



MS NURSED

HARNESSING KNOWLEDGE

Living well with MS: The nurse's role in lifestyle management

Tuesday 10 September 2019

Karolinska Institute, Stockholm Sweden



US/NPR/0120/0022 March 2020
This program was the result of a collaboration between IOMSN and Merck KGaA, Darmstadt, Germany, and therefore was not available to US healthcare professionals. Merck KGaA, Darmstadt, Germany only sponsors medical education programs for US healthcare professionals consistent with ACCME guidelines or similar grantors of accreditation, and consistent with US law and guidance.

Merck KGaA
Darmstadt, Germany

Executive summary



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Living well with MS: the nurse's role in lifestyle management

Live, educational, full day, international program targeting nurses, focusing on the critical role of the nurse in MS lifestyle management through the viewpoints of three main stakeholders: neurologists, nurses and patients.

The programme was in partnership with and endorsed by the International Organization of MS Nurses (IOMSN) and fully accredited by the Royal College of Nursing (RCN).

The meeting took place at the prestigious Karolinska Institute in Stockholm, Sweden.

The programme was initiated, funded and organised by Merck Global Medical Education & External Relations.

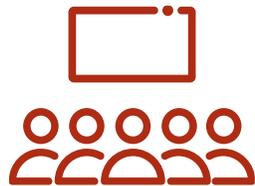
MS NursED educational meeting snapshot



10 expert faculty members comprising neurologists, nurses and MS patients



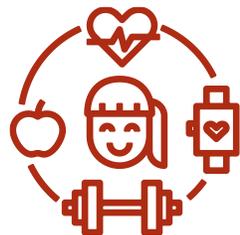
115 attendees onsite and via live webcast from 22 different countries



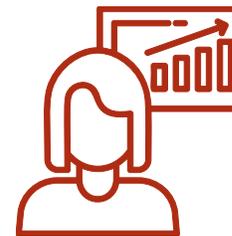
2 MS in the 21st Century workshops on communicating disease progression



100% of participants strongly agreed or agreed that the meeting fulfilled their overall learning objectives as measured by the feedback form data



89% of delegates felt very confident discussing lifestyle management with their MS patients as a result of attending the meeting



18.5% increase in learning achieved by all delegates

Meeting report

Learning objectives



Educate MS nurses on current topics of interest in MS, specifically related to lifestyle management



Explore topical MS issues through the viewpoints of three main stakeholders: neurologists, nurses and people with MS



Provide a forum for MS nurses to engage directly with experts and peers to gain comprehensive advice on multidisciplinary MS care

Programme was led and expertly delivered by a group of high profile international experts



co-Chair
Ms June Halper

CEO, International Organization of MS Nurses
New Jersey, USA



Morning co-Chair
Prof Gavin Giovanonni

Chair of Neurology
Barts and The London School of Medicine and Dentistry, London, UK



Afternoon co-Chair
Dr Martin Duddy

Clinical Director and Consultant Neurologist, Newcastle upon Tyne Hospital Trust, Newcastle, UK



The international, multi-disciplinary faculty ensured a diverse perspective

NURSES



Ms Colleen Harris

Nurse Practitioner,
University of Calgary
MS Clinic,
Calgary, Canada



Ms Kitty Harrison

Nurse Practitioner,
Tergooi Hospital,
Hilversum, Netherlands



Ms Patricia Pagnotta

Nurse Practitioner and
President of International
Organization of
MS Nurses,
Orlando, USA

HCPs



Dr Jens Bansi

Rehabilitation & Exercise
Scientist, Kliniken Valens,
Pfäfers, Switzerland



Asst Prof Sarah Morrow

Associate Professor
of Neurology
Western University, London,
Ontario, Canada

PATIENT ADVOCATES



Ms Stanca Potra

Patient advocate,
Member of the MS in the
21st Century Steering
Group, Bucharest,
Romania



Mr Pieter Van Galen

Patient advocate,
Member of the MS in the
21st Century Steering
Group
Overijse, Belgium

Incorporating the patient voice

Agenda was carefully designed to incorporate different formats and learning styles

