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## Multiple Sclerosis, Physical Therapy, and Quality of Life Insights

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# Multiple Sclerosis, Physical Therapy, and Quality of Life Insights

By Claire Simon

## Introduction

Multiple sclerosis (MS) is a progressive neurological disease with no known cure. Current medications and therapies can only treat symptoms and slow disease onset, but they cannot reverse the permanent brain damage.

MS is caused by brain damage induced by constant attacks from the immune system on neurons. Specifically, T-cells, cytokines, and other molecules from immune and inflammatory responses damage the myelin, which is the fatty layer surrounding the neuronal axis that helps propagate an action potential [1]. Myelin degradation thereby slows action potentials, prevents electrical signal transduction, and effectively suppresses communication between the brain and spinal cord [2]. This leads to the most notable MS symptoms of mobility impairment, muscle weakness, spasticity, urinary and bowel incontinence, and chronic pain [3]. The immune and inflammatory response molecules also damage myelin repair cells known as oligodendrocytes, which prevents myelin sheath repair and leads to the progressive nature of neuronal loss that can be viewed in an MRI as brain lesions [4]. Other symptoms of MS include depression, chronic fatigue, and anxiety [1].

MS is also characterized by symptom relapse and remittance that falls into three distinct pathologies. The most prevalent type of MS, termed relapsing remitting, constitutes 85% of MS diagnoses and is defined by periods of relapse (worsening inflammatory processes that last longer than 24 hours) and remittance (periods of little to no symptoms) [1, 4]. Over time, these episodes of relapse get progressively more frequent, intense, and lengthy corresponding to the disease progression and brain damage [1]. In primary progressive MS, symptoms continue to worsen without periods of remission and may have plateaus; this affects ~10% of MS patients and is the type generally less responsive to drug treatments [1]. The third type, secondary progressive, usually develops from relapsing remitting and is a continuous state of worsening disease progress with or without remittance. Finally, the rarest form of MS (less than 5%) is essentially a more intense version of primary progressive where disease progressively worsens faster with occasional flare-ups and fewer plateau incidents [1].

Although there is no known direct cause, trends of MS diagnosis suggest genetic contributions along with non-genetic factors, such as the environment, viral infections, and metabolism [1]. The most common diagnosed case of MS occurs in women from 20-40 years old of Northern European descent, who are twice as likely to have MS than men [1, 5]. Another study using a MS patient database found peoples of African ancestry conferred more risk for secondary progressive MS in age of onset and number of relapses [6]. While the cause of MS is not yet clear, genetic studies are facing challenges in an attempt to find specific alleles and causative genes and continue to find a causative link between MS, genes, and the environment [7].

While a cure for MS remains elusive, there are several treatment options that are mainly disease modifying. The MS demyelination mechanism cannot yet be reversed by drug therapies, but interferon- $\beta$  (IFN) is the primary disease-modifying drug therapy since 1994 and is used in multiple prescribed medications [1, 8]. IFN formulates neutralizing antibodies and reduces the efficacy of disease progression [8]. Early

diagnosis is useful for IFN medical treatment since the medication is beneficial when administered at the time of the first and early relapse periods, halting disease progression as early as possible [4, 5].

Other MS treatments ranging from mental to physical therapies target symptoms such as depression, cognitive decline, fatigue, bladder incontinence, and spasticity. Behavioral learning therapies may be effective in preventing certain aspects of cognitive decline [9], and antidepressants and exercise protocols are being examined to combat MS fatigue [3,10]. An analysis of four qualified studies found that alternative treatment options such as mindfulness, yoga, biofeedback, and relaxation techniques positively affect depression, anxiety, quality of life (QoL), and fatigue [11]. Even smoked cannabis has been shown to reduce pain and treatment-resistant muscle spasticity in a trial of 30 patients [12].

Physical therapy (PT) offers profound benefits to patients with MS in alleviating adverse side effects and improving QoL. PT improves muscle strength, flexibility, and mobility training for daily life activities. Even small improvements in fatigue from exercise protocols [3], and improvements in bladder incontinence from pelvic floor exercises directly contribute to an improved QoL from symptom reduction [13]. A consistent PT treatment may also reduce forms of disability in patients suffering from muscle weakness and coordination loss [14].

After learning of the prevalence of MS in young women and gaining an interest in the neuropathology and treatment of the disease, I sought to gain perspective of this disease through observing on-site MS clinical PT sessions at my university and interviewing MS patients. After shadowing the clinic, interviewing three MS patients, and administering a standard QoL assessment test, I found support for the unique benefits of PT for treating disease and improving QoL.

