

The Clinical Nurse Practitioner's Essential Role in Early Diagnosis and Management of Multiple Sclerosis in Europe: A Consensus Report

Francesco Pastore, PhD, CNP, RN; Miguel Angel Robles Sanchez, MHP; Catharina Maria Harrison, CNP; Konstantinos Ntinoulis, MSc; Sabine Staller, CNP; Tatsi Theano, BSc; and Santosh B. Shirol, MD

ABSTRACT

Timely diagnosis of multiple sclerosis (MS) is a challenge due to factors such as prompt identification of symptoms and consequent delays in hospital visits and treatment initiation. In part to address this challenge, an expert scientific advisory panel of clinical nurse practitioners (CNPs) from different European nations was convened by Viatris on October 25, 2022, in Amsterdam, the Netherlands. This meeting was an interactive discussion to understand the role of clinical nurse practitioners in MS management. The objectives were to (1) understand the current delays in MS diagnosis from the perspective of expert CNPs; (2) determine the role of the CNP in MS management; and (3) identify the opportunities to improve accessibility, foster collaboration among stakeholders, and promote initiatives to educate people with MS. The recommendations of the panel underline the multidimensional role of CNPs in the management of MS at all stages. Health care stakeholders need to work together to achieve better access to treatment regimens and facilitate outcomes in the management of MS through shared decision-making and follow-ups. Further exploration of the role of CNPs in the management of MS, as well as recommendations for early diagnosis, will help both general practitioners and specialists better manage MS care.

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Globally, the number of people with multiple sclerosis (MS) rose from 2.3 million in 2013 to 2.9 million in 2023.^{1,2} The number of individuals with MS in Europe has notably risen since 2017, reaching a total of over 1 million.³ The mean age at MS diagnosis is 32 years, and women are twice as likely to be diagnosed with MS as men.¹

Early diagnosis increases the opportunity for timely intervention, enhances therapeutic options, and also helps mitigate the economic burden associated with the severity of MS.^{4,5} However, the misdiagnosis rate of MS is still as high as 10% and prolonged time to diagnosis is a widespread issue in many nations, with a reported duration of 21.5 weeks to 7 years between the initial onset of symptoms and diagnosis.^{4,5} The delay could be attributed to limited MS awareness and late presentation to clinic, which affects treatment initiation.^{6,7} This latency is further amplified due to factors such as low literacy, poor infrastructure, disease progression, and advanced age at MS diagnosis.⁶ Additional factors are insufficient awareness of MS symptoms among primary care physicians (PCPs) and clinical nurse practitioners (CNPs), difficulty accessing specialized facilities, and limited availability of diagnostic tools like MRI scanners.^{6,8} This delay in MS diagnosis reduces the likelihood of early access to optimal treatment,⁸ and this access is crucial as it slows irreversible neurological damage and delays disease progression.⁹

As treatment options advance and health care systems face higher demands, the need for CNPs specializing in MS has expanded.¹⁰ They serve as comprehensive care coordinators and specialized caregivers equipped to address the diverse and changing needs of people with MS, along with their families and caregivers.^{10,11} Ultimately, the coordination and collaboration between PCPs, CNPs, MS neurologists, and other supportive stakeholders is crucial to effectively manage MS.

