DX27

Patient–reported experience measures and outcomes in multiple sclerosis

Nikki Embrey,[1] Delyth Thomas,[2] Laura Parkes[3]

[1]University Hospital of North Staffordshire NHS Trust, Staffordshire, UK; [2]Wye Valley NHS Trust, Hereford, UK; [3]Merck Serono Ltd, UK*†

27th Annual Meeting of the CMSC and the 5th Cooperative Meeting of the CMSC-ACTRIMS; May 29–June 1, 2013; Orlando, Florida

Introduction

- Multiple sclerosis (MS) is a chronic, progressive, neurodegenerative disease that can affect physical and/or cognitive functioning in patients.[1]
- Disease-modifying drugs (DMDs) can reduce the frequency of disease exacerbations and inflammation in MS, as shown by magnetic resonance imaging.[2] Certain agents may also delay disability progression.[2]
- The Merck Serono PROMs (Patient-Reported Outcome Measures) Survey is an ongoing, observational, prospective, cohort survey of UK patients newly diagnosed with relapsing MS receiving an injectable DMD (subcutaneous [sc] interferon [IFN] β-1a [Rebif®, Merck Serono S.A., Switzerland†] or 'other DMD'), which aims to evaluate patient-reported outcomes and patient satisfaction with the available support services.
  - PROMs aim to establish patients' views of their symptoms, functional status, and health-related quality of life (HRQoL),[3] and are assessed using validated instruments and scales.
  - Patient-reported experience measures (PREMs) focus on the humane aspects of patient care, such as being treated with dignity or being kept waiting. Examples of PREM questions include rating of the patient's consultant and/or MS Specialist Nurse on a 5-point scale from "very poor" to "very good" with regard to their personal manner (courtesy, respect, sensitivity, friendliness), how well they listened to what the patients had to say about their MS or treatment, and their practical skills (expertise, degree of care, thoroughness), as well as the patients' views on the type and amount of information provided to them.
  - Use of these types of measures helps to increase patient involvement in the treatment process and avoid observer bias.[3]

Objective

- To establish the impact of DMDs and associated support services on PROMs and PREMs in MS.

Methods

- Independent homecare companies, responsible for delivering prescription medications directly to patients with MS in the UK, are administering online questionnaires to patients at baseline and every 12 weeks thereafter, up to a maximum of 96 weeks.
- The baseline questionnaire is completed before the patients receive their first injection.
- Patients are given up to 4 weeks to complete each follow-up questionnaire.
- The study is designed to assess treatment satisfaction with sc IFN β-1a versus 'other DMD'; HRQoL using the generic EuroQoL (EQ-5D) questionnaire; experience of support services; and the impact of MS on work productivity and activity impairment.
  - EQ-5D is a generic HRQoL instrument for deriving utility values of health states with five descriptive response levels (EQ-5D-5L).[4,5] The EQ-5D self-reported questionnaire includes a visual analog scale (VAS), which records the respondent's self-rated health status on a graduated (0–100) scale, with higher scores for higher HRQoL.
  - The Work Productivity and Activity Impairment (WPAI) index is a generic measure of work productivity[6] with the ability to be adapted to include disease-specific terminology. It is expressed as impairment percentages, with higher numbers indicating greater impairment and less productivity.
- According to the nature of the variables, parametric (Student *t*-test) or nonparametric tests (Mann–Whitney U test) were used to compare continuous variables, and the chi-square test was used to compare categorical variables, in this interim analysis.

Results

- Recruitment into this survey is ongoing. The final number of patients is anticipated to be 500 (250 patients in each cohort).
- A description and comparison of characteristics of an initial cohort of patients is reported in this interim analysis.
- A total of 168 patients are included in this analysis: 62 receiving sc IFN β-1a and 106 receiving 'other DMD'.
- The majority of participants were female (75%) and white (94%); the mean age was 38 years (**Table 1**).

Table 1. Baseline patient demographics.

	sc IFN β-1a (n=62)	Other DMD (n=106)	Overall (N=168)	p-value
Sex, n (%)				
Female	47 (75.8)	79 (74.5)	126 (75.0)	0.8535
Ethnicity, n (%)				
White/Caucasian	62 (100.0)	96 (90.6)	158 (94.0)	0.2855
Afro-Caribbean	0	3 (2.8)	3 (1.8)	
Middle Eastern	0	1 (0.9)	1 (0.6)	
Asian – Indian subcontinent	0	2 (1.9)	2 (1.2)	
Asian – other	0	3 (2.8)	3 (1.8)	
Other	0	1 (0.9)	1 (0.6)	
Age, years				
Mean (SD)	38.79 (7.88)	38.08 (8.62)	38.35 (8.34)	0.7199
Median	39.0	38.5	39.0	

DMD, disease-modifying drug; IFN, interferon; sc, subcutaneous; SD, standard deviation.

Table 2. Patient ratings of MS nurses, taking into account NHS consultations.

	sc IFN β-1a (n=62)	Other DMD (n=106)	Overall (N=168)	p-value
Personal manner (courtesy, respect, sensitivity, friendliness)				
Very poor	0	1 (1.0)	1 (0.6)	0.2408
Poor	0	0	0	
Fair	0	3 (3.1)	3 (1.9)	
Good	7 (12.5)	20 (20.4)	27 (17.5)	
Very good	49 (87.5)	74 (75.5)	123 (79.9)	
How well they listened to what you had to say about your MS or your treatment				
Very poor	0	2 (2.0)	2 (1.3)	0.5048
Poor	0	1 (1.0)	1 (0.6)	
Fair	1 (1.8)	4 (4.1)	5 (3.2)	
Good	8 (14.3)	19 (19.4)	27 (17.5)	
Very good	47 (83.9)	72 (73.5)	119 (77.3)	
Practical skills (expertise, degree of care, thoroughness)				
Very poor	0	1 (1.0)	1 (0.6)	0.5636
Poor	0	2 (2.0)	2 (1.3)	
Fair	1 (1.8)	1 (1.0)	2 (1.3)	
Good	10 (17.9)	24 (24.5)	34 (22.1)	
Very good	45 (80.4)	70 (71.4)	115 (74.7)	

Data shown as n (%).
DMD, disease-modifying drug; IFN, interferon; MS, multiple sclerosis; NHS, National Health Service; sc, subcutaneous.

