Factors influencing work retention for people with multiple sclerosis
Cross-sectional studies using qualitative and quantitative methods

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Abstract  Objective To identify factors that impact on the ability of patients with multiple sclerosis (MS) to remain in work in order to make recommendations for future clinical management. Methods Cross-sectional studies using qualitative (phase one) and quantitative (phase two) methods. In phase one, 62 patients were interviewed and completed an exploratory questionnaire regarding the impact of MS on employment. In phase two, 100 patients attending an MS outpatient clinic completed an impact on work questionnaire, the self-report Barthel index, and the General Health Questionnaire (GHQ-28). Results In phase one, 17 areas were identified as impacting on MS patients' ability to remain in work, either relating to MS or environment. In phase two, both MS-related factors and environmental factors were reported to have a major impact on ability to work. Only 20% of patients had received any advice about work retention. Unemployed patients (N = 64) had greater disability than employed patients on the Barthel index (difference 5.1; p < 0.001), but similar psychological wellbeing on the GHQ-28. Conclusion The issues that prevent people with MS from working tend to be disease-related, as well as work-related. Many patients are isolated, as they are unaware of sources of help. Effective management by healthcare professionals has a potentially important role in helping people with multiple sclerosis to remain employed.

Keywords  work · multiple sclerosis · rehabilitation

Introduction

Work contributes to adult identity [7], confers financial benefits and status [6] and can improve quality of life [1]. At diagnosis most people with multiple sclerosis (MS) are in full-time education or employment. However, as the condition progresses, the number of patients able to remain in work decreases, with employment estimates ranging from 23% to 32% [1, 14].

The specific areas of MS that impact on work retention are incompletely understood and currently there are no provisions made to provide specialist employment services for people with MS in the UK. The importance of employment, and the impact of MS on the ability of people to retain work, highlights the need to identify contributory factors in order to inform clinical management policy and recognise the role of clinicians in helping people with MS with work retention. The aim of this study was to identify factors that impact on work retention in patients with MS.

Methods

Overview

The study was undertaken in two phases. The aim of phase one was to identify the areas that impact on work retention in patients with MS. The aim of phase two was to measure physical, psychological and social factors effecting work retention in a hospital-based survey of an independent group of patients, based on the information collected in phase 1.
The joint research ethics committee of the National Hospital for Neurology and Neurosurgery and the Institute of Neurology approved the study and all patients gave their written informed consent.

Phase one

All patients with MS, attending the National Hospital for Neurology and Neurosurgery, aged 18 to 65 years, were eligible to participate in the study. Patients were recruited from an MS outpatient clinic and the inpatient rehabilitation unit of the hospital to ensure a wide range of age, duration of MS and disability.

Patients were asked about their MS, their experiences of employment and their social circumstances. This interview was supplemented by completion of a questionnaire comprising open-ended questions regarding the effect that MS had on ability to remain in work. Demographic information was obtained during the patient interview and from the medical notes. The results of patient interviews and questionnaires were entered into a database and content analysed. Areas relating to work retention were categorised, with additional themes from articles identified by a search of Medline, from 1966 to 2003, and Web of Science, from 1981 to 2003.

Phase two

One hundred patients with MS, aged 18 to 65 years, attending an MS outpatient clinic, were invited to participate. Patients were asked to complete a questionnaire booklet containing physical, psychological and vocational self-report outcome measures. The booklet comprised the self-report Barthel index [9], a 10-item personal activities of daily living questionnaire; the General Health Questionnaire (GHQ-28) [8], a 28-item psychological wellbeing questionnaire; and the Work Impact Questionnaire (a new measure developed and validated as part of this study; results not reported) [Appendix]. Questions relating to training and advice on employment were also included. In addition, the Expanded Disability Status Scale (EDSS), a clinician-rated MS disability measure was recorded for each patient [12].

Results

Phase one

Sixty-two patients participated in the first phase of this study. Fifty-three patients were attending the MS outpatient clinic and nine had been admitted from home for a short period of inpatient rehabilitation. The mean age of the patients was 46 years and ranged from 19 to 65. Forty patients (65 %) were female. All patients had clinically definite MS with a mean duration of 12 years (range 1–43). Twenty-four patients (39 %) were employed at the time of the interview. Seventeen areas were identified as impacting on MS patients’ ability to remain in work. These were divided into those relating to: the person and their disease; and societal and employment environments.

The person and their disease

Patients often described a particular problem that had a major impact on their ability to remain in work and that concerned them a great deal. For example, a 49 year old woman with MS for 19 years who had recently become unemployed from an office job stated:

“This illness has devastated my life and the way I deal with things. My main concern is my bladder problems.”

At times, a specific problem was cited as creating difficulty with work retention, such as poor vision or ataxia, which impacted on the ability to use particular equipment. For example, a 48 year old female who had worked as a civil servant commented on her ability to use the mouse of a computer:

“I would have liked to work 10 to 12 hours a week, but my hand-eye co-ordination was too poor.”

At other times, it was a symptom of MS that impacted on all activities, both in work and at home. For example, a 45 year old male patient with MS for 13 years had worked as a social worker until five years previously:

“Normal daily things take so long unfortunately. I get very fatigued very quickly.”

By contrast, other patients reported having flexible working environments that allowed them to take time off if they were unwell. For example, one patient was able to work from home on days that he was particularly fatigued. Fatigue could lead onto other problems with work retention, such as depression or anxiety, as well as being an issue in itself. This is illustrated by a 42 year old female’s comment:

“I feel very tired in the afternoons. I feel a burden on people in work.”

Societal and employment environments

The difficulties identified most were travelling to and from work, and access at work. The interaction between increasing difficulty walking, and managing steps and stairs (disease related factors) and the environment were clearly articulated by patients. For example, a 42 year old male quantity surveyor with MS for 12 years commented on the effect that reduced ability to perform physical tasks had in his particular work environment:

“My concern revolves around my ability to undertake certain tasks such as walking, climbing ladders and stairs. I therefore need to learn to delegate to others and am slowly coming to terms with this.”