Impact of Mobility Impairment in Multiple Sclerosis 2 – Patients' Perspectives

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Abstract

In the second of two articles, the impact of mobility impairment in multiple sclerosis (MS) is examined from the patients' perspective. Nearly half (45 %) of patients reported experiencing mobility difficulties within a month of diagnosis and nearly all patients (93 %) report difficulties within 10 years. Three quarters of the patients surveyed considered mobility impairment to be a significant problem and two-thirds believed it had contributed toward loss of earnings. Mobility difficulties were consistently reported across all age groups, but were a greater issue for men than women. Geographical differences were observed, particularly in the type of healthcare professional (HCP) with whom problems were discussed, the prevalence of mobility symptoms and the treatment options offered. These findings support previous studies on the impact of mobility difficulties on patients' quality of life and highlight discrepancies between HCPs' and patients' perceptions, particularly in the severity of mobility impairment and treatment options. Patients consider loss of mobility to be limiting, challenging and frustrating, highlighting the need for long-term management of their mobility issues and new or improved therapeutic options.

Keywords

Mobility impairment, mobility survey, multiple sclerosis, patient perspective, quality of life, working life

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Mobility impairment, particularly walking, is one of the most common and disruptive consequences of multiple sclerosis (MS) and can have a profound effect on independence, quality of life (QoL) and activities of daily living (ADL) for many patients.[1–8] Impaired mobility results in a loss of work-related productivity,[6,9–11] and is the single greatest economic burden of MS.[12,13] Furthermore, QoL is consistently lower in patients with MS than in patients with other chronic disorders.[14–16] Although mobility impairment can be subclinical or barely perceptible at the time of diagnosis,[17–19] even mild or subclinical mobility impairment may impact on QoL and ADL.[5,6] The degree of mobility impairment is progressive and irreversible, resulting in worsening disability.[20,21] Not surprisingly, severity of mobility impairment is a major focus of clinical outcome measures for MS including the Expanded Disability Status Scale (EDSS), the MS Functional Composite (MSFC, which includes the timed 25-foot walk, Nine-hole peg test and paced auditory serial attention test) and specific tests of walking ability including the timed 25-foot walk, the six- or two-minute walk test, the Six Spot Step test and the MS walking scale (a patient-reported outcome measure). Despite the variable prognosis and onset of disease in individual patients, estimates of the median times to mobility impairment landmarks using the EDSS are eight years to walking impairment (EDSS score = 4), 20 years to walking with a stick (EDSS score = 6) and 30 years to wheelchair dependency (EDSS score = 7).[21,22]

Recent studies have indicated that MS patients consider mobility impairment to be the symptom that concerns them the most.[7] Patients consistently ranked walking as their highest priority among thirteen bodily functions including visual function, lack of pain, cognition and bladder and bowel control,[23] and ambulation had a greater impact on QoL than pain, dexterity or cognition.[14] Furthermore, maintaining mobility was ranked as one of the highest priorities irrespective of the degree of impairment or disease duration.[7,23,24] Mobility impairment in MS patients is also a significant, long-term burden on caregivers, particularly informal or unpaid caregivers, including physical, emotional, psychosocial and economic burdens.[25–27] The impact of mobility impairment is therefore not solely restricted to patients.

In this second of two articles, the impact of mobility impairment on MS patients is examined from the perspective of the patients themselves. In a survey, commissioned by Biogen Idec Inc., MS patients were asked about the severity of their mobility impairment, the symptoms they experienced, the clinical management of their mobility issues including types of therapy offered, and the impact it had on their working, family and social lives.

Methodology

MS patients were recruited from the UK, France, Germany, Sweden, Spain and Canada either online or through patient groups. The

