The financial toxicity of multiple sclerosis

Multiple sclerosis (MS) is a neurologic autoimmune disease that is generally diagnosed in young adults. It is a lifelong condition, as it is currently incurable. The medical costs are high, as patients have to cover frequent hospital visits and prescription medications, such as emerging disease modifying drugs. As a result, many patients do not adhere to treatment plans, which further reduces their quality of life. There are also non-medical costs to consider, such as loss of productivity at work and early retirement. Research led by Professor Carl Asche at the University of Illinois, explores the financial burdens of multiple sclerosis and advocates for improved strategies to reduce the cost burden of the disease.

Multiple sclerosis (MS) is an autoimmune condition that affects the brain and spinal cord. Specifically, the immune system attacks the myelin sheath, the protective layer surrounding the nerves. As a result, electrical transmission along the nerves become disrupted, causing a range of symptoms including blurred vision, uncoordinated movement, and muscle stiffness. As well as physical symptoms, patients are also at an increased risk of experiencing depression. MS can affect people of any age but most are diagnosed in their 20s and 30s, making it the most common cause of disability in young adults. It is estimated that one million people in the United States and 2.5 million people globally are living with MS, with approximately 12,000 new cases diagnosed each year in the United States.

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MS is a chronic, progressive, and incurable disease. Patients can only manage the symptoms throughout their lifetime. Due to long-term management of the disease, patients can incur a lot of healthcare costs. As MS progresses, an onset of new symptoms will require more emergency care and hospitalisations for patients.

FINANCIAL COSTS
A systematic review of fifteen studies found that total direct and indirect costs per patient ranged from $8,529 to $54,244 annually. Direct costs include medical bills, such as hospitalisations and pharmaceuticals, and comprise 77% of the total cost, with prescription medications accounting for majority of the cost. Indirect costs include expenses associated with short- and long-term disability, productivity losses, unemployment, and early retirement, and comprise 23% of the total cost. In general, the greater the disease progression, the cost associated with treatment and indirect costs (such as assistance for social activities and productivity loss) will increase exponentially.

MEDICAL COSTS OF MS
Using data from the National Inpatient Sample database in the United States from 1994 to 2013, it was projected that MS hospital admissions will exceed $43.5 million every year. MS patients also require imaging scans like MRI during diagnosis and follow-up hospital visits to assess levels of lesions in the brain and spinal cord, which can incur large medical bills. However, this was based on data of 20% of admissions in US hospitals in 44 states. When extrapolated, the total national bill for managing MS is estimated at $4.3 billion in 2013. This is a huge economic burden for both patients and taxpayers.

Even though insurance in the United States can cover part of the medical costs for MS patients, they would still need to pay for out-of-pocket costs, depending on treatments and insurance coverage. Researchers in one 2016 study tracked spending on out-of-pocket costs by individuals with Medicare Part D and found that out-of-pocket costs were seven times higher than a decade earlier. Among medically bankrupt individuals, MS is associated with the highest total out-of-pocket spending, at an average of $34,167 at the point of bankruptcy filing.

THE IMPORTANCE OF HOME MODIFICATIONS
Home and work modifications are very important for individuals with MS. Home modifications to improve safety for MS patients fall under the umbrella of medical expenses, and can be tax deductible. People living with MS may find that their daily lives can be improved through modification to their homes to increase accessibility and safety. The cost of home modifications vary widely and estimates range from $100 to $50,000. Home modification assistance programmes not only benefit people with MS by allowing them to stay safe and independent in their own homes but also result in savings for the healthcare system and for the economy overall by reducing injuries due to falls and premature admission to long-term care facilities.

NON-ADHERENCE TO TREATMENT OF MS
MS patients are at an increased risk of facing financial hardship that often results in non-adherence to treatment plans. A study of 243 patients found that 34.7% (75 patients) reported non-adherence to care (medications and imaging) due to treatment expenses. 28.9% of participants also reported delaying filling of prescription medication because they were too expensive or were denied of insurance coverage. Therefore, MS patients are at a risk of low health-related quality of life, as they are subjected to high levels of anxiety to manage finances and often do not adhere to treatment plan due to financial hardships. This further debilitates their well-being through increased risks of relapse, subsequent hospitalisations, and emergency department visits.

Prescription drugs incur the largest cost of MS management. A new type of treatment for MS is the disease modifying drugs (DMDs). On average, patients with relapsing remitting MS experience one or two episodes annually, which can be very distressing. DMDs aim to reduce inflammation in the nerve cells for people with relapsing episodes of MS, which can reduce the number and severity of relapses. The popularity of this drug has increased over the years but so has the costs in the last 20 years. Prices are set to continue increasing over the foreseeable future. In the United States, the cost of first-generation DMDs was shown to
increase annually at a rate of five to seven times higher than that of prescription drug inflation. First-generation DMDs originally cost $8,000 to $11,000 when they entered the market, but now cost approximately $60,000 annually. Newer generations of DMDs commonly costs 25%-60% higher than existing ones.

Some researchers have suggested that due to the effectiveness of DMDs, hospital admission rates would decrease, therefore saving healthcare costs. Others have suggested that rising prices alienate most patients, resulting in under-treatment, increased number of relapses, and shorter remission periods, which would then require more hospital visits. It is important to note that the rising prices are likely to increase the price of drugs for patients, so their living costs do not mount up and quality of life can improve. Thorough and improved discussions surrounding costs has to occur between healthcare professionals and patients when planning treatment strategies. It will be interesting to study costs with the Expanded Disability Status Scale (EDSS) in future work. Policies to improve access and affordability to therapies, such as high-efficacy DMDs, are needed, so the economic burden shared by MS patients can be decreased.

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