

An evidence based Global MS Patient Charter created by a multi-stakeholder alliance

Title (83 characters/max 83)

Short title (Creating a Global MS Patient Charter:35 characters/ max 45 characters)

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ABSTRACT (300/max 300 excluding title and author details)

OBJECTIVE

To develop an evidence-based Global Multiple Sclerosis (MS) Patient Charter that aims to establish guidance towards improving patient-centered MS care.

BACKGROUND

Despite advances in the treatment and disease landscape of MS, people living with MS (PwMS) often experience unmet needs in their care provision that impact the quality of daily living. For optimal, patient-centered MS care, it is key to utilize multi-stakeholder shared partnerships to develop evidence-based guidance that accurately reflects current patient unmet needs.

DESIGN/METHODS

A systematic literature search of key databases (EMBASE™, MEDLINE®, MEDLINE®-In-Process, and Cochrane library) spanning 01.01.2017 to 07.07.2022, was performed. Furthermore, grey literature from relevant websites were screened. Studies reporting unmet needs in PwMS were included. The methodological quality of the included studies was assessed using the Mixed Methods Appraisal Tool (MMAT). A multi-stakeholder alliance of

experts assessed and categorized the findings of the unmet needs systematic literature review (SLR) to develop a Global MS Patient Charter.

RESULTS

Overall, 148 studies (157,507 PwMS), age ranging from 27 to 64 years, and disease duration of 1.7 to 32 years, were included. While 50% (n=74) were qualitative surveys, 32% (n=48) were quantitative surveys. Geographically, 43% (n=64) of studies were from Europe and 33% (n=49) from North America. The SLR identified unmet needs, subsequently categorized into key themes covering disease (diagnosis, control, and management); communication (the right to understand, meaningful dialogue between patient and healthcare professionals, and shared decision making to support and optimize MS care); holistic care (social stigma, isolation, and psychological distress); and supporting caregiver and care partners. Each theme was then formulated into a charter for the provision of optimal MS care.

CONCLUSIONS

The Global MS Patient Charter highlights the clinical, lifestyle, professional workspace, and counselling services needed to deliver timely and appropriate care, offering guidance for optimal patient care throughout the MS journey.

DISCLOSURES

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Author disclosures

Pauline Gieseler reports personal fees for activities as a patient consultant from Novartis.

Martin Duddy, MD FRCP, Consultant Neurologist reports speaker or consulting honoraria and/or travel/congress grants in the last 3 years from: Biogen, Bristol Myers Squibb, Janssen, Merck, Novartis, Roche, Sanofi.

Anita Williams reports acting as an independent MS patient consultant for Novartis and received fees for services.

Edmund Pezalla, MD, MPH is an independent consultant. He has received honoraria and consulting fees related to market access consulting from several firms including Sanofi, Novartis and Bristol Myers Squibb.

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Santosh Tiwari and Akshay Joshi are employees of Novartis Healthcare Pvt Ltd, Hyderabad, India.

Leonhard Schaetz is an employee of Novartis Pharma AG, Base, Switzerland.

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