Neurol Ther
https://doi.org/10.1007/s40120-026-00942-y

ORIGINAL RESEARCH

Understanding the Unmet Needs of People with MS at Diagnosis and Throughout Their Care Journey: Insights from a Survey-Based Study

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Received: March 5, 2026 / Accepted: April 14, 2026

ABSTRACT

Introduction: Multiple sclerosis (MS) has a broad range of symptoms and heterogenous trajectory that requires individualised care. To optimise shared decision-making between healthcare professionals (HCPs) and people with MS (PwMS), it is important to understand communication needs from the patient perspective at diagnosis and throughout their care journey.
Methods: Two multinational online surveys were conducted to explore (1) communication needs around the time of diagnosis, and (2) PwMS empowerment in communicating their specific needs and symptoms. Questionnaires included ten close-ended questions and were shared among 100 PwMS aged 18–50 years in Australia, Spain, the UK and the USA. Anonymised data were analysed by a core panel of HCPs, PwMS and patient advocacy group representatives, and key recommendations were agreed.
Results: The majority of respondents were female (65–80%) and from the UK (80–87%). PwMS and caregivers are often overwhelmed and feel 'lost' at the time of diagnosis. Early regular contact is critical for effective delivery of key information and building a trusting relationship. PwMS value a clear explanation of the healthcare team and next steps, but only around

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s40120-026-00942-y.

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Published online: 01 May 2026

a quarter (26%) had HCP roles clearly explained. PwMS are often uncertain if health changes are related to MS and 42% reported not feeling comfortable discussing 'invisible' symptoms such as cognitive, mood and emotional changes. Most respondents (54%) reported that their MS nurse was the person they were most likely to consult. Support services were not routinely offered; only 26% were informed about patient support groups. The most reported benefit of an MS-specific patient group was 'feeling less alone'.
***Conclusion*:** Regular HCP contact after diagnosis, peer group support for PwMS and their caregivers, signposting of reliable and accurate online resources and the timely offer of support services, including psychological support, should be routine elements of care from the point of diagnosis.

PLAIN LANGUAGE SUMMARY

Multiple sclerosis (MS) is a long-lasting illness that affects the brain and spinal cord. In MS, the body's own defence system attacks a coating around the nerves, which causes damage. This leads to many symptoms. Some are easy to see, like trouble walking or speaking. Others are 'hidden', such as feeling very tired, changes in mood, bladder problems or trouble remembering things. These hidden symptoms can impact quality of life, but they are often missed or ignored. The MS in the 21st Century (MS21) group works with people who have MS, doctors, nurses and patient support groups to make care better. To learn more about what people need, MS21 talked to 30 people recently diagnosed with MS in five European countries. They also did two online surveys with 100 people each in Australia, Spain, the UK and the USA. One survey asked about needs at diagnosis. The other asked about helping patients feel comfortable speaking with their care team. Four important needs came up: first, clear communication about what will happen next and who is in the care team; second, helpful information given at the right time, including for families; third, trusted resources like reliable websites and MS nurses; fourth, support services, such as counselling and patient groups to help with feelings of loneliness. Many people wanted more time with their doctors, more discussion about hidden symptoms and regular offers of emotional support. Meeting these needs early could help people manage MS better and feel more confident about their care.

Keywords: Caregiver; Communication; Diagnosis; Multiple sclerosis; Patient empowerment; Shared decision-making; Support

Key Summary Points

Why carry out this study?
Multiple sclerosis (MS) is a chronic neurological condition with a range of visible and invisible symptoms and a trajectory individual to each person, and so the needs of each person need to be carefully identified in order to enable effective communication and shared decision-making
Surveys were conducted to explore: (1) the specific unmet communication needs of people with MS (PwMS) at and around the time of diagnosis, and (2) how PwMS could be empowered to communicate more confidently about their needs and symptoms
What was learned from the study?
Early regular contact with the healthcare team is required for building the trust required for open and effective communication
Patients are frequently overwhelmed with information at the time of diagnosis and there is a need for regular and sustained support from the outset
Peer support for PwMS and their caregivers, signposting of reliable and accurate online resources, and the timely offer of individualised support services should be routine elements of care

INTRODUCTION

Multiple sclerosis (MS) is a chronic, immune-driven disorder of the central nervous system characterised by inflammatory demyelination, neuroaxonal and synaptic damage and loss and gliosis (scar formation) [1–4]. The global prevalence of MS has increased over the past several decades, with an estimated 2.8 million people currently living with the condition worldwide [5]. Advances in therapy have markedly improved outcomes for people with MS (PwMS), and early clinical trials have demonstrated the feasibility of remyelination as an approach to restore function and prevent irretrievable damage [6].

