

Discussing multiple sclerosis (MS) progression with patients: experiences of UK healthcare professionals from the SPECTRUM project



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Introduction

- Secondary progressive multiple sclerosis (SPMS) is characterised by a gradual worsening of neurological function and accumulation of disability over time, following an initial relapsing-remitting disease course¹.
- Receiving a diagnosis of SPMS can have a significant psychological impact on people with MS². Identifying how and when to initiate discussions about MS progression may be challenging for healthcare professionals (HCPs).
- SPECTRUM (Secondary Progressive Multiple Sclerosis – Understanding Diagnosis, Treatment and Management) was a United Kingdom (UK)-wide survey of HCPs involved in managing people with SPMS. The project was designed to capture information about current diagnostic and treatment pathways, with the overall aim to inform future SPMS service review and improvement.
- Results relating to the definition and diagnosis of SPMS have been presented previously³; this analysis focuses on current practices for discussing SPMS with patients.

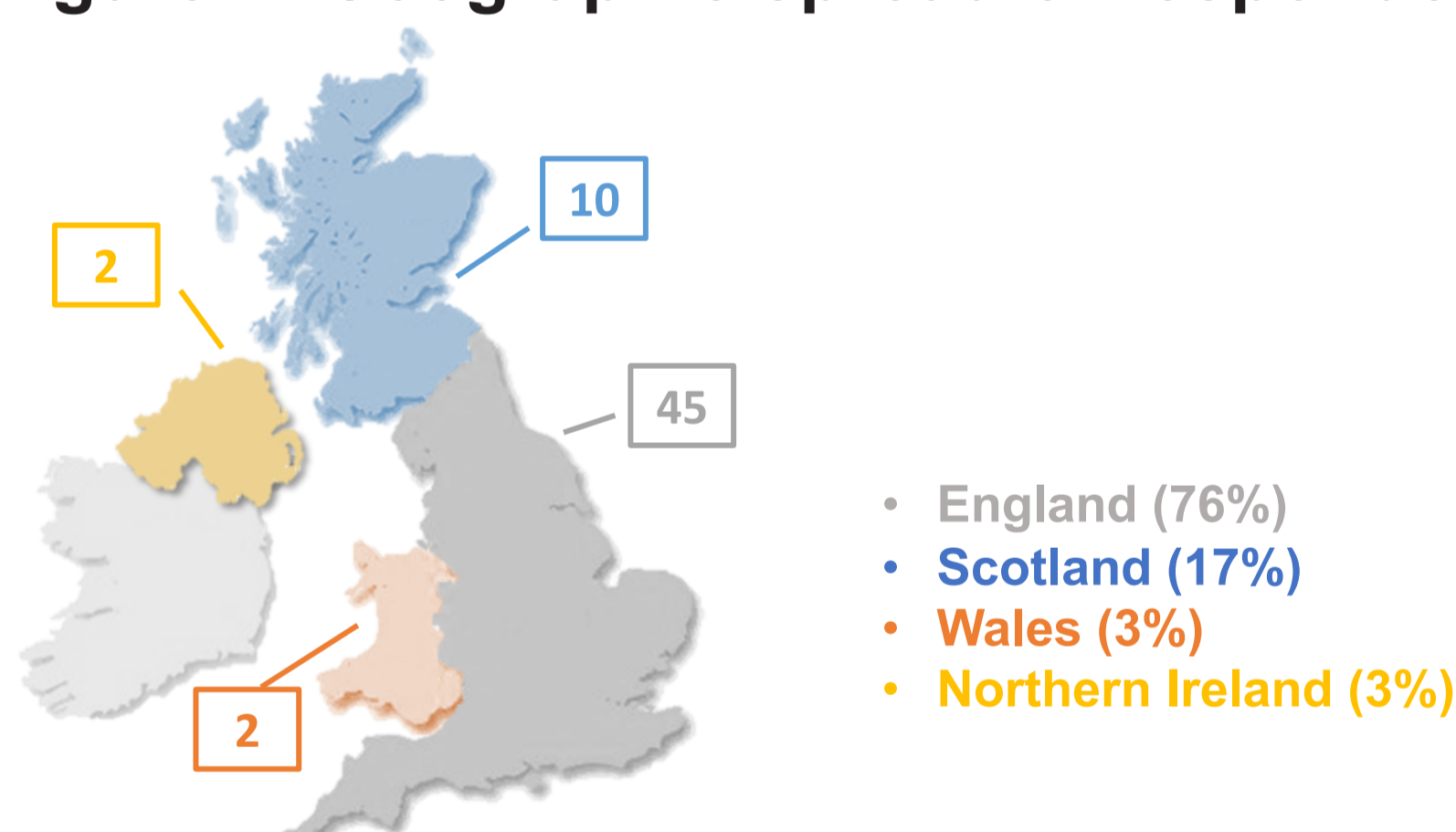
Objectives

- To understand how HCPs in the UK discuss the transition from relapsing-remitting multiple sclerosis (RRMS) to SPMS with patients.

Methods

- Between March and July 2019, interviews were conducted by members of the Novartis Neurology Medical Science Liaison (MSL) team with 59 HCPs involved in managing patients with SPMS.
- A total of 95 HCPs were initially approached and invited to participate by email (response rate 62%).
- The participating HCPs were from 59 centres spread geographically across the UK (Figure 1).
- Interviews were conducted face-to-face using a structured questionnaire, which was designed in collaboration with a consultant neurologist and a MS Specialist Nurse. Topics covered included current practices for the definition, diagnosis and management of SPMS, and discussing SPMS with patients.
