

Understanding Drivers of Employment Change in a Multiple Sclerosis (MS) Population

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INTRODUCTION

- Multiple sclerosis is a neurological disorder commonly affecting young people between the ages of 20 and 40 years¹; important years for adults for their career progression and earnings²
- Growing research has been dedicated to the impact of MS on patient employment status because various studies have estimated that approximately 43% to 67% of patients with MS are unemployed within 12 to 15 years of receiving a diagnosis, respectively²⁻⁴
- Most studies assessing the impact of MS on employment have relied on mailed questionnaires or surveys. Qualitative data assessing patients' decision-making process are lacking

OBJECTIVE

- To gain an understanding of the key symptoms and factors that lead patients with MS to leave the workforce or reduce their employment hours

METHODS

- Qualitative study among adults with MS, recruited through four clinical sites located across the United States for a one-time interview. No interventions were administered
- To be eligible, patients were required to have a clinical diagnosis of MS and must have reported applying for disability, leaving the workforce, reducing work hours, or changing jobs because of MS within the past 6 months
 - Patients with significant cognitive impairment, hearing difficulty, visual impairment, severe psychopathology, or limited understanding of the English language were excluded
- Interviews used a semi-structured standardized interview guide to elicit information about the key MS symptoms and drivers that led patients to make changes to their employment status
- Audio data collected during the interviews were transcribed and then imported into an ATLAS.ti qualitative tool for content analysis
- Descriptive statistics were used to characterize the study sample and content analysis was used to analyze the qualitative data

RESULTS

- A total of 27 patients with MS were enrolled and completed the qualitative interview and questionnaires
- Most patients were white (81.5%) and female (70.4%), and the mean age was 46.3 years (Table 1)
- Nearly half of the population reported being married (48.1%) and having a college degree (44.4%)

Patient- and Clinician-Reported Clinical Characteristics

- Based on clinician report, the mean (standard deviation) number of years since patients were first diagnosed with MS was 10.2 (±7.4), and most patients were categorized as having relapsing–remitting MS (85.2%) (Table 2). Most patients (n=24, 88.9%) were receiving treatment for MS (Table 2)
- Among the patients who reported to have health conditions other than MS, the most common was depression (n=10, 37.0%) (Table 3)
- Fourteen patients (51.9%) reported normal, mild, or moderate disability; 4 patients (14.8%) gait disability; and 9 (33.3%) the need to use a cane or wheelchair (Patient-Determined Disease Steps scale, Table 3)

Table 1. Patient-Reported Sociodemographic Characteristics

Characteristic	Mean ± SD	N=27
Age, y	46.3±11.0	
	Range	23–67
Female, n (%)	19 (70.4)	
Racial/ethnic background, n (%)	White	22 (81.5)
	Black or African American	2 (7.4)
	Asian	2 (7.4)
	Other*	1 (3.7)
Marital status, n (%)	Married	13 (48.1)
	Single	7 (25.9)
	Divorced/separated	6 (22.2)
	Widowed	1 (3.7)
Employment status, n (%)	Full-time or part-time	10 (37.0)
	Disabled/applied for disability	11 (40.7)
	Unemployed	5 (18.5)
	Retired	1 (3.7)
Education level, n (%) ^b	Secondary/high school	2 (7.4)
	Some college	8 (29.6)
	College degree	12 (44.4)
	Postgraduate degree	3 (11.1)
	Technical or vocational degree	1 (3.7)

SD, standard deviation.
*Other includes white and Hispanic; ^bMissing education data for one patient.

Table 2. Clinician-Reported Characteristics

Characteristic	Mean ± SD	N=27
Time since diagnosis, y	10.2±7.4	
	Range	0.2–30
No. of years patient has been at practice	10.1±6.1	
	Range	2–24
Type of MS, n (%)	Relapsing–remitting MS	23 (85.2)
	Secondary progressive MS	2 (7.4)
	Progressive MS without relapse	1 (3.7)
	Unknown	1 (3.7)
Current MS treatment, n (%)	No current treatment	3 (11.1)
	Alemtuzumab ^a	4 (14.8)
	Interferon β-1a	2 (7.4)
	Interferon β-1b	1 (3.7)
	Daclizumab ^a	2 (7.4)
	Fingolimod	5 (18.5)
	Dimethyl fumarate	3 (11.1)
	Natalizumab	3 (11.1)
	Glatiramer acetate	4 (14.8)
	Dalfampridine	2 (7.4)
Past MS treatment, n (%)	IV/peroral steroids	10 (37.0)
	Interferon β-1a	14 (51.9)
	Interferon β-1b	8 (29.6)

IV, intravenous; SD, standard deviation.
^aExperimental.

Qualitative Findings

General MS Experience and Symptom Descriptions

- Seventeen patients (63.0%) cited fatigue as the most bothersome symptom
- Other bothersome symptoms included numbness or tingling (n=11, 40.7%); difficulty walking (n=7, 25.9%); general aches or pain (n=7, 25.9%); loss of muscle control or fine motor skills (n=5, 18.5%); memory issues or forgetfulness (n=5, 18.5%); weakness (n=5, 18.5%); sensitivity to heat or cold (n=5, 18.5%); vision problems or eye pain (n=4, 14.8%); and urinary or bowel issues (n=4, 14.8%)

Jobs/Roles Held by Study Patients and Changes Made to Employment

- Patients represented a diverse sample with a wide variety of occupations ranging from office jobs to delivery and truck driving, waitressing to nursing, and gas station attendant to scientist

Table 3. Clinical Information (Patient Reported)

Characteristic	None	N=27
Other health conditions, n (%)	None	12 (44.4)
	Depression	10 (37.0)
	Allergic rhinitis	6 (22.2)
	Anxiety	3 (11.1)
	Hypertension	3 (11.1)
	Other*	10 (37.0)
Patient-Determined Disease Steps, n (%)	Normal	5 (18.5)
	Mild disability	5 (18.5)
	Moderate disability	4 (14.8)
	Gait disability	4 (14.8)
	Early cane	5 (18.5)
	Late cane	1 (3.7)
	Bilateral support	0 (0.0)
	Wheelchair/scooter	3 (11.1)
	Bedridden	0 (0.0)

*Other includes allergy (n=1); arthritis (n=2); asthma (n=2); chronic obstructive pulmonary disease (n=1); diabetes (n=1); heart disease (n=1); gastroparesis and idiopathic thrombocytopenic purpura (n=1); Lyme disease (n=1).

