

# How understanding of MS patient experiences, with respect to conversations about disease progression, differs among healthcare professions

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## BACKGROUND



The MS in the 21<sup>st</sup> Century initiative is led by a Steering Group of international multiple sclerosis (MS) healthcare professionals (HCPs) and people with MS (PwMS).



The Steering Group is committed to improving communication between HCPs and PwMS, with a view to ultimately supporting more effective shared decision-making and improving patient engagement and outcomes.



In 2018, the Steering Group developed a survey with the aim of identifying key differences in the perspectives of HCPs and PwMS with respect to perceptions of communication about the topic of disease progression.

## OBJECTIVES

To examine factors that influence the initiation of conversations about disease progression between HCPs and PwMS, and to see if understanding of PwMS experiences differs between neurologists and MS nurses.

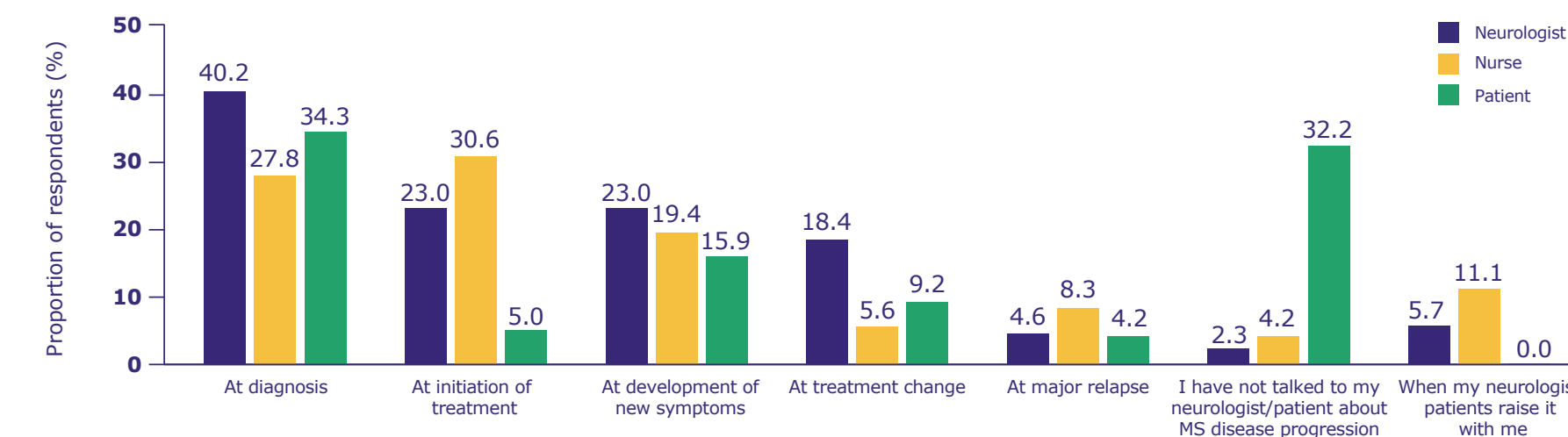
## METHOD

- A 6-question electronic survey was developed to gain insights into HCPs' and PwMS' perceptions of disease progression conversations.
- The survey was conducted amongst PwMS and HCP attendees at a series of international conferences: European MS Platform (EMSP) 2019, European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) 2018 and 2019, a Merck Patient Ambassador Summit 2019, Consortium of Multiple Sclerosis Centers (CMSC) 2018, Treatment and Research in Multiple Sclerosis (TriMS) 2019, European Academy of Neurology (EAN) 2019 and Charity Action for Relief of Multiple Sclerosis (CHARMS) 2020.
- Finally, an online version of the survey was available for PwMS and HCP visitors to the MS in the 21st Century website from 2019 - 2020.

