

Impact of Mobility Impairment in Multiple Sclerosis 1 – Healthcare Professionals' Perspectives

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Abstract

Loss of mobility is one of the most widespread and debilitating consequences of multiple sclerosis (MS). In the first of two articles, the results of a survey on MS patient mobility from the perspective of healthcare professionals (HCPs), specifically neurologists and MS specialist nurses who treat patients with mobility issues, are presented. The vast majority of HCPs stated that they specifically asked patients about mobility issues during consultation, or that the patients spontaneously raised the subject. Most HCPs rated loss of mobility as having a significant impact across all aspects of patients' lives. Although 80 % of HCPs believed they had sufficient knowledge to identify mobility impairment, only 50 % felt they had the necessary tools available to fully assess the loss of mobility. Considerable differences existed between neurologists and MS specialist nurses, and across geographical regions, in the tools used to assess mobility impairment and the subsequent treatment options offered. This study shows that HCPs are aware of the potential impact of mobility difficulties on their MS patients, and highlights the need for novel or improved therapy options.

Keywords

Clinical management, mobility impairment, multiple sclerosis, treatment, mobility survey, clinical perspective

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Mobility impairment, particularly walking, is one of the most common and severely disabling consequences of multiple sclerosis (MS), and it has a profound, negative impact on the quality of life of many patients.^{1,2} Currently, >2 million people are estimated to suffer with MS worldwide,³ and as of 2005 an estimated 380,000 individuals out of 466 million people were estimated to suffer from MS in 28 European countries.^{4,5} Since MS is most often diagnosed during a person's most productive years,^{6,7} and the life expectancy of patients is similar to that of the general population,⁸ MS is associated with a significant socioeconomic burden,^{4,9–11} estimated at an annual cost of approximately €12.5 billion in Europe.⁴ The highest cost is the loss of productivity owing to work absence or early retirement,^{4,9–12} and one of the major reasons for reduced productivity is the loss of mobility.¹ Walking impairment is often the most visible sign of MS and is commonly used as part of the clinical diagnosis by healthcare professionals (HCPs). Indeed, assessment of walking ability is a major component in most clinical outcome measures of MS severity, including the Expanded Disability Status Scale (EDSS) and the MS Functional Composite (MSFC, which includes the timed 25-foot walk, 9-hole peg test and paced auditory serial attention test). However, mobility impairments occurring during the early stages of MS, when treatments are most effective,^{13–17} are often subtle and may not be detectable on routine physical examination.¹⁸

In the first of two articles, the results of a survey, commissioned by Biogen Idec Inc. and conducted among HCPs involved in the management of MS, are presented. The study was designed to explore the impact of MS on patients' mobility, with the specific aims to examine the HCPs' perception of the impact of loss of mobility on patients and their management of mobility issues, including the use of clinical outcome measures and treatment options.

Methodology

The survey, entitled 'Multiple sclerosis (MS) quality of life research – IMPACT', was performed by Brand Health (Harpenden, UK) and conducted online. Participants were recruited from the UK, France, Germany, Sweden, Spain and Canada. A total of 182 HCPs (121 neurologists and 61 MS specialist nurses) (see *Table 1*) who were actively involved in the management of MS patients completed a quantitative questionnaire of approximately 10 minutes duration between the 7 June and 2 July 2010. Eligibility criteria included:

- involvement in the management of MS patients;
- seeing more than 15 MS patients in a three-month period; and
- having more than 15 % of MS patients experiencing some sort of difficulty in walking.

Data are representative of the entire sample population except where specifically stated. It should be noted that this market research survey is descriptive only and contains no detailed statistical analysis or comparisons. When findings are therefore described as significant this relates to the terminology as set down in the original questions.

Summary of Findings

Perceptions on the Impact of Loss of Mobility

The mean number of MS patients seen by individual HCPs participating in the survey in the three months prior to survey completion was 91, with the largest percentage of HCPs (16 %) having seen between 41 and 50 patients. MS nurses saw significantly more patients than neurologists saw during this time period. HCPs estimated that 56 % of MS patients under their care had experienced some loss of mobility, and 46 % had difficulties in walking. Moreover, HCPs believed that patients wanted help to find a physical treatment plan for their mobility issues (mean score = 4.6 on a scale where 1 = not at all and 6 = extremely).

