ORIGINAL REPORT

IMPACT OF MULTIPLE SCLEROSIS ON EMPLOYMENT AND USE OF JOB-RETENTION STRATEGIES: THE SITUATION IN FRANCE IN 2015

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Objective: The main objective of this survey of persons with multiple sclerosis was to describe their employment situation. Secondary objectives were to ascertain when and how multiple sclerosis symptoms first impact employment per se and what strategies persons with multiple sclerosis use to cope with their employment problems.

Methods: A retrospective survey was conducted to collect data from persons with multiple sclerosis aged 18 years and over, using a computer-assisted web tool.

Results: A total of 941 respondents were working at the time of their multiple sclerosis diagnosis or had worked subsequently. Median time since diagnosis was 10 years. Multiple sclerosis had an impact on employment for 74.3% of respondents. The overall employment rate at the time of the survey was 68.1%; 27.2% had discontinued their occupational activity for a multiple sclerosis-related reason. Median time from diagnosis to multiple sclerosis-related cessation of occupational activity was 24.0 years (95% confidence interval (CI) 21.7–26.3 years). Respondents were poorly aware of available tools designed to assist them in retaining employment.

Conclusion: This study highlights the importance of early intervention by the occupational medicine physician in order to favour job retention and use of available tools by all workers with MS and not only those with a recognized status as a disabled worker.

Key words: multiple sclerosis; occupational status; unemployment; survival analysis.


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Accepted Mar 8, 2016; Epub ahead of print May 30, 2016

INTRODUCTION

In France, there are 7.6–8.8 new cases of multiple sclerosis (MS) per year per 100,000 inhabitants (1, 2). Prevalence is 94.7 per 100,000 inhabitants (3), age at diagnosis ranges from 25 to 35 years, and three-quarters of patients are female (4).

Because of its significant impact on occupational activities (5) better knowledge of the professional history of persons with MS is needed in order to ascertain the efficacy of preventive measures designed to help persons with MS to retain employment. This is particularly important because persons with MS are young people (6) whose quality-of-life can be expected to decline early (7).

Employment rates in persons with MS have shown a wide range of figures, from 26% to 74% across studies, depending on disease duration, educational level, and local conditions (6, 8–10). According to Pfleger et al. (11), half of persons with MS will lose their job 9–15 years after disease onset. The main factors associated with loss of employment are: Expanded Disability Status Scale (EDSS) score > 4 (12), cognitive disorders (memory, concentration, etc.), fatigue (9), depression (13), anxiety, pain (14), and type of employment (physical activity, accessibility, rigid schedule/lack of pauses, attitude/comprehension of fellow workers, etc.).

Although the interaction between MS and job retention/loss has been the object of much research, few studies have focused on the specific strategies people use to retain their employment. There has been some work suggesting that adapting working conditions to individual disease expression can be an effective way of preserving employment (10, 12, 15). However, as such adaptations often depend on local policies, international comparisons can be hazardous. In France, all workers, irrespective of the size or status of the employing entity, have free access to an occupational medicine physician. Nevertheless, use of job-retention strategies appears to be heterogeneous and is not well understood. In order to better comprehend these questions and gain insight into how people cope with the impact of their disease on their occupational career, the Ligue Française Contre la Sclérose En Plaques, a national patient association, conducted a survey among persons with MS in France.

The main objective of this survey was to describe the occupational situation of persons with MS. The secondary objectives were to ascertain when and how MS symptoms first impact employment per se and what strategies persons with MS use to cope with their employment problems, as well as to determine which persons in the workplace are informed about the respondent’s health status, the accessibility/usefulness of vocational services, and the percentage of individuals who actually seek assistance.
METHODS

Data collection
A self-questionnaire was developed by the members of the Ligue Française Contre la Sclérose En Plaques, using the focus group method. Members of this association work closely and regularly with persons with MS, and so are fully aware of their problems with working conditions and job retention. The questionnaire was designed to collect data on the respondent’s sociodemographic and occupational situation, certain characteristics of past and current jobs, year of MS diagnosis, and disease history and interference with work and employment status. Questionnaire items included: year symptoms first interfered with work; types of symptoms; measures taken to adapt working conditions; year adapted working conditions began; year occupational activity ended; primary reasons for ceasing or continuing occupational activity; persons in the workplace informed about the respondent’s health status and their levels of disease awareness; strategies used to cope with employment problems and their accessibility and usefulness; and the match between current job status and self-perceived ability to work. The questionnaire was presented as a Computer-Assisted Web Interview (CAWI) by the polling institute OpinionWay (ISO certification number 20252 2019), and was made available to people who logged onto the Ligue Française Contre la Sclérose En Plaques website from 23 April through 18 May 2015. Questionnaires included in the analysis were completed by respondents with MS aged 18 years and older who were employed at the time of MS diagnosis or had been thereafter. The inclusion criteria were checked with the first items of the self-administered questionnaire. The main elements supporting employment in France (rehabilitation services, allowances) are described briefly in Table I.