Morning agenda

Time	Topic	Speaker(s)
09:30	Arrivals and Registration	
10:00	Welcome and Introductions	<ul style="list-style-type: none"> • Gavin Giovannoni (Chair) • June Halper (co-Chair)
10:05	Opening Address	<ul style="list-style-type: none"> • June Halper (co-Chair)
10:15	Presentation: Treatment advances in MS; the impact on the wider HCP team	<ul style="list-style-type: none"> • Gavin Giovannoni • Colleen Harris
11:15	Nurse-led presentation: Supporting the ageing MS population and managing comorbidities	<ul style="list-style-type: none"> • Patricia Pagnotta • Kitty Harrison
11.45	Break	
12:00	[Breakout] MS21 facilitated workshop: Speaking a common language: Communicating a future with MS	Breakout 1: Gavin Giovannoni <ul style="list-style-type: none"> • Stanca Potra Breakout 2: Sarah Morrow <ul style="list-style-type: none"> • Pieter van Galen
13:00	Lunch break and networking	

A lively audience debate with the panel concluded the meeting summarising the role of the nurse in MS lifestyle management

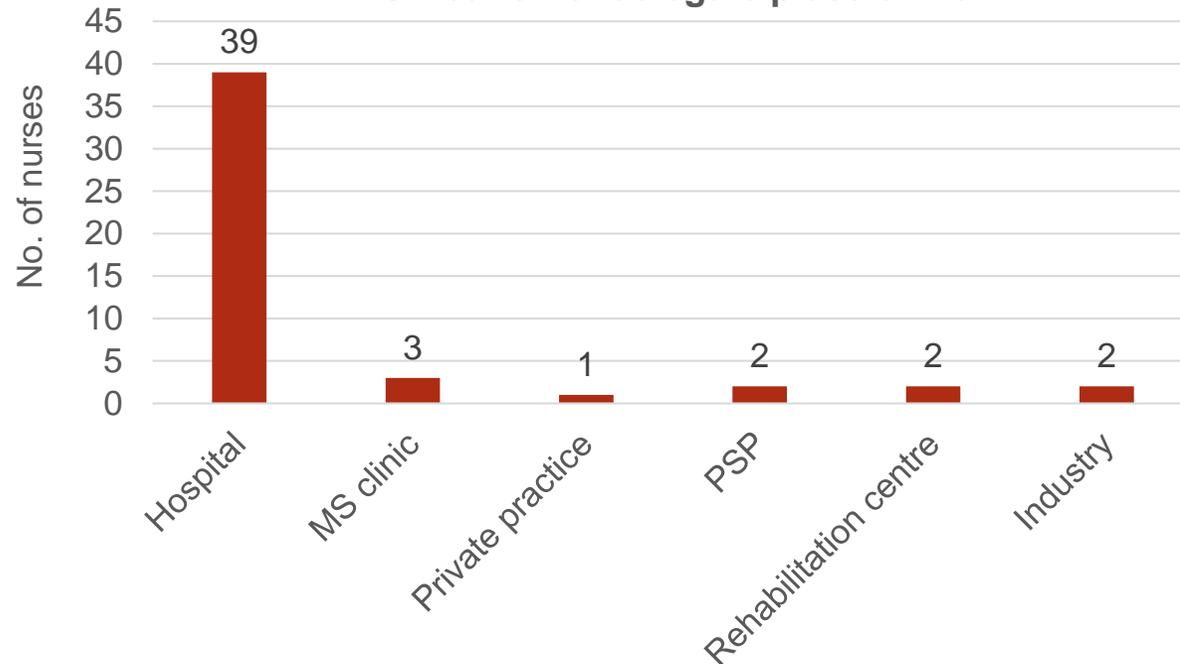
Afternoon agenda

Time	Topic	Speaker(s)
14:00	Afternoon welcome and recap	<ul style="list-style-type: none">• Martin Duddy (Chair)• June Halper (co-Chair)
14:05	Presentation: Improving patient quality of life through rehabilitation	<ul style="list-style-type: none">• Jens Bansi
14:35	Panel Presentation: Session 1 Case study: Psychosocial aspects of MS - challenges and solutions	<ul style="list-style-type: none">• Martin Duddy, Sarah Morrow• Patricia Pagnotta, Pieter van Galen
15:20	Break	
15:30	Panel Presentation: Session 2 Bringing it all together: The nurse's role in lifestyle management	<ul style="list-style-type: none">• Martin Duddy, June Halper• Colleen Harris, Kitty Harrison
16:15	Summary and closing remarks	<ul style="list-style-type: none">• Martin Duddy• June Halper
16:30	Meeting concludes	