- Fourteen patients (51.9%) felt their job was both physically and cognitively demanding, while 8 (29.6%) found their job more physically demanding, and 5 (18.5%) found their job more cognitively demanding
- Eleven patients (40.7%) reported being on disability or having applied for disability in the past 6 months. The remaining patients reduced their working hours (n=6, 22.2%), stopped work entirely (n=6, 22.2%; now in early retirement or unemployed), or switched jobs because of their MS (n=3, 11.1%)
- Patients most commonly reported having to stop or cut back on certain roles or tasks (n=9, 33.3%); having to take multiple breaks during the work day (n=6, 22.2%) and requiring additional help from coworkers (n=5, 18.5%)
- Patients most commonly reported paying attention, focusing, or concentrating (n=8, 29.6%); working in the heat or cold (n=7, 25.9%); lifting or picking up and carrying objects (n=7, 25.9%); walking or standing (n=7, 25.9%); and typing or writing (n=7, 25.9%) as the most difficult aspect of the job
- Despite the variety in jobs and positions held by study patients, the types of changes or adjustments made and the aspects of jobs that had become the most difficult as a result of MS were relatively similar

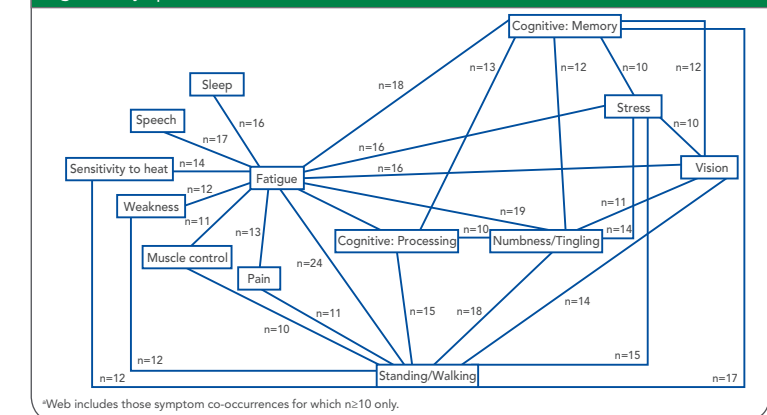
Key Factors and Symptoms Driving Employment Changes and Adjustments

- Most patients reported two or more symptoms as being key drivers for changes or adjustments made to employment
- Twenty one patients (77.8%) mentioned at least one physical symptom. The most common physical symptom reported was feeling tired or fatigued (n=16, 59.3%). Seven patients (25.9%) mentioned feeling weak or lacking strength/energy. Five patients (18.5%) discussed issues with muscle control, mentioning challenges with discrete tasks like typing
- Eleven patients (40.7%) mentioned at least one cognitive symptom. Memory loss or easily forgetting things was the most common cognitive symptom reported (n=7, 25.9%)
- Nine patients (33.3%) ascribed their cognitive problems as worsening when feeling tired or fatigued
- In addition to physical and cognitive symptoms, ten patients (37.0%) reported stress as an underlying factor ultimately affecting their employment situation. Many patients talked about stress as a trigger or an underlying agent for worsening their MS symptoms
- Three patients (11.1%) mentioned a fear as an important reason for changing, stopping, or reducing their work, mainly due to the fear of injuring someone while performing their job

The Interconnectedness of MS Symptoms: "The Fatigue Cascade Effect"

- Patients described multiple symptoms occurring simultaneously, linking their MS symptoms back to their most bothersome symptom—fatigue. When describing symptoms, patients reported that fatigue and general exhaustion or tiredness triggers a cascade of other issues (both physical and cognitive) (Figure 1)

Figure 1. Symptom Co-occurrence Web*



*Web includes those symptom co-occurrences for which n≥10 only.

Impacts of MS Symptoms and Changes in Employment

- Nine patients (33.3%) alluded to having lower self-worth, describing frustration or depression as a result of no longer doing their job well, or working less or not at all, and/or feeling like a burden to coworkers
- Five patients (18.5%) discussed the impact on family or home life and described financial stress of the change in their employment

CONCLUSIONS

- This qualitative study explores and documents the many reasons that influence patients with MS to leave their employment or reduce or change circumstances in their employment status. Physical and cognitive issues were noted and factored into job decisions, regardless of the type of occupation held by patients
- Fatigue was the key indicator for deciding to reduce work or stop working entirely, although certainly not the sole cause, supporting previous study findings.⁵ The cascade effect of fatigue on other symptoms cannot be underestimated because this had an overarching impact on the ability to work
- While these results have limited generalizability due to the small sample size, this study suggests that loss of employment has a negative impact on patients' mental status and family life, in addition to added financial strain. The effective management of MS symptoms may help patients to enhance productivity, continue working longer, and improve their overall health-related quality of life

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