INTRODUCTION

Multiple sclerosis is a neurological disorder commonly affecting young people between the ages of 20 and 40 years,1 important years for adults for their career planning and earning capacity.2 Growing research has been dedicated to the impact of MS on patient employment status because various studies have estimated that approximately 40% to 45% of patients with MS are unemployed within 12 to 15 years of receiving a diagnosis, respectively.3-5 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 to be living in the United States.
  - Patients with significant cognitive impairment, hearing difficulty, visual loss, or malignancy 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 content analysis tool.
  - 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 (51.9%) and female (70.4%), and the mean age was 46.3 years (Table 1).
  - Nearly half of the population reported being married (46.1%) and having a college degree (64.4%).

Patient- and Clinician-Reported Clinical Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean ± SD</th>
<th>n=27</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, y</td>
<td>46.3 ± 8.9</td>
<td>27</td>
</tr>
<tr>
<td>Sex, %</td>
<td>Female 70.4</td>
<td>19</td>
</tr>
<tr>
<td>Race, %</td>
<td>White 51.9</td>
<td>14</td>
</tr>
<tr>
<td>Education level, %</td>
<td>Some college 33.3</td>
<td>9</td>
</tr>
<tr>
<td>Employment status, %</td>
<td>Retired 33.3</td>
<td>9</td>
</tr>
<tr>
<td>Marital status, %</td>
<td>Married 48.1</td>
<td>13</td>
</tr>
</tbody>
</table>

• The cascade effect of fatigue on other symptoms cannot be fully explained in isolation, as patients attribute their worsening fatigue, memory, and other symptoms to each other (Table 2).

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=6, 22.2%); problems with sleep (n=6, 22.2%); weakness (n=5, 18.5%); sensitivity to heat or cold (n=5, 18.5%); and urinary or bowel incontinence (n=4, 14.8%).

Jobs/Roles Held by Patients and Changes Made to Employment

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


The Interconnectedness of MS Symptoms:

“Fatigue is a cascade effect”

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

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 strain as the change in their employment.

REFERENCES


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