Most HCPs believed that mobility impairment had a substantial impact on MS patients’ lives. Specifically, they considered the loss of mobility owing to MS to be significant (mean score = 5.1 on a scale where 1 = not at all significant and 6 = extremely significant) with considerable impacts on working life (mean score = 5.0), social life (mean score = 4.9) and family life (mean score = 4.7). Ratings were similar between neurologists and MS nurses. Almost all of the HCPs (99 %) stated that patients spoke to them about the impact of mobility impairment, particularly on their ability to work.

More than half (52 % across the entire sample; 79 % in France) of HCPs stated that walking or moving about was the primary activity that patients claimed to be affected by mobility impairment, while activities of daily life including work (27 %) and shopping (10 %), as well as sports and exercise (9 %), were also impacted (see *Figure 1*). The symptoms most frequently reported to HCPs by patients experiencing walking difficulties were lack of balance and coordination (86 %; 100 % in Canada), inability to walk long distances (85 %), leg weakness (79 %; 91 % in the UK) and fatigue (79 %; 90 % in Germany) (see *Table 2*).

Managing Mobility Issues

The majority of HCPs (85 %) stated that during a consultation they specifically asked patients whether they were experiencing mobility difficulties. Moreover, 74 % of HCPs also reported that during a consultation most patients spontaneously mentioned any mobility difficulties they were experiencing. Approximately one quarter (26 %; 50 % in the UK) of HCPs stated that patients mentioned their mobility difficulties to another HCP. Of the HCPs surveyed, 80 % believed that they had sufficient knowledge to identify mobility impairment in their MS patients, and 50 % believed they had the appropriate tools at their disposal to assess and quantify mobility impairment (70 % in Canada). The EDSS was the tool most commonly used to assess mobility impairment, followed by the MSFC, MS Walking Scale and Six Spot Step Test (see *Table 3*). Neurologists were more likely to use the EDSS than MS specialist nurses were (89 % versus 69 %, respectively); of the HCPs that used the EDSS, 34 % conducted assessments at each consultation (see *Table 3*). Nurses were more likely than neurologists to use the MSFC (38 % versus 23 %, respectively), MS Walking Scale (38 % versus 22 %, respectively), Six Spot Step test (25 % versus 12 %, respectively) and Disease Steps Test (15 % versus 5 %, respectively) to assess mobility loss. The MS Walking Scale was used more in Germany than in the rest of the sample population (37 % versus 27 %, respectively), and the Six

Table 1: Geographical Split of Participants in the IMPACT Survey

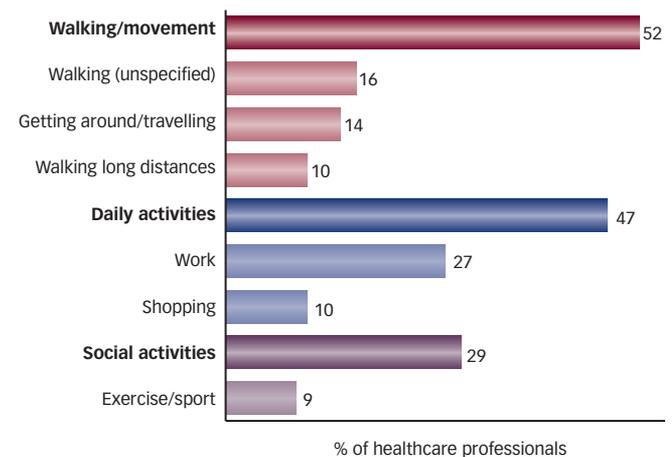
	Neurologists	Multiple Sclerosis Nurses	Total (%)
Canada	20	10	30 (16.5)
France	20	10	30 (16.5)
Germany	20	10	30 (16.5)
Spain	20	11	31 (17.0)
Sweden	20	9	29 (15.9)
UK	21	11	32 (17.6)
Total	121	61	182 (100)