From the Department of Biomedicine and Prevention, TorVergata University, Rome, Italy (FP); University Hospital Polyclinic of Bari, Department of Translational Biomedicine and Neurosciences, MS Centre Bari, Italy (FP); Multidisciplinary Nursing Research Group, Vall d'Hebron Institut de Recerca, Vall d'Hebron University Hospital, Vall d'Hebron Barcelona Hospital Campus, Barcelona, Spain (MARS); Neurology Department, Multiple Sclerosis Centre of Catalonia, Vall d'Hebron Barcelona Hospital Campus, Barcelona, Spain (MARS); Faculty of Nursing, University of Girona, Girona, Spain (MARS); Neurology Clinic, Tergooi Hospital, Hilversum, the Netherlands (CMH); Neurology Department, Papageorgiou General Hospital, Pavlos Melas, Greece (KN); private practice, Kleinhögl, Piding, Germany (SS); Multiple Sclerosis Centre, Second Department of Neurology, AHEPA University Hospital, Thessaloniki, Greece (TT); and Global Noncommunicable Diseases team, Viatris Pharmaceuticals, Kadubeesanahalli, Bangalore, India (SBS). *Correspondence:* Francesco Pastore, PhD, CNP, RN, University Hospital Polyclinic of Bari, Department of Translational Biomedicine and Neurosciences, Piazza Giulio Cesare, 11, MS Centre Bari, Italy; *email:* francesco.pastore@uniba.it.

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Need for a Consensus Statement on the Role of CNPs in Europe

Despite their immense potential to deliver high-quality health care, there is no global understanding of the role of CNPs and there are significant disparities in regulations, licenses, education, and credentialing criteria.^{12,13} Despite these inconsistencies, CNPs in European nations have been shown to provide improved access to good-quality care.¹⁴

Recent evidence emphasizes the positive impact of CNP-led care on depression and quality of life (QOL) in people with MS, aligning with neurologist-led care.¹⁵ However, across Europe, the variance in CNPs' skills impedes uniform integration, emphasizing the need for a consensus to optimize scarce resources and improve outcomes,¹⁶ particularly for chronic diseases like MS.¹³

The International Organization of Multiple Sclerosis Nurses is a structured organization that promotes best practices in MS nursing care worldwide, and in the United States, it supports nurses specializing in MS. European MS CNPs lack a dedicated scientific society or a structured training program,¹⁷ which hinders the standardization of care for MS patients. This is compounded by differences in health care services based on MS center location,¹⁷ a lack of standardized procedures, a lack of specific training beginning with degree courses, the different educational paths of nurses, and the different approaches to pathology affect care outcomes. There is also a need for a clearer definition of task shifting, ie, transition of tasks from physicians to nurses, along with explicit descriptions of patient outcomes.¹⁸

Now more than ever, there's a pressing need for a European consensus on a common minimum framework of competencies for CNPs, particularly in the MS nursing community. This collaborative effort would harmonize diverse practices, ensuring consistency in roles, responsibilities, and skills. Such a consensus would enhance care quality and facilitate mobility and collaboration, establishing a unified standard for MS CNPs' roles and promoting cohesive and efficient health care provision across Europe.

Advisory Panel Meeting on Understanding the Role of CNPs

On October 25, 2022, in Amsterdam, the Netherlands, an expert scientific advisory panel of 8 CNPs from different European nations was convened by Viatrix. The purpose of the meeting was to review the current delivery of MS care in Europe, identify gaps in MS care, and assess the role of CNPs in closing these gaps. Other objectives included understanding the current challenges in the detection and diagnosis of MS, identifying opportunities to improve access to care, fostering collaborations among stakeholders, and identifying initiatives to educate people with MS. The CNPs shared insights and recommendations based on their clinical experience in the management of MS. This paper presents the key insights and recommendations that were shared and is further supported in the context of contemporary published evidence. A literature search was conducted using PubMed,

Google Scholar, and Cochrane Library databases to identify available evidence on MS, its diagnosis and management, and the evolving role of CNPs in MS management. The literature search had no date restrictions.

The panel's key insights were in the areas of delay in MS diagnosis, the role CNPs can play in MS care and disease management, identifying opportunities to facilitate more education for people with MS, and naming research and development needs.

