The high cost of spasticity in multiple sclerosis to individuals and society

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Abstract

Background: Spasticity is an extremely common, distressing and disabling symptom of multiple sclerosis. Limited data suggest the associated health care costs correlate with increasing severity and place a high economic burden on individuals, health care systems and society.

Objective: The aim of this study was to quantify the impact of multiple sclerosis spasticity on health care resources and the associated costs at different levels of severity in people with multiple sclerosis in the United Kingdom.

Methods: An online survey was carried out to understand the resources used in the management of spasticity in multiple sclerosis. The questionnaire asked health care specialists to estimate their involvement and the resource use associated with different levels of spasticity, and the survey outputs were used to derive the resource costs.

Results: The level and cost of care substantially increased with the degree of spasticity. Key factors contributing to high annual costs per patient were home care, hospital admissions and high-cost items, such as hospital beds.

Conclusions: Based on the survey results, it can be assumed that managing spasticity early and effectively could result in substantial cost savings, in addition to the improvements in health-related quality of life.

Keywords: Multiple sclerosis, spasticity, pharmacoeconomic, disease burden, questionnaire, treatment costs, health-related quality of life

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Introduction

Multiple sclerosis (MS) is one of the most common neurological disorders; it primarily affects young adults at a time of their lives when working and parenting are often key roles. Life expectancy, although reduced, is still long, with a median survival time of 40 years from diagnosis; unfortunately though, this is often associated with significant levels of disability. Despite considerable advances in the treatment of MS over the last decade, with several immunosuppressant treatments becoming widely available to modify the disease outcomes by reducing inflammatory activity or slowing disease progression, these agents have little or no impact on existing impairments; consequently, much of the management of the person with MS must be focussed on optimising function and in the control of symptoms. Appropriate symptom management is therefore essential in aiding rehabilitation and to promote well-being.

Spasticity (stiffness or spasms) is an extremely common symptom of MS. In a large survey of the North American Research Committee on Multiple Sclerosis (NARCOMS), 84% of 18,727 patients with MS reported at least some symptoms of spasticity, and 30% reported moderate to severe symptoms. The impact of spasticity on individuals is extremely variable, ranging from minor discomfort to complete immobility with pressure sores and contractures. Pain, spasms and sleep disturbance are frequently reported. Spasticity contributes to reduced mobility and a reduction in quality of life, increasing the burden of disease both for patients and caregivers.

Early effective management of spasticity is essential; if poorly managed, serious long-term consequences can occur, including muscle shortening and tendon or soft tissue contracture that may lead to restriction of passive movement, physical deformity or pressure...
sores.\textsuperscript{8} Once contractures are present, these are often very difficult to modify and can have long-lasting, major functional implications, including difficulties carrying out personal hygiene, dressing or even sitting. Management of spasticity is often complex; side effects can occur from therapeutic agents, and in some individuals, it may be necessary to maintain a level of spasticity to preserve function (e.g. walking, standing or transferring).\textsuperscript{8,9} However, even in such cases, it is important to recognise the potential for long-term secondary complications. Individualised, goal-directed care therefore requires co-ordinated input from different health and social care professionals, working in partnership with the patient and their families and/or carers.\textsuperscript{8,10} Careful multidisciplinary assessment is essential in devising a treatment plan, including physical management strategies, first-line oral therapies as well as timely consideration of tetrahydrocannabinol/cannabidiol spray (Sativex\textsuperscript{®}), botulinum toxin and intrathecal baclofen or phenol.\textsuperscript{11}

From a health care/societal perspective, MS spasticity has been shown to be associated with substantial costs, although interestingly, only 7\% of costs were shown to be due to direct medical costs in a recent study from Sweden.\textsuperscript{12,13} The associated costs have also been shown to correlate with increasing severity of spasticity, as does the deterioration of health-related quality of life (HRQoL).\textsuperscript{13} The aim of this study was to quantify the impact of spasticity on health care resources and the associated costs at different levels of spasticity severity in people with MS (PwMS) living in the United Kingdom (UK).

Methods

Survey methodology

An online survey was designed in order to understand the resources used in the management of spasticity in PwMS at all stages of their disease trajectory, living in the UK. The questionnaire asked health care specialists involved in the management of PwMS to estimate their involvement and the resource use associated with different levels of spasticity. The survey was conducted online during December 2013 to January 2014 amongst the following specialties: neurologists, neurological and MS nurse specialists, neuro-physiotherapists, neuro-rehabilitation specialists (consisting of neurologists and rehabilitation medicine consultants with neuro-rehabilitation as a special interest), occupational therapists (OT) and social care specialists (case managers and social workers). The survey questionnaire consisted of 15 questions (Supplementary data), although not all participants were asked all questions, depending on their role. For example, social care specialists were not asked how many times their patients were seen in accident and emergency (A&E).