Table 2: Healthcare Professionals’ Responses to a Question About Patients’ Walking Difficulties

	Overall (n=182)	Neurologist (n=121)	MS Nurse (n=61)
Lack of balance/coordination	86	89	80
Inability to walk long distances	85	89	77
Weakness in legs	79	79	79
Fatigue	79	83	72
Numbness in legs	53	50	59
Dropping/dragging one foot behind the other	48	45	54
Slowness in movement	37	36	38

Healthcare professionals’ responses to the question, ‘Which of the following symptoms are most frequently reported by your patients who are experiencing walking difficulties?’ Data are presented as percentage of healthcare professionals. n = number of healthcare professionals.

Figure 1: Healthcare Professionals’ Response to a Question About Patients’ Mobility

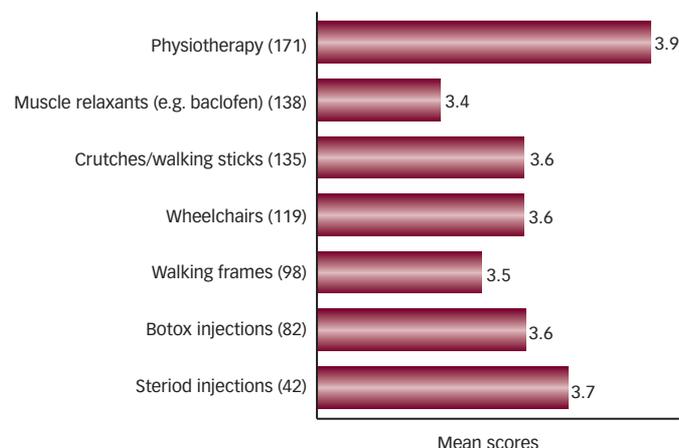


Healthcare professionals’ response to the question, ‘What is the main activity affected as a result of difficulties with mobility that patients complain about?’

Spot Step Test was used more in France than in the rest of the sample population (40 % versus 16 %, respectively).

Approximately three-quarters (74 %) of HCPs believed that they were able to offer both medical and non-medical treatments for walking impairment; this belief was held by considerably more neurologists (79 %) than MS nurses (64 %). HCPs in Canada (87 %) and Germany (90 %) were more likely to believe they were able to offer these treatments. Physiotherapy was the most common treatment offered, followed by muscle relaxants such as baclofen, crutches or walking sticks and wheelchairs (see *Table 4*). Participants were not questioned about the treatment of patients with nabiximols (Sativex®), a novel therapy for

Figure 2: Healthcare Professionals' Response to a Question About Efficacy of Treatment Options on Mobility



Healthcare professionals response to the question, 'On a scale of 1–6, where 1 = not at all and 6 = completely, to what extent have these treatment options addressed your patients' mobility issues?' Number of healthcare professionals is in brackets.

Table 3: Tools Employed by Healthcare Professionals to Assess the Severity of Mobility Impairment in Multiple Sclerosis

	EDSS (n=150)	MSFC (n=51)	MS Walking Scale (n=50)	Six Spot Step Test (n=29)
Overall	82	28	27	16
At each visit	34	16	20	34
Every month	6	4	6	14
Every three months	14	22	32	24
Every six months	25	20	20	21
Every year	15	18	16	0

Data are presented as percentage of healthcare professionals. n = number of healthcare professionals. EDSS = Expanded Disability Status Scale; MSFC = Multiple Sclerosis Functional Composite.

the treatment of spasticity in MS,¹⁹ but were asked whether they offered patients 4-aminopyridine (dalfampridine; Ampyra®), a novel therapy for walking disability in MS.²⁰ However, only 8 % of HCPs considered offering 4-aminopyridine to patients. Additional rehabilitation techniques such as occupational therapy were not covered in the survey. There were some differences in the treatments offered among countries, although physiotherapy was consistently the most commonly offered treatment in all countries, and more striking differences were apparent between neurologists and MS specialist nurses (see Table 4). Of all treatments, HCPs considered physiotherapy to be the most successful in resolving patients' mobility issues (mean score = 3.9 on a scale where 1 = not at all and 6 = completely), but not appreciably more than other treatment options (see Figure 2).