Table 1: Sample Split of Participants in the Patient Perspective Study

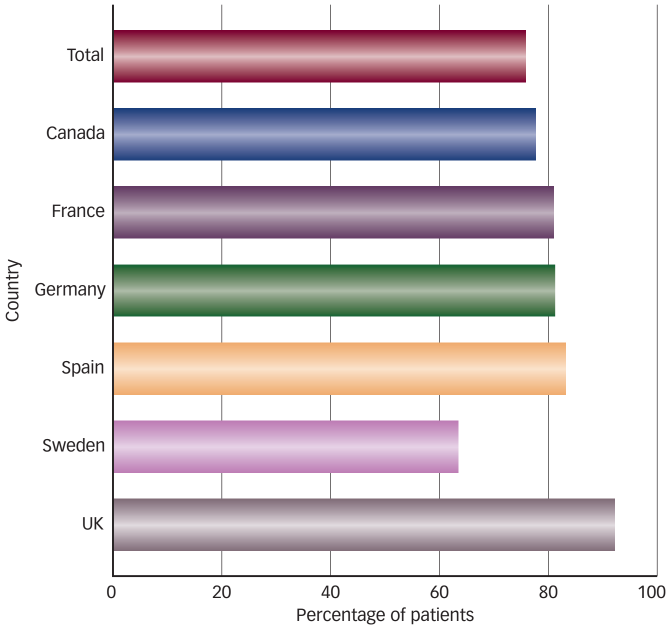
		Gender	
Country	Patients (%)	Male n (% of country)	Female n (% of country)
Canada	50 (11.5)	25 (50.0)	25 (50.0)
France	70 (16.1)	31 (44.3)	39 (55.7)
Germany	53 (12.1)	28 (52.8)	25 (47.2)
Spain	51 (11.7)	18 (35.3)	33 (64.7)
Sweden	159 (36.5)	45 (28.3)	114 (71.7)
UK	53 (12.1)	34 (64.2)	19 (35.8)
Total	436	181	255

n = number of patients. % of country = proportion of male and female patients present in each country.

Table 2: Comparison of Significance, Incidence, Changing Severity and Time to Follow-up Assessment of Mobility Impairment by Age

	Age Range				
	16–24	25–34	35–44	45–54	55+
Number of patients (%)	7	21	25	29	18
Patients for whom mobility impairment is a significant problem (%)	72	78	74	77	77
Patients experiencing mobility impairment daily (%)	31	43	47	64	86
Patients experiencing increased mobility impairment in the previous 12 months (%)	45	51	50	45	56
Patients experiencing decreased mobility impairment in the previous 12 months (%)	28	18	20	14	5
Mean time to follow-up assessment of mobility (days)	117	126	173	257	508

Figure 1: Patients' Responses When Asked if Mobility was a Significant Problem*



**Patients' responses when asked the question 'How significant a problem is mobility for you?' High scores were ≥4.0 (on a scale of 1–6, where one is not at all significant and six is extremely significant). Data are presented as % of patients.*

anonymous survey entitled 'Mobility in MS research: Patient perspectives' was performed by Opinion Matters (London, UK) and was validated to ensure compliance with the guidelines of the European Society of Opinion and Marketing Research (ESOMAR) and The Market Research Society's Code of Conduct 2010. The survey was translated so that patients could read it in their own language and was conducted online to enable respondents to complete the survey in their chosen environment and in their own time. Completion of the survey took approximately 10 minutes. The only criterion for participation was that patients had to have been diagnosed with MS and have some experience of mobility impairment, although a clinical score of the severity of patient mobility was not recorded. It is important to note that 'mobility' was not specifically defined in this survey. A total of 436 participants out of 512 randomly selected patients completed the questionnaire between 4 June 2010 and 29 June 2010 (see *Table 1*). Data are representative of the whole sample population unless specifically indicated. On questions where patients were asked to score their response on a scale from 1–6, where 1 = low score and 6 = high score, mean scores ≥4.0 were viewed as being significantly positive. 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

Patient Demographics

The average time from disease onset for patients participating in the survey was 11 years and three months. The sample population comprised three different disease classes: relapsing-remitting (45 %), primary-progressive (14 %) and secondary-progressive (41 %). Participants' ages ranged from 16 to >55 years (see *Table 2*). The gender split was 42 % male and 58 % female, but considerable variation in gender breakdown was observed between countries (see *Table 1*).

The Impact of Multiple Sclerosis on Mobility

Mobility impairment can begin early in the disease. Nearly one in two (45 %) of patients surveyed reported to have experienced mobility issues within the first month following diagnosis, with women (51 %) more likely to be affected at this early stage than men (37 %). Within one year of diagnosis, 58 % of patients reported problems, within two years 67 %, within five years 84 % and within 10 years 93 %. Markedly more patients reported mobility impairment in Germany and France (98 % and 97 %, respectively) within the first 10 years of diagnosis than in the UK (89 %).