All experts involved in the interviews worked in the UK and had experience in the treatment of MS and spasticity. Participants were asked to define the following: the nature of their role (as defined by the categories listed) and level of seniority, geographic location, how many MS patients they had under their care, what disease state the patients were classed with and the responders’ level of involvement in their care, estimates of the proportion of patients who would require consultations as outpatients or inpatients due to spasticity-related problems and the frequency (times/year) of these visits, and the proportion of patients who would require home care and enabling equipment due to spasticity-related problems. All results were anonymised.

Disease states

To quantify the severity of spasticity, five disease states were defined (Table 1). Each disease state is associated with a numerical rating scale (NRS), where 0 represents no symptoms and disability from spasticity and 10 represents worst possible spasticity (Table 1). The relationship definitions and association between the NRS values and disease state description was established by an expert in the treatment of spasticity.

Valuation of costs

Unit cost data were estimated from a UK National Health Service (NHS) and personal social services perspective. All unit costs for consultations and admissions were collected from the National Schedule of Reference Costs (https://www.gov.uk/government/publications/nhs-reference-costs-2012-to-2013) and from the Personal Social Services Research Unit (PSSRU; http://www.pssru.ac.uk/project-pages/unit-costs/2013/). For consultations, the price per visit was used and, when not available, the price per hour. For hospital admissions, the cost per day was used. Home carer costs were taken from the PSSRU 2013 and accounted for as 60-minute visits. For other social services, the National Schedule of Reference Costs 2012–2013 was used. For all equipment costs, which were not available in the PSSRU 2013, websites specialised in selling disability equipment were used as a source. It was assumed that a single piece of equipment would last 10 years before a replacement is required.
Data from the survey outputs were used to derive the quantity of individual resources required annually per patient multiplied by the proportion of patients requiring individual resource in each health state, and then multiplied by the corresponding unit cost for this resource:

\[
\text{Health state cost} = \text{Resource quantity} \times \frac{\text{Proportion of patients}}{\text{Unit cost}}
\]

### Results

#### Participants

A total of 372 health care specialists were invited to participate in the survey, and 221 completed the online questionnaire. The majority of participants were neurologists, neurological/MS nurse specialists or neuro-physiotherapists (23% for each category, respectively), with the remainder of respondents consisting of neuro-rehabilitation specialists (11%), OTs (11%) and social care specialists (9%; Table 2).

#### Management of MS patients

When asked about the nature of their role and the level of involvement in the care of their MS patients, 86% of respondents stated that they participate in the management of their patients’ spasticity, whereas less than half (42%) reported that they oversee patient care packages. Substantially fewer neuro-physiotherapists (8%) had an overseeing or managerial role (Figure 1(a)).

Not surprisingly, social care specialists demonstrated a reversal of this pattern; on average, less than one fifth (14%) of survey participants actively managed spasticity, with 90% stating their role to be of an overseeing nature (Figure 1(a)).

### Disease states

Survey participants were asked to group their MS patients into the five disease states (Table 1), according to the severity of their spasticity. Overall, most MS patients (38%) were classified as disease state 1; fewer patients (24%, 18%, 12% and 8%) were grouped into disease states 2, 3, 4 and 5, respectively (Figure 1(b)). A similar trend, where more patients were assigned disease state 1, was observed from the answers of neurologists, nurse specialists, physiotherapists and OT specialists (Figure 1(b)). However, the differing case mix experienced by specific health and social care providers was illustrated by the higher levels of disability seen by rehabilitation and social care specialists, with the most frequent disease states being 3 and 4, respectively. Only 16% and 6% of their patients were classed as disease state 1 (Figure 1(b)).

