

Comparing patient and healthcare professional perceptions on multiple sclerosis management and care – a sub-analysis of disease progression perceptions.

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Background

- MS in the 21st Century is an initiative led by a Steering Group comprised of international multiple sclerosis (MS) specialists and patient advocates.
- The Steering Group's current focus is to improve education and communication between healthcare professionals (HCPs) and patients with MS (PwMS). Other study groups have shown that shared-decision making and improved communication resulted in better clinical outcomes and influenced patient satisfaction with treatment^{1,2}.
- In 2016, the Steering Group developed a survey with the aim of identifying key differences in the perspectives of HCPs and PwMS with respect to various aspects of MS care.

Objective

- To compare the priorities of HCPs and PwMS with respect to MS management and care.
- To specifically identify disparities between HCP and PwMS perceptions of how disease progression is communicated.

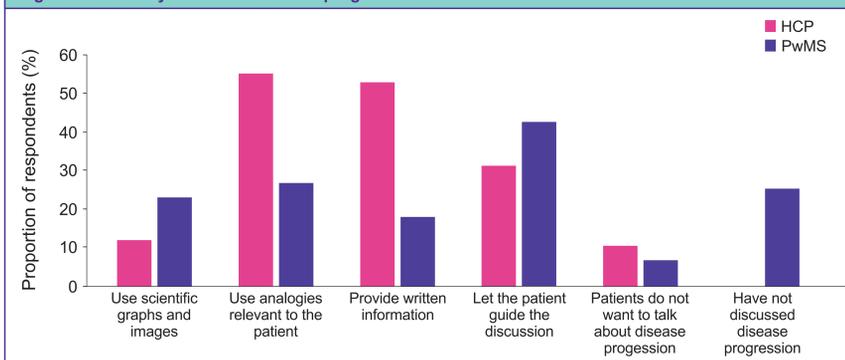
Method

- A 10-question electronic survey was developed by the Steering Group to evaluate HCPs' opinions on various aspects of MS management.
- This survey was then conducted at four international neurology congresses – ECTRIMS 2016, CMSC 2017, CONy 2017, and EMSP 2017.
- An equivalent patient survey was conducted at EMSP 2017, CMSC 2017, and the Merck MS Patient Ambassador Summit 2017.
- The surveys emphasised aspects of patient support relating to diagnosis, treatment decisions, and communicating the concept of disease progression.
- Following analysis of the responses from these events, the survey was adapted to include new questions with a specific further focus on how disease progression is communicated.
- The updated HCP and patient surveys were conducted at ECTRIMS 2017, MS Trust 2017, and CMSC 2018.

Results

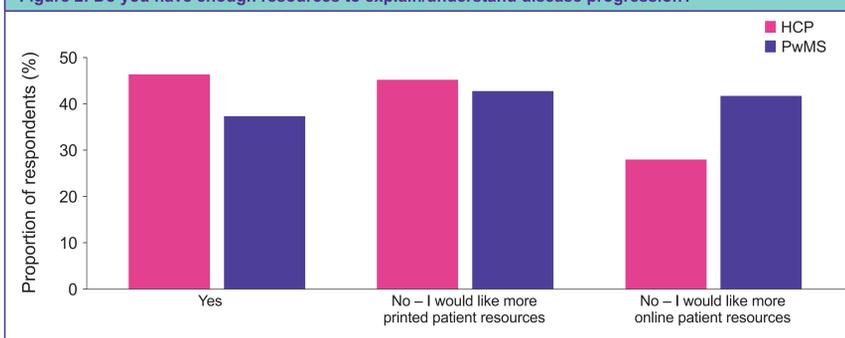
- A total of 196 HCPs and 143 PwMS completed the surveys. Respondents could select one or more answers and the questions were non-compulsory.
- When asked about what form disease progression discussions take, HCPs said that they used analogies relevant to the patient (55.3%, n=57) and provided written information on the topic (53.3%, n=32) (Figure 1).
- PwMS were less likely to agree with these statements with only 27.2% (n=28) saying their HCP used analogies and 18.6% (n=19) saying they had been provided written information on the topic (Figure 1).
- However, PwMS were almost twice as likely (23.3%, n=24) as HCPs (12.6%, n=13) to say that the discussion focussed on scientific graphs and images (Figure 1).
- A high proportion of both HCPs (30.1%, n=31) and PwMS (42.7%, n=44) said that the patient is allowed to guide the discussion (Figure 1).
- A quarter of PwMS (25.5%, n=26) stated that they had not had any discussions with their HCP about disease progression (Figure 1).