## **Materials and Methods**

### *Clinical Observation*

The University of Puget Sound PT clinic is a relatively free service of physical and occupational therapies that is run by graduate student therapists under the supervision of professional and experienced instructors. During my internship, I shadowed a physical therapist and observed various PT sessions in the UPS PT clinic for three days (total of six hours). During my observations, I was instructed on clinical techniques in treating various neurological diseases, including MS, and reviewed clinical charts and treatment histories of MS patients.

### *Quality of Life Assessment and Patient Interview*

With written permission, I interviewed three patients with different types and stages of MS (Table 1). I asked several questions pertaining to their personal experiences with the disease, treatment histories, and perspectives on various received treatments, with a focus on PT.

In addition to the interview, I administered a Schedule for the Evaluation of Individual Quality of Life Direct Weighting (SEIQoL-DW) procedure as described by O'Boyle and colleagues [15]. I asked the five areas ("Cues") that contributed to the patients' happiness and QoL and asked them to rate how important each cue was relative to the others (Weight) by assigning each cue a percent out of the total 100% on a pie chart. I then asked each patient to rate the level of satisfaction with each

respective cue at the current moment in his or her life by drawing a representative bar graph (“Level”) to indicate a score of satisfaction. The height of the bar in millimeters corresponded to a score out of 100 (Fig. 1). All interviews were recorded for later analysis (Supplemental Interviews available upon request).

### *Literature Research*

To compliment my observations and experiments, I conducted a preliminary literature research on current medications, treatment options, and neuropathology theories (presented mainly in the Introduction) using a variety of search engines (e.g. Google Scholar, UPS Collins Memorial Library, and PubMed).

## **Results and Discussion**

Table 1. Patient Interviewee Profiles

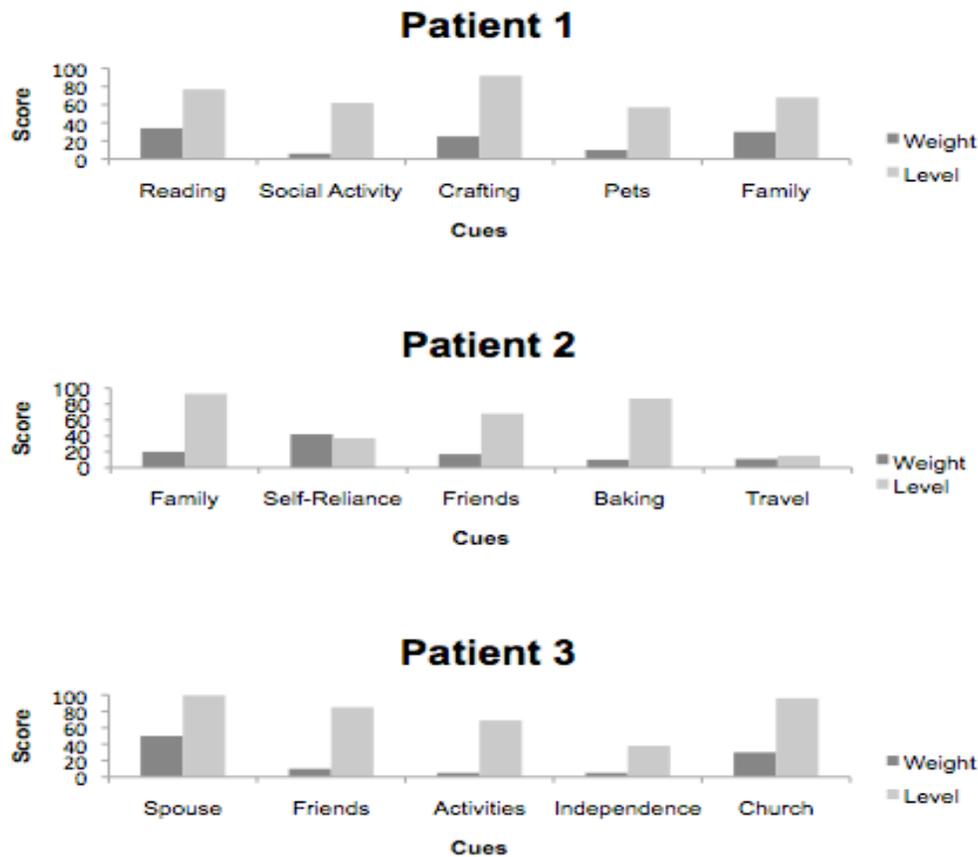
Patient	Gender	Age (years)	Age of Diagnosis (years)	Disease Type	Mobility Profile
1	Female	54	29	Primary Progressive	Wheelchair
2	Female	64	44	Secondary Progressive	Limited walking with cane assistance
3	Male	55	37	Secondary Progressive	Wheelchair

Each patient was cognitively able and engaged in SEIQoL-DW procedure, which took an average of 15 minutes each to complete. Some patients were more responsive to the interview portion than others, but each session was informative and lasted one hour at maximum. In administering a standard QoL procedure I was able to quantify my results and have the ability to compare with other studies using the same measurement. A study by Hickey and colleagues [16], for example, uses the SEIQoL-DW to measure QoL in HIV/AIDS and drug users and could be used as a reference point for the QoL outcome by similar symptoms in MS.

