

Clinicians' perceptions of how current practice meets multiple sclerosis patient needs: results from a qualitative survey

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BACKGROUND

- In 2011, led by a steering group of international multiple sclerosis (MS) specialists, the *MS in the 21st Century* initiative was formed.
- The mission of this group is to define and align MS standards of care worldwide.
- In 2016, the group took a unique step forward and expanded to include a group of patient representatives to incorporate the patient perspective.
- The group's current focus is to improve communication and education between clinicians and people with MS.
- To assist with the development of such programmes, the group conducted a survey to gain a broader perspective on the issues from the clinician perspective. A patient perspective survey is also planned.

OBJECTIVE

The clinician survey aimed to better understand the views of the MS clinical community on unmet needs, treatment burden and disease management.

METHODS

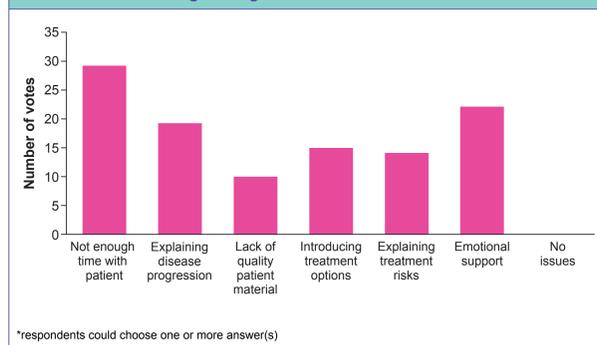
- The steering group discussed and agreed upon a set of six multiple-choice questions.
- The questions focused on three topics: patient support, treatment decisions, and the concept of disease progression.
- These questions were developed into an electronic iPad survey which was piloted among delegates at the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) congress, 2016.

RESULTS

Clinicians' issues experienced at the time of their patients' diagnosis

- The survey received 57 responses from clinicians; all respondents selected at least one challenge at diagnosis.
- The main issue reported was not having enough time with the patient (29%; Figure 1).
- The other most notable issues were explaining disease progression (33%) and offering emotional support (39%).

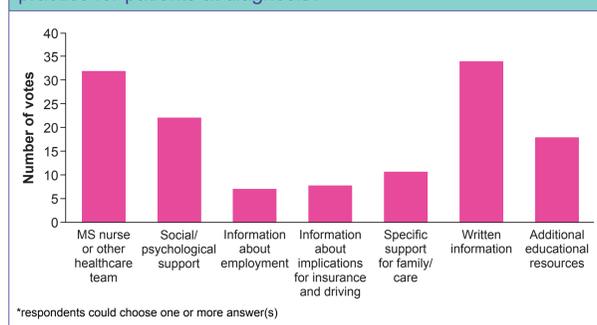
Figure 1. In your opinion, what is the biggest challenge for clinicians when diagnosing MS?*



Support materials available to clinicians for their patients at diagnosis

- When asked about additional support available for MS patients at diagnosis (Figure 2), most respondents indicated that they relied on written information (59%) or MS nurses and other members of their healthcare team (55%).

Figure 2. What type of additional support is available in your practice for patients at diagnosis?*

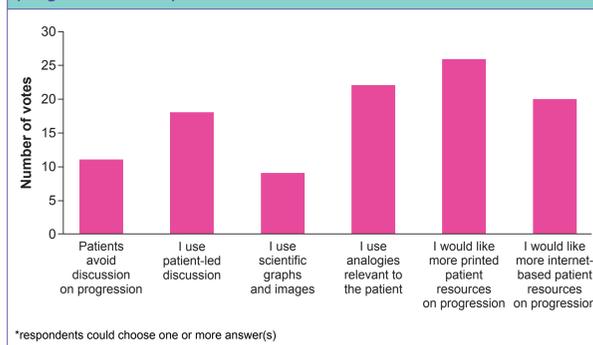


- Other responses highlighted a low proportion of respondents had available information surrounding 'disease-specific' topics, including the impact of a diagnosis on employment (12%), insurance or driving (14%), or support for families or carers (19%).

Clinicians' approaches to describing disease progression to their patients

- There was no clear consensus among respondents regarding how they approached the concept of disease progression with patients (Figure 3).

Figure 3. How do you approach the concept of disease progression with patients?*

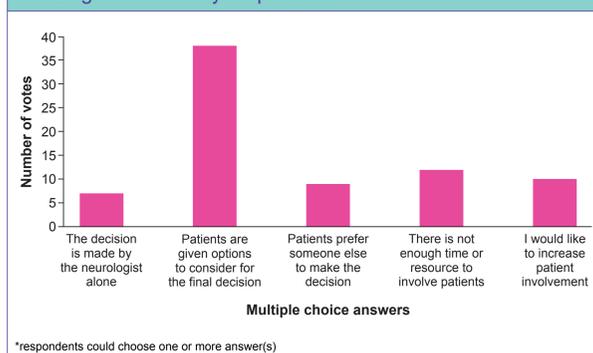


- When asked about their approaches, respondents most often relied on analogies to explain difficult concepts (39%) and on patient-led discussion (32%); the use of scientific graphs and images was the least widespread approach (15%).
- Respondents frequently indicated that they would prefer more printed resources (45%) and more internet-based resources (34%).