- The survey data were analysed descriptively. If n<59, this indicates missing responses.

Figure 1: Geographic spread of respondents



Results

- The respondents comprised of 41 MS neurologists, 15 MS specialist nurses and 3 other HCPs.
- Progression from RRMS to SPMS is most commonly discussed with patients at the following time points (not mutually exclusive): when the diagnosis is made (n=56/58, 97%), when a patient asks about SPMS after researching their condition (n=56/58, 97%) or when SPMS is first suspected (n=45/58, 78%). Only 20/58 HCPs (34%) routinely discuss SPMS at initial RRMS diagnosis and 28/58 (48%) during the RRMS disease course (Figure 2).
- Most HCPs reported that a neurologist is usually the first person to discuss progression with the patient (Figure 3).
- The terms used most commonly by HCPs when discussing SPMS with patients were 'progression or progressive' (n=45/59, 76%), followed by 'transition' (n=19/59, 32%), 'worsening' (n=16/59, 27%) and 'disability' (n=9/59, 15%) (Figure 4 and Table 1). However, a number of HCPs reported that they would specifically avoid using the same terms ('disability' [n=13/59, 22%], 'progression or progressive' [n=10/59, 17%], 'worsening' [n=8/59, 14%], 'transition' [n=4/59, 7%]) (Table 1).
- The median (IQR) estimated time between first suspecting and diagnosing SPMS was 12.0 months (12.0–24.0, n=45).
- The most common explanations for reluctance to diagnose SPMS were *concerns over withdrawing disease modifying treatments (DMTs)* and *psychological impact on patients* (Figure 5).

Acknowledgements

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- OPEN VIE Ltd, who provided medical editorial assistance with this poster.

Figure 2: When is the transition from RRMS to SPMS usually discussed with the patient?