The SEIQoL-DW procedure was chosen based on literature support as the most appropriate standard for general QoL analysis. In general, this type of protocol is focused on an individual frame of reference for QoL analysis, and the SEIQoL-DW (when compared to other QoL protocols) specifically focuses on intrinsic feelings of health and vitality, as opposed to physical ability or other aspects of a disease [17]. However, there are notable limitations in this analysis since a small sample size was used and patient self-ratings may come with a variety of biases, including a reflection of coping strategies (i.e. staying positive) [17]. Yet for my purposes, this procedure was beneficial and advantageous in general QoL analysis.

As a general trend, all patients listed a version of social support among their cues and with the most weight in QoL (Fig.1). Patient 2 applied more weight for self-reliance than did others and Patient 3 was the only one that mentioned any spirituality or religion

(Fig. 1). Notably, none of the patients explicitly referenced health as a factor for QoL, although it can be argued that health is implied in categories such as self-reliance and independence.



**Figure 1.** Quality of life profile of multiple sclerosis (MS) patients. "Cues" were offered by the patient in the interview as the most important factors in their personal happiness. "Weight" is a percentage value of how important that cue is in their life and "Level" corresponds to the current level of happiness in that cue.

The common cues that contribute to QoL in patients seem to provide emotional support, which makes sense given the nature of the disease and the fears mentioned in the interview. According to Patient 1, "[MS] just continued to get worse and worse. And that is really depressing—being able to do less and less." Patient 2 said, "I think the unknown and not knowing what's going to happen...in the future is kind of scary." In light of these fears, positivity, staying active, and having healthy, supportive relationships is intuitively crucial to QoL with MS.

In agreement with the literature, patient interviews revealed the fundamental benefits of PT in QoL. All three patients agreed that PT provides a goal and source of motivation that acts as a "vital tool" for a healthy mental and physical state. The motivation they spoke of gets them out of the house, which benefits familial caregivers by providing a break and adds a sense of independence and daily activity to the patient's life, an important factor in self-rated QoL (Fig. 1). PT is also very interactive, as it requires communication on the part of both the therapist and patient and requires physical participation from the patient. This not only initiates a social relationship but also instills a feeling of control and self-confidence in the patient. A patient is actively

participating, meeting goals, and taking action to improve their health situation, which may help stave off anxiety, depression, and passive, pessimistic feelings known to persist when one has a perceived loss of control [10]. One patient reports on the mental and social benefit of PT, "...your mental state will be better because when you have to think and you have to work you're causing your mind to work...I enjoy working with the student [therapists]." As I observed in the clinic, student therapists not only focused on symptom improvement and muscle strengthening but also tailored treatments specific to the patients' requests and encouraged mental strength by establishing goals, assigning home exercises, and explicitly calling attention to and praising improvements.

A sense of control and active physical and mental participation is notably unique to PT in comparison to drug therapy. According to patients, benefits of medicine are less apparent, which often leads to frustration: "I'm not even sure [medications] are doing anything. I take them mostly to keep [symptoms] from progressing," "[PT] so improves the quality of my life...Medication is just keeping things from getting worse, but it's not like I really *know* what it's doing," and "...when I started getting worse—my walking [and] fatigue got worse—the medicine just didn't seem to be helping." Because medicine can't reverse brain damage and the effects of MS, it can often be frustrating to patients with false expectations or unfounded optimism. While medicine is physiologically important to sustain health and slow disease progress, PT seems to foster beneficial optimism and improve symptoms such as muscle strength that may directly apply to daily life activities. The mental well-being and sustained QoL offered by PT is crucial for one who must live with the mental and physical anguish of an incurable disease.

The UPS PT clinic was particularly unique and benefitted both patients and student therapists. Patients benefit from nearly nonexistent fees, unique attention (often by one or more therapists at one time), student enthusiasm, and creative therapy techniques. For some of the interviewed patients, a majority of PT progress was lost after insurance coverage expired. The UPS clinic helped continue much needed PT treatment for those without insurance. Student therapists benefit from the clinic because of the access to hands-on, professional, and rewarding experience in PT.