The majority of patients (76 %) considered mobility to be a significant problem. Men considered mobility to be a greater issue than women (86 % versus 69 %, respectively), but scores ≥ 4.0 were remarkably similar across all age groups (see *Table 2*). Considerably more patients rated mobility as a significant problem in the UK than in Sweden (see *Figure 1*; 92 % versus 63 %). Provided with a selection of words to describe their current feelings about mobility impairment owing to MS (see *Table 3*), the five most commonly chosen words were 'limited', 'frustrated', 'powerless', 'challenged' and 'accepting'. Words with more negative associations such as 'angry', 'depressed', 'helpless', 'pessimistic', 'demoralised' and 'frightened' were less frequently chosen (see *Table 3*).

Symptoms Affecting Mobility

MS patients reported that several symptoms affected mobility, including weakness in the legs (81 %), fatigue (73 %), difficulty walking

(69 %), lack of balance and coordination (67 %), slowness in movement (59 %), numbness in the legs (54 %) and dropping of one foot or dragging one foot behind the other (41 %). Although these symptoms were common to the majority of patients, some gender differences were noted. Women were more likely than men to suffer from fatigue (79 % versus 65 %, respectively) and to complain of balance and coordination problems (71 % versus 62 %, respectively). In general, apart from numbness in the legs, the number of patients reporting each symptom increased as their age increased.

The majority (81 %) had difficulties with mobility at least once a week, with more than half of patients (57 %) experiencing mobility impairment every day. Only 2 % of patients experienced problems less than once every six months. There was no difference in the daily incidence of mobility impairment between men and women (55 % versus 59 %, respectively), while older patients had a higher incidence of daily mobility impairment than younger patients (see *Table 2*). The majority of Swedish patients reported daily mobility impairment (81 %). In the previous 12 months, 49 % of patients considered that their mobility impairment had become more of an issue, whereas 35 % stated that their mobility impairment was unaltered and 16 % considered mobility impairment was less of an issue. The increase in mobility impairment was similar in men and women (52 % versus 48 %, respectively) and across age groups (see *Table 2*), although fewer patients aged 55 years and over reported a lessening of mobility impairment than those aged 16–24 years (see *Table 2*). Increased severity of mobility impairment was reported more by patients in the UK and France and least by patients in Canada (see *Table 4*).

Contact with Healthcare Professionals, Clinical Management and Treatment Options

A previous study in the US found that ~72 % of MS patients saw a neurologist for their usual MS-related care.[28] In this survey of European and Canadian residents, patients stated that they most commonly discussed their mobility issues with a hospital doctor or consultant specialising in MS, followed by a primary care physician (PCP), general practitioner (GP) or family practitioner (FP), a rehabilitation specialist or physiatrist and a specialist MS nurse (see *Table 5*). Women were more likely than men to seek mobility advice from neurologists, PCPs/GPs/FPs, physiatrists and MS specialist nurses, whereas men were more likely than women to seek advice from a private physiotherapist, private doctor or nurse (see *Table 5*). The vast majority of patients aged 55 years or more had contacted a neurologist (89 %), considerably more than younger patients (55 % in patients aged 16–24 years). In Sweden, almost all patients (93 %) had discussed mobility with a neurologist, and were also more likely to visit a physiatrist (68 %).

Of all the treatment options offered to patients to manage their mobility issues (see *Figure 2*), physiotherapy was the most commonly offered (67 %), followed by crutches or walking sticks (45 %) and wheelchairs (35 %). Those aged ≥45 years were more likely to be offered physical therapies (physiotherapy, crutches or walking sticks, walking frames, wheelchairs and yoga) but less likely to be offered drug-related therapies (muscle relaxants, onabotulinumtoxin A [Botox], steroids, 4-aminopyridine, methoxyphenyl and Ritalin). Patients in Sweden were most likely to be offered physical therapies, whereas those in the UK were most likely to be offered drug-related therapies. The greatest proportion of participants had follow-up assessments to monitor mobility at yearly intervals (23 %), while 15 % had monthly and 13 % twice yearly assessments; 7 % of patients had follow-up assessments less than once a year. The mean time to a follow-up assessment was 244 days, and was considerably longer in women than in men (285 days versus 187 days, respectively). Time to

Table 3: Patients' Descriptions of Their Difficulties with Mobility as a Result of Their Multiple Sclerosis*