Delay in MS Diagnosis

A timely MS diagnosis depends on various factors including patients recognizing their symptoms, promptly seeking initial consultation, and an early referral to specialists.^{7,19} People with MS may seek out orthopedic or ophthalmology specialists in the early disease stages because they lack information that is essential to recognizing their symptoms as neurological.¹⁹ A delay may also be due to limitations related to geographical location, eg, difficult and less accessible terrain or a longer distance to hospitals and specialized centers. The financial status of individuals and their preference for complementary and alternative therapies may also prolong the time before an appointment.¹⁹ PCPs, burdened by clinic demands and constrained by short appointment windows, might not have adequate time to thoroughly address all concerns raised by individuals with suspected MS, which can result in overlooking symptoms and contribute to a prolonged time to diagnosis.²⁰ In addition, there may be a limited number of well-equipped MS clinical centers to perform instrumental tests that are necessary for the diagnosis (ie, MRI, evoked potentials, diagnostic lumbar puncture, and specific biomarkers for differential diagnosis).^{6,21} Nursing assessments are vital in identifying primary symptoms of chronic diseases. Prior to an examination by a specialist, the CNP's assessment provides an initial understanding of the individuals' needs and concerns.²² Experts in the field also suggest that individuals with suspected MS would benefit from a formal consultation with a multidisciplinary team that includes CNPs specializing in MS.²³

The expert scientific advisory panel put forth a series of consensus recommendations aimed at reducing the delay in diagnosing MS. The first was to increase PCPs' MS awareness. The need for prompt action by both PCPs and neurologists upon detecting MS symptoms was also emphasized, along with educating PCPs to swiftly refer cases to specialists. The second recommendation was to train young neurologists through knowledge sharing and to refine diagnostic skills via improved teleconsultation modalities with experienced neurologists. Other highlighted suggestions were to standardize patient care practices, educate patients on optimal diagnostic methods, increase patient awareness about MS, and foster the exchange of best practices among colleagues and MS CNPs to enhance and facilitate patients' access to MS centers. Finally, the panel suggested exploring the potential of social media in providing early MS detection guidance.

Early diagnosis and treatment initiation has the most impact on slowing MS progression and preventing permanent disability. Simply put, MS treatment shows greater effectiveness when initiated early.²⁴ The consensus recommendations stated that nurse-led educational initiatives may have potential benefits in this area, as they are likely to improve awareness and early symptom identification and diagnosis.

Role of CNPs in the Management of MS

The second area highlighted by the panel was CNPs' pivotal role in managing MS. Acting as coordinators of care, they can offer tailored support and care to people with MS and their families and their expertise allows them to provide high-quality clinical care based on evidence-based practices so they can serve as accessible primary contacts for individuals with MS.¹⁷ CNPs can bridge the gap between patients and neurologists to help optimize the neurologist's time, delegate symptom management, and ensure the patient's understanding of the treatment and successful treatment implementation. Economically, employing specialist nurses for MS management has been shown to be cost-effective while improving clinical outcomes, reducing wait times, avoiding unnecessary hospital admissions, and introducing innovative care frameworks. In addition, CNPs provide crucial advice and support to families and caregivers, further enhancing their significance in MS care.¹⁷ A strong correlation exists between the needs of individuals with MS and the skills of CNPs, such as patient education and psychological support and specialized counseling, which underscores their integral role in MS care.^{10,11,17}

CNPs encompass a range of specialized roles that are vital in health care delivery. Home health CNPs, also known as visiting nurses, provide essential care within patients' homes, supporting recovery from surgery or illnesses and assisting patients with disabilities or frailty.²⁵ Similarly, family CNPs prioritize holistic family health, operating in a collaborative, physician-like capacity with prescription-writing capabilities and a broad skill set for comprehensive patient care.²⁵ Another slightly different but critical role is performed by nurse managers, CNPs who oversee clinical trials and help in maintaining a balance between caring for research participants and adhering to rigorous research protocols.²⁶ Furthermore, with a rise in the use of technology, CNPs involved in telenursing have transformed care delivery while upholding fundamental nursing practices like assessment, intervention, and evaluation.²⁷ These varied roles played by CNPs represent critical facets of health care, significantly contributing to diverse and accessible services.