The meeting was attended by 115 delegates

- 22 countries were represented by the 71 delegates present at the Karolinska Institute
- 44 viewers joined the meeting via webinar throughout the day,
 - Including delegates from the webinar, the meeting represented 22 countries
- Attendees were asked to complete pre-meeting and post-meeting surveys
 - 48 completed the pre-meeting survey with 51 completing the post-meeting survey

Distribution of delegate place of work



Gavin Giovannoni and June Halper chaired the informative morning agenda

Treatment advances in MS; the impact on the wider HCP team

Prof Gavin Giovannoni and Colleen Harris



Overview of some of the recent advances in MS therapies, particularly those related to lifestyle management, and what implications these advances have for MS nurses.

Supporting the aging MS population and managing comorbidities

Patricia Pagnotta and Kitty Harrison



Identifying invisible symptoms, depression, cognition issues and their effects on the patient and carer and to identify best practice for nurses dealing with the psychosocial impact of MS on their patients and carers.

Communication of disease progression can be challenging

- Two breakout sessions chaired by an HCP and patient member of the MS in the 21st Century steering group
 - Gavin Giovannoni and Stanca Potra
 - Sarah Morrow and Pieter van Galen
- Ensuring patients and HCPs are speaking a common language through
 - “Communication Conundrum” card game explored specific language used in consultations
 - Patient Journey group discussions looked at when the topic of disease progression is typically raised



Delegates reinforced the importance of language and terminology through small group discussions

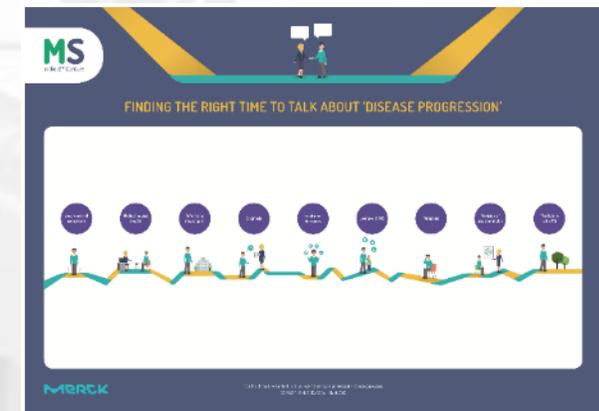
Communication conundrum

- Many definitions and measures used to describe MS are complicated, easy to misunderstand and negatively perceived
- A redefinition of disease progression or simplified language needs to be agreed
- “Disease progression” is often confused with “progressive MS”
- Language should be adapted depending on patient’s understanding



When to hold disease progression conversations

- Every patient is different – personalise conversations
- Introducing disease progression earlier in patient journey can help with adherence
- Nurses have a unique relationship with patients
- Empathy and sensitivity are vital



Martin Duddy summarised and led the interactive debates in the afternoon sessions

Improving patient quality of life through rehabilitation

Jens Bansi



Looking at the importance of rehabilitation, specifically through physical therapy and activity, for people with MS, in order to maintain a good quality of life, highlighting the MS nurses' role in ensuring rehabilitation is part of the lifestyle management of the patient.

Case study: Psychosocial aspects of MS - challenges and solutions

Martin Duddy, Sarah Morrow, Patricia Pagnotta and Pieter van Galen



Identifying invisible symptoms, depression, cognition issues and their effects on the patient and carer and to identify best practice for nurses dealing with the psychosocial impact of MS on their patients and carers.