The symptoms of MS are broad and impactful, and can affect people's physical, cognitive and psychological health [7, 8]. Owing to the relatively young age of onset, MS has a long-term impact on life events, such as building a career or having children, and may be associated with economic and societal burden [1, 5, 9, 10]. Symptoms of MS can be 'visible', such as mobility issues and speech problems, or 'invisible', meaning they are not immediately apparent to other people, such as fatigue, mood changes, bladder and bowel dysfunction, sexual dysfunction and cognitive changes [7, 8]. Invisible symptoms, especially when unaddressed, can negatively impact a person's overall quality of life, their own health perception and disability progression [8].

Since the approval of the first disease-modifying therapy (DMT) for MS in the USA by the Food and Drug Administration in 1993, the portfolio has expanded with the development of new classes of therapy offering different mechanisms of action, efficacy and tolerability profiles, delivery routes and administration schedules [11–13]. Greater flexibility in the treatment landscape, coupled with the changing needs of patients as their MS evolves over time, makes effective communication and shared decision-making between PwMS and healthcare professionals (HCPs) essential [13–16]. This process of shared decision-making has been associated with better health outcomes, greater adherence to DMT and greater patient satisfaction [15].

The MS in the 21st Century (MS21) initiative is an international collaboration between HCPs, PwMS and patient advocacy group representatives, with the overall aims of improving patient–HCP communication and optimising MS care. Established in 2011, the guiding principles of MS21 are to further understand real-world unmet needs in MS and develop practical educational resources and tools to support PwMS and HCPs involved in MS care. Gathering PwMS' insight and perspectives is a critical element of achieving the goals of the MS21 initiative. Herein we report and discuss findings from survey-based research, exploring two important themes in MS care: (1) understanding the specific needs of PwMS at and around the time of diagnosis (Needs at Diagnosis), and (2) recognising how to empower PwMS to feel confident in communicating with their healthcare team about their needs and symptoms (Patient Empowerment).

METHODS

To better understand the patient experience of being diagnosed with MS and help design quantitative surveys, preliminary web-assisted, 60-min, semi-structured interviews were conducted among 30 PwMS, aged 18–50 years, who had been diagnosed with MS within the previous 3 years (Fig. 1). Interviews took place among PwMS in France, Germany, Italy, Spain and the UK (each $n=6$), moderated in the local language and held over the Zoom platform by an agency (Lumanity, London, UK). PwMS were identified through an internal database and financially compensated for their time.

To generate wider quantitative insights across the MS community, two multinational surveys exploring 'Needs at Diagnosis' and 'Patient Empowerment' were developed. Questionnaires (see Electronic Supplementary Material [ESM] documents S1 and S2) included ten close-ended questions and were shared among 100 PwMS who were aged 18–50 years and living in Australia, Spain, the UK or the USA. The online surveys were conducted in English during May 2024 through Realworld MS (Leeds, UK),