### Types of care required for spasticity-related problems

#### Outpatient clinics

It was evident that the higher the disease state, the greater the proportion of PwMS attending treatment clinics as outpatients. A similar trend was observed by the different types of health care specialists (Figure 2(a)). Between 4% and 16%...
patients in disease state 1 were estimated to attend the health care specialists’ clinics as outpatients, whereas 43%–86% of PwMS in disease state 5 required attendance at outpatient clinics due to spasticity-related problems over the past year (Figure 2(a)). This trend was also reflected by the frequency of visits to an outpatient clinic: Patients in higher disease states attended clinics more often than patients in the lower

Table 2. Health care roles of survey participants and number of multiple sclerosis (MS) patients.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Average number of MS patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>All</td>
<td>221 (100)</td>
</tr>
<tr>
<td>Neurologist</td>
<td>50 (23)</td>
</tr>
<tr>
<td>Neurological nurse specialist</td>
<td>50 (23)</td>
</tr>
<tr>
<td>Neuro-specialist physiotherapist</td>
<td>50 (23)</td>
</tr>
<tr>
<td>Neuro-rehab specialist</td>
<td>25 (11)</td>
</tr>
<tr>
<td>Occupational therapy (OT) specialist</td>
<td>25 (11)</td>
</tr>
<tr>
<td>Social care specialist – social worker</td>
<td>21 (9)</td>
</tr>
</tbody>
</table>

Figure 1. Survey participants’ role in patient management and assessment of disease states.

MS: multiple sclerosis; OT: occupational therapist.
Figure 2. Levels of care required, stratified by disease state.
OT: occupational therapist; A&E: accident and emergency.
A+E. Overall, less than 15% of PwMS in any disease state were required to attend A+E due to spasticity-related problems over the past year, and the higher the patients’ disease state, the greater the proportion of patients attending A+E (Figure 2(b)). The different health care specialists reported 9%–28% of MS patients in disease state 5 attending A+E for spasticity-related problems, but only a maximum of 1% of patients in disease state 1. Overall, MS patients were estimated to visit A+E once or twice a year for spasticity-related problems (Figure 2(b)).

Hospital admissions. Responses regarding hospital admissions were similar to those for A+E visits. The higher their disease state, the greater the proportion of patients admitted (0% patients in disease state 1, 18% in disease state 5; Figure 2(c)). Physiotherapists and OTs reported the highest proportion of PwMS under their care requiring hospital treatment (41% and 36% of state 5 patients, respectively). Overall, MS patients were admitted once or twice over the past year to receive treatment for spasticity-related issues (Figure 2(c)).

District nurse support. Not surprisingly, the proportion of PwMS requiring support from a district nurse increased with disease state. Only 4% of patients received treatment in disease states 1 and 2, and this steadily increased to 14%, 38% and 60% of patients with disease state 3, 4 and 5, respectively (Figure 2(d)). Similarly, patients with lower disease states (1–3) were seen by a district nurse only up to six times in the past year, whereas patients with disease states 4 and 5 required district nurse support every two to three weeks (Figure 2(d)).

Home care
PwMS with higher degrees of spasticity required substantially more home care, social support and specific living aids for spasticity-related problems (Figure 3). Whereas patients with disease state 1 needed no support from home carers, patients with disease states 2–4 received up to 18 hours of assistance at home per week over the past year. For PwMS in disease state 5, this increased to 30 hours per week of assistance at home required (Figure 3(a)). Similarly, on average, only 3%–12% of MS patients with lower disease states (1–2) had need for social support or living aids for spasticity-related problems, which increased dramatically to 50% of state 3 patients and even further to 87% of patients in disease state 5 (Figure 3(b)). Again, due to case mix, OTs and social care specialists identified the greatest need for this support, regardless of the patients’ disease state (Figure 3(b)).

Requirements for specialised equipment
In line with other results, MS patients with disease states 1 and 2 required on average substantially less specialised home equipment and care for spasticity-related problems than patients with disease states 3–5 (Figure 3(c)). Equipment required by PwMS in disease state 1 was mainly composed of walking aids (39%), grab rails (23%) and bath aids (20%), and very few (<5%) of these patients required more expensive items, such as wheelchairs or specialist beds. In contrast, the need for walking aids and grab rails dramatically increased for patients with disease state 2 (79% and 69%, respectively), and more than 40% of these patients required more specialised items, e.g. bath and shower aids or specialised toilet seats at home (Figure 3(c)). About two-thirds of all PwMS in disease states 4 and 5 required home equipment, and more than 90% were in need of home care. State 3 patients did not require highly specialised items, e.g. hoists or specialist beds, to the same extent; however, 66% were wheelchair users, and more than two-thirds had home modifications such as grab rails, bath and shower aids and specialised toilet seats (Figure 3(c)).

It is evident that disease states 4 and 5 are associated with not only the highest proportion of PwMS needing adaptations in their homes, but that these individuals also needed more specialised items. Whereas 64%–79% of patients with disease state 4 had a pressure mattress, specialist bed, wheelchair or hoist, these adaptations were necessary for more than 90% of people in state 5 (Figure 3(c)). Not surprisingly, the need for walking aids or grab rails dropped to 42% and 58%, respectively, for PwMS in disease state 5, whereas 96% required a wheelchair, reflecting disease progression and the loss of walking/standing ability (Figure 3(c)).