Bringing it all together: The Nurse's role in lifestyle management

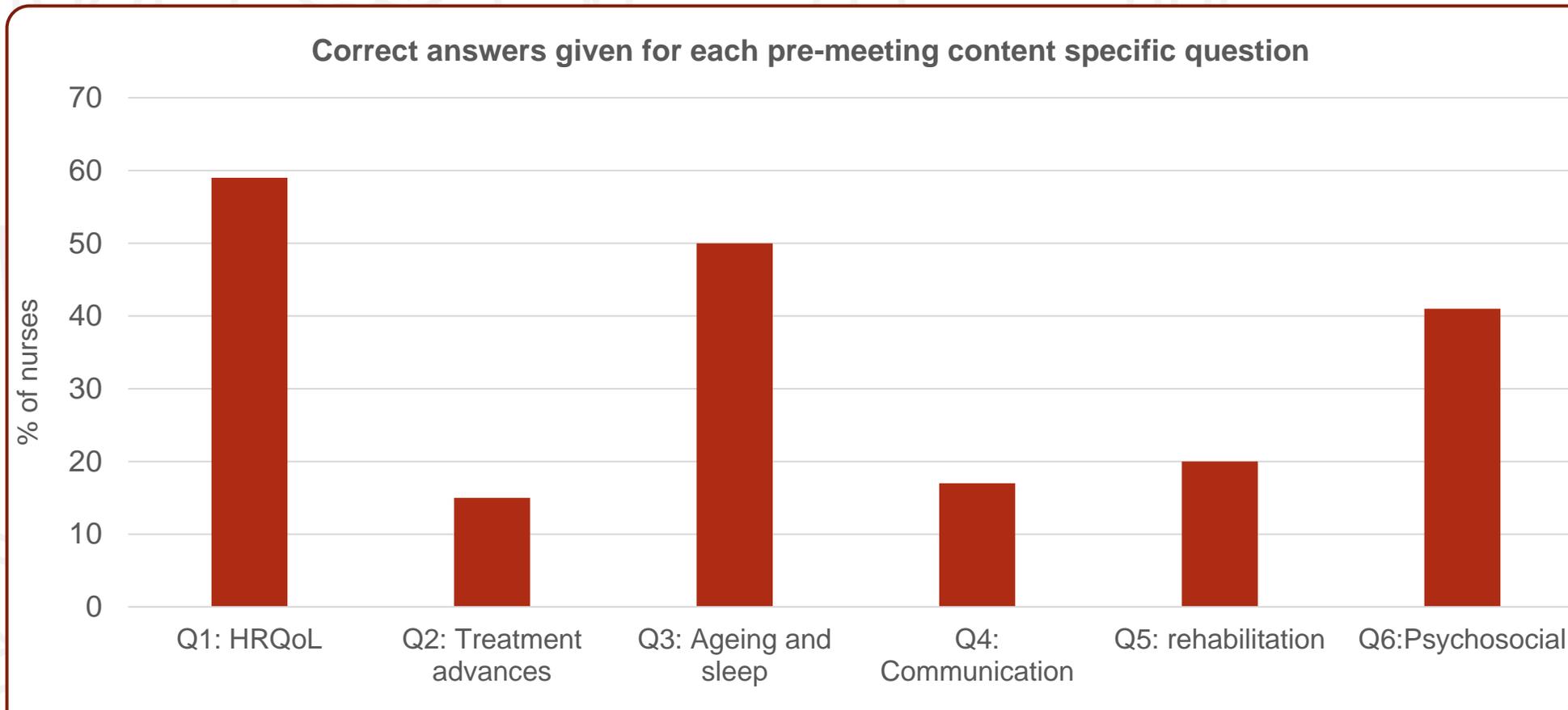
Martin Duddy, June Halper, Colleen Harris and Kitty Harrison



Summarising the key learnings and actions from the day and discussing specific, actionable 'next steps' for delegates.

