagnosed.[7] The trauma of diagnosis can be remembered for decades afterwards, the emotions it embodies are vivid and deep-rooted.[8] The diagnosis of progressive MS can be particularly overwhelming, with few treatment options and progressive neurological deterioration requiring more supportive care in the community and at an earlier stage.

Communication and discussion of an MS diagnosis is potentially an opportunity for the HCP to strengthen emotional ties with the patient, despite prevailing sorrow and concerns.[9] This may necessitate a focus by the GP on mental health strategies and wellbeing, especially during the adjustment phase, during which people with MS can experience significant fear and distress. People often report overwhelming thoughts of being confined to a wheelchair,[10] which, for some, may be unlikely depending on their type of MS. For people diagnosed with progressive forms of MS, both the emotional and practical aspects of supportive care need addressing early in the diagnosis.[11] It is also important to realise that for a similar level of disease measured objectively by electrophysiological and radiological tests, people may have vastly different levels of disability, and this may require open discussion.

Box 2. Key trigger points for fear, where extra support may be required

- Lead-up to diagnosis
- Time of diagnosis and immediate aftermath
- When considering disclosure of diagnosis to others
- Initial disease-modifying therapy (DMT) decisions; later switching of DMTs
- Pre, peri and postpartum period
- Transitioning from relapsing remitting multiple sclerosis to secondary progressive multiple sclerosis
- Time of relapse and recovery
- Change in symptoms or intensity
- Premature loss of employment, responsibilities or career path
- Progression of disease and accumulation of disability
- Recommendation of assistive devices such as walking sticks and wheelchair
- Change in relationship status, including loss of partner, carer or significant support

Disclosing the diagnosis and employment

Disclosure is a major issue for people with MS, with significant worries about employment and stigma.[7,12] People with MS often conceal their diagnosis to help maintain their sense of identity[13] and avoid being labelled as disabled.[14] People with MS also often worry about their ability to provide for their family and the potential loss of employment.[15] Engagement by the GP with counselling options can be crucial to future decisions and pathways at this significant point in time.

Managing loss and uncertainty

Many feelings of loss accompany living with MS, not just after diagnosis, but throughout life. This includes feelings relating to the loss of paid employment, career opportunities, leisure and recreation activities, social interactions, relationships and future certainty in life.[12] Gaining a sense of control in the face of daily uncertainty demands ongoing self-surveillance, evaluation and reconciliation of fluctuating MS symptoms with management strategies.[16] The implications of these concepts of loss for the GP include appropriate referrals to help manage these emotions and incorporating the concept of uncertainty into care options.

Dealing with multiple, complex and invisible symptoms

Symptoms of MS can vary greatly depending on the part of the CNS affected. Invisible symptoms including fatigue, depression, anxiety, incontinence and cognition issues can cause significant upheaval in the lives of people with MS[17] and commonly lead to reducing or ceasing employment.[18,19] Affecting more than 80% of people with MS,[20] physical and mental fatigue consistently feature as the invisible symptoms that are highly debilitating and resistant to management, creating a negative influence on life.[12] Invisible symptoms also result in people with MS not feeling validated by others and questioning the legitimacy of the illness.[7,17] Raising awareness of invisible symptoms, openly discussing their impact and providing appropriate management strategies can greatly improve quality of life.

Sexual health issues are also prevalent in MS, particularly with fear of rejection,[21] and sexual needs may change after diagnosis, with reports that this is not routinely addressed by HCPs because of lack of time and a perception that it is not as important as other symptoms.[22] However, setting up a support network, providing resources early and approaching the topic consistently and regularly can have many positive effects.

Depression, anxiety, worry, fear and despair can all feature in living with MS, sometimes as a more fulminant symptom than the neurological symptoms, threatening treatment compliance and adherence.[7] Dealing with the early signs of cognitive issues can also present special challenges for the patient, family and GP. It is imperative to help the patient develop a toolkit of skills to deal with the unpredictable years ahead. Additionally, the National Disability Insurance Scheme (NDIS) can be helpful, even in the early years of living with MS, to provide financial assistance with therapies to maintain quality of life, mental health and/or employment.

Surplus suffering

Although there are many stories of outstanding support from HCPs in MS care, lived experience studies have reported further suffering in addition to the burden of living with MS.[23] 'Surplus suffering' is distress experienced by people with MS over and above suffering from the existing physical, emotional and mental burdens of the disease. It is often caused by the actions of others, including HCPs, the healthcare system, family, friends or community.[23] It commonly presents in MS as brushing off vague or invisible symptoms by HCPs (pre and post diagnosis of MS) and misunderstanding or underappreciation of invisible symptoms by family, friends and work colleagues. If the road to diagnosis has been a long and arduous one, there may be some negativity experienced by the patient and reflected back to the GP. This should be addressed early and acknowledged, providing an opportunity for active engagement and frank discussion about the difficulties with diagnosis. Additionally, the GP may be the person the patient turns to when feeling the mental health threats that may arise after experiencing surplus suffering at the hands of others, both medical and non-medical sources. The GP can offer understanding, counselling or psychological referrals as a key to moving forward, developing self-management skills and a more positive future.