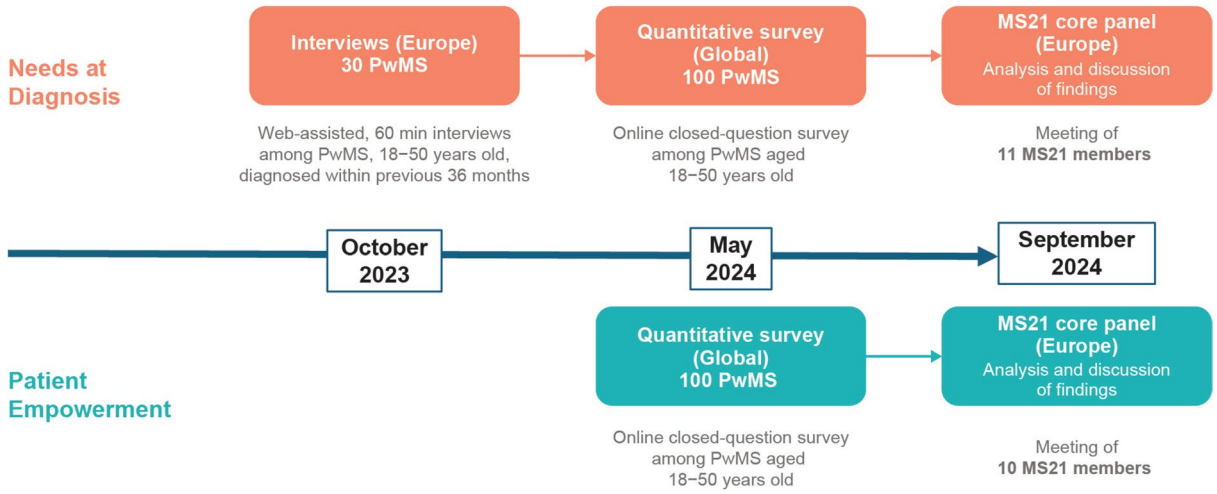

Fig. 1 Study overview. *MS21* MS in the 21st Century, *PwMS* people with multiple sclerosis

a partner organisation of the patient advocacy group Shift.ms (Leeds, UK).

Anonymised data from the 'Needs at Diagnosis' and 'Patient Empowerment' surveys were reviewed by two core MS21 panels ($N=11$ and $N=10$, respectively; see ESM Table S1 for panel members) to identify major unmet needs. Key recommendations to improve the experience of PwMS at diagnosis and throughout their MS care journey were agreed.

Ethics Compliance

This study was performed in accordance with the Helsinki Declaration of 1964 and its later amendments. All participants provided informed consent and data were anonymised. The survey protocols were reviewed by an independent institutional review board, WCG Clinical (Cary, NC, USA), and determined to be exempt from full review (Protocol numbers 5653 and 5652 for the 'Patient Empowerment' and 'Needs at Diagnosis' surveys, respectively).

RESULTS

A total of 100 PwMS completed the quantitative surveys (Table 1), the majority of whom were female (65–80%) and from the UK (80–87%).

Several key themes of unmet need emerged that were relevant to the findings of both surveys: effective communication, meaningful

Table 1 Demographics of participants with multiple sclerosis who completed online surveys

Demographics	NAD survey ($N=100$)	PE survey ($N=100$)
Gender		
Female/male	80/20	65/30
Not disclosed	–	5
Country		
UK	87	80
Spain	1	1
USA	11	18
Australia	1	1
Time since diagnosis		
< 2 years	36	5
2–4 years	62	45
5–9 years	6	47
10–15 years	–	1
> 15 years	–	2

NAD 'Needs at Diagnosis', *PE* 'Patient Empowerment'

information, reliable resources and support services (Table 2).

Effective Communication

Interviews revealed that newly diagnosed PwMS valued clarity around the immediate next steps in their care, including how care will be delivered and what to expect from each member of the care team. However, the 'Needs at Diagnosis' survey found that only around a quarter (26%) of PwMS had the role of each HCP in their care team clearly explained to them (Fig. 2).

The 'Patient Empowerment' survey demonstrated that PwMS commonly experience uncertainty about whether health changes are related to MS, with 88% of respondents experiencing mood or emotional changes, 80% experiencing cognitive changes and 79% experiencing physical changes uncertain if their symptoms were related to MS. PwMS reported that they were likely to withhold information about symptoms because of uncertainty as to whether the symptom warranted attention (47%) or which healthcare team member was the right person to help (29%). While two-thirds of respondents (67%) reported wanting to discuss health changes with their neurologist, 42% reported not feeling comfortable discussing any changes outside of the commonly known visible MS symptoms (e.g. cognitive, mood and emotional changes or bowel issues). PwMS agreed that less reliance on questionnaires and implementation of certain conversational strategies by healthcare teams would encourage