- At baseline, the EQ-5D score (assessed on the VAS) for the whole population was 73.21, equating to a utility of 0.71. There was no significant difference between the sc IFN β-1a and 'other DMD' groups (p>0.05).

Table 3. Patient responses to whether their diagnosis and possible treatment options were discussed with them when they were first referred to the NHS.

	sc IFN β-1a (n=62)	Other DMD (n=106)	Overall (N=168)	p-value
Yes, and I completely understood what was said	27 (48.2)	35 (35.7)	62 (40.3)	0.3788
Yes, and I understood some of what was said	20 (35.7)	49 (50.0)	69 (44.8)	
Yes it was discussed, but I did not understand what was said	2 (3.6)	3 (3.1)	5 (3.2)	
No it was not discussed at all	7 (12.5)	11 (11.2)	18 (11.7)	
I did not want to discuss it	0	0	0	

Data shown as n (%).
DMD, disease-modifying drug; IFN, interferon; NHS, National Health Service; sc, subcutaneous.

Table 4. Patient responses regarding the information received about treatment options.

	sc IFN β-1a (n=62)	Other DMD (n=106)	Overall (N=168)	p-value
Written information?				
n	56	98	154	
Yes	40 (71.4)	67 (68.4)	107 (69.5)	0.6915
No	16 (28.6)	31 (31.6)	47 (30.5)	
If yes, name the source[a,b]				
NHS	20 (50.0)	31 (46.3)	51 (47.7)	0.7085
Drug manufacturer of your DMD	16 (40.0)	21 (31.3)	37 (34.6)	0.3624
MS Trust	17 (42.5)	25 (37.3)	42 (39.3)	0.5950
MS Society	26 (65.0)	39 (58.2)	65 (60.7)	0.4864
Shift.MS	3 (7.5)	1 (1.5)	4 (3.7)	0.1130
MS Decisions website	6 (15.0)	7 (10.4)	13 (12.1)	0.4856
Other internet source	0	0	0	
Other	14 (35.0)	25 (37.3)	39 (36.4)	0.8099
If yes, the information was[a,b]				
n	40	67	107	
Easy to understand	40 (100.0)	64 (95.5)	104 (97.2)	0.1746
Helpful to you	40 (100.0)	64 (95.5)	104 (97.2)	0.1746
Given at the right time	39 (97.5)	61 (91.0)	100 (93.5)	0.1914
If no, would you have found it useful to take written information home with you?[c]				
n	16	31	47	
Yes	13 (81.3)	26 (83.9)	39 (83.0)	0.8208
No	3 (18.8)	5 (16.1)	8 (17.0)	
Kind of information you found to be the most useful[a]				
Leaflets	10 (17.9)	12 (12.2)	22 (14.3)	0.3384
Booklets	11 (19.6)	19 (19.4)	30 (19.5)	0.9693
DVD	10 (17.9)	20 (20.4)	30 (19.5)	0.7006
List of websites for further information	4 (7.1)	11 (11.2)	15 (9.7)	0.4112
Other	0	0	0	

Data shown as n (%).
[a]Patients could give multiple responses to this question.
[b]Percentages calculated using the number of patients who had written information.
[c]Percentages calculated using the number of patients who did not have written information.
DMD, disease-modifying drug; IFN, interferon; MS, multiple sclerosis; NHS, National Health Service; sc, subcutaneous.

- EQ-5D-5L descriptive system scores at baseline showed that 30.1% of patients had moderate or worse problems completing their usual activities; 30.2% had moderate or worse problems walking; 25.2% were experiencing moderate or worse levels of pain or discomfort; and 18.2% were moderately or more anxious or depressed.
- According to the WPAI index, 122 (76.7%) patients were currently in paid employment. There was no significant difference in work-related impairment. At baseline, total mean time missed from work was 14.6%, mean percent impairment while working was 26.4%, and mean impairment in non-work activity due to health during the previous 7 days was 39.0%.
- Generally, patients rated their MS nurses as "very good" in terms of personal manner, listening, and practical skills (**Table 2**).
- Few patients (3.2%) were unable to understand explanations about diagnosis and treatment options during their National Health Service consultation (**Table 3**).
- Of the 30.5% of patients who did not receive written information about their treatment options, 83.0% thought it would have been useful to do so (**Table 4**).
- The majority (80.5%) of patients said that they do have access to support services, and the preferred methods of accessing these services (in decreasing order of preference) were face-to-face, by telephone, and on the internet.

Conclusions

- This interim report provides an initial overview of patients with MS participating in the PROMs Survey and their baseline responses prior to starting DMD therapy.
- As expected, there were no significant differences in baseline characteristics between patients in the sc IFN β-1a and 'other DMD' group.
- Further data will be reported as they become available.

References

1. Compston A, Coles A. *Lancet* 2008;372:1502–17.
2. PRISMS Study Group. *Lancet* 1998;352:1498–504.
3. Black N. *BMJ* 2013;346:f167.
4. The EuroQol Group. *Health Policy* 1990;16:199–208.
5. Herdman M *et al. Qual Life Res* 2011;20:1727–36.
6. Reilly MC *et al. PharmacoEconomics* 1993;4:353.

Acknowledgments

Disclosures