A significant gap in knowledge was shown from the meeting survey

- 48 nurses completed the pre-meeting questionnaire
- Before the meeting, the nurses did not consistently give correct answers (<60%) demonstrating a gap in knowledge in the programme topics



The majority of delegates did not feel very knowledgeable about supporting patients with lifestyle issues



Psychosocial support was the area where nurses felt most knowledgeable (14.58%)

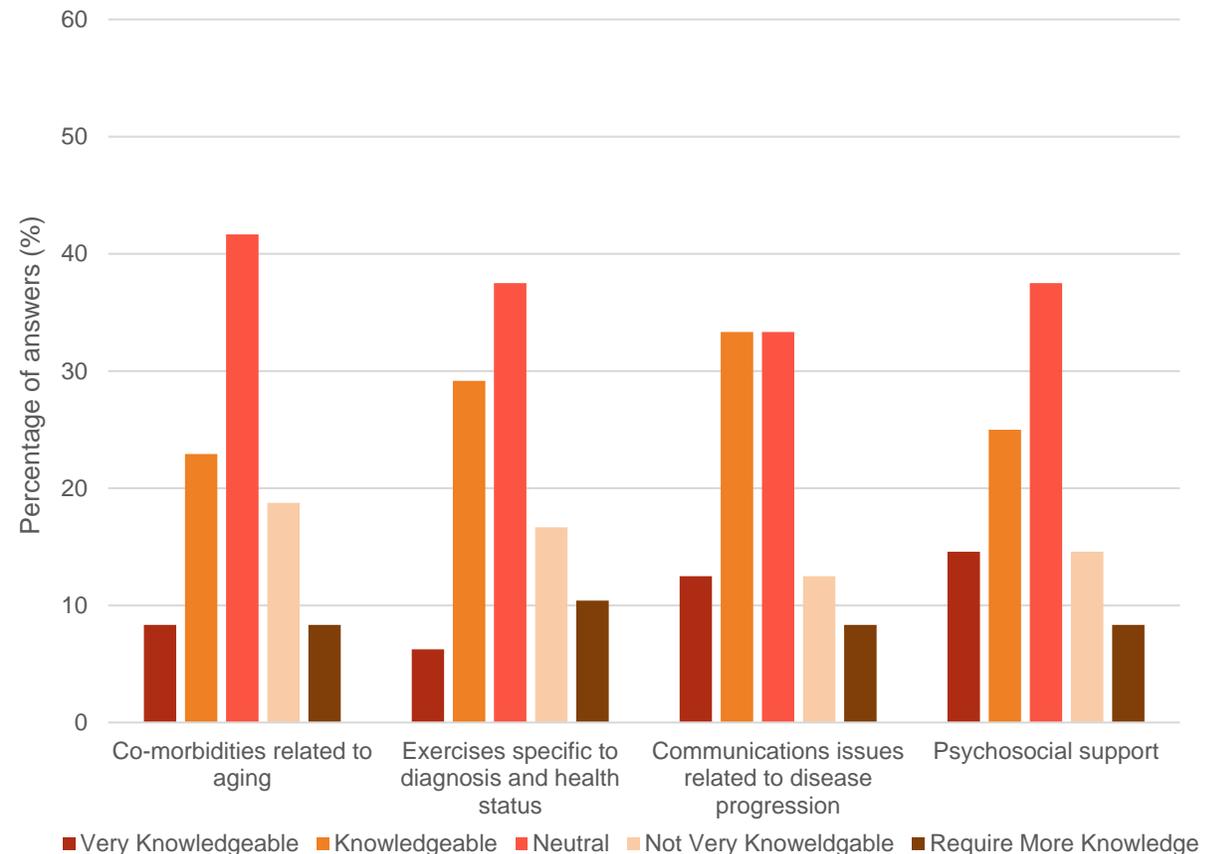


Exercises specific to diagnosis and health status was the area where the highest percentage of nurses (10.42%) reported to requiring more knowledge.