Selected word	Patients % (n)
Limited	51 (220)
Frustrated	34 (148)
Powerless	30 (131)
Challenged	30 (129)
Accepting	25 (108)
Concerned	24 (106)
Angry	22 (97)
Depressed	21 (90)
Unhappy	19 (83)
Unsure	18 (79)
Anxious	15 (67)
Insecure	14 (62)
Helpless	14 (60)
Calm	12 (53)
Pessimistic	11 (46)
Demoralised	10 (45)
Embarrassed	10 (45)
Frightened	9 (38)
Confused	6 (25)
Indifferent	5 (20)
Other	4 (17)
None of the above	0 (1)

** Patients' responses when asked the question 'From the following words, please select up to five that best describe how you currently feel about difficulties with mobility as a result of your MS'.*
n = number of patients.

Table 4: Change in Severity of Mobility Difficulties in the Preceding Twelve Months

	Patients % (n)		
Country	More Severe	Less Severe	No Change
Overall	49 (215)	16 (68)	35 (153)
Canada	22 (11)	22 (11)	56 (28)
France	62 (43)	14 (10)	24 (17)
Germany	47 (25)	25 (13)	28 (15)
Spain	31 (16)	20 (10)	49 (25)
Sweden	52 (83)	10 (16)	38 (60)
UK	70 (37)	15 (8)	15 (8)

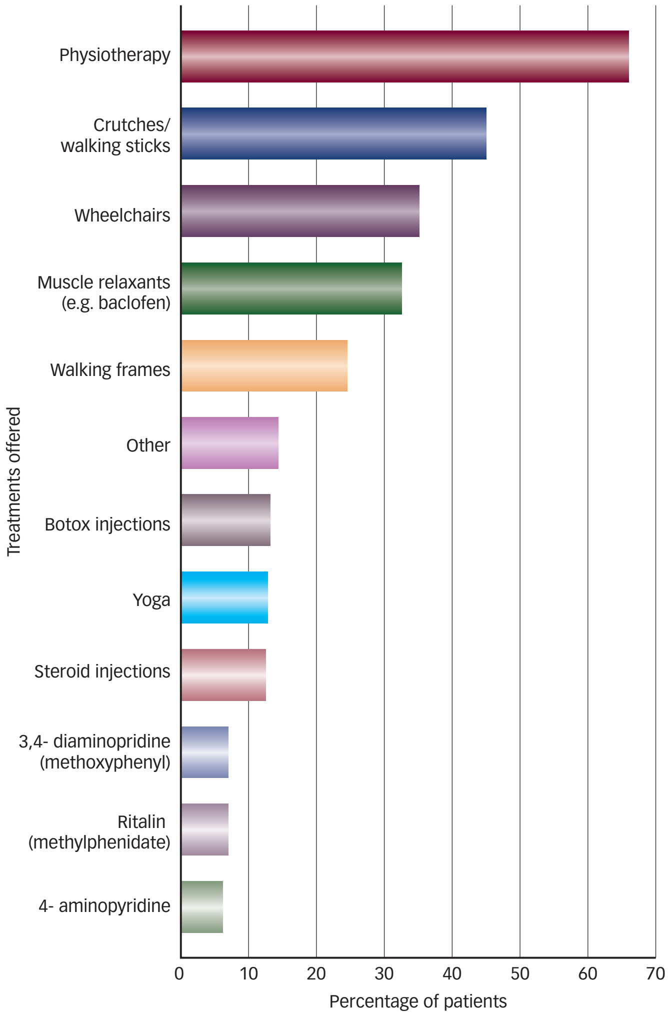
n = number of patients.

Table 5: Types of Healthcare Professionals With Whom Patients Discussed Their Mobility Difficulties

Type of HCP	Total (%)	Male (%)	Female (%)
Hospital doctor/ specialist MS consultant	71	60	79
PCP/GP/FP	39	37	41
Physiatrist	38	34	42
Specialist MS nurse	38	35	40
Private physiotherapist	24	28	21
Private doctor/specialist	22	27	18
Patient association	19	23	17
Nurse	19	24	16
Other	8	3	11