Treatments for MS

Despite the availability of highly effective disease-modifying therapies, the side-effect profile of some medications can cause significant fear for patients and requires careful safety monitoring.[3] Vigilant communication and providing the reasoning for tests, as well as handing over some responsibility to the patient for attendance, can help to build self-efficacy and engagement with the care plan. If people with MS do not see benefit from treatments, they often turn to self-care, self-treatment and complementary and alternative therapies,[24] and the GP may see this regularly in practice. Connecting the patient with a specialist MS neurologist and allied healthcare team who can offer multidisciplinary care can provide valuable opportunities for the patient and be a source of support for the GP.

Maintaining health and wellness; regaining control

Despite the concerns discussed in this article, most people with MS express a determination to adapt to MS,[25] which presents an excellent opportunity for GPs to collaborate with the patient to maintain wellness in all areas of health, not just MS.[26] This extends to a greater understanding of the disease and may require some guidance to connect with MS organisations, support groups and adjustments to modifiable lifestyle factors to promote health and wellbeing.[27] MS Australia provides an electronic hub of information, support and information.

Fear points can be times when excess worry and concern can override positive advances made when living with MS (Box 2). Being aware of these times and the potential need for extended or new support and resources is critical to managing MS well at the general practice level. As the patient vignette in Box 3 shows, people with MS want to live, not just exist, and a supportive GP can be crucial to living well. There is scarce literature addressing end-of-life care concerns in MS, but as with all chronic illness, the GP is an integral part of this discussion, regardless of the level of disability or positioning of the patient on the overall disease trajectory.

Conclusion

While it is not feasible in the general practice setting to ask about the extensive lived experience of every patient, asking the right questions to bring to light the most pressing worries and concerns may significantly improve the quality of life of people living with MS. The day of diagnosis is a critical event, and care focusing on support and managing the adjustment period with the GP can have

Box 3. Patient vignette by Erin

In 1997, I was an incredibly fit and healthy 18-year-old who had spent their life outdoors, playing every sport I could, bushwalking and hiking, rock climbing and white-water rafting. I was looking towards a bright future, which was limited only by my imagination. The possibilities were endless. Little did I know that the universe had different ideas and that intermittent feelings of numbness and tingling would turn out to be something much more sinister. By the age of 21 years, a diagnosis of multiple sclerosis (MS) was confirmed, but what did that mean?

Was I fully prepared for what my life would now look like? My hopes and dreams were crushed in an instant. Was I prepared for what would happen 20 years down the track? The short answer is no. How can you ever be prepared for an illness that plays by its own rules? An illness that goes up and down and round and round, and never knowing if tomorrow you will be able to walk? And at some points in this journey that is exactly what would occur: the pain, the fatigue, the cognitive failures, the inability to walk, where getting dressed would resemble an Olympic sport. These things I did not know, or even begin to comprehend.

My neurologist saw in me a strength that I would need, not only as I navigated into adulthood with a chronic illness, but a strength I would need as I came to the realisation of just what I had. One general practitioner (GP) told me, 'you'll be fine, they'll have a cure in 10 years'. I didn't sense there would be more assistance beyond that. An encounter with a radiologist felt dismissive and condescending, leaving me wondering what was wrong with me and questioning the symptoms I was feeling. The neurologist got me through. These were my first medical encounters on the very long road of MS treatment.

I later moved to the 'big smoke' and found another GP, who was a godsend. A woman who would continue to be my GP for 15 years. She was there every step of the way from those not-so-fun interferons, through to the frightening disease-modifying therapies Tysabri, Tecfidera, Lemtrada, through the horrible and costly side effects and then finally on to Ocrevus. She saw me as my own person, not as someone who just had MS. Not every symptom was automatically assumed to be from MS. I was someone who had injured their knee playing sport. I was someone who just had a cold. She was my GP who willing to think outside the square, who was interested in neuroplasticity, someone who listened to my questions, my goals, my concerns and helped make my life worth more than a mere statistic. A GP whose support, encouragement and belief helped me to really live, not just exist.

a significant positive impact on the years ahead. Essentially, time spent here can benefit the patient–GP relationship for decades to come.

Being aware of the fear points and the impact that these can have on mental health and the multitude of often invisible symptoms presenting in MS is challenging. The GP is a critical link in the wider healthcare team, and selection of the best medical team ensures quality of life is maximised. Understanding the lived experience of MS can lead to faster and more appropriate referrals and greater partnership between the GP and the person living with MS to maintain overall health and wellbeing for the long journey ahead.

Key points

- MS can lead to mental health issues such as depression and anxiety.
- Early intervention can have profound positive effects on adjustment and coping.
- Time spent developing a working partnership early can reap many benefits in the long term.
- Acknowledgement of invisible symptoms can have a positive impact on quality of life.
- Awareness of surplus suffering can lead to healing of relationships and trust with the GP.

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