Cost analyses
Analyses clearly showed an increasing annual cost when moving through disease state 1 to 5 (Figure 4). The most prominent cost escalation was associated with the transition from disease state 1 to 2, with the annual cost of £217 for disease state 1 rising 11-fold...
Figure 3. Home care.
OT: occupational therapist.
to £2,404 for disease state 2, with further two- to three-fold increases for transitions up to disease state 5 (Figure 4).

For disease state 1, key contributors to the overall annual cost of disease management were outpatient clinic visits (£144) and community-based visits (£41), whereas home care visits required the lowest contribution per year (£1; Figure 4). In contrast, home care visits represented the most cost-intensive contributions for disease states 2–5, followed by outpatient clinic visits, hospital admissions and community-based visits. The proportion of costs accounted for by A&E visits were low across all stages of the disease (Figure 4).

Discussion

With its relatively early age of onset (average age at diagnosis in the UK: 40 years) and significant impact on HRQoL, MS requires life-long, co-ordinated treatment and therefore places a substantial economic burden on individuals, health care systems and society. The prevalence of MS in the UK has increased from 110 to 164 per 100,000 from 2008 to 2013, with the estimated number of PwMS living in the UK rising from 85,000 to 100,000 in that time. This increase is associated with mounting financial investments required to meet patients’ needs, including training of more health care specialists, acquisition of specialised instruments or home care equipment. For example, the number of neurologists and MS nurses in the UK increased by 18% and 29%, respectively, between 2008 and 2013. Taken together, these findings clearly indicate that there is a need to understand what drives costs associated with MS treatment.

The results of this survey consistently demonstrate that the level and cost of care for PwMS increase with their degree of spasticity, with annual cost per patient being much higher for disease state 4 and 5 than for the lower disease states. Previous studies have also confirmed similar escalating costs with increasing levels of spasticity severity. Key factors contributing to high annual costs per patient were the home care cost, hospital admissions both to general and neurology wards and high-cost items, such as hospital beds, specialist seating or hoists. Based on the results presented here, it can be assumed that delaying the transition from disease states 1 and 2 to 3 and upward could result in substantial cost savings.

There is evidence from other conditions that providing early medical intervention that prevents or slows disease progression can significantly contribute to reducing overall cost, for example, rheumatic conditions, such as rheumatoid arthritis (RA) or ankylosing spondylitis (AS). People with RA experience structural joint damage with associated loss of function, pain and...
Fatigue, resulting in similar issues to PwMS with reduced HRQoL and loss of productivity.\textsuperscript{20,21} Treatment of RA is associated with significant costs, both direct (medications, outpatient visits, hospitalisations, home adjustments, assistive devices and external help) and indirect (reduced productivity in the workplace and disability).\textsuperscript{22,23} Cost-effectiveness studies have, however, indicated that prevention of disease progression in RA can limit future costs, such as those related to surgery and hospitalisation.\textsuperscript{24} Minimised disease progression improves patients’ well-being and can improve work productivity.\textsuperscript{24,25} Importantly, studies have shown improved outcomes (decreased job loss, reduction in the amount of work days missed) and cost effectiveness with treatment in early stages of RA vs later ones.\textsuperscript{20,26,27}

Clearly, the analyses of health care costs associated with a single symptom (spasticity) in PwMS is complex; however, due to its prevalence and impact on HRQoL, it is important to try to understand more about it to guide decisions on treatment recommendations. There are clearly limitations to this study: Firstly, the survey results presented here were based on subjective estimates from experts and not on prospectively collected data; secondly, no data are presented on the costs and efficacies of treatments for spasticity, as this is beyond the scope of this study.

Various options for spasticity management are available, and the choice of treatment depends on a combination of symptom severity, functional impact, patient preference and availability of services.\textsuperscript{8} Previous studies have found that new interventions can be cost effective, even if they initially increase treatment costs, by reducing the overall costs of managing spasticity including the provision of costly home care and equipment.\textsuperscript{15,17,24,26–28} This study suggests that cost savings could be achieved simply by delaying transition between disease states, in addition to the improvements in HRQoL seen with individualised, function-focussed, early and effective treatment of MS-associated spasticity.

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Conflicts of interest
- V.L. Stevenson has received honoraria from Bayer plc, Almirall and Medtronic.
- A. Gras is an employee of GfK.
- J. Bárdos is an employee of Costello Medical Consulting.
- J. Broughton is an employee of Bayer plc.

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References