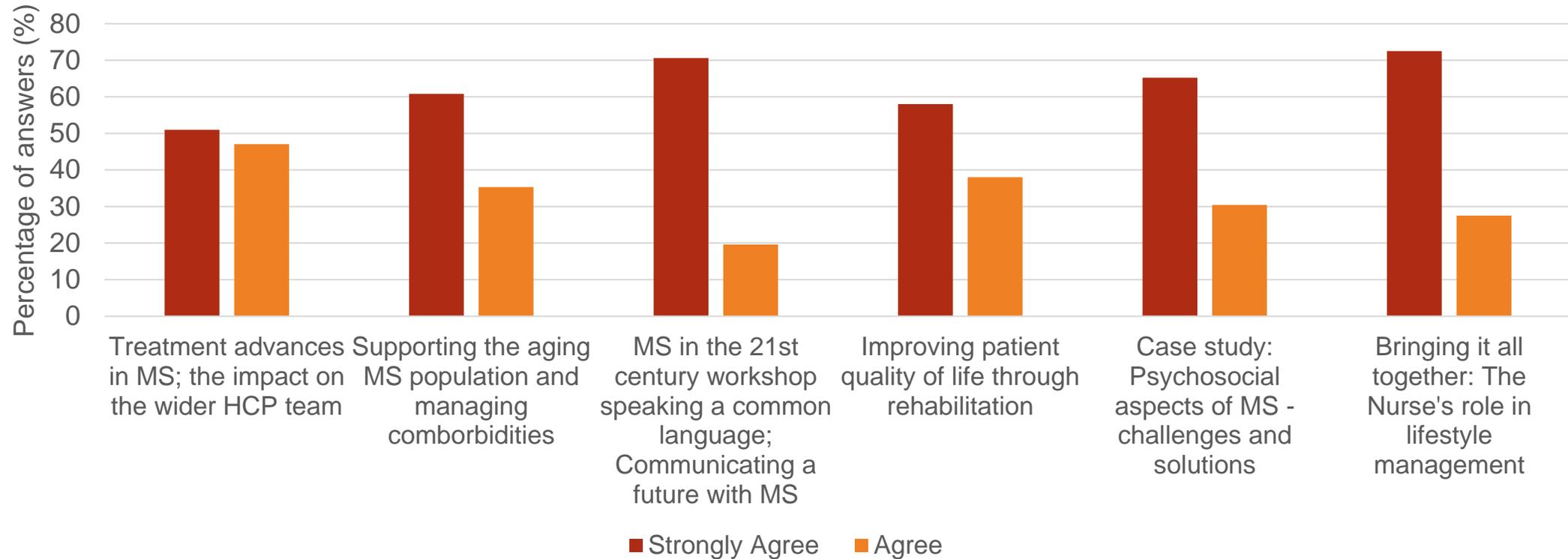
Only 33% of nurses reported having completed additional courses relating to improving patient lifestyle management in MS.

Participant knowledge levels on topics relating to patient lifestyle issues before the meeting

