Patient involvement in treatment decision-making: a sub-analysis of the ‘MS in the 21st Century international unmet needs survey’ comparing patient and healthcare professional perspectives

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BACKGROUND

• The majority of both HCPs (63.5%, n=66) and PwMS (40.6%, n=43) stated that their treatment decision discussions have led to better clinical outcomes and treatment satisfaction in multiple sclerosis (MS)1,2.

• The ‘MS in the 21st Century’ initiative, established in 2011, includes MS specialists and patient advocates and is focused on improving education and communication between HCPs and patients.1

• An electronic survey was conducted to compare HCP and patient perceptions of unmet need in these key areas: patient support, shared treatment decision-making, disease progression and communication.

OBJECTIVE

• To examine the influencing factors and extent of patient involvement in treatment decision-making and to explore whether HCP perceptions are aligned with these findings.

METHODS

• Comparable HCP and patient surveys were conducted at multiple international congresses between 2016 and 2017.3

• A 10-question electronic survey, developed by the Steering Group to evaluate HCPs’ opinions on unmet needs in MS management, was conducted at six international neurology congresses.

• The equivalent patient survey was conducted at three international congresses and the Merck MS Patient Ambassador Summit 2017.

• Overall results from a dataset of 162 HCPs and 108 patients with MS (PwMS) were presented in 2017.4

• The survey included questions about the importance of factors influencing treatment decisions, how patient involvement impacted treatment discussions, and patient preferences.

• The survey also asked about the usefulness of various formats of information, and patient satisfaction with their involvement in treatment decision-making.

• A greater emphasis around joint education of HCPs and PwMS, as well as the production of more patient-focused resources to help them make these decisions.

• There were striking differences between patient and HCP perceptions of involvement in treatment decision-making.

• As well as wanting more involvement in treatment decisions, PwMS also indicated an interest in having more resources available to them to help make these decisions.

• When asked about the usefulness of various formats of information, PwMS uniformly reported a greater degree of usefulness, than HCPs, for each type of information (except for written resources).

RESULTS

• The dataset included responses from 233 HCPs and 120 PwMS. The questions weren’t compulsory and respondents could select one or more answers to the questions.

• The majority of both HCPs (63.5%, n=66) and PwMS (40.6%, n=43) stated that their treatment decision discussions covered both the risks and benefits of all treatments (Figure 1).

• While 15% (n=10) of PwMS felt that HCPs focused on the risks of treatments, only 3% (n=6) of HCPs agreed with this opinion. This result may indicate the impact of negativity bias on the perception of interactions (Figure 1).

• Almost one in four HCPs (24%, n=25) reported discussing data and scientific evidence during the consultation, compared to just 12.3% of PwMS (n=13) (Figure 1).

• Separately, 16.2% (n=17) of PwMS reported not having discussed treatment risks with their doctors (data not available in HCP responses).

• These results highlight the different perceptions that PwMS and HCPs have about their interactions. The disconnects highlighted here may reflect a difficulty for PwMS to follow complex treatment discussions during an appointment.

• APPRAISALS TO TREATMENT DISCUSSIONS

• HCPs tend to underestimate how many patients have an equal interest in the risks and benefits of treatment, with just 51.0% of HCPs (n=53) reporting this, versus 69.4% of PwMS (n=75) (Figure 2).

• Similarly, while only 15.5% (n=16) of HCPs stated that patient involvement should increase, 26.2% (n=28) of PwMS indicated that they should be more involved (Figure 4).

• The majority of both HCPs and PwMS reported that patients are being included in the final decision about their treatment (64.4%, n=66 and 62.6%, n=47, respectively). However, HCPs underestimated the level of patient involvement (Figure 4).

• While 19.4% (n=20) of HCPs felt that patients preferred to let them make the decision, only 8.4% of PwMS (n=9) stated this is the case (Figure 4).

• Similarly, while only 15.5% (n=16) of HCPs stated that patient involvement should increase, 26.2% (n=28) of PwMS indicated that they should be more involved (Figure 4).

• When asked about the usefulness of various formats of information, PwMS uniformly reported a greater degree of usefulness, than HCPs, for each type of information (except for written resources) (Figure 6).

• As well as wanting more involvement in treatment decisions, PwMS also indicated an interest in having more resources available to them to help make these decisions.

• When asked about the usefulness of various formats of information, PwMS uniformly reported a greater degree of usefulness, than HCPs, for each type of information (except for written resources).

• One of the main findings from this data was the disparity in perception of how treatment benefits and risks are explained. It is essential to ensure that HCPs understand their patient’s priorities and to have the training, tools and time to better these discussions.

• Improved communications between HCPs and PwMS in daily practice may help to address this discrepancy. HCPs should be aware of how factors such as negativity bias can influence patients’ perceptions of their interactions.

• There were striking differences between patient and HCP perceptions of involvement in treatment decision-making. With the patients reporting a desire to have greater involvement in deciding treatment, it is important that they 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.

CONCLUSIONS

• The majority of both HCPs and PwMS reported that patients are being included in the final decision about their treatment (64.4%, n=66 and 62.6%, n=47, respectively). However, HCPs underestimated the level of patient involvement. The disconnects highlighted here may reflect a difficulty for PwMS to follow complex treatment discussions during an appointment.

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DISCLOSURES

REFERENCES

