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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 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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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 Pflieger 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 method was used to estimate delays from diagnosis to first symptoms affecting occupational activity and from diagnosis to cessation of occupational activity (quartile and 95% confidence interval (CI)). The end-point was the date on which the respondent first experienced the event studied, the study censor date, or the date the respondent reached the calculated mean retirement age (62 years in France in 2014). 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 work contract of limited duration, and 38.2% 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 adapted 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%

Table I. Vocational rehabilitation services and other assistance available in France for workers with disabilities

Name	Service	Implications
Maison Départementale des Personnes Handicapées (MDPH)	Single-window service in charge of counselling and accompanying disabled persons	Available for individuals with a recognized disability
Reconnaissance de la Qualité de Travailleur Handicapé (RQTH)	Recognized qualification as a disabled worker	Confers entitlement to specific compensatory advantages designed to facilitate familial, social and occupational life
Service d'appui au maintien dans l'emploi des personnes handicapées (SAMETH)	Employment retention service reserved for disabled workers	Applications must be confirmed by the MDPH
CAP Emploi	Placement service	Designed to prevent disability-related dismissal or layoff
Invalidity pension	Substitution revenue	Reserved for unemployed disabled workers
		For people with a medical inaptitude
		Paid by the health insurance fund
		May be compatible with part-time employment
Therapeutic part-time employment	Service enabling progressive return to work while continuing rehabilitation care	Compatible with invalidity pension

Table II. Study population (n = 941)

Variable	n					%
Sex						
Male	190					20.2
Female	751					79.8
Employment status at time of survey						
Employed	632					68.1
Unemployed	296					31.9
	Min	P25	P50	P75	Max	
Age at time of survey, years	21.0	37.0	46.0	54.0	84.0	
Age at diagnosis, years	12.0	27.0	34.0	41.0	70.0	
Time since MS diagnosis, years	0.3	5.0	10.0	17.0	47.0	

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

(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.

Take-up of vocational rehabilitation services and respondents' opinions concerning the usefulness of these services are summarized in Tables III and IV, together with the reasons for not taking up such services. Most of the available services designed to help people find a job or retain their current employment were not used because the persons with MS were unaware of their availability and utility: for example, 38.7% of respondents were not recognized as disabled workers (RQTH) because half of them were unfamiliar with this vocational rehabilitation service; 45.8% had not benefited from adaptation services for the same reason.

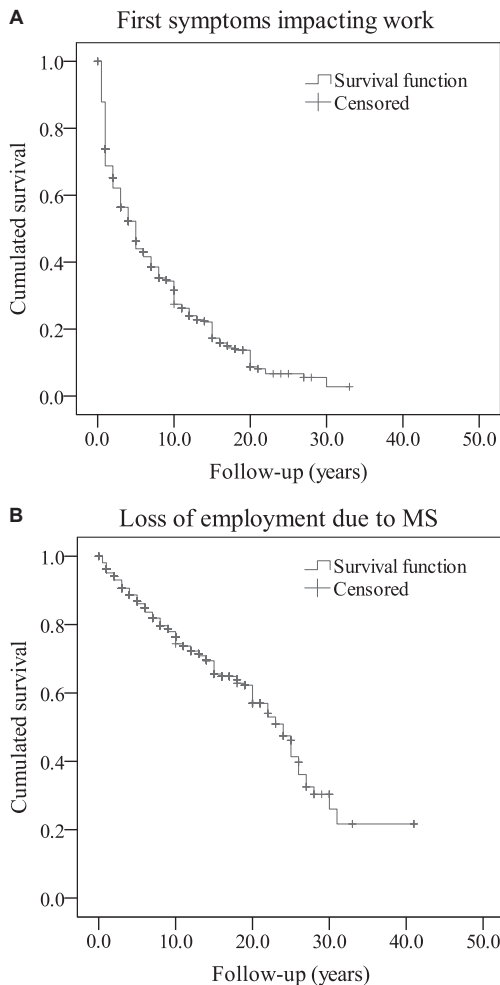


Fig. 1. Kaplan–Meier survival plots of: (A) first symptoms of multiple sclerosis (MS) impacting work and; (B) loss of employment due to MS.

Table III. Use of occupational rehabilitation services generally proposed to retain or access employment (n = 941)

Services solicited	Rate of use %	Services provided were considered			Rate of non-use %
		Not useful %	Somewhat useful %	Very useful %	
Employer human resources service	36.3	11.5	13.7	11.2	63.7
MDPH	66.4	11.0	21.4	34.0	33.6
SAMETH	12.1	4.2	3.0	4.8	87.9
CAP Emploi	15.0	5.7	4.9	4.4	85.0

MDPH: Maison Départementale des Personnes Handicapées; SAMETH: Service d'appui au maintien dans l'emploi des personnes handicapées.

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 Pflieger 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

Table IV. Use of occupational rehabilitation services generally proposed to retain or access employment, and when applicable, usefulness of the service or reasons for non-use (n = 941)

Occupational service	Total users %	Services provided considered			Total non-users %	Reasons for non-use			
		Not useful %	Somewhat useful %	Very useful %		Not aware of service %	Not eligible %	Too complex %	Considered not useful %
RQTH	61.2	13.4	15.7	32.1	38.7	16.9	13.9	3.3	4.6
Ergonometry study – post adaptation	17.7	3.0	6.0	8.7	82.3	45.8	22.9	1.9	11.8
Adaptation of work time and schedule	40.0	4.5	5.7	29.8	60.1	28.6	18.6	1.9	11.0
Therapeutic part-time	36.3	3.1	4.7	28.5	63.7	26.3	26.6	1.3	9.6
Invalidity pension	30.2	2.0	2.2	26.0	69.8	26.4	34.6	1.5	7.2

RQTH: Reconnaissance de la Qualité de Travailleur Handicapé.

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 needed 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 provide more adapted counselling, both for the person with MS and for the employer and co-workers (15). Measures could then be taken to maintain employment without necessarily violating medical confidentiality. While the vast majority of persons whose disease affected their work performance had had at least 1 measure for adapting their work post, the extent of this adaptation was found to be insufficient in 1 out of 4 cases; many measures were ineffective in protecting the person from disease-related loss of employment.

One-third of persons with MS who no longer had an occupational activity believed they were still able to work, suggesting that all of the measures designed to maintain employment were not applied fully or early enough to be efficient (as seen by the fact that many of the measures proposed were considered useless), although barriers to work were not explored in our

study. It is also surprising to note that despite the functional impact of the disease, only slightly more than half of the respondents benefited from the French administrative status of a disabled worker (61.2%) that would have facilitated measures for adapting their work post or vehicle, or enabled the reorientation of their occupational activity. Recognition of this administrative status initiates the implementation of job-retention strategies specifically reserved for disabled workers who make the request. The low rate of requests for adapted working schedules or adapted work posts, and the low rate of use of specific strategies for maintaining employment were attributed to the lack of knowledge about these strategies by the persons with MS. Nevertheless, the fear of stigmatization or of losing their job may have been other important factors explaining this finding; however, these reasons were not addressed in our questionnaire.

For persons with MS, maintaining an occupational activity is a priority because, beyond the financial aspects, working has, according to some authors, a positive impact on social life, quality-of-life and self-esteem (26, 27). This survey highlights several aspects that are important for helping persons with MS access and retain employment:

- better public awareness of MS: symptoms, need for an adapted working environment, co-worker understanding (6);
- assistance in disclosure at the workplace, in particular 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.

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