Congress Consortium of Multiple Sclerosis Centers (CMSC)

Congress date and location 27-30th May, 2020, Orlando, Florida, USA

Congress website https://cmscscholar.org/annual-meeting/

Submission deadline 10 January, 2020

Publication All accepted abstracts will be published for distribution during

the meeting and posted on the CMSC Annual Meeting website

at www.mscare.org/2020.

Presentation preferencePoster or Platform

Abstract category Case reports / case series; Complementary and alternative

therapies; Disease modifying therapy; Epidemiology and genetics; Ethics; Family and caregivers; Imaging; Internet and information services; Methods of care; Multidisciplinary care; Neuroimmunology and disease models; Neuropathology and pathogenesis; Neurophysiology, neuropsychology and neuropsychiatry; Non-imaging biomarkers; Programs; Psychosocial factors; Quality of life and outcomes;

Rehabilitation; Relapse therapy; Self-care; Symptom

management

Guidelines

Title The title should be no more than 150 characters and should be in

appropriate upper and lower cases

Permitted abstract length 2500 characters INCLUDING spaces, excluding title and authors

Tables and figuresTables, charts or images are NOT allowed

Format Background, Objectives, Methods, Results, Conclusions

Other guidelines Platform presentations: The work of commercial interest

authors and presenters will be considered for review provided that the content focuses on basic science and not on the product

or on the commercial aspects of the discovery.

Poster presentations: Authors of poster submissions should present information about studies or projects of benefit to the multiple sclerosis scientific and/or clinical community. The work of authors who are industry employees will be considered provided that the authors are employed by the scientific and/or medical divisions. The work of authors in industry sales or marketing posts will not be considered for inclusion in the scientific poster session. This policy shall apply to work submitted individually or in a co-authoring capacity.

Current abstract length 2498 characters

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

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Background: Receiving a diagnosis of secondary progressive multiple sclerosis (SPMS) can have a significant psychological impact on patients. Identifying how and when to initiate discussions about MS progression may be challenging for healthcare professionals (HCPs).

Objectives: To understand how HCPs in the UK discuss the progression from relapsing-remitting (RR)MS to SPMS with patients.

Methods: Interviews were conducted in 2019 with 59 HCPs from geographically-dispersed UK MS centres (MS neurologist, n=41; MS specialist nurse, n=15; other HCP, n=3), using a structured questionnaire. Topics covered included current practices for defining, diagnosing and managing SPMS, and discussing SPMS with patients. This analysis focuses on discussing SPMS with patients. n<59 indicates missing responses.

Results: Progression from RRMS to SPMS is most commonly discussed with patients at the following time points (not mutually exclusive): when the SPMS diagnosis is confirmed (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%) discuss SPMS at initial RRMS diagnosis and 28/58 (48%) during the RRMS disease course. Most HCPs (n=43/57, 75%) reported that a neurologist is usually the first person to discuss progression with the patient. The most common terms used 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%). 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%]). The median estimated time between first suspecting and diagnosing SPMS was 12.0 months (IQR 12.0–24.0, n=45). The most common explanations for reluctance to diagnose SPMS were concerns over withdrawing treatment (n=49/59, 83%) and psychological impact on patients (n=39/59, 66%).

Conclusions: There is substantial variation in the UK in both how and when HCPs discuss the transition from RRMS to SPMS with patients. Discussions may be delayed until SPMS is suspected or even confirmed, which can take a year or more. Further training and support for HCPs may be needed in order to facilitate discussions with patients about MS progression and provide them with appropriate support during the transition period.