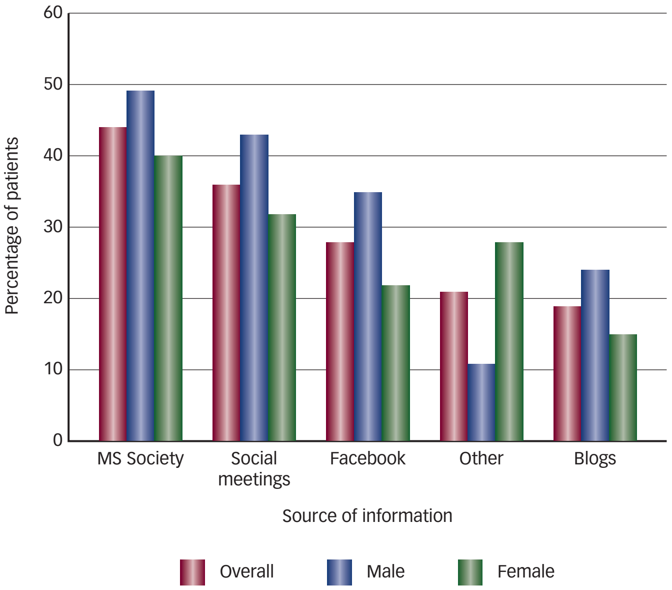
FP = family practitioner; GP = general physician; HCP = healthcare practitioner; MS = multiple sclerosis; PCP = primary care physician.

Figure 2: Patients' Responses When Asked Which Treatment They Were Offered*



*Patients' responses to the question 'Which of the following treatment options have you been offered to manage your difficulties with mobility?' Data are presented as % of patients.

Figure 3: Patients' Responses When Asked How They Discuss Mobility with Other Multiple Sclerosis Patients*



*Patients' responses to the question: '[How] Do you share your experience of mobility difficulties with other multiple sclerosis (MS) patients?'

follow-up assessment was also considerably longer in older than younger patients (see *Table 2*). Furthermore, time to follow-up assessment varied considerably between countries, ranging from 39 days in the UK to 474 days in Sweden.

Impact on Working Life

Almost three-quarters of patients (72 %) stated that mobility problems had significantly affected their working life, with the highest proportion of patients observed in Spain and the UK (86 % and 83 %, respectively). Of these patients, 61 % had not worked at all in the preceding six months, and 39 % had taken a mean number of 16 days off work. Of the patients whose work life had been affected by mobility impairment, more women than men had not worked in the preceding six months (64 % versus 58 %, respectively), more older patients had not worked than younger patients (55+ years: 78 %; 16–24 years: 59 %) and the greatest number of people who had not worked were in Spain (75 %). Of the entire sample population, 64 % believed they had lost earnings owing to mobility impairment (mean score ≥ 4.0 on a scale where 1 = I do not agree at all, 6 = I agree completely), with considerably more in the UK and France (74 % and 73 %, respectively). Importantly, 83 % of the patients who had worked in the preceding six months considered their colleagues to be supportive (mean score ≥ 4.0 on a scale where 1 = not at all supportive, 6 = extremely supportive), a noteworthy finding since the attitudes of co-workers can affect the employment status of MS patients.[10] The greatest level of support was observed in Canada, and the lowest in Sweden (100 % and 63 %, respectively).

Impact on Family and Social Life

When asked about the impact of their mobility impairment on family life, 65 % of patients stated that their family life had been affected by their mobility issues (mean score ≥4.0 on a scale where 1 = not all significant, 6 = extremely significant), with patients in the UK declaring the greatest effect (91 %). Almost two thirds of patients (62 %) agreed that mobility impairment had had a negative impact on their sexual or romantic relationships, whereas 36 % agreed that their mobility issues had left them contemplating suicide (mean score ≥ 4.0 on a scale where 1 = I do not agree at all, 6 = I agree completely). In terms of social life, 70 % of patients believed it had been significantly affected by their mobility impairment (mean score ≥ 4.0 on a scale where 1 = not at all significant, 6 = extremely significant), with the greatest number in the UK (83 %). When communicating and sharing their experiences of mobility difficulties, most did so through their local MS society, followed by social meetings, social networking sites such as Facebook and Twitter and blogs. All forms of communication were more commonly used by men than women (see *Figure 3*) whereas older patients were more likely to use MS societies than younger patients. Perhaps unsurprisingly, Facebook/Twitter and blogs were more commonly used by younger patients (41 % and 31 % in those aged 16–24 years, respectively) than older patients (9 % and 3 % in those aged 55+ years, respectively). Facebook/Twitter and blogs were most popular in the UK (45 % and 34 %, respectively).