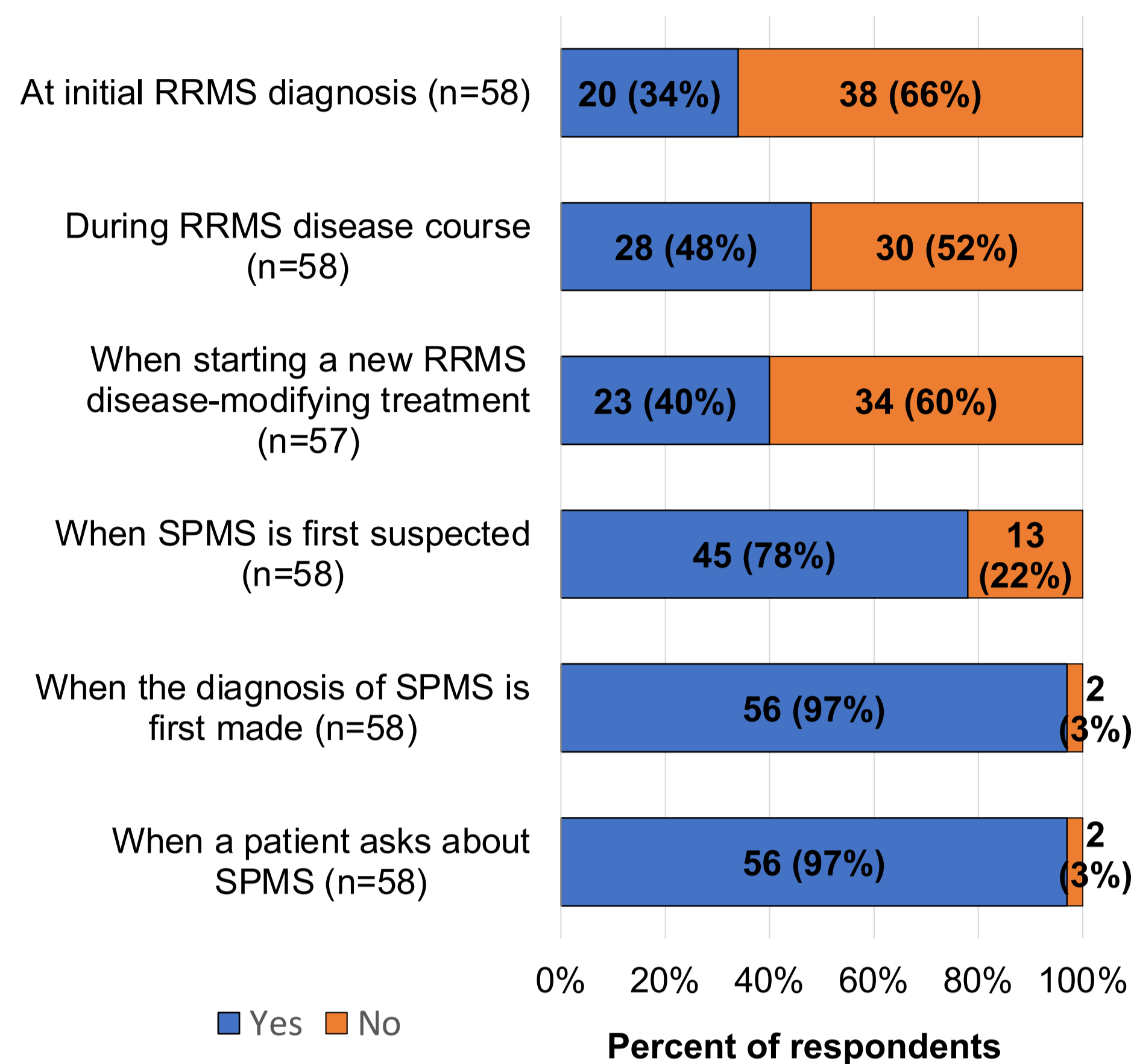


Figure 4: Word cloud showing the terms used most commonly when discussing SPMS with patients*



Figure 3: Who is usually the first person to discuss the transition from RRMS to SPMS with the patient?