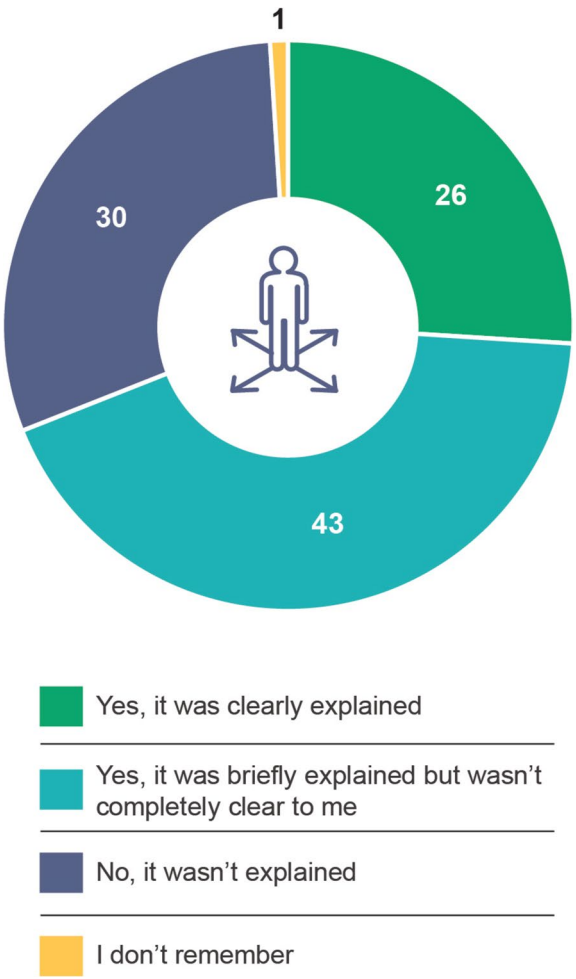

Fig. 2 People with multiple sclerosis who had the role of each healthcare professional in their care team clearly explained to them at diagnosis ($N = 100$)

Table 2 Unmet needs identified through responses from patients with multiple sclerosis to the 'Needs at Diagnosis' and 'Patient Empowerment' surveys

Effective communication	Meaningful information	Reliable resources	Support services
• Clarity around process and next steps • Uncertainty about whether symptoms are linked to MS • Lack of time in consultations • Building trust	• Information at the 'right' level and at the right time • Information provision for family at diagnosis	• Signposting to trustworthy educational material • Value of MS nurses in MS care	• Access to support services • Peer support

MS multiple sclerosis

them to be more open about health changes that were bothering them such as, for example, the HCP mentioning common MS symptoms that are not often spoken about (hidden symptoms), using open-ended questions and/or asking the PwMS directly whether there are any changes that are worrying them. Almost a third of respondents (31%) answered that they were less likely to share information with care team members with whom they had not built a trusting relationship. The most important PwMS-reported factors for building a trusting relationship were confidence in HCPs' knowledge of how to treat their MS, a clear explanation of next steps and whom to contact about concerns and the ability of HCPs to listen and understand their priorities. However, time constraint was revealed as a barrier to this, with almost half of respondents (49%) feeling that there was not enough time for a general discussion with their neurologist about how they were feeling.

Meaningful Information

Interviews with PwMS revealed that they often feel overwhelmed at hearing their diagnosis, which can result in them missing information and feeling lost. Almost two-thirds (65%) of the 'Needs at Diagnosis' survey respondents reported that they would have appreciated being asked how much detail about MS they were ready to hear at the time of diagnosis. From the PwMS perspective, the most important questions for HCPs to address at diagnosis were "What treatment options do I have?" (92%), "What can I do to help myself and manage my MS?" (89%), "What is MS?" (88%) and "What does life with MS look like in the long-term?" (86%). Two-thirds of respondents (67%) thought information for families and partners of newly diagnosed PwMS would be very useful.

Reliable Resources

People with MS may not be aware of how to manage relapses or where to get answers for urgent questions, with the 'Needs at Diagnosis' survey finding that only around half of PwMS (48%) received such guidance (Fig. 3). PwMS interviews revealed that advocacy organisations and patient stories are valuable resources, providing additional information to that shared by HCPs, including practical aspects of living with MS. Three quarters of respondents (76%) used social media to find information. The majority of PwMS reported that their MS nurse was the person they were most likely to consult about health changes that were worrying them (Fig. 4) because of their ability to listen and understand, in addition to having the knowledge and skills to provide answers.