Clinicians' involvement of their patients in treatment decisions

- A large proportion (66%) of respondents expressed the importance of patient involvement (Figure 4).
- However, a sizeable proportion of respondents did report a lack of time or resources to accommodate patient involvement (21%), and an interest to include the patient more in treatment discussions (17%).

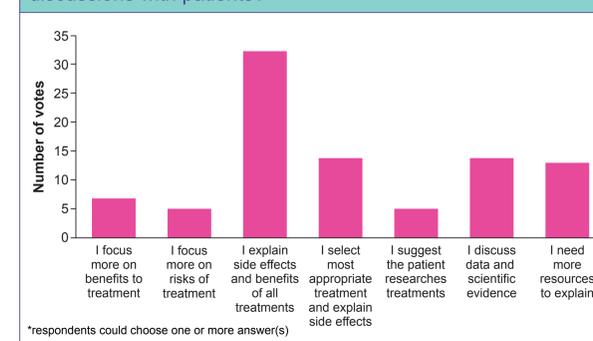
Figure 4. How much involvement do patients have when deciding treatment in your practice?*



Clinicians' approaches to 'risk : benefit' treatment discussions with patients

- When asked about how they described treatment options to patients, most respondents said that they explained side effects and benefits of all treatments (55%) (Figure 5).

Figure 5. How do you approach the 'risk : benefit' treatment discussions with patients?*

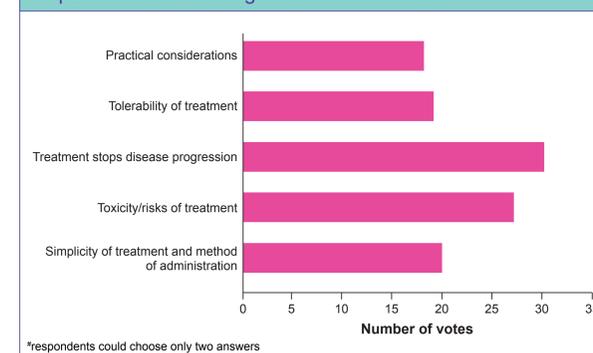


- Other notable responses included using data and scientific evidence (24%) and focusing on explaining side effects of most appropriate treatments (24%).
- A sizeable proportion (22%) of respondents felt that they needed more resources to help explain treatments to patients.

Clinicians' opinions on the most important consideration for patients regarding treatment

- There was no clear consensus from respondents regarding what they thought patients considered the most important factor when making treatment decisions (Figure 6).

Figure 6. What do you feel is the most important consideration for patients when making treatment decisions?*



CONCLUSIONS

- This survey highlighted a number of challenges that clinicians face when communicating with MS patients.
- There was a distinct recognition among clinicians of a lack of time and resources, particularly at diagnosis. Clinicians highlighted that extra time/resource was needed for offering emotional support and to aid disease progression conversations.
- Most striking was the variation in clinicians' perceptions of patients' priorities regarding treatment decisions, and the differences in the manner in which disease progression was discussed with patients.
- Clinicians did not agree on the most important factors for patients; as such, they may not be tailoring conversations accordingly.
- This pilot survey will be developed to seek additional clinician feedback and will be conducted with patients in order to identify differences in perception.
- Once established, the patient priorities will be used to tailor materials and programmes to address those needs.

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MS IN THE 21ST CENTURY MEMBERS

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DISCLOSURES

Peter Rieckmann receives honoraria for lectures from: Almirall, Apple Healthcare, Baxter, Bayer, Biogen Idec, Boehringer-Ingelheim, Cerner, Daiichi Sankyo, Genpharm, Genzyme, Medtronic, Merck Serono, Novartis, Pfizer, Roche, Sanofi-Aventis, Siemens AG and Teva. He receives research grants from: Bayer, EMD Serono, Novartis, Teva, MS Society of Canada, Canadian Institute of Health Research, Hertie Foundation, Oberfranken-Stiftung and German Neurology Foundation. He is on an advisory board or steering committee for: Abbvie, Bayer, Biogen Idec, Novartis, Merck Serono, Teva, German Multiple Sclerosis Society and Canada Drug Review. Elisabetta Verdun Di Cantogno is an employee of Merck KGaA.