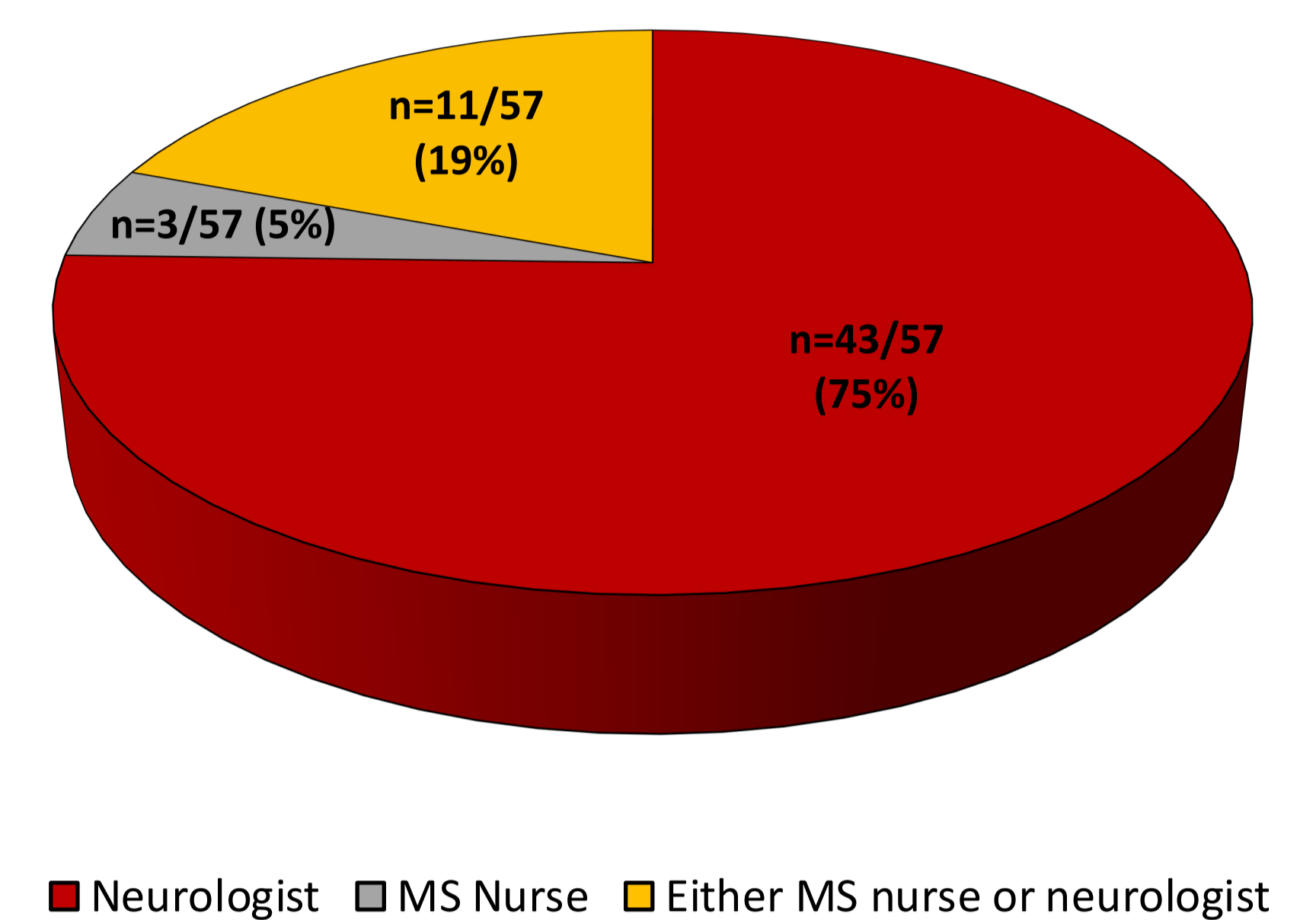
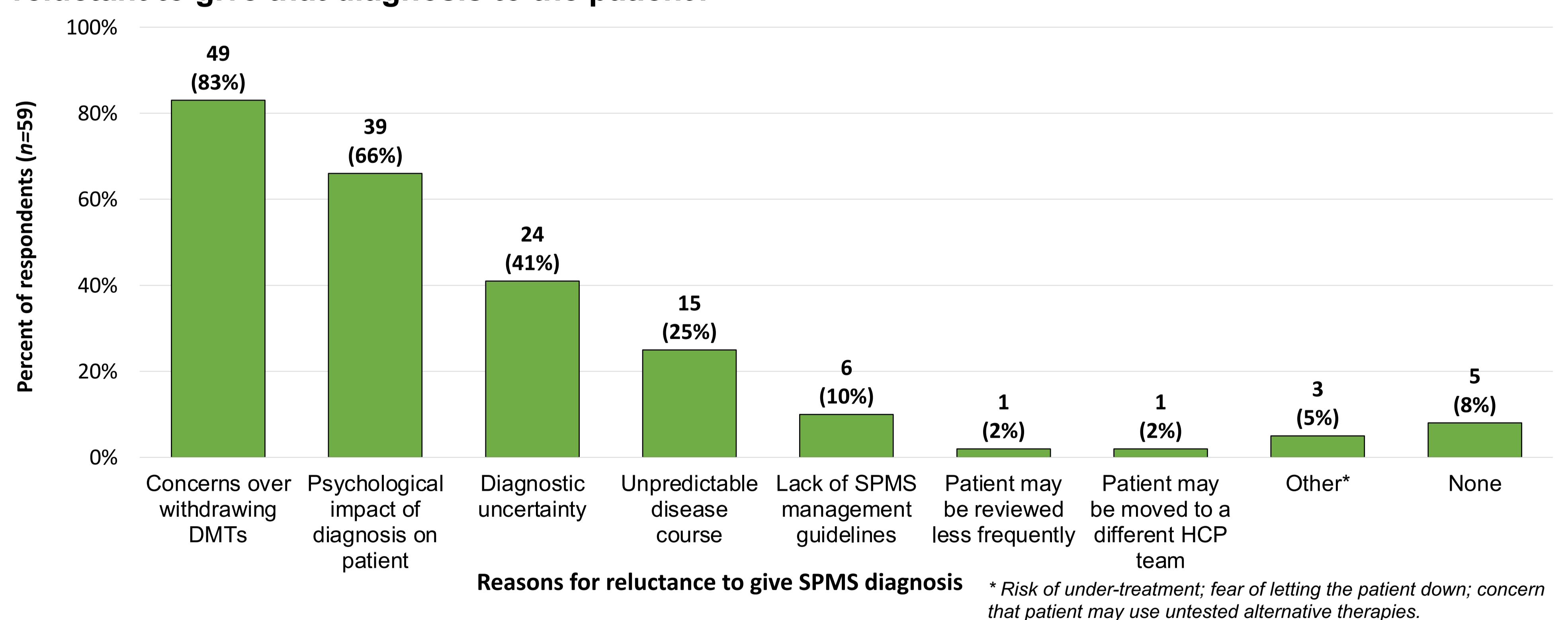