Acknowledging the various roles fulfilled by CNPs in Europe, the panel of experts reached a consensus on defining MS CNPs as "specialized health care professionals possessing educational proficiency, clinical expertise, and interpersonal skills tailored for multiple facets of MS care, encompassing diagnosis, treatment, palliative care, and rehabilitation." This

definition aligns with studies highlighting the comprehensive role of CNPs in MS management.^{28,29}

The panel also recognized the pivotal role of European CNPs in MS management and their wide array of responsibilities, such as educating people with MS, developing training content, administering and ensuring medication and treatment adherence, managing adverse reactions to drugs, offering counseling to people with MS and their caregivers, providing both physical and emotional support, monitoring MS progression, conducting follow-ups, performing triage, ensuring timely referrals to specialized care, supporting clinical trials, tracking and supporting the QOL of people with MS, taking care of common MS symptoms, and, in some cases, even scheduling appointments. The panel recognized lesser-known advantages of MS nursing care, such as improved health outcomes and QOL, reduced emergency department/neurologist visits, fewer hospital admissions, and cost-effective treatment.

In addition, the panel discussed the emerging specialized roles of MS nurses which include, but are not limited to, clinical trial nurses, nurse managers, telenurses, infusion nurses, and day-care clinic staff. The experts emphasized the challenges faced by aging people with MS, highlighting increasing disability levels and difficulties in travel that are often addressed by telenurses. Mobile community nurses were identified as key players in providing ongoing care, referrals, and rehabilitation services. Family nurses, often the initial point of contact, were noted for indirectly educating physicians and thus expediting the diagnosis process. The importance of CNPs conducting QOL assessments using tools such as the EuroQol 5-Dimensions twice a year to evaluate disease progression and document clinical outcomes was mentioned. Finally, community nurses were also acknowledged for delivering home-based care, patient education, and training. Despite these diverse roles and contributions, there is a requirement for more research on the role of CNPs in the management of MS.

Opportunities to Improve Education

The MS in the 21st Century Steering Group, a Merck KGaA initiative bringing together health care professionals (HCPs) and the MS community, has highlighted the importance of improving access to treatment and fostering collaborations to educate people with MS, emphasizing that these efforts are crucial steps for improved care.³⁰ Local treatment limitations and high costs often prevent patients from obtaining necessary therapies and HCPs and people with MS in the steering group acknowledged the significance of access. There is also a need for better education to help HCPs understand the treatment-specific requirements of people with MS. Addressing the gaps in unmet needs, treatment burdens, and engagement between people with MS and HCPs and facilitating shared decision-making will empower people with MS to actively participate in disease management alongside their HCPs. Although present research focuses on developing patient-centered educational tools to enhance

comprehension and communication during consultations with their HCPs,³⁰ evidence from randomized controlled trials indicates that nurse-led information dissemination and counseling can significantly improve informed decision-making.³¹ Approximately 1500 nurses reportedly care for people with MS across 19 European nations, although this might be an underestimate due to varying reporting methods.³² Expanding the presence of MS specialist nurses throughout Europe could significantly enhance the quality of care available. Initiatives such as the MS Nurse PROfessional course, an e-learning training program, are an important aspect of clinical empowerment and continued education. Further investments in similar initiatives could effectively optimize the MS care and expertise available.³³

The panel emphasized the need to educate people with MS about the significance of early treatment, treatment choices and adherence, and lifestyle adjustments, recognizing that education is crucial to enhance patient self-care and empowerment, and especially to encourage collaborative clinical decision-making. Among their education suggestions were simple audiovisual tools, like patient orientation sessions, to address concurrent multifunctional MS impairments and telehealth applications to facilitate timely identification of MS progression and treatment-related adverse events.