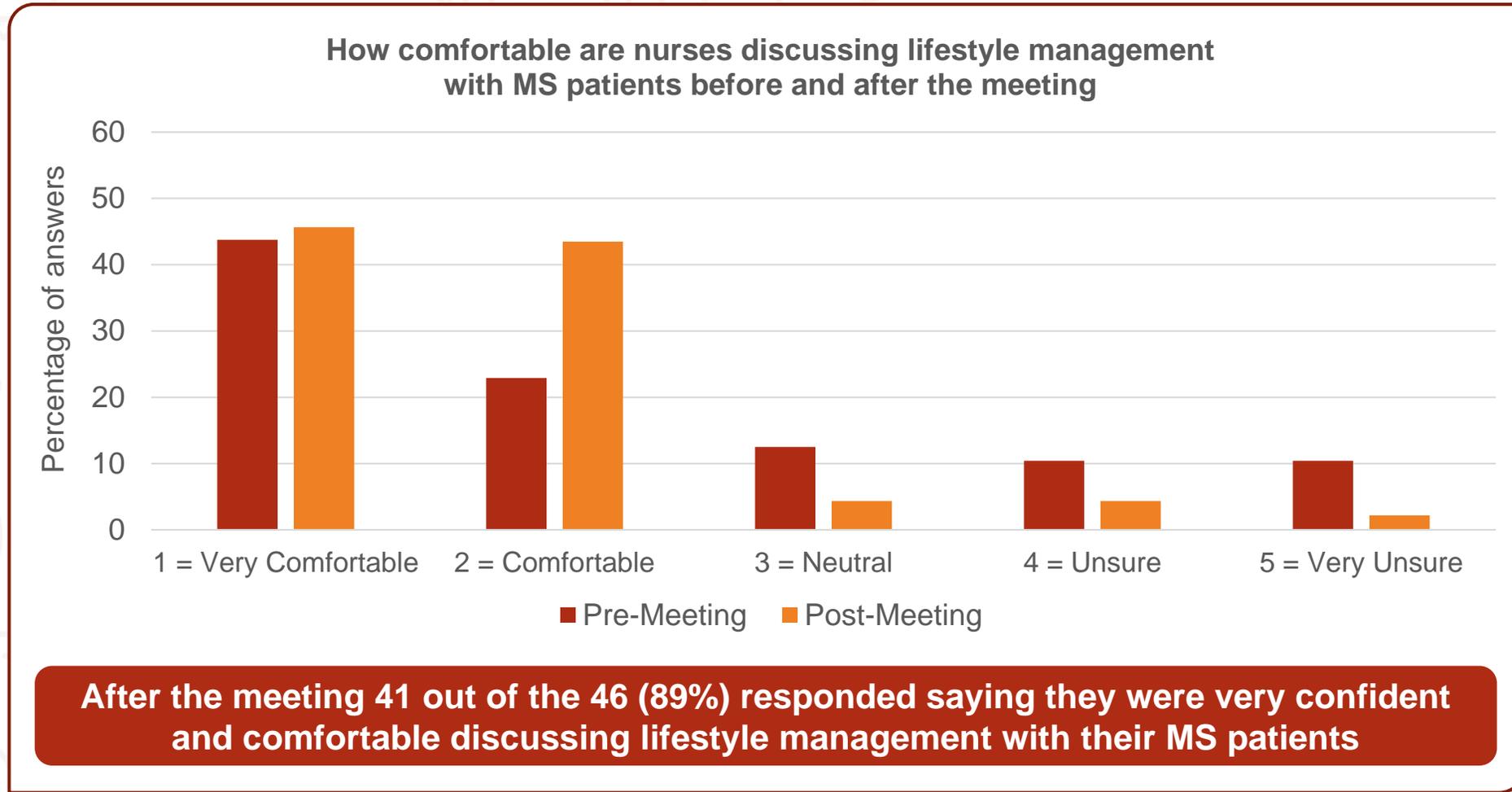


Engaging speakers delivered highly relevant and quality sessions

Participants strongly agreeing or agreeing that the sessions contained relevant and high quality content



Delegates demonstrated a 22% increase in confidence discussing lifestyle issues with their patients



Delegates offered ways in which they would apply learnings to change behaviour*

Focus on individual patient rehabilitation

Encourage a nutrient rich diet for patients
Support patients with exercise plans

Be aware of communicating clearly

Offer greater attention to managing comorbidities

Adapt clinical language when speaking to patients

Educate patients on the importance of staying active

Provide informative resources for patients to help understanding of lifestyle management

Consider patient perspective

Consider referral of relevant patients to psychologist

Empathise

*Topics proportionally represented according to number of times suggested

Faculty-led content fulfilled all delegates' overall learning objectives

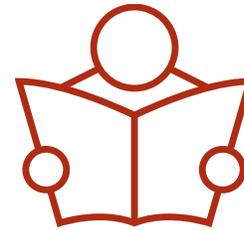
All 51 (100%)

participants who completed the feedback form strongly agreed or agreed that the meeting fulfilled their overall learning objectives



50 out of the 51 (98%)

found their personal learning objectives were met



Over 70%

strongly agreed that the meeting interactivity offered good value to the meeting



Over 60%

strongly agreed that the content was relevant to their practice, had varied sessions that added value to the meeting and that having CME accreditation also added value to the meeting



More than 70%

of delegates strongly agreed or agreed that the meeting was well organised, well facilitated and held at a good venue



All elements of the meeting received positive feedback

Delegate quotes

“Case studies were really effective to show us how to apply what we have learnt”

“Hearing experiences of nurses from other countries was great”

“Great faculty and a great meeting”

“Hearing from an MS patient really helps to understand their MS journey”

“I feel empowered to make a difference to patients’ wellbeing”

“Inspiring speakers”