

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

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Background: The MS in the 21st Century initiative is led by a steering group (SG) of international multiple sclerosis (MS) specialists and patient advocates with a current focus of improving education and communication between healthcare professionals (HCPs) and people with MS.

Objective: To compare the perceptions of the MS clinical community and patients on the topic of communicating the topic of disease progression.

Method: An electronic survey was developed to gain insight into HCPs' and patients' opinions on unmet needs in MS management. The surveys were conducted at seven international neurology congresses (2016, 2017, 2018) and a patient meeting in 2017. Multiple answers were solicited in response to 10 questions.

Results: A total of 196 HCPs and 143 MS patients completed the survey. A quarter of patients (25.5%) reported that they had not discussed disease progression with their HCP. A large proportion of both HCPs (64.0%) and patients (62.5%) reported that a lack of time in appointments might prevent disease progression discussions taking place. HCPs stated that progression is a topic that patients want to avoid (72.0%) but only a quarter of patients agreed with this (25.0%). Both patients (37.5%) and HCPs (36.0%) reported a lack of patient understanding as a barrier to progression discussions. HCPs stated that they use analogies to explain progression (55.3%) but patients were more likely to say that their HCP focuses on scientific information (23.3%).

Conclusion: There were distinct variations between HCP and patient perceptions of disease progression discussions. Both groups reported a number of barriers that might prevent disease progression discussions from taking place, notably a lack of time. However, in situations where progression discussions do take place HCPs and patients disagreed on both the frequency and format of these conversations.

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