A particular patient education area where CNPs could play a pivotal role is providing information about the equivalent efficacy and comparable safety of biosimilars. The collaborative effort by health care stakeholders supports the widespread adoption of biosimilars, which also contributes to the goal of providing high-quality, cost-effective, and equitable health care without imposing additional burdens on HCPs.³³ The panel also suggested that education on biosimilars was needed by CNPs, in particular family nurses, who could benefit from an enhanced understanding of biosimilar drugs in MS management. In addition, understanding how HCPs and people with MS perceive biosimilars and nonbiological complex molecules in MS management would be beneficial.

The panel also recommended that, during drug design and trials, companies and researchers could learn from the MS community (both patients and clinicians) about what might improve patient adherence to treatment, including dosage form, dosing frequency, and noise-free designs for injectable therapies. Companies should also make it a priority to consider the patient perspective on adverse effects of drugs and their implications; this is an especially important consideration for individuals with MS in their childbearing years.

CNPs themselves would benefit from more access to educational programs/initiatives, especially regarding the use of digital media and ways to better understand symptomatology to help improve medication adherence. The panel recognized the significance of the MS Nurse PROfessional training course for ongoing education and professional development. Nevertheless, various challenges hinder enrollment in

PRACTICE POINTS



Recommendations from a panel of European certified nurse practitioners (CNPs) for CNP integration in multiple sclerosis (MS) care.

Develop standardized competencies and a unified framework for CNPs in MS care across Europe.

Facilitate active involvement of CNPs in monitoring disease progression, documenting outcomes, managing medications and adverse effects, providing counseling to people with MS and referral to specialized MS care centers.

Implement comprehensive education programs to enhance nursing skills for improved care of individuals with MS. ■

training programs, including language barriers, work leave, familial responsibilities, and financial requirements.

Research and Development Needs

The panel of experts emphasized the need for new tools, especially digital ones. Access to the latest digital tools, including those that monitor QOL (eg, EuroQol 5-Dimensions, Multiple Sclerosis Quality of Life-54) and bowel and bladder scales, could help CNPs map the disease progression and personalize health education programs for people with MS. Ideally, these tools should be able to integrate the information collected into MS registries, which will improve the data available to researchers.

In line with the registries, the panel also proposed having a platform for European nations to share research ideas and advancements in MS. Such a platform would also encourage the exchange of best practices, ultimately leading to better counseling and therapy that could impact management strategies and clinical outcomes. Similarly, the creation of digital platforms could facilitate continuous engagement between CNPs and people with MS. Programs and initiatives sponsored by corporate social responsibility could also be extended to provide economic or administrative support to help CNPs.

CONCLUSIONS

This consensus report is based on the recommendations made by a panel of CNPs from different European nations.

The insights and recommendations reflect a pivotal need for unified standards and approaches to managing MS across Europe. The delayed diagnosis of MS imposes a significant burden on individuals as well as society. The lack of timely diagnosis, which is attributed to various challenges like limited awareness, delayed referrals, and accessibility issues, underscores the urgency for cohesive strategies. The panel highlighted essential steps to mitigate delays, emphasizing the crucial role of PCPs and neurologists to facilitate quick diagnosis upon symptom recognition. Moreover, CNPs are major contributors and play a critical role in MS management with their multifaceted contributions, including patient education, holistic care coordination, and fostering collaborative partnerships. Improving access to treatment and empowering patients through education and shared decision-making were focal points of discussion. CNPs were acknowledged as pivotal educators, guiding patients on treatment choices and the significance of early intervention. The integration of digital tools and platforms emerged as a potential pathway for better engagement and continuous monitoring of MS progression and QOL.

The expert scientific advisory panel's comprehensive recommendations underscore the crucial need for a unified framework and increased education and collaborative efforts to optimize MS management in Europe. Achieving uniformity and standardization in the role of CNPs across Europe necessitates collaboration, partnerships, and support from various stakeholders like patient organizations, scientific bodies, regulators, payors, policy makers, and industry entities. Empowering CNPs, improving patient and provider education, and leveraging technological advancements will be pivotal to bridge the existing gaps and to ensure optimal MS care across Europe. ■

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