Comparing patient and healthcare professional perceptions on multiple sclerosis management and care – where do their priorities differ? Results from a qualitative survey

Introduction
- The MS in the 21st Century initiative, formed in 2011, is comprised of a group of international multiple sclerosis (MS) specialists.
- In 2015, the group was expanded to include MS patient advocates, thus creating a Steering Group that provided a combined perspective from healthcare professionals (HCPs) and people with MS (PwMs).
- The Steering Group’s current focus is to improve education and communication between HCPs and PwMs. Other study groups have shown that shared decision making and improved communication resulted in better clinical outcomes and influenced patient satisfaction with treatment.
- In 2016, a Steering Group workshop aimed to identify where HCPs and PwMs perspectives differed within key areas of unmet needs, treatment burden, patient engagement and priorities of care.
- Following this workshop, the Steering Group decided to investigate whether there were differences in priorities and perceptions between the groups and how this may affect disease management.

Objectives
- To compare the priorities of HCPs and PwMs with respect to MS management and care.
- To identify disparities between HCP and PwM perceptions on communication barriers and unmet needs in MS care.

Method
- A 10-question electronic survey was developed by the Steering Group to evaluate HCPs’ opinions on unmet needs in MS care. Respondents were able to select multiple answers to 9 out of the 10 questions.
- Surveys were undertaken at 4 international neurology congresses – ECTRIMS 2016, ICCMS 2017, CCO 2017 and EIMP 2017.
- An equivalent patient survey was conducted at EIMP 2017, ICCMS 2017 and the Merck MS Patient Ambassador Summit 2017.
- The surveys emphasised expertise of patient support, including at diagnosis, shared treatment decision making, and disease progression and communication.

Results

Patient support, including at diagnosis
- A total of 162 HCPs and 108 PwMs completed the survey. Respondents could select one or more answers to the questions.
- The majority of HCPs (79.7%, n=128) and PwMs (85.2%, n=92) reported at least one communication challenge at diagnosis (Figure 1).
- Lack of time with the patient was the communication challenge most frequently reported by HCPs (31.2%, n=57) and PwMs agreed that this is a significant barrier (27.5%, n=49) (Figure 1).
- Along with lack of time during interactions, the communication challenges most frequently reported by PwMs were: difficulty in understanding their disease and how it might progress (42.6%, n=46), finding emotional support (38.5%, n=41), understanding their treatment options (38.2%, n=42), and lack of good quality patient materials (32.4%, n=35) (Figure 1).

Shared treatment decision making
- PwMs were of varied opinion with respect to how involved they would like to be in decisions about their treatment, indicating the requirement for personalised communication. While 32.4% (n=33) of PwMs indicated that they were happy to let their doctors make decisions about their treatment, 38.9% (n=42) said they like to participate in the final decision and 23.1% (n=25) said they would like to be more involved but lack the time to participate (Figure 2).

Disease progression and communication
- One of the most striking results was the number of PwMs (1 in 4) who reported that they had not discussed disease progression in the last 6 months (61.1%, n=99 and 38.9%, n=42 respectively). However, responses were relatively evenly distributed over a number of other possibilities. Treatment decisions are clearly influenced by numerous factors and, as such, need to be highly personalised decisions between patients and their doctors (Figure 5).

Conclusions
- This survey highlighted a number of challenges that HCPs and PwMs face which could negatively impact the standard of MS care provided to patients; the results show that HCPs and PwMs often have different perceptions of their interactions. Given the importance of tailoring communications to the patient, this disconnect is a significant barrier to efficient communication; PwMs’ perceptions may be a greater awareness of this issue than HCPs.
- A notable number of PwMs indicated that their clinics did not provide personal support, proving that there is an opportunity to stimulate further communication at a patient level.
- Most of the striking results were the number of PwMs (1 in 4) who reported that they had not discussed disease progression with their HCP. It is essential to ensure HCPs have the training, time and resources required to facilitate these discussions, so that patients have the education and empowerment to approach these discussions.
- A greater emphasis around joint education of HCPs and PwMs, as well as the production of more patient-focused educational resources, might help to address some of the problems with communication, and help increase shared-decision making during appointments.

Future surveys will focus on the areas identified where HCP and PwMs opinions differ most and aim to provide more detailed country- and discipline-specific sub-analyses.

References
2. Tintoré M et al. 2016. The State of Multiple Sclerosis: Current Insight Into the Patient/Health Care Provider Relationship, Treatment Challenges, and Satisfaction.}

Acknowledgements and disclosures

The MS in the 21st Century initiative is financially supported by Merck KGaA, Darmstadt, Germany. Scientific support and editorial input was provided by Cello Health Communications. Medical writing assistance was provided by Cello Health Communications (Dawn Wells and Fiona Hatch) and was funded by Merck KGaA, Darmstadt, Germany.

Peter Rieckmann receives honoraria for lectures from: Almirall, Apple Healthcare, Baxter, Bayer, Biogen Idec, Boehringer-Ingelheim, Cerner, Daiichi Sankyo, Merck KGaA, Darmstadt, Germany.


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