## RESULTS

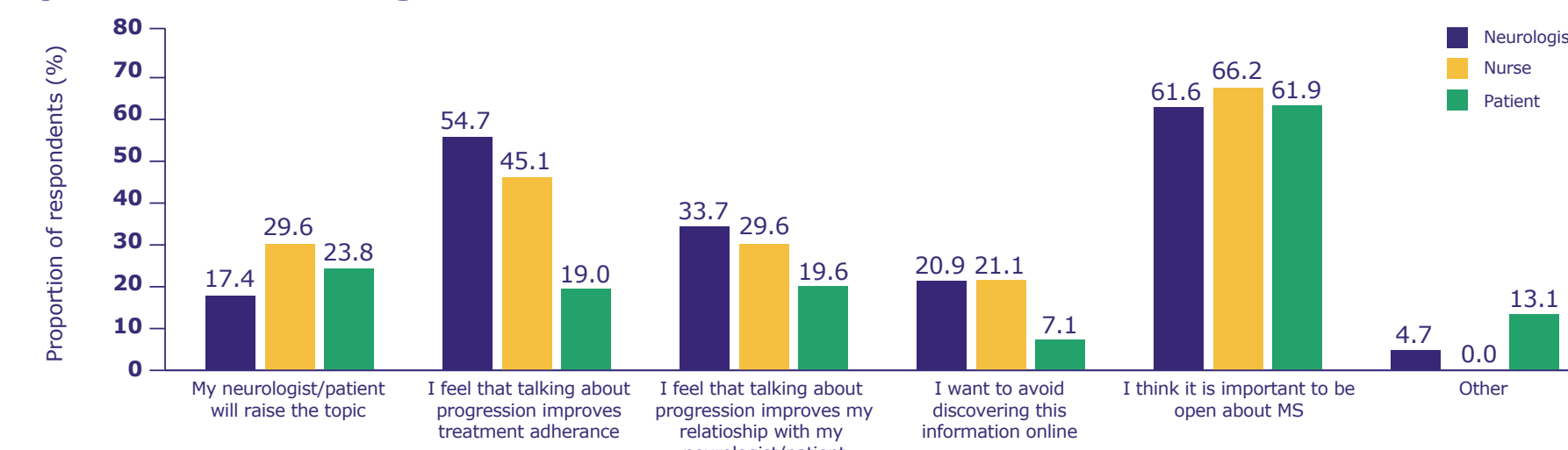
- Responses were received from 249 PwMS, 106 neurologists, 83 nurses and 50 "other" HCPs (GPs, physical therapists, psychologists, etc.). Due to the small individual numbers for each of the "other" types of HCPs, this data is not presented here.
- Questions permitted multiple answers and were non-compulsory.
- One in three PwMS (32.2%, n=77) reported that their HCP had never discussed disease progression with them, however very few neurologists (2.3%, n=2) and nurses (4.2%, n=3) reported that they had not discussed the topic with their patients (Figure 1).
- Nurses were twice as likely as neurologists to wait until the patient raises the subject (11.1%, n=8 vs. 5.7%, n=5, respectively) (Figure 1).
- Most neurologists (40.2%, n=35) first discuss disease progression with their patients at diagnosis, initiation of treatment (23.0%, n=20) or development of new symptoms (23.0%, n=20), and nurses reported most conversations at treatment initiation (30.6%, n=22) and diagnosis (27.8%, n=20) (Figure 1).