Table 1: Which terms do you use when discussing SPMS with patients?

Terms*	Terms USED		Terms specifically AVOIDED	
	n	% (n=59)	n	% (n=59)
Progression / Progressive [#]	45	76%	10	17%
Transition	19	32%	4	7%
Worsening	16	27%	8	14%
Disability	9	15%	13	22%
Change / Gradual / Gentle / Accumulative [#]	5	8%	-	-
Constant / Permanent [#]	1	2%	-	-
Other	5 [*]	8%	3 [‡]	5%
None specified	6	10%	24	41%

* Not mutually exclusive; [#] HCP may have mentioned either of these words but it was counted once for analysis purposes; ^{*} Grumbling, ageing, limited recovery, movement, lack of inflammation, neurodegenerative phase; [‡] Cognitive worsening, deterioration, any terms that may be perceived as 'negative'.

Figure 5: If you suspect that a patient has SPMS, are there any reasons that might make you reluctant to give that diagnosis to the patient?



Conclusions

- There is substantial variation among UK HCPs as to how and when the transition from RRMS to SPMS is discussed with patients. A small number of outlying responses in which HCPs did not recognise SPMS as a diagnosis (n=2, see Figure 2) may have impacted the final results.
- More than half of respondents do not discuss SPMS during the RRMS disease course. For around a quarter, they still do not discuss progression even when they suspect clinically that the patient has transitioned. This potentially excludes patients from being a partner in decisions about their treatment and is likely to undermine patient efforts to discuss worsening of symptoms.
- Currently, discussion of SPMS rests to a greater extent with doctors than MS nurses:
 - Doctors need to reflect on how the MS trajectory is discussed with patients and how this aligns with patients' desire to be informed. Further training and support for medical staff may be needed in order to facilitate discussions with patients about MS progression and provide them with appropriate support during the transition phase.
 - With MS nursing services advanced and very well-established in the UK, further consideration may need to be given as to how nurses can be supported to hold these discussions.
- As we enter an era with active treatments for progressive forms of MS, such disparity in prevailing practice may lead to wide variations in future patterns of treatment.

Conflicts of Interest

MD and CW report no conflicts of interest. KR is an employee of Novartis Pharmaceuticals UK Ltd. Financial support for this work was provided by Novartis Pharmaceuticals UK Ltd. OPEN VIE Ltd was commissioned by Novartis to support the authors in the conduct of the survey, analysis of the results and provide medical editorial assistance.

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