Neurologists and MS nurses reported that they assessed mobility issues somewhat differently. Nurses were more likely to use physician assessment (64 % versus 54 %), while neurologists were more likely to use scales and measurements (48 % versus 33 %), specifically the EDSS and timed 25-foot walk test. There was a wide variety in the frequency of follow-up assessments, to monitor mobility, by country and type of HCP (see Table 5). HCPs in Sweden were more likely to have longer follow-up times between mobility assessments and MS specialist nurses across all countries assessed mobility more frequently than neurologists. Approximately one third of HCPs (35 %; 73 % in Spain)

would consider more frequent assessments if new treatments became available, 30 % (55 % in the UK) if the patient deteriorated and 26 % (50 % in Sweden) if they had more time. More neurologists than MS nurses said that new treatments would encourage them to make more frequent assessments (42 % versus 15 %, respectively).

Interactions Between Neurologists and Multiple Sclerosis Specialist Nurses

This study also asked MS specialist nurses to respond to questions about how they interacted with neurologists in the diagnosis and treatment of their patients. Nurses stated that they interacted most with neurologists when assessing mobility issues (mean score = 4.3 on a scale where 1 = not at all and 6 = completely) and when managing and recommending a treatment plan (mean scores = 4.1 and 4.0, respectively), but not as often when writing a prescription (mean score = 3.0). The mean scores were higher for all situations in Sweden (mean scores = 5.0, 4.8, 4.4 and 3.4, respectively), possibly indicating a greater level of communication between HCPs than in other countries.

Discussion

The results of the IMPACT survey provide a valuable insight into the perceived abilities of HCPs to deal with mobility issues in MS patients, revealing considerable differences between neurologists and MS nurses, and between countries. The vast majority of HCPs (85 %) in the survey stated that they raised the issue of mobility impairment with their patients, or that patients spontaneously raised the issue themselves (74 %). This is in reasonably good agreement with the proportion of patients in the accompanying survey²¹ that discussed mobility difficulties with a neurologist (71 %) or specialist MS nurse (38 %); patients in the accompanying survey may have brought mobility issues to other types of HCPs. It is important to remember that one criterion for participants in the current survey was having more than 15 % of patients exhibiting mobility impairment, so the HCPs who participated in this survey may be particularly aware of their patients' mobility issues.

HCPs were generally confident in their ability to identify mobility impairment, although only half of them believed they had the necessary tools at their disposal to fully assess and quantify patients' mobility difficulties. The most commonly used means of assessment was the EDSS. It is important to note that walking distance is the primary driver of EDSS assessment, and thus it may underestimate other mobility-related difficulties that can be more readily assessed with tools more specifically targeted to mobility. There were substantial geographical differences in the tools used to assess mobility, presumably owing to availability of resources and the professional preferences of the individual HCPs. Geographical differences were also apparent in the reporting of symptoms. This variation may be owing to a real difference in the incidence of each symptom between geographical locations, or more likely to an emphasis on identifying specific symptoms in specific regions. Similarly there were geographical differences in the treatments offered and the means of assessing mobility difficulties that may again be owing to variation in availability of resources or professional preferences. The observation of longer follow-up times to reassessment in Sweden, for example, is in good agreement with the findings in the accompanying patient survey,²¹ and may reflect the Swedish HCPs view that they would consider more frequent assessments if they had more time. It may also reflect the fact that MS nurses provided more frequent follow-ups and there was relatively stronger communication between neurologists and MS nurses

Table 4: Treatment Options Offered to Mobility-impaired Multiple Sclerosis Patients by Healthcare Professionals

	By country							By Healthcare Professional	
	Overall (n=182)	Canada (n=30)	France (n=30)	Germany (n=30)	Spain (n=31)	Sweden (n=29)	UK (n=32)	Neurologist (n=121)	MS Nurse (n=61)
Physiotherapy	94	100	87	97	87	100	94	97	89
Muscle relaxants	76	77	83	73	71	76	75	84	59
Crutches/walking sticks	74	80	83	67	65	76	75	78	67
Wheelchairs	65	67	70	67	65	52	72	70	56
Walking frames	54	50	63	43	58	28	78	57	48
Botox injections	45	53	37	40	39	41	59	54	28
Steroid injections	23	17	47	30	13	7	25	21	26

Data are presented as percentage of healthcare professionals.
MS = multiple sclerosis; n = number of healthcare professionals.