**Figure 1: When do you generally first talk about MS progression with your patients/neurologist?**



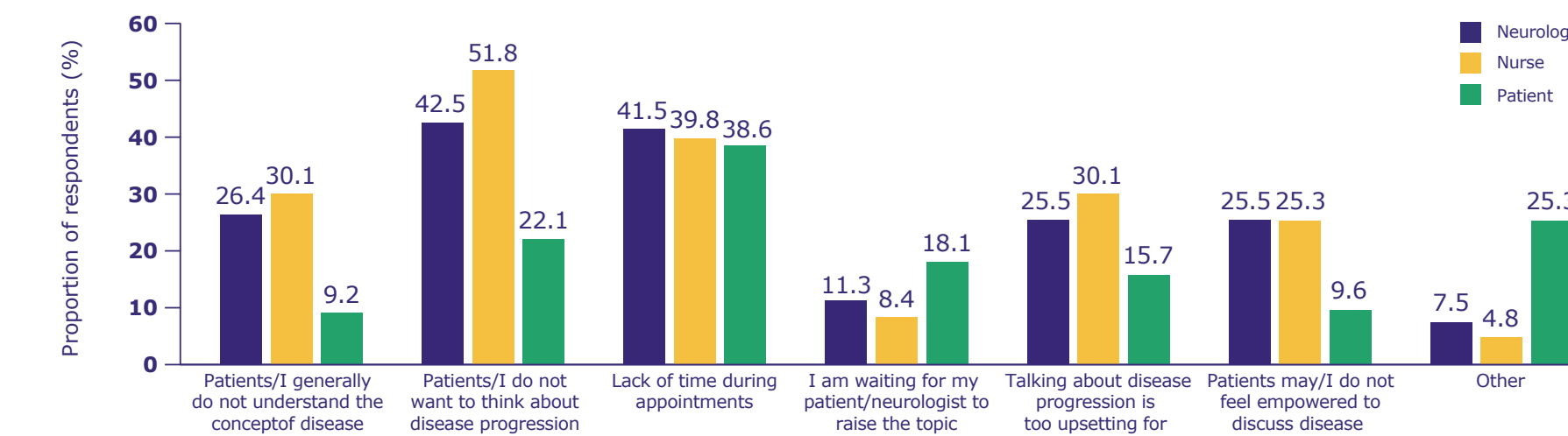
- Being open and honest about MS was ranked by all responder groups as the most important factor for discussing disease progression (61.6%, n=53 neurologists, 66.2%, n=47 nurses and 61.9%, n=104 PwMS) (Figure 2).
- Neurologists are more likely than nurses to discuss disease progression in order to improve treatment adherence (54.7%, n=47 vs. 45.1%, n=32, respectively) or to improve their relationship with the patient (33.7%, n=29 vs. 29.6%, n=21, respectively) (Figure 2).
- One in five HCPs (20.9%, n=18 neurologists and 21.1%, n=15 nurses) discuss disease progression in person to avoid their patient discovering the information online, however PwMS were less concerned about this (7.1%, n=12) (Figure 2).
- More nurses reported PwMS raising the subject than neurologists (29.6%, n=21 and 17.4%, n=15, respectively) (figure 2).

**Figure 2: What prompts you to talk about disease progression with your patients/neurologist?**



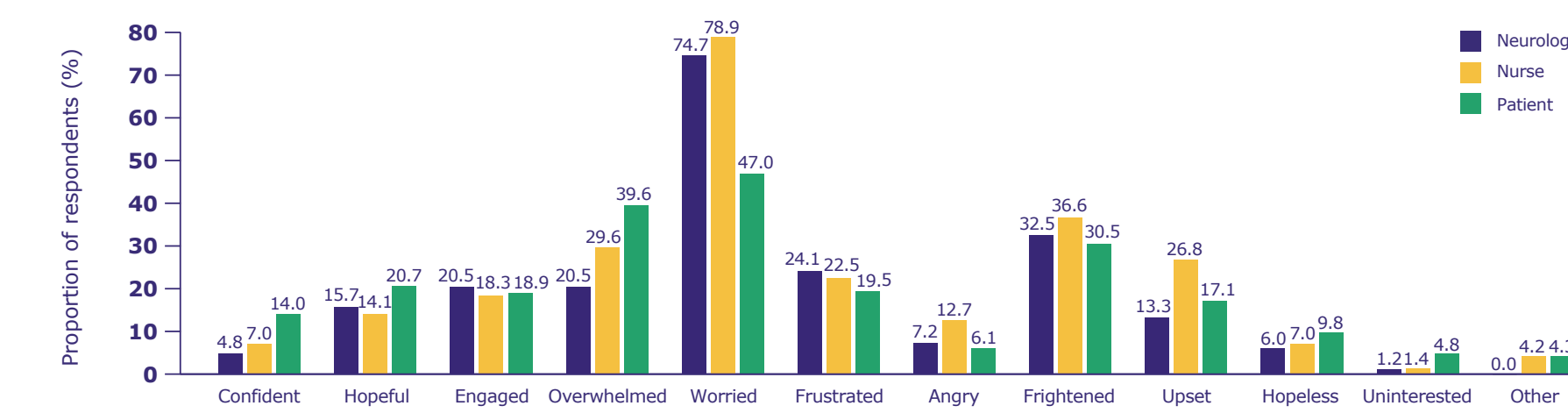
- PwMS most frequently (38.6%, n=96) ranked lack of time during appointments as the reason why discussions about disease progression do not happen, and neurologists (41.5%, n=44) and nurses (39.8%, n=33) agreed that this is a key issue (Figure 3).
- Nurses were slightly more likely than neurologists to report that patients did not want to think about disease progression (51.8%, n=43 vs. 42.5%, n=45), found the subject too upsetting (30.1%, n=25 vs. 25.5%, n=27) or generally did not understand the concept (30.1%, n=25 vs. 26.4%, n=28, respectively), however PwMS were much less likely to agree with any of these reasons for not discussing disease progression (22.1%, n=55, 15.7%, n=39 and 9.2%, n=23, respectively) (Figure 3).
- While a quarter of HCPs thought patients do not feel empowered to discuss disease progression (25.2%, n=27 neurologists and 25.3%, n=21 nurses), only 9.6% (n=24) of PwMS reported this. However, around a fifth of PwMS (18.1%, n=45) stated they were waiting for their HCP to raise the subject (Figure 3).