Statistical analysis
Data were processed with SPSS v.20. After control of inclusion criteria, a simple descriptive analysis was carried out to describe the respondents. Because no upper age limit for exclusion from the study was defined, all respondents with MS were taken into account, even though the age of mandatory retirement in France is theoretically 70 years. Answers to the main and secondary objectives were determined using simple descriptive summaries on the total number of non-missing data (more than 95% for each variable). The Kaplan–Meier plots were drawn to analyse the time curve of MS impact on employment.

RESULTS

Study population
During the data collection period, 941 respondents fulfilling the inclusion criteria completed the online questionnaire. Respondents were predominantly female (79.8%). The median age of respondents was 46 years (range 21–84 years). The median age at diagnosis was 34 years (range 12–70 years). For 50% of respondents, the diagnosis of MS had been established more than 10 years earlier (range 0–47 years) (Table II).

Concerning work experience since the diagnosis of MS, 16.5% had an occupation requiring physical activity, 36.9% worked in a standing position, 15.9% had a part-time job.

Symptoms impacting occupational status
Symptoms having an impact on occupation life were reported by 74.3% of respondents. According to the respondents, the 4 leading causes of MS impact on occupational life were: fatigue (91.8%); motor disorders (47.6%); pain (38.2%); and cognitive disorders (21.6%). The median time from diagnosis to first symptoms requiring adopted working conditions was 5.0 years (95% CI 4.4–5.6 years); this time was ≤ 1 year for 25% of respondents, and ≤ 12 years for 75% of respondents (Fig. 1A). More than three-quarters (78.8%) had benefited from at least one measure for adapting their work conditions to their health status, involving a reduction in the total number of work hours (45.1%), adapted working hours (33.5%), fewer displacements (25.3%), technical adaptation of work post (25.0%), or assistance for workplace displacements (6.6%).

Cessation of occupational activity
Their disease had led 27.2% of respondents to discontinue their occupational activities. Median time from diagnosis to MS-related cessation of occupational activity was 24.0 years (95% CI 21.7–26.3); this time was ≤ 10 years for 25% of respondents, and ≤ 31 years for 75% of respondents (Fig. 1B).

The overall employment rate among respondents at the time of the survey (median 11.9 years after diagnosis) was 68.1%
Employment and job retention tools for persons with multiple sclerosis

(27.2% had ceased occupational activity because of their disease and 4.7% for other reasons). Respondents who were employed at the time of the survey reported 4 major reasons for continuing work: financial considerations (69.6%); social life (59.5%); self-esteem (45.4%); concentration on something other than their disease (37.7%). Interest in their job was the fifth reason (33.5%). Among respondents not working at the time of the questionnaire, 31.1% felt that they were still able to work.

Knowledge of the respondent’s health status at the workplace

Concerning knowledge of their health status at the workplace, less than half of the respondents (48.4%) with an occupational activity after diagnosis stated that they spoke of their disease spontaneously before the presence of symptoms requiring a disclosure of their condition. The respondents stated that at some time their health status was disclosed to their hierarchy (87.4% of respondents), colleagues (87.0%), occupational medicine physician (89.5%), and director of human resources (74.3%). The percentage of respondents who felt that these categories of co-workers had satisfactory knowledge of their disease was 80.6% for the occupational medicine physician, but only 24.1%, 26.7% and 32.5%, respectively, for the employer’s director of human resources, colleagues and hierarchy.

Use of vocational services

Information concerning work regulations for disabled persons was considered unclear by 62.3% of respondents and difficult to access by 75.5%.

Solicitation of vocational rehabilitation services was reported by 92.5% of respondents and considered very useful by 63.7%. The local centre for disabled persons (Maison Départementale des Personnes Handicapées) was solicited by 66.4% of respondents, but only 36.3% sought assistance from their employer’s director of human resources.

Fig. 1. Kaplan–Meier survival plots of: (A) first symptoms of multiple sclerosis (MS) impacting work and; (B) loss of employment due to MS.

Table II. Study population (n = 941)

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
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<td></td>
</tr>
<tr>
<td>Male</td>
<td>190</td>
<td>20.2</td>
</tr>
<tr>
<td>Female</td>
<td>751</td>
<td>79.8</td>
</tr>
<tr>
<td>Employment status at time of survey</td>
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<td></td>
</tr>
<tr>
<td>Employed</td>
<td>632</td>
<td>68.1</td>
</tr>
<tr>
<td>Unemployed</td>
<td>296</td>
<td>31.9</td>
</tr>
<tr>
<td>Age at time of survey, years</td>
<td>21.0</td>
<td>37.0</td>
</tr>
<tr>
<td>Age at diagnosis, years</td>
<td>12.0</td>
<td>27.0</td>
</tr>
<tr>
<td>Time since MS diagnosis, years</td>
<td>0.3</td>
<td>5.0</td>
</tr>
</tbody>
</table>

P25, P50 and P75: 25th, 50th and 75th percentiles of the variables distribution, respectively.
DISCUSSION

This study, involving more than 900 persons with MS with a median time since diagnosis of 10 years, highlights that MS had an impact on employment for 74.3% of respondents. The overall employment rate at the time of the survey was 68.1%. Among respondents, 27.2% had discontinued their occupational activity for an MS-related reason and 4.7% for other reasons. Median time from diagnosis to MS-related cessation of occupational activity was 24.0 years (95% CI 21.7–26.3 years). Respondents were poorly aware of available tools designed to assist them in retaining employment.