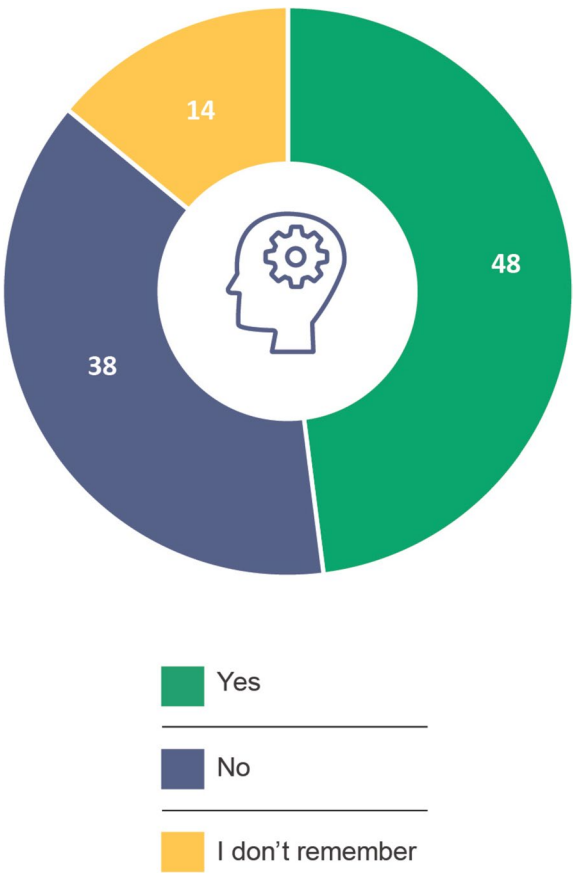

Fig. 3 Provision of guidance to people with multiple sclerosis (PwMS) regarding action to take in the case of relapse (with relapse defined as when a PwMS experiences new symptoms, or existing symptoms worsen for ≥ 24 h) or urgent health concerns ($N = 100$)

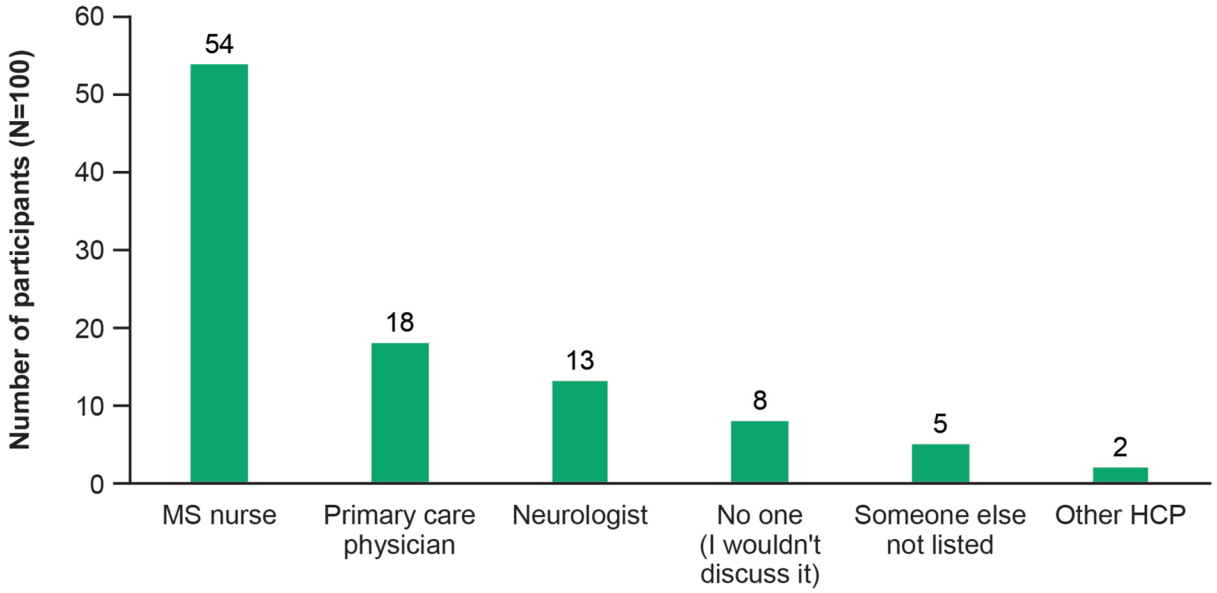

Fig. 4 Which healthcare professional people with multiple sclerosis would approach for advice about health changes. *HCP* healthcare professional, *MS* multiple sclerosis

Support Services

Patient interviews revealed that learning the diagnosis can be followed by a feeling of being misunderstood and a profound sense of isolation, and that being able to overcome this feeling was perceived as an important step in disease acceptance. The 'Needs at Diagnosis' survey revealed that PwMS valued counselling, with 92% agreeing that routine offering of counselling at the time of diagnosis was very important or somewhat important. Nearly half of respondents (47%) joined an MS-specific patient group, the benefits of which included feeling less alone, accessing information on managing MS in daily life, and learning where to look online for reliable and accurate information (Fig. 5). Support services were not routinely offered around the time of diagnosis, but when they were, they were often utilised (Fig. 6).