**Figure 3: Why might discussions about disease progression with your patients/neurologist not take place?**



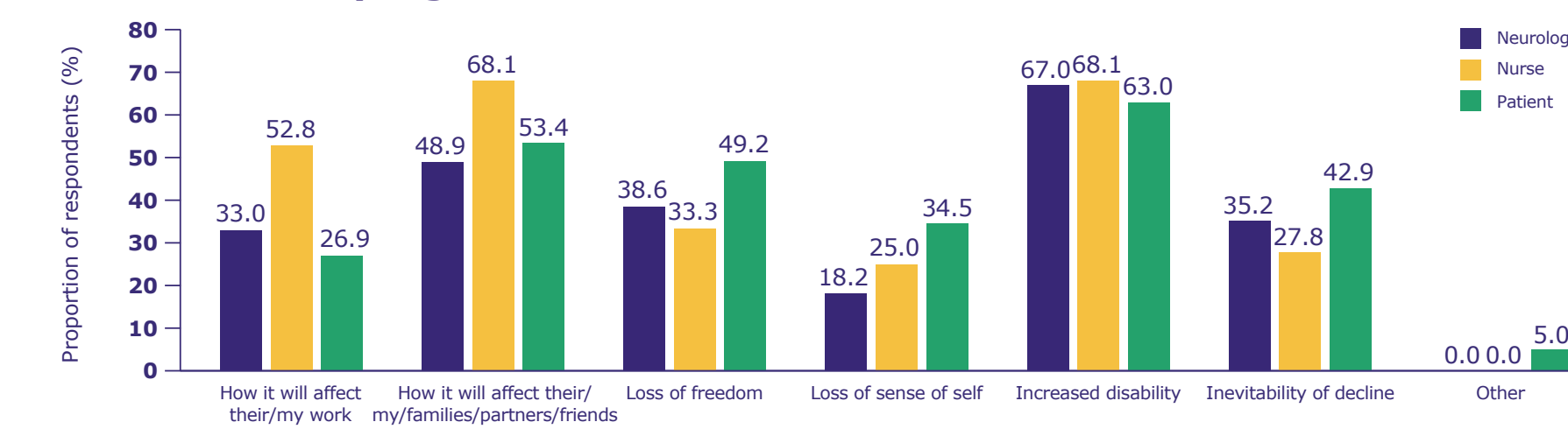
- Most HCPs reported "worried" as their patients' most common immediate reaction to talking about disease progression (74.7%, n=62 neurologists and 78.9%, n=56 nurses). This was also the most common response from PwMS (47%, n=77) (Figure 4).
- Nurses were slightly more likely than neurologists to report patient reactions such as "frightened" (36.6%, n=26 vs. 32.5%, n=27) and "overwhelmed" (29.6%, n=21 vs. 20.5%, n=17), and twice as likely to report "upset" (26.8%, n=19 vs. 13.3%, n=11) and "angry" (12.7%, n=9 vs. 7.2%, n=6, respectively) (Figure 4).
- Roughly twice as many HCPs reported "hopeful" (15.7%, n=13 neurologists and 14.1%, n=10 nurses) rather than "hopeless" (6.0%, n=5 and 7.0%, n=5 respectively) patient reactions to the conversation (Figure 4).