Table 5: Length of Time to Follow-up Assessment of Mobility Impairment

	By country							By Healthcare Professional	
	Overall (n=182)	Canada (n=30)	France (n=30)	Germany (n=30)	Spain (n=31)	Sweden (n=29)	UK (n=32)	Neurologist (n=121)	MS Nurse (n=61)
Weekly	2	0	3	0	10	0	0	0	7
Every couple of weeks	3	0	3	10	6	0	0	2	7
Monthly	13	0	27	23	13	3	9	7	23
Every couple of months	25	37	23	43	16	0	28	26	21
Every six months	35	33	40	7	42	31	53	46	11
Yearly	6	3	0	3	0	28	3	6	7

Data are presented as percentage of healthcare professionals.
MS = multiple sclerosis; n = number of healthcare professionals.

in Sweden. Differences in the perception and management of mobility issues in different countries may also be owing to the different clinical setting of individual HCPs. A recent pilot study aimed at developing a European-wide MS registry noted differences in disease-related characteristics and disease-modifying therapy among countries owing to differences in the type of healthcare centre, e.g. neurological centre, rehabilitation centre or outpatient clinic and types of MS seen, e.g. relapsing-remitting, secondary progressive or primary progressive.²² In the current survey, however, the type of healthcare centre of participating HCPs was not covered in sufficient detail, and the disease type of individual patients was not noted.

Differences were also observed in the responses of neurologists and MS specialist nurses. For instance, there were considerable differences in the assessment tools used. Notably, the EDSS was more commonly used by neurologists than MS specialist nurses, probably because it is based on neurological examination, whereas MS specialist nurses were more likely than neurologists to use the MSFC, which does not require formal neurological examination. In addition, the treatments offered and the time to follow-up assessments differed between the two types of HCPs, presumably owing to availability of resources or professional preference. MS nurses were less likely to believe they had the ability to offer mobility-specific treatments. While the reasons behind this are unknown, it does suggest that patients should contact their neurologist to explore potential treatment options.

MS specialist nurses reported that they interacted with neurologists to a moderate extent in assessing mobility difficulties and managing and developing a treatment plan for their patients. Given the importance that patients attach to mobility impairment,^{1,2,21,23-25} the level of interaction between neurologists and MS nurses can only be seen as positive. It is to be hoped that similarly high levels of interactivity exist between neurologists, MS nurses and other HCPs, including primary care physicians, general practitioners, family practitioners, occupational therapists, psychiatrists, physiatrists, physiotherapists etc, in order to fully address patients' mobility issues and thereby improve their quality of life and independence.²⁶

Conclusions

The results from this survey support previous findings on the impact of mobility impairment on MS patients. HCPs believe that mobility impairment has a considerable effect on all aspects of MS patients' lives, and that whereas they are capable of identifying such impairment, only half believe they have adequate tools to accurately quantify the level of disability. Differences between geographical regions and between neurologists and MS specialist nurses highlight important historical, cultural and social variables that may need to be addressed to improve MS patient care. The perceived lack of effect of even the most common treatment offered, physiotherapy, indicates that there is a substantial unmet clinical need for novel and/or improved therapies to treat mobility impairment. ■

1. Sutliff MH, Contribution of impaired mobility to patient burden in multiple sclerosis, *Curr Med Res Opin*, 2010;26:109–19.
2. Zwiibel HL, Contribution of impaired mobility and general symptoms to the burden of multiple sclerosis, *Adv Ther*, 2009;26:1043–57.
3. National Multiple Sclerosis Society, Available at: www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/who-gets-ms/index.aspx (accessed 4 January 2011).
4. Sobocki P, Pugliatti M, Lauer K, et al., Estimation of the cost