Discussion

The Mobility in MS research: Patient perspectives study has provided a valuable assessment of mobility issues in MS from the patients' point of view and has highlighted considerable geographical-, gender- and age-related differences. Although an experience of mobility impairment owing to MS was a criterion for inclusion in the survey, the speed of onset of mobility impairment (within a month for 45 % of patients and within two years for 67 %) and the appearance of mobility difficulties in almost all patients within 10 years of diagnosis, confirm previous reports on the progressive deterioration of mobility in this disease.[21,22] Moreover, the fact that mobility was seen as an issue across all ages again confirms previous findings.[7,23,24] As this was a survey of patients' perceptions of mobility impairment, it did not request clinical information, such as EDSS scores or other mobility assessments; thus, data are not available to compare clinical and perceived measures of disability. Nevertheless, it is clear that mobility impairment is a significant problem for MS patients, as demonstrated by the high percentage who reported daily and weekly mobility difficulties. Interestingly there were some differences in perceived mobility issues between men and women. Men reported a greater number of significant mobility difficulties than women, while women reported greater levels of fatigue. One possible cause for the increased incidence of mobility problems in men may be work-related. Although participants in this survey were not specifically asked whether they were employed, more women than men had been unemployed in the preceding six months (64 % versus 58 %, respectively, substantially higher than the unemployment rates in the countries surveyed). Furthermore, previous studies have indicated that men with MS are more likely to be employed, either full- or part-time, than women, irrespective of the severity of mobility impairment.[6,9] A greater incidence of fatigue has been previously documented in women,[29,30] but this is not a universal finding[31,32] and possible reasons for this discrepancy are not clear. Evident differences were also observed between different countries, for instance mobility impairment was more of an issue for patients in the UK than in Sweden. Country-specific variations in mobility impairment may depend on a host of possible causes including differences in definitions, perceptions and attitudes to mobility impairment symptoms; infrastructure and structure and organisation of healthcare systems and policies. The impact of mobility impairment may also be affected by the extent of support networks including social security and welfare systems; cultural and historical background such as a day-to-day dependency on ambulation and rural or urban residency.

In this study, the majority of patients stated that they discussed their mobility issues with HCPs, similar to findings in the companion article.[33] These findings differ from the results of a previous survey of MS patients in the US where 39 % of patients reported that they rarely or never discussed mobility issues with a physician.[34] It is possible that methodological differences between the surveys, including wording of the surveys, or participants' interpretation of the questions may be responsible for this discrepancy. However, it is important to note that a specific criterion for participation in this survey was experience of mobility impairment. The point of contact for individual patients, however, was particularly dependent on geographical location. Again this may be owing to the cultural and historical background of individual countries, and the structure, organisation and availability of healthcare and social support systems. Surprisingly, the follow-up time to reassessment of mobility issues varied significantly between countries and was especially long in Sweden. One possible explanation is that most patients in Sweden discussed mobility issues only with hospital doctors or neurologists specialising in MS, whereas in other countries patients discussed their mobility with other HCPs, therefore presenting more opportunities for these assessments. It is also possible, however, that differences in the patients' understanding of what constitutes mobility impairment and what constitutes an assessment may be responsible. Interestingly, the long follow-up times reported by patients in Sweden are supported by the long follow-up times reported by Swedish HCPs in the accompanying survey,[33] indicating that it might be a genuine phenomenon.

Table 6: Healthcare Professionals' and Patients' Ranking of Symptoms of Mobility Impairment

	Ranking	
Symptom	Healthcare Professionals	Patients
Weakness in the legs	3=	1
Numbness in legs	5	6
Slowness in movement	7	5
Difficulty walking	2	3
Lack of balance/co-ordination	1	4
Fatigue	3=	2
Dropping one foot or dragging one foot behind the other	6	7

Symptoms are ranked in order of prevalence where 1 = most prevalent and 7 = least prevalent.

Mobility impairment was shown to have a significant effect on working life in the majority of patients, with approximately two thirds of respondents believing that mobility difficulties had contributed to a loss of earnings, similar to previous findings.[6,9–11] Again, there were significant geographical differences in the number of patients for whom mobility difficulties affected working life. Such variations may reflect differences in cultural and historical background and also social security systems, as well as the presence and availability of facilities to keep people in work and legal and financial support for the unemployed. Between 60–70 % of patients also believed that mobility difficulties significantly impacted on their family and social lives,[2] with approximately one third exhibiting suicidal ideation.[35,36] It is interesting to note that many patients are now turning to new social networking media to communicate their experiences with mobility impairment. However, local MS societies clearly remain an integral part of MS management and communication.