**Figure 4: How do patients/you generally react to the first conversation about disease progression?**



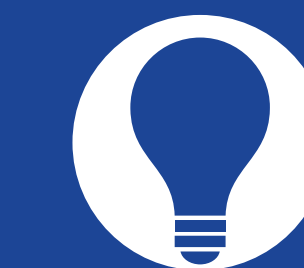
- All three groups agreed that a major concern for PwMS was increased disability (68.1%, n=49 nurses, 67.0%, n=59 neurologists and 63.0%, n=150 PwMS) (Figure 5).
- Nurses were more likely than neurologists to report patient concerns regarding the impact of disease progression on family/partner/friends (68.1%, n=49 vs. 48.9%, n=43, respectively) and work (52.8%, n=38 vs. 33.0%, n=29 respectively) (Figure 5).
- Conversely, while neurologists ranked "loss of freedom" (38.6%, n=34) and "inevitability of decline" (35.2%, n=31) higher than nurses (33.3%, n=24 and 27.8%, n=20, respectively), this was still an underestimation of that reported by PwMS (49.2%, n=117 and 42.9%, n=102 respectively) (Figure 5).

**Figure 5: What do you think are patients'/what are your biggest concerns about disease progression?**



## DISCUSSION

- In this survey, nurses were more likely than neurologists to be concerned about the ability of PwMS to cope with discussions about disease progression: nurses were half as likely as neurologists to raise the topic, and more frequently overestimated patient concerns and associated negative emotions with the conversation.
- Similarly, the discrepancy between nurses and neurologists as to when disease progression is first discussed likely reflects these HCPs' respective roles in the patient pathway, e.g. neurologists typically deliver the diagnosis while nurses may be more involved in treatment initiation.
- The third of PwMS who report they have not discussed disease progression with their HCP may be at a relatively early stage of disease; a significant number of HCPs reported waiting until development of new symptoms, treatment change, major relapse, or when the patient raises it with them.
- However, despite feeling worried, overwhelmed and frightened by the prospect of disease progression, PwMS disagreed with HCPs that it was something they did not want to think about, cannot understand, or find too upsetting to discuss. Most PwMS do report feeling empowered enough to have these important conversations and do not want to wait until someone else raises the topic.
- Of note, the high level of patient concern regarding increased disability represents an opportunity for both neurologists and nurses to proactively communicate the significant advances that have been made in MS care to slow disease progression and maintain quality of life.
- Nurses more commonly reported PwMS raising the subject of disease progression than neurologists. Nurses are more likely to be a regular point of contact for PwMS than a neurologist, so they may have more opportunities to get to know the patient, talk about social issues such as the impact of MS on their daily lives and recognise when patients are feeling upset or overwhelmed. PwMS may also feel more comfortable and confident to talk with their nurse about disease progression than their neurologist.



## Conclusions



All responder groups felt it was important to be open about MS but recognised a lack of time in appointments as being a major barrier to discussing disease progression.



HCPs consistently underestimated the strong resilience of PwMS and their desire to discuss disease progression, however nurses were more likely than neurologists to "protect" PwMS from the perceived negativity of the conversation. This highlights the importance of HCPs collectively being more proactive about initiating conversations with PwMS.



Improved communications between all HCPs and PwMS can result in a better understanding of each other's perspectives and optimise conversations about disease progression to help PwMS deal with their practical and social concerns.

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