- of MS in Europe: extrapolations from a multinational cost study, *Mult Scler*, 2007;13:1054–64.
5. Pugliatti M, Rosati G, Carton H, et al., The epidemiology of multiple sclerosis in Europe, *Eur J Neurol*, 2006;13:700–22.
6. Compston A, Coles A, Multiple Sclerosis, *Lancet*, 2002;359:1221–31.
7. Weinschenker BG, Natural history of multiple sclerosis, *Ann Neurol*, 1994;36:S6–S11.
8. Ragonese P, Aridon P, Salemi G, et al., Mortality in multiple sclerosis: a review, *Eur J Neurol*, 2008;15:123–7.
9. Kobelt G, Berg J, Lindgren P, et al., Costs and quality of life of

- patients with multiple sclerosis in Europe, *J Neurol Neurosurg Psychiatry*, 2006;77:918–26.
10. Kobelt G, Texier-Richard B, Lindgren P, The long-term cost of multiple sclerosis in France and potential changes with disease-modifying interventions, *Mult Scler*, 2009;15:741–51.
11. Asche CV, Ho E, Chan B, et al., Economic consequences of multiple sclerosis for Canadians, *Acta Neurol Scand*, 1997;95:268–74.
12. Kobelt G, Berg J, Atherly D, et al., Costs and quality of life in multiple sclerosis: a cross-sectional study in the United States, *Neurology*, 2006;66:1696–702.

13. Comi G, Filippi M, Barkhof F, et al., Effect of early interferon treatment on conversion to definite multiple sclerosis: a randomised study, *Lancet*, 2001;357:1576–82.
14. Hartung HP, Early treatment and dose optimisation BENEFIT and BEYOND, *J Neurol*, 2005;252 (Suppl. 3):iii44–iii50.
15. Jacobs LD, Beck RW, Simon JH, et al., Intramuscular interferon beta-1a therapy initiated during a first demyelinating event in multiple sclerosis, *N Engl J Med*, 2000;343:898–904.
16. Kappos L, Freedman MS, Polman CH, et al., Long-term effect of early treatment with interferon beta-1b after a first clinical event suggestive of multiple sclerosis: 5-year active treatment extension of the phase 3 BENEFIT trial, *Lancet Neurol*, 2009;8:987–97.
17. Kinkel RP, Kollman C, O'Connor P, et al., IM interferon beta-1a delays definite multiple sclerosis 5 years after a first demyelinating event, *Neurology*, 2006;66:678–84.
18. Martin CL, Phillips BA, Kilpatrick TJ, et al., Gait and balance impairment in early multiple sclerosis in the absence of clinical disability, *Mult Scler*, 2006;12:620–8.
19. Wade DT, Collin C, Stott C, et al., Meta-analysis of the efficacy and safety of Sativex (nabiximols), on spasticity in people with multiple sclerosis, *Mult Scler*, 2010;16:707–14.
20. Goodman AD, Brown TR, Edwards KR, et al., A phase 3 trial of extended release oral dalfampridine in multiple sclerosis, *Ann Neurol*, 2010;68:494–502.
21. van Asch P, Impact of mobility impairment in multiple sclerosis II. Patients' perspectives, *European Neurological Review*, 2011;6(2):115–20.
22. Flachenecker P, Khil L, Bergmann S, et al., Development and pilot phase of a European MS register, *J Neurol*, 2010;257:1620–7.
23. Finlayson M, Concerns about the future among older adults with multiple sclerosis, *Am J Occup Ther*, 2004;58:54–63.
24. Heesen C, Bohm J, Reich C, et al., Patient perception of bodily functions in multiple sclerosis: gait and visual function are the most valuable, *Mult Scler*, 2008;14:988–91.
25. Jones CA, Pohar SL, Warren S, et al., The burden of multiple sclerosis: a community health survey, *Health Qual Life Outcomes*, 2008;6:1–7.
26. Freeman JA, Improving mobility and functional independence in persons with multiple sclerosis, *J Neurol*, 2001;248:255–9.