DISCUSSION

The early period of the MS journey is a time when PwMS feel particularly vulnerable, and unmet needs at diagnosis can impact long-term care [17]. These survey findings highlight the need for clear, consistent communication before, during and after diagnosis, while the interviews revealed that many PwMS feel overwhelmed, causing them to miss important information.

Fear and anxiety at diagnosis can stem from uncertainty about the diagnostic process, multiple medical tests, limited knowledge of MS and concerns for the future [17]. Providing clear explanations of procedures and next steps, along with early follow-up consultations, can help patients and their families adjust and prepare questions. Contact details for an MS nurse or designated team member who can respond to questions can further reassure patients and foster trust.

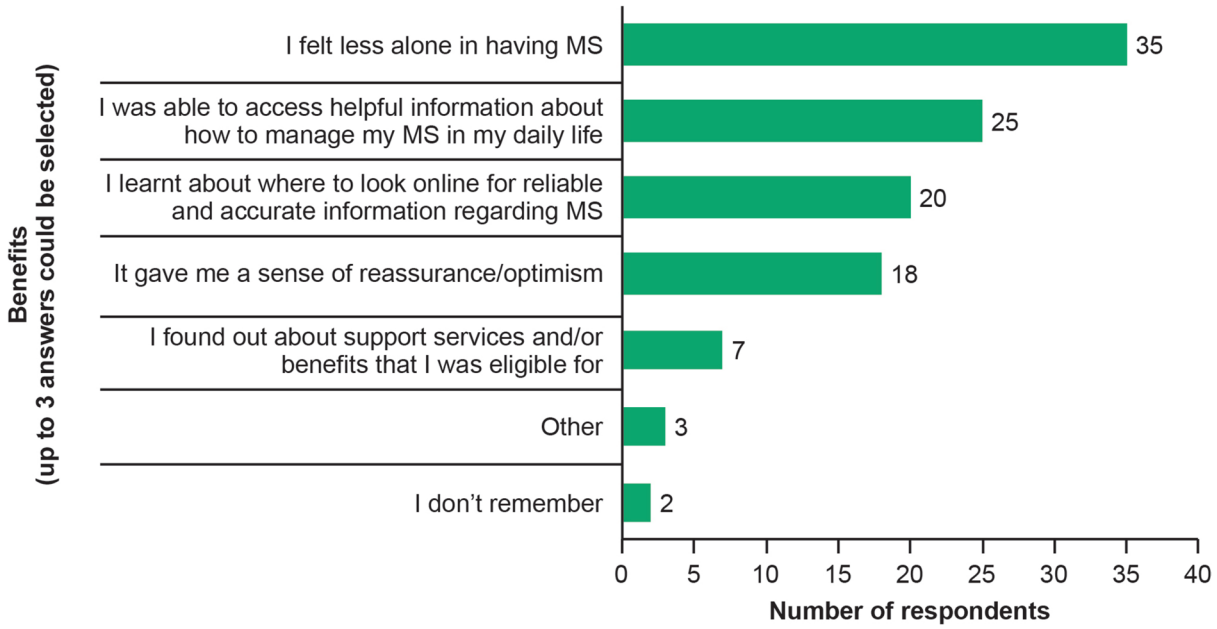

Fig. 5 Benefits of joining a multiple sclerosis-specific group around the time of diagnosis. *MS*, multiple sclerosis

