Diagnosis of Secondary Progressive Multiple Sclerosis in UK Centres: Results from the SPECTRUM project

Martin Duddy1, Carmel Wilkinson2, Katherine Rhys3

1The Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle, UK; 2South Tyneside and Sunderland NHS Foundation Trust, Sunderland, UK; 3Novartis Pharmaceuticals UK Ltd, Frimley, UK

Introduction

• Diagnosing secondary progressive multiple sclerosis (SPMS) in clinical practice can be challenging for healthcare professionals (HCPs)1.
• SPMS is diagnosed retrospectively and there are no definitive biomarkers or imaging tests that can be used to aid diagnosis2.
• Consequently, there is thought to be variation in the approach amongst healthcare professionals (HCPs) to diagnosing SPMS, discussing SPMS with patients and allowing diagnosis to influence disease modifying treatment (DMT) decisions.
• As new treatment approaches emerge for progressive forms of multiple sclerosis (MS), it is important to understand the factors underlying current practice.

SPECTRUM (Secondary Progressive Multiple Sclerosis – Understanding Treatment and Management) was a UK-wide survey of HCPs involved in managing patients with SPMS.

Objectives

• To map the current diagnostic, referral and treatment pathway of patients with SPMS in UK centres.
• To understand the challenges facing clinicians when diagnosing and managing patients with SPMS.

Methods

• Between March and July 2019, interviews were conducted with 59 HCPs involved in managing patients with SPMS. A total of 96 HCPs were initially approached and invited to participate by email.
• The participating HCPs were from 59 centres spread geographically across the UK (Figure 1).
• Interviews were conducted face-to-face using a structured questionnaire, which was designed in collaboration with a consultant neurologist and a MS Specialist Nurse. Topics covered included current practices for the definition, diagnosis and management of SPMS, and discussing SPMS with patients. Respondents replied on behalf of their whole centre.
• The survey data were analysed descriptively and results relating to the diagnosis of SPMS in the UK are presented here.

Results

• The respondents comprised 41 MS neurologists, 15 MS specialist nurses and 3 other HCPs.
• The median (interquartile range [IQR]) estimated number of patients with MS under current management was 1,200 (700 to 2000) per centre and of these, the estimated percentage with confirmed SPMS was 30.0% (24.2% to 39.5%).
• Of the HCPs using a specific definition of SPMS (n=36/59, 61%), a minority use the Lublin 2014 phenotype criteria (n=23/36, 6%); the remainder (n=43/36, 94%) use a variety of other definitions (Figure 2, Table 1).
• The most important of the elements included in considering a diagnosis of SPMS was expansion disability status scale (EDSS) score increase and absence of relapses (n=21/59, 36%) however many other criteria were also used (Figure 3).
• At SPMS diagnosis, the median (IQR) estimated percentage of patients with EDSS score 25.5 was 90.0% (80.0–100.0, n=35) (Table 2).
• The median (IQR) estimated time between first suspecting and diagnosing SPMS was 12.0 months (12.0–24.0, n=45).
• The most common explanations for reluctance to diagnose SPMS were concerns over withdrawing DMTs and psychological impact on patients (Figure 4).

Conclusions

• There is substantial variation in the UK in how HCPs define and diagnose SPMS.
• Diagnosis is often made at advanced levels of disability and can take a year or longer from first suspicion of SPMS.
• HCPs may be reluctant to diagnose SPMS, primarily due to concerns about withdrawing DMTs and the potential psychological impact on patients.

Table 1: Other definitions of SPMS

<table>
<thead>
<tr>
<th>Other definitions of SPMS*</th>
<th>n</th>
<th>% (n=59)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Progression of disease/disability and absence of relapse</td>
<td>8</td>
<td>24%</td>
</tr>
<tr>
<td>Progression of disease/disability independent of relapses</td>
<td>3</td>
<td>9%</td>
</tr>
<tr>
<td>Absence of relapse (without mention of disease progression)</td>
<td>2</td>
<td>6%</td>
</tr>
<tr>
<td>Disease progression or disability (without mention of relapse)</td>
<td>2</td>
<td>6%</td>
</tr>
<tr>
<td>Progression or disease/disability based on EDSS score</td>
<td>13</td>
<td>38%</td>
</tr>
<tr>
<td>Stable magnetic resonance imaging/reduced signs of inflammation</td>
<td>7</td>
<td>21%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>3%</td>
</tr>
</tbody>
</table>

* Not mutually exclusive

Table 2: Estimated percentage of patients in each EDSS score category at SPMS diagnosis

<table>
<thead>
<tr>
<th>EDSS score category</th>
<th>Estimated % of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.0 to 3.0</td>
<td>40</td>
</tr>
<tr>
<td>3.5 to 5.0</td>
<td>37</td>
</tr>
<tr>
<td>5.5 to 6.5</td>
<td>38</td>
</tr>
<tr>
<td>7.0 to 10.0</td>
<td>35</td>
</tr>
<tr>
<td>5.5 to 10.0</td>
<td>35</td>
</tr>
</tbody>
</table>

* Respondents providing a valid response (remainder answered 'not known')

References


Acknowledgements

The authors wish to thank the following for their contribution to this project:

• The healthcare professionals who participated in the survey.
• The Novartis UK Medical Team, in particular Adam Brown and Dean Patrick, who contributed to the design of the survey and collection of data.
• OPUS Ltd, who provided medical editorial assistance with this poster.

Disclosures

MD and CW report no conflicts of interest. IR is an employee of Novartis Pharmaceuticals UK Ltd.

Financial support for this work was provided by Novartis Pharmaceuticals UK Ltd. OPUS WC Ltd was commissioned by Novartis to support the authors in the conduct of the survey, analysis of the results and provide medical editorial assistance.

Poster presented at the MS Trust Annual Conference, Hinckley, United Kingdom, November 3-5 2018