Figure 1: How do you discuss disease progression?



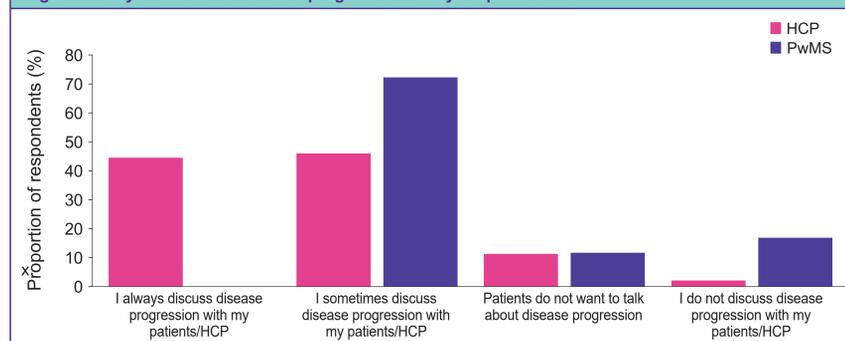
- When asked whether there were enough resources to explain disease progression, both HCPs (45.2%, n=47) and PwMS (42.6%, n=46) said that they would like more printed patient resources (Figure 2).
- However, HCPs and PwMS disagreed on the need for online patient resources with only 27.9% (n=29) of HCPs stating they wanted more compared to 41.7% (n=45) of PwMS (Figure 2).

Figure 2: Do you have enough resources to explain/understand disease progression?



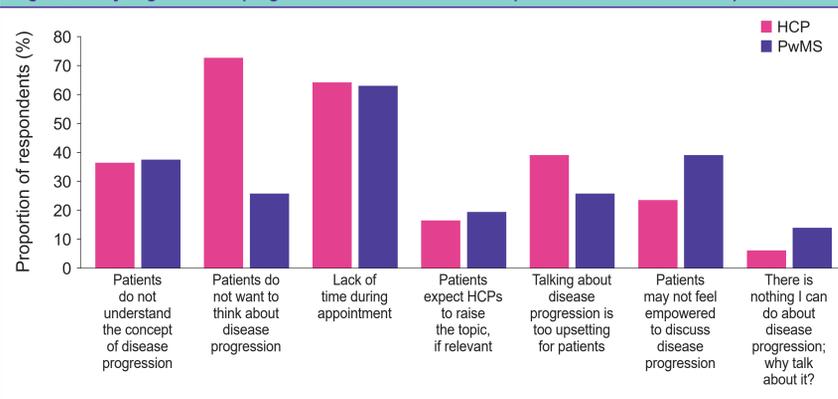
- Following analysis of the results from these two questions, the survey was updated with three new questions aimed at further understanding when and how discussions take place and reasons why, sometimes, they might not.
- When specifically asked if they discuss disease progression in consultations, 44.1% (n=30) of HCPs said that they always discuss the topic, however, not a single patient agreed with this statement (Figure 3).
- The majority of PwMS (72.2%, n=13) said that they sometimes discuss the topic but around a quarter said either that they hadn't (16.7%, n=3) or don't want to (11.1%, n=2) discuss the topic (Figure 3).
- The same proportion of HCPs (10.3%, n=7) stated that patients don't want to talk about disease progression as in the original survey question (10.7%, n=11) (Figures 1 and 3).

Figure 3: Do you talk about disease progression with your patients/HCP?