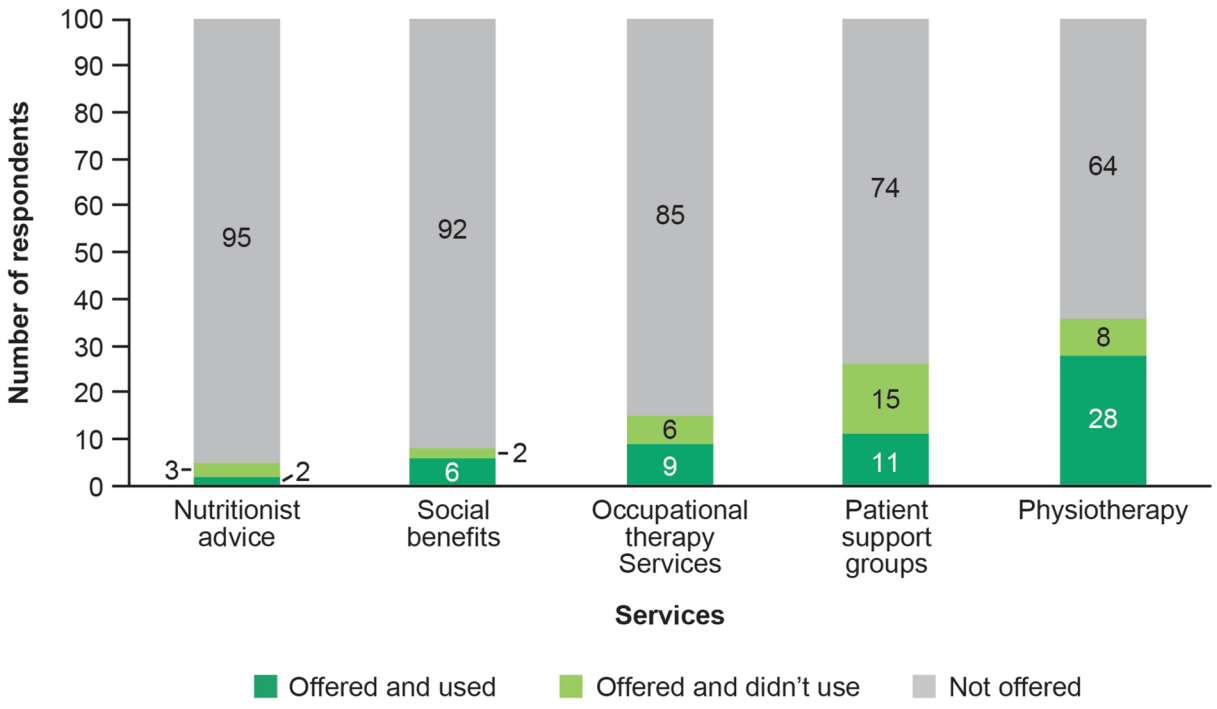

Fig. 6 Support services offered and used around the time of diagnosis ($N = 100$)

While MS nurses were identified as a key and trusted point of contact in this study, their availability and scope of practice may vary across countries and healthcare systems. In settings where MS nurses are part of the healthcare team, they play a central role in patient education, advocating for patients and care coordination [18]. Not having access to an MS nurse may contribute to inequities in patient experience and access to timely support. From a patient and public involvement perspective, it is important to recognise that while some individuals benefit from structured MS nurse-led care, others may not have access to such services, highlighting the need for adaptable care models and clear alternative points of contact within the multidisciplinary team.

The evolving landscape of MS diagnosis and disease classification, including updates to diagnostic criteria and increasing interest in biology-guided definitions of progression, has important implications for patient communication. Emerging frameworks conceptualise MS as a continuum with progression present from early disease stages, rather than distinct phenotypic phases [19, 20]. While these advances may improve precision in disease monitoring and treatment decisions, they also risk introducing complexity and inconsistency in how disease progression is communicated to patients. From a patient perspective, inconsistent terminology between HCPs may lead to confusion and anxiety. Therefore, there is a growing need for aligned, clear and accessible communication strategies, alongside education for both neurologists and MS nurses, to ensure that evolving scientific concepts are translated into meaningful and consistent explanations for PwMS.

Social media was reported as a common source of information but can increase anxiety if content is misleading. Signposting to reliable, accessible online resources, especially those featuring relatable stories from PwMS, can answer practical questions and reduce misinformation. Accreditation marks can help patients identify trusted content. For example, 'PIF TICK' is an accreditation scheme run by an independent UK-based charity, with the PIF TICK logo awarded to content that meets certain criteria for being evidence-based, produced by trained staff and written in plain language [21].

Group learning clinics, where PwMS meet collectively with a neurologist to ask questions and learn from each other, offer emotional support, practical advice and the opportunity to reduce feelings of isolation. Evidence from telenursing and empowerment programmes shows improved self-management and MS knowledge [22]. Support for caregivers is also important, as they often face challenges in adjusting to their role [23, 24].

Invisible symptoms, including fatigue, mood changes, sexual dysfunction and cognitive changes, are often under-discussed yet can be highly distressing. From an HCP perspective, MS progression tends to focus on physical disability, leaving patients with less overt symptoms feeling their experience is not validated by others and something they need to cope with alone [25, 26]. Acknowledging these symptoms during consultations validates patient experiences and encourages further exploration and discussion about support options. Digital health and telemedicine apps are being increasingly integrated into multiple aspects of medicine, including MS care [27, 28]. Digital tools, such as the MS21 *myMS priorities* planner, can prompt discussion and help track invisible symptoms. Even small adjustments during consultations, like HCPs asking open-ended questions about health changes, could make a big difference in terms of encouraging open discussion.