This study has several limitations. The study population is defined by respondents enrolled in a national patient association, and thus selection bias is possible. Females were also marginally over-represented (79.8% vs 72.5% regularly observed) (3). However, it has been shown that the incidence of MS among women has a general tendency to increase over time (16, 17). It should also be noted that the questionnaire did not collect information on educational level or EDSS score. This study also has several strong points: very large study sample for this type of survey; median time since diagnosis of 10 years and detailed information about the vocational structures and services solicited.

The study showed that MS had a significant impact on the respondents’ occupational activities and that many required an early adaptation of their working conditions, with half reporting that these adaptations had taken place during the first 5 years following diagnosis. This meant, in compliance with French regulations, irrespective of the health problem involved, that these persons had to disclose their personal health status to the occupational health physician or their employer’s human resources manager, something many hesitated to do. Nevertheless, several studies have shown that, for the persons with MS, several factors have a determining impact on retaining employment; for example, an adapted work post; knowledge of available vocational services and the social and economic benefits of employment (8, 18). Few studies have examined level of knowledge about vocational services and access to such services. As shown by the data collected in the present survey, for 16.9–45.8% of respondents, non-use of such services simply resulted from lack of awareness.

MS is a disease with a highly significant impact in the work environment. The overall employment rate in our study population was 68.1% for those 10 years after diagnosis. This percentage is in the upper level of published figures that have ranged from 26% to 74% depending upon the duration of the disease. Our findings are very similar to those reported by Kobelt et al. (19), who found that 28% of 1,355 French persons with MS (mean age 49.3 years) interrupted their occupational activities early. Results from Ponzio et al. (6) are similar, where 1,000 persons with MS reported a 74% employment rate 9 years after disease diagnosis, a rate that to our knowledge is the highest reported. Older studies reported lower employment rates, such as 32.4%, but at 22.2 years of disease duration (13). This might be a sign of the impact of duration and/or recent changes in therapeutic and socio-occupational management schemes.

In our study, the mean delay to disease-related cessation of employment was estimated at 24 years. This could be seen as long considering the data reported by Pfleger et al. (11) who mentioned a delay of 10 years for early pensions for persons with MS. While the mean age at disease onset was similar (35.3 vs 34.0 years) their study involved a different older population with disease onset between 1980 and 1989, 20 years before our population. Moreover, in France, an early pension can precede...
total cessation of occupational activity since the available measures allow persons to continue part-time employment while receiving an early pension. This observation provides further insight into the progress that has been made in improving the integration of disabled persons in the work environment.

The factors mentioned by respondents as the cause of their disease’s impact on their occupational activities were similar to those described by many other authors, with special emphasis on fatigue, the leading cause of early pension (12, 15, 20). A number of authors have found that persons with MS need help in evaluating the impact of their symptoms on their performance, in determining possible options for adapting their work post, and in making the request to their employer (21, 22). Several authors and certain guidelines conclude that it is important to develop occupational rehabilitation programmes designed to prevent early pensioning (23, 24). However, the corollary of these programmes is often disclosure of the person’s disease status at the workplace (to the employer or to the occupational medicine physician), a step people hesitate to take.

One of the important lessons of our study is that it shows how difficult it is to talk about MS. This leads to late disclosure in the work environment (including disclosure to the occupational medicine physician) and to disclosure in a context of overt symptoms, probably reducing the possibilities for anticipating adaptation measures. In our study, since 78.8% of respondents had benefited from at least 1 measure for adapting their work conditions to their health status, there was absolutely no adaptation of the work environment for 1 out of 5 persons with MS with disabling symptoms. We hypothesized that reticence about disclosure can be explained by fear of what others will think, of being stigmatized and put aside. Kirk-Brown et al. (25) have nevertheless demonstrated the positive effect of disclosure, even to the employer, in terms of maintaining employment. Several studies have also found an association between the failure to adapt work conditions (6) and the lack of support by co-workers, with the risk of losing employment. This lack of support could reflect the lack of co-worker awareness of the MS person’s disease status, or a poor understanding of the functional implications of MS among informed co-workers. These aspects would thus be in favour of earlier disclosure to the occupational medicine physician, who could then help the person maintain an occupational activity; simplified access to vocational services reserved for disabled persons: opening up access to specifically designed strategies that, to date, have been accessible only to persons who specifically request an intervention and have a recognized medical inaptitude for a specific work post; studies measuring the effectiveness of procedures designed to maintain employment, in terms of job retention and impact on the disease.

ACKNOWLEDGEMENTS

This study was financed by Biogen. This pharmaceutical company has had no influence on the interpretation of data and the final conclusions drawn.

REFERENCES