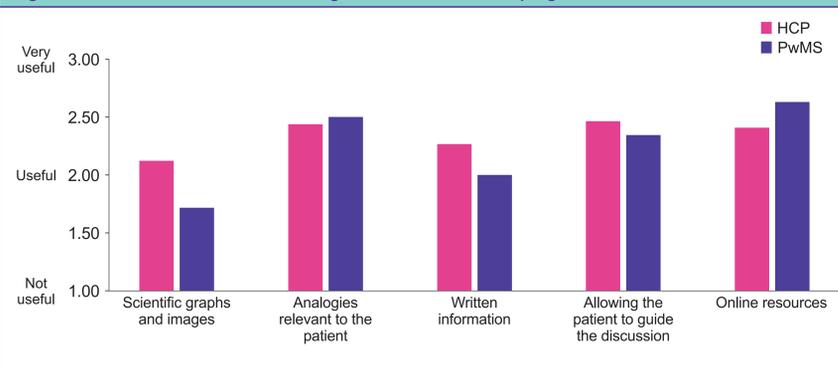
- When asked why, in some cases, these disease progression discussions might not take place a large majority of HCPs (72.0%, n=36) said that patients do not want to think about disease progression. Only 25.0% (n=4) of PwMS agreed with this statement (Figure 4).
- Both HCPs (64.0%, n=32) and PwMS (62.5%, n=10) agreed that one of the biggest barriers preventing disease progression discussions taking place is a lack of time in appointments (Figure 4).
- HCPs and PwMS were aligned on the fact that a lack of patient understanding of the concept of disease progression might prevent effective communication with 36.0% (n=18) of HCPs and 37.5% (n=6) of PwMS listing it as an issue (Figure 4).
- Over half of PwMS (56.3%, n=9) stated that they were either waiting for their HCP to raise the topic of progression if it was relevant to them or that they did not feel empowered to raise it as a topic (Figure 4).

Figure 4: Why might disease progression discussions between patients and HCPs not take place?



- PwMS rated scientific graphs and images as the least useful form of information to aid disease progression discussion (1.71, n=14) (Figure 5).
- Both PwMS (2.64, n=11) and HCPs (2.41, n=34) rated the usefulness of online resources as high despite HCPs having previously showed less interest in online resources compared to PwMS (Figures 2 and 5).
- After scientific graphs and images, written information was the next lowest rated form of information for both HCPs (2.27, n=41) and PwMS (2.00, n=11) (Figure 5).

Figure 5: How beneficial are the following resources for disease progression discussions?



Discussion

- These data show a large disconnect in HCP and patient perspectives around disease progression communication, not only on how the conversations are taking place but also if they are occurring at all.
- An interesting difference in perspective was PwMS being twice as likely to say that the conversations focussed on scientific graphs and images as HCPs. PwMS rated this form of information as the least useful in the follow up question and therefore this might be an example of how negativity bias can influence the perception of patient-HCP interactions.
- The large disparity in perceptions of the occurrence of disease progression discussions is important to note with around 1 in 4 of PwMS stating that they had never discussed the topic with their HCP.
- A potential explanation for this disconnect may be the complexity of the subject matter. Over a third of PwMS and HCPs said that patients don't understand the concept of disease progression. If patients are not properly educated about what disease progression is then they might not recognise when their HCP raises the subject with them.
- However, it is still likely that, in particular cases, HCPs avoid discussing disease progression with their patients. It is important to note that this may be due to a misunderstanding of patient needs; with HCPs seemingly under the false impression that patients don't want to think or talk about this subject, a view that only a small proportion of PwMS hold.
- Increasing patient engagement and empowerment in MS could help to address this misalignment of perceptions by giving patients the confidence to raise the topics that are important to them with their HCP.
- Regardless of these different perceptions, HCPs and PwMS are both agreed that a lack of time in appointments is a major barrier to effective communication, particularly when it comes to sensitive and complicated subjects such as disease progression.

Conclusions

- There are numerous communication gaps between HCPs and PwMS around the topic of disease progression.
- This data suggests three major areas where patient-HCP communication about disease progression could be improved to help bridge these communication gaps:
 - More efficient use of time in appointments to allow for the discussion of complex topics like disease progression
 - Greater HCP understanding of patient perspectives and priorities
 - More educational resources to help introduce patients to the concept of disease progression and help them take a more active role in discussions with their HCP

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