Mental health needs should be addressed proactively, with accessible counselling offered routinely and in a timely fashion. PwMS may not feel ready to use these services immediately, but the vast majority (92%) of respondents agreed that offering counselling at the time of diagnosis was important. Psychological interventions benefit individuals with both visible and invisible symptoms, although their emotional trajectories differ [29]. This underscores the personalised nature of MS care and the central role of open communication in fostering acceptance and engagement.

Addressing unmet needs at diagnosis requires collaboration across MS stakeholders to ensure effective HCP–patient communication, delivery of relevant and reliable information and

individualised support for PwMS and caregivers. To retain and facilitate brain health from the point of diagnosis, 'coaching' of newly diagnosed PwMS, involving HCPs and experienced PwMS, is an innovative approach combining information delivery, emotional support and goal setting in a collaborative setting [30–32]. Further research is needed to explore its feasibility and efficacy [32].

Limitations

The observational, survey-based methodology used in this research was associated with some limitations. The population surveyed through the patient organisation, Shift.ms, may not be representative of the wider MS community. The survey questions in each of the two surveys were aimed at different MS populations, and while we would expect that patients would only complete the survey that was most relevant to them, due to the nature of the anonymous data collection, we are unable to guarantee that there was no duplicate participation. The online surveys were completed by PwMS who were computer literate and able to understand English, which limits the generalisability of the findings. The majority of participants were from the UK, so answers may be dependent on the nationalised UK-based healthcare system. The quantitative surveys did not allow open-text responses, and interpretation of the findings was based on the opinions of committee members actively involved in the MS21 initiative, which is an industry-funded initiative.

CONCLUSION

Providing PwMS with effective communication, reliable resources and support services remain key unmet needs, especially at the time of an MS diagnosis. They also represent key opportunities for improving the patient experience. Looking to the future, it is clear that engaging with both the patient and healthcare community is essential to developing solutions that address patients' needs in a sustainable and reproducible way.

ACKNOWLEDGEMENTS

We thank the participants of this study for their time and valuable contributions.

Medical Writing, Editorial and Other Assistance. Editorial assistance in the preparation of this article was provided by Lisa O'Rourke, PhD, for Lumanity (London, UK). Sharon Pickett, Scientific Director (Lumanity, London, UK), managed the project, and Robert Sloan, Associate Director (Realworld MS), oversaw the data collection for the quantification surveys. Support for this assistance was funded by the healthcare business of Merck KGaA, Darmstadt, Germany (CrossRef Funder ID: https://doi.org/10.13039/100009945).

Author Contributions. All authors (Klaus Schmierer; Pieter van Galen; Helen Gray; Alice Laroni; Amanda Montague; Stanca Potra; Heidi Thompson) critically reviewed and revised the manuscript for important intellectual content and approved the final version of the article, including the authorship list. All authors meet the ICMJE authorship criteria.

Funding. Sponsorship for this study and Rapid Service Fee was funded by the healthcare business of Merck KGaA, Darmstadt, Germany (CrossRef Funder ID: https://doi.org/10.13039/100009945) in accordance with Good Publication Practice (GPP 2022) guidelines (http://www.ismpp.org/gpp-2022).

Data Availability. The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Conflict of Interest. Klaus Schmierer has received speaker honoraria from Neuraxpharm, Novartis, Roche, Sanofi, the healthcare business of Merck KGaA, Darmstadt, Germany and EMD Serono Research & Development Institute, Inc., Billerica, MA, an affiliate of Merck KGaA, Darmstadt, Germany; research grants, through Queen

Mary University of London, from Biogen, JUVISE, the healthcare business of Merck KGaA, Darmstadt, Germany, Novartis, Roche and Sandoz; he is Chair of the MACiMiSE-BRAIN DMEC and has received service support, through Queen Mary University of London and Barts Health NHS Trust, from Neuraxpharm. Pieter van Galen has received consulting fees from Roche and the healthcare business of Merck KGaA, Darmstadt, Germany. Helen Gray is an employee of Merck Serono (Ireland) Ltd., Dublin, Ireland, an affiliate of Merck KGaA, Darmstadt, Germany. Alