Improving reporting of multiple sclerosis relapse

In this article...

- How multiple sclerosis affects the body
- Why reporting relapse is so important for patients
- How the SymTrac app could improve relapse-reporting rates

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Many people with multiple sclerosis do not report a relapse. When it is reported, it is not always recorded in their notes. This can mean patients do not always have the most appropriate treatment. This article reviews some of the reasons why relapse reports are lacking and how the problem could be addressed. As a result, the decision was made to develop an app that patients could use to record their symptoms and wellbeing over time, to help identify and record relapses. Information could then be passed to their health professional via email, if desired.

Smartphone apps are increasingly a part of everyday life for us all and can be a valuable aid to self-management for people with long-term health conditions, such as multiple sclerosis.

MS is a disease of the central nervous system that can cause a whole range of symptoms. Some of the most common include fatigue, weakness, altered sensation and cognitive problems. MS affects about 100,000 people in the UK (Mackenzie et al, 2013) and almost three times as many women as men. Most people are diagnosed between 20 and 40 years (Webster and Whittam, 2013).

The most common type of MS is relapsing remitting MS, which is characterised by periods of worsening function followed by full or partial recovery. Approximately 85% of people with MS present with a relapsing form (Lublin et al, 2014). A relapse is defined as the development of new symptoms or the worsening of existing symptoms that lasts for more than 24 hours and follows a period of stability that has lasted for at least 30 days. It is important to rule out infection, as this can cause symptoms similar to relapse but should be treated very differently (NHS England, 2014).

A relapse is caused by an area of localised inflammation (a lesion) in the brain or spine. The clinical symptoms experienced depend entirely on the:
- Site of the lesion;
- Size of the lesion;
- Amount of remaining neuroplasticity – how much capacity the brain has to reroute messages around the damaged area to effect a clinical recovery.

Over time, people with MS are less able to recover after a relapse, as scarring affects more of the central nervous system.

Managing MS

While there is no cure for MS, various disease-modifying drugs (DMDs) are available for people with relapsing forms of the condition.

These work primarily to:
- Reduce the number of relapses experienced;
- Reduce the amount of inflammation that occurs within the central nervous system;
- Slow down, to some extent, the rate of disability progression.

5 key points

1. Apps can aid self-management of long-term health conditions
2. 85% of people with MS relapse. Disease-modifying drugs can reduce these
3. Identifying the most effective medication depends on the number of relapses
4. Many people do not report their relapses
5. An app that tracks symptoms and wellbeing can aid self-management

FIG 1. SYMPTOM TRACKER

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Deciding which DMD is likely to be the most effective depends primarily on the number of relapses someone has had over the last two years. It also depends on the amount of inflammation that can be seen on an MRI scan.

Treating the disease early with a DMD provides a better chance of delaying or reducing progression, improving long-term outcomes (Cocco et al, 2014).

Relapses are a sign of active disease in MS and should not be ignored; they should be recognised, recorded, reported and reviewed with an MS specialist. The National Institute for Health and Care Excellence (2014) recommends an annual review with an MS health professional as a minimum requirement.

**Relapse reporting**

Duddy et al (2014) found 28% of people with MS had not reported their most recent relapse and 46% had not reported a previous relapse.

If people do not report relapses to their MS teams, it is difficult to make sure they are prescribed the most appropriate DMD. They also showed that relapses affect every aspect of an individual’s life.

As well as the physical symptoms, patients reported increased anxiety and an impact on family, with partners often having to take time off work to provide additional support.

Relapses can also have a lasting effect on someone’s ability to work.

Given the devastating effect relapses can have on people’s lives and the fact that treatments are available that can reduce their frequency and severity in the longer term, we wanted to understand why people with MS were not reporting relapses and to look at potential solutions to the problem.

**Tackling the problem**

**Focus and steering groups**

We set up a focus group comprising people with, and affected by MS; representatives from the voluntary sector; and an MS nurse. The group was supported by a trained facilitator with experience of working with people with MS.

People who were actively involved in communicating about MS were invited to join the group (eg, via blogs or social media). Health professionals also nominated individuals they recognised as being good communicators with valuable insights to share.

All efforts were made to recruit a diverse but representative group of people with MS, who brought with them a broad range of experiences – both positive and negative – of interacting with health professionals. There were approximately 15 people involved altogether. The numbers varied depending on commitments and general health.

We asked the group to:

- Discuss issues they had experienced with reporting relapses;
- Find ways to make this easier for other people with MS.

**Reasons for not reporting relapses**

Reasons for not reporting relapses identified by the group are outlined in Box 1. The group agreed that it was essential the outcome agreed upon to tackle the problem should be usable and attractive to people with MS, without serving to constantly remind people about their MS. A strong message from the group was to make sure the solution took account of possible cognitive issues and was easy to use when dexterity or vision are poor – both common symptoms of MS.

A steering group comprising eight MS nurses and three neurologists from across the UK and Ireland was formed to explore this and other issues around relapse service provision.

The group worked alongside the patient group; an MS nurse from the steering group joined the patient group (with its permission) to ensure ideas were exchanged effectively between both groups, and that any potential solutions worked for people with MS, as well as healthcare professionals.

To our knowledge, no other groups of professionals and service users have been brought together to objectively review current practice and design solutions for future MS relapse management. The groups each met two or three times during 2013.

**Box 1. Reasons for not reporting relapses**

- Feeling like a burden to the healthcare team
- Not understanding that a symptom experienced before could be a relapse
- Loss of faith that something can be done
- Believing it will pass quickly and, therefore, there is no reason to see the doctor
- Lack of recall – cognition is an issue for many people with multiple sclerosis, and if they fail to remember a relapse, it goes unreported
- Fear of being left with no treatment options at all

**Table 1. Feedback on the usefulness of SymTrac**

<table>
<thead>
<tr>
<th>Components</th>
<th>Mean rating (N=7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identifying pattern of MS over time to help diagnose type of MS</td>
<td>9</td>
</tr>
<tr>
<td>Helping patients record and report relapses</td>
<td>8.7</td>
</tr>
<tr>
<td>Assessing effectiveness of newly prescribed symptom-management medications</td>
<td>8.4</td>
</tr>
<tr>
<td>Helping patients to identify triggers for their “bad” days</td>
<td>8.3</td>
</tr>
<tr>
<td>Monitoring symptoms over time to identify or rule out relapse</td>
<td>8.1</td>
</tr>
<tr>
<td>Identifying when someone may be transitioning between RRMS and SPMS</td>
<td>8</td>
</tr>
<tr>
<td>Helping patients remember to take their medications as prescribed</td>
<td>7.2</td>
</tr>
<tr>
<td>Monitoring exercise regimes</td>
<td>6.5</td>
</tr>
</tbody>
</table>

MS = multiple sclerosis; RRMS = relapsing remitting MS; SPMS = secondary progressive MS

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**Group findings**

The steering group identified various challenges for MS-specialist teams trying to provide relapse services, including lack of formal training for MS nurses; poor provision of information for people with MS; lack of consensus on the best way to deliver relapse services; and a lack of capacity in already overstretched MS nurse services (Mynors and Bowen, 2014).

Having identified the main issues, discussions with both groups focused on how to improve relapse services, the understanding of relapses and their treatment. Several resources for MS nurses and people with MS were developed, with input from both groups and support/funding from Novartis Pharmaceuticals.

These include:

- The SymTrac app
- An eight-step guide to best practice for MS nurses (this is currently being rewritten and updated and is due to be published by the MS Trust in 2016);

A series of “talking heads” of patients and health professionals discussing how they manage relapse (bit.ly/MSRelapseVideos).

The SymTrac app

The focus group quickly identified the need for a mechanism to record and track symptoms and wellbeing over time. Developing an app to help people do this seemed to be a good solution and this meant that the information recorded was also available and much less likely to be forgotten when attending clinic appointments. Patient and health-professional involvement was key to the design process, as it was vital the solution worked well for both. Feedback to and from the groups was provided via face-to-face meetings and email. An agency working closely with project stakeholders brought the app to fruition.

How SymTrac works

Patients download the app to their Android or Apple mobile device and record their information, which remains entirely private.

- The key sections within SymTrac are:
  - Introductory video: explains how the app works;
  - Symptom tracker: allows users to track and record the impact of individual symptoms over time;
  - Wellbeing: records how the user is feeling in relation to concentration, memory, mood, exercise, energy and sleep. This section also includes an animated series of exercises, which people with all types of MS can use to improve their wellbeing, these are provided courtesy of the MS Trust;
  - My MS overview: gathers the information recorded by the user into a simple chart.

The symptom tracker is one of the main features of the app. The focus group was keen that this should be as easy to use as possible. When adding a new symptom, a body map is displayed (Fig 1); the affected area can be tapped and a drop-down menu appears, listing possible symptoms. The user taps the appropriate symptom and is then asked to rate it in terms of its “bother-someness” and its impact on daily activities (sliding scale from 0 = low impact, to 10 = high impact). The date and time are automatically recorded.

The user is prompted on a regular basis to record if/how their symptom has changed; this feature can be personalised and switched off if required.

The Wellbeing section of the app allows users to record on a sliding scale how they feel about the categories listed above; this can be done daily or less often, as desired. The date, time and weather are recorded automatically. The focus group was keen to include weather in the record as this can affect symptoms and wellbeing for many patients; for example, cold weather might increase problems with spasticity, while hot weather can exacerbate patients’ fatigue and weakness.

The recorded information is collected by SymTrac into a simple chart (My MS overview) that shows how both have changed over time. The chart can be emailed by the user to their MS nurse or neurologist, if desired.

SymTrac is an effective self-management tool that allows the user to link “good” and “bad” days with possible triggers; for example, is their foot drop worse when their fatigue is most troublesome? This knowledge can help people to pace themselves more appropriately and understand how one symptom impacts on another. This is key to managing daily activities more effectively.

As well as self-management, the charts can show patterns of MS over time. This might show up relapses that the user has forgotten about or did not consider worthy of reporting.

Nurse and patient feedback

As part of an initial evaluation, seven MS nurses rated the usefulness of SymTrac using a 1-10 scale (1 = not useful, 10 = extremely useful). The results are shown in Table 1. Feedback from people with MS who are using the app has been gained directly from members of the steering group and indirectly via their MS nurses. They have highlighted some areas that could be improved upon in future versions of the app, such as capturing film of symptoms, such as tremor, to share with the MS team. Others felt that the body-map areas were too general and that it would be useful to be able to identify more clearly the specific area affected by a symptom. MS nurses reported that they found many people used it only when their MS was particularly active.

Conclusion

Relapses affect people’s lives as they occur and could also affect longer-term disease outcomes. Accurate reporting of relapses is important to allow robust, clinically based decision-making about treatment options. SymTrac was designed by people with MS for people with MS, to help the consultation process and the identification of relapses. It is hoped that further evaluation will be carried out, although the app does appear to go at least some way to addressing the challenges associated with relapse reporting.

SymTrac and the Relapse campaign were wholly funded by Novartis Pharmaceuticals

References


Weaver S, Whitton A (2013) MS Explained. Bit.ly/1SDk4BJ

For more on this topic go online...

Training staff to empower people with long-term conditions to undertake self-care activities

Bit.ly/NTLTCSelfCare