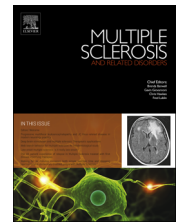




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The UK patient experience of relapse in Multiple Sclerosis treated with first disease modifying therapies

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KEYWORDS

Multiple sclerosis;
Disease modifying
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Patient survey;
Patient perspective

Abstract

Background: The fixed, progressive disability associated with late Multiple Sclerosis (MS) is known to have a major impact on patients and their families, but the impact of relapse earlier in the disease course is less well documented, particularly from the patient's perspective. This study aimed to understand the effects of relapse for people with MS (PwMS), focussing on the years immediately after starting disease modifying therapy (DMT) when experience of a relapse may particularly influence a patient's opinions of their disease and its therapy.

Methods: This was a multi-centre, retrospective, observational research study, recruiting patients from 7 UK NHS Hospital Trusts. Consenting patients with relapsing-remitting MS (RRMS), who had started a DMT more than 36 months before screening, were sent a study questionnaire. Data on MS relapses and treatments over 3 years were collected simultaneously from medical records.

Results: One hundred and three patients completed the questionnaires. Relapses were under-reported to health care professionals, with 28% of respondents failing to report their most recent attack and 46% declaring they had failed to report an attack in the past. During their most recent relapse, 67% of those in paid employment reported taking time off sick, 48% reduced working hours temporarily, and 41% worked reduced hours and took time off sick. Sixty-six percent required additional support to undertake routine daily tasks during their most recent relapse. A range of effects of relapse which cannot be measured in financial terms were also reported, including effects on physical abilities, mental health and family roles and relationships.

Conclusion: This contemporary UK-based study provides an insight into the experience of relapse early in the treatment of RRMS from the patient perspective. The comparison of documented

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patient reported relapses reveals some deficiencies in the recording of relapses which is important to address in view of the reported impact of individual relapses, and emphasises relapse reduction as a worthy treatment aim.

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1. Introduction

Multiple Sclerosis (MS), with an onset typically between the ages of 20 and 40, has a major impact on the physical wellbeing and social role not only of the person directly affected, but also of their relatives. The cost of late disability is the main driver in economic impact models (Hakim et al., 2000). A UK cost-of-illness analysis showed that employment rates reduce from 82% in early disease to 6% at an Expanded Disability Status Scale (EDSS) score of 7 (Kobelt et al., 2006).

However, a focus on the health economics of progressive disease may underestimate the impact of relapse on patients, carers and healthcare providers. Some effects, such as the strong emotional reactions elicited in patients and loved ones (Kalb, 2007), may not routinely be measured. In clinical trials of existing DMTs, reduction in disability appears to be driven by reduction in the clinical relapse rate. The occurrence of relapse remains the principal determinant for starting or escalating Disease Modifying Therapies (DMTs) under current UK DMT guidance (Association of British Neurologists, 2001; National Institute for health and Care Excellence, 2007, 2012).

This report describes the impact of relapse in a cohort of patients recruited to study the experience of the first 3 years of de novo DMT treatment. We focus here on the wider burden of relapse, including the change in patient contact with health care professionals, the financial impact of a relapse on People with Multiple Sclerosis (PwMS) and the impact of a relapse on patients' attitudes to DMT. Discrepancies between clinician-documented and patient-reported relapse symptoms were also explored.

2. Methods

This was a multi-centre, retrospective survey of patients recruited from 7 UK NHS Hospital Trusts, selected to give a geographical spread across England and Wales. The study received a favourable ethical opinion from the London-Bromley Research Ethics Committee (ref. 12/LO/0248).

2.1. Study subjects

Data were obtained from participant self-completed questionnaires. Demographic details and information on relapses reported to the clinician within the first 3 years following DMT initiation were obtained from hospital medical records and, where possible, compared with patient-reported details. Inclusion criteria were: (1) RRMS diagnosis by 2005 MacDonald criteria (Polman et al., 2005); (2) first DMT after 1st July 2007 and at least 36 months before screening inclusion date; (3) ability to complete study questionnaires (by carer or self);

and (4) consent to complete study questionnaires and for a researcher to review medical records.

To characterise the cohort, patients were also asked to complete an EQ5D, Beck's Depression Inventory scale and the Patient Determined Disease Steps score (PDDS) (Learmonth et al., 2013).

Written consent was sought from eligible patients by post by their clinician. Patients were approached in consecutive date order of DMT initiation, until all eligible or 40 study participants per site had been recruited.

2.2. Data collection, quality control and analysis.

Patient questionnaires were completed between July 2012 and March 2013. Some patients did not fully complete the questionnaire, therefore the number of respondents (n) varied by question. Where self-evident from subsequent answers, blank yes/no questions were completed by an investigator.

Relapse symptoms were grouped into domains to compare clinician and patient reports. In clinician notes, relapse severity was defined as:

- Severe: if documented as 'severe' or 'disabling', required hospitalisation or steroid therapy.
- Moderate: if neither criteria for 'severe' nor 'mild' were applicable.
- Mild: if documented as 'mild' or equivalent.

The term 'relapse' was defined for patients in the questionnaire as: either the appearance of new symptoms related to MS or very definite worsening of old symptoms, which lasted for at least 24 h and occurred after the patient had been stable for at least a month (with the absence of raised temperature, infection, or any other health problem).

Patients were asked to comment in detail on their most recent relapse. For some patients ($n=27$), the relapse described was outside the 3-year period following drug initiation, so for these patients no comparison with a relapse documented in the medical record was possible. Patients were also asked to record details of all MS-related visits they made to Health Care Professionals (HCPs) during their most recent relapse.

Responses to questions with multiple-choice options were analysed quantitatively and summarised as percentages. The responses to the open 'comments' question were analysed qualitatively, by thematic analysis. This was conducted by two researchers separately, with a third researcher arbitrating between any differences in the themes identified.

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