When asked to choose words that describe their current feelings about mobility-related issues, the five words most frequently chosen by patients ('limited', 'frustrated', 'powerless', 'challenged' and 'accepting') had fewer negative connotations than some of the words less often chosen ('angry', 'helpless', 'depressed', 'demoralised' and 'frightened'). The choice of 'accepting' in particular suggests that most patients are resigned to having mobility difficulties, but they are inclined to take action to prevent it interfering with their everyday lives as much as possible.[37]

Comparing Impact of Mobility Impairment in Multiple Sclerosis – Patients' versus Healthcare Professionals' Perspectives

Irrespective of any inconsistencies in methodology, the parallel commissioning of two surveys, one targeting HCPs[33] and the other targeting MS patients, enables the broad comparison of each groups' perspectives on the impact of mobility difficulties for MS patients. Such comparisons are rare in the published literature,[38] but may provide valuable insights. When comparing the two surveys, there were clear discrepancies between HCPs' and patients' perspectives on the impact of mobility impairment. Perhaps surprisingly, neurologist and neurology nurses in a recent survey believed that only 56 % of MS patients under their care experienced mobility issues.[33] Although this is similar to previous findings,[5,16] higher values have also been reported.[3,39] The incidence reported by HCPs is less than the number of patients who reported significant mobility problems (76 %), although a specific criterion for inclusion in the present survey was mobility impairment. It is conceivable that the incidence of mobility difficulties in the patients seen by the HCPs was unusually low. However, it is also possible that mild mobility issues went unrecognised[19] and were therefore underreported by HCPs. In previous studies, discrepancies between HCPs' and patients' perspectives, or clinical- and patient-specific outcome measures, on the impact of impaired physical function on QoL have been documented,[40–42] although in no instance was mobility specifically examined. Despite this apparent discrepancy between HCPs and patients, most HCPs did consider that mobility impairment had a significant impact on patients' lives, particularly on patient's working life.[33] Furthermore, HCPs believed that most patients wanted help to combat their mobility difficulties.

When ranked by order of prevalence, there were clear differences in HCPs' and patients' perceptions of the severity of individual symptoms of mobility impairment (see *Table 6*). Furthermore, there were also significant differences in how often different treatments were offered. Almost uniformly, HCPs stated that they offered treatments more frequently than patients said they had been offered them. For instance, although physiotherapy was the most commonly offered treatment in both surveys, 94 % of HCPs stated that they had offered it, but only 67 % of patients said it had been offered to them. A similar discrepancy was observed for crutches or walking sticks (HCPs: 74 %; patients: 45 %) and wheelchairs (HCPs: 65 %; patients: 35 %). Discrepancies were also apparent in the follow-up time to reassessment of mobility. The greatest proportion of HCPs monitored mobility every six months, whereas the greatest proportion of patients reported monitoring yearly. An important and consistent finding, despite the difficulty in drawing exact comparisons between the two surveys, was that both HCPs and patients considered that mobility had a significant impact on working life. In addition, both surveys demonstrate that HCPs and patients believe mobility impairment has a significant effect on family and social lives.

Conclusions

The findings presented in this study confirm the significance that MS patients place on their mobility impairment, irrespective of gender, age and geographical location. The severity of mobility impairment on working, family and social lives, and the apparent paucity of therapeutic options offered, indicate that long-term management of mobility issues remains fundamental to improve patients' QoL. Taken together with the findings of the companion survey, considerable differences exist between HCPs' and patients' perceptions of the importance of mobility impairment on patients' lives. Furthermore, substantial differences in the clinical management of patients' mobility are apparent, depending primarily on the geographical location of individual patients. Comparisons of the HCPs' and patients' surveys suggest that patients' perceptions of their mobility impairment are just as important as clinical outcome measures in the successful management of their mobility difficulties. Only through the concerted effort of all HCPs involved in the treatment of MS, and the development of new or improved therapeutic options, can mobility impairment be adequately monitored, assessed and controlled for the benefit of MS patients. ■

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