In conducting my interviews, many other questions arose for future research and discussion. For one, patient access to research and MS news was limited to magazines, newsletters from local or national MS community chapters, public websites, and pamphlets released by drug companies. Biased drug information provided by companies may instill false expectations of medicine and contribute to a sense of frustration in patients. For example, one patient became discouraged after taking a drug she read about called "The Walking Cure" when it failed to work with her disease. The dramatic name may look good for a drug company, but it instilled a sense of false optimism in a patient struggling with MS. Additionally, I would like to research and discuss regulations for age of MS diagnosis and potential drug therapies that attempt to repair myelin damage instead of simply preventing it.

In conducting this neuroscience internship, I gained first-hand experience with personal aspects of MS and a PT treatment option. This offered me several perspectives into a complex neurological condition ranging from molecular pathology to personal human struggle that doubles as invaluable insight in pursuing a career in neuroscience.

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Supplemental Interviews available upon request.

## References

1. Goldenberg MM. (2012) Multiple sclerosis review. *P & T*: a peer-reviewed journal for formulary management 37: 175–84.
2. Kornek B, Lassmann H. (2003) Neuropathology of multiple sclerosis—new concepts. *Brain Research Bulletin* 61: 321-326.
3. Heine M, Reitberg MB, van Wagen EEH, Port IVD, Kwakkel G. (2012) Exercise therapy for fatigue in multiple sclerosis (Protocol) 7.
4. Berkovich R. (2013) Treatment of acute relapses in multiple sclerosis. *Neurotherapeutics* 10: 97–105.
5. Jacobs LD, Beck RW, Simon JH, Kinkel RP, Brownschidle CM, et al. (2000) Intramuscular Interferon Beta-1a Therapy Initiated During a First Demyelinating Event in Multiple Sclerosis. *The New England Journal Of Medicine* 343: 898-904.
6. Ferreira Vasconcelos CC, Cruz Dos Santos GA, Thuler LC, Camargo SM, Papais Alvarenga RM. (2012) African ancestry is a predictor factor to secondary progression in clinical course of multiple sclerosis. *ISRN neurology* 2012: 1-7.
7. Gourraud PA, Harbo HF, Hauser SL, Baranzini SE. (2012) The genetics of multiple sclerosis: an up-to-date review. *Immunological reviews* 248: 87–103.
8. Barnard JG, Babcock KEN, Carpenter JF. (2012). Characterization and Quantitation of Aggregates and Particles in Interferon- $\beta$  Products: Potential Links Between Product Quality. Attributes and Immunogenicity 1–14, doi:10.1002/jps.
9. Chiaravalloti ND. (2012) Could behavioral therapies target specific deficits in multiple sclerosis patients? *Expert review of neurotherapeutics* 12: 755–7.
10. Bakshi R, Shaikh ZA, Miletich RS, Czarnecki D, Dmochowski J, et al. (2000) Fatigue in multiple sclerosis and its relationship to depression and neurologic disability. *Multiple Sclerosis* 6: 181–185.
11. Senders A, Wahbeh H, Spain R, Shinto L. (2012) Mind-body medicine for multiple sclerosis: a systematic review. *Autoimmune Diseases* 2012: 1-12.
12. Corey-Bloom J, Wolfson T, Gamst A, Jin S, Marcotte TD, Bentley H, Gouaux B. (2012) Smoked cannabis for spasticity in multiple sclerosis: a randomized, placebo-controlled trial. *CMAJ* 184: 1143–50.

13. Lúcio AC, Perissinoto MC, Natalin RA, Prudente A, Damasceno BP, D'ancona CAL. (2011) A comparative study of pelvic floor muscle training in women with multiple sclerosis: its impact on lower urinary tract symptoms and quality of life. *Clinics* 66: 1563–1568.
14. Solari A, Fillippini G, Gasco P, Colla L, Salmaggi A, et al. (1999) Physical rehabilitation has a positive effect on disability in multiple sclerosis patients. doi: 10.1212/WNL.52.1.57.
15. O'Boyle CA, Browne J, Hickey A, McGee HM, Joyce CRB. (1993) The Schedule for the Evaluation of Individual Quality of Life (SEIQoL): a Direct Weighting procedure for Quality of Life Domains (SEIQoL-DW) Administration Manual. Department of Psychology, Royal College of Surgeons in Ireland, 1–13.
16. Hickey AM, Bury G, O'Boyle CA, Bradley F, O'Kelly FD, et al. (1996) A new short form individual quality of life measures (SEIQoL-DW): application in a cohort of individuals with HIV/AIDS. *BMJ* 313: 29-33.
17. Lintern TC, Beaumont JG, Kenealy PM, Murrell RC. (2001) Quality of Life (QoL) in severely disabled multiple sclerosis patients: comparison of three QoL measures using multidimensional scaling. *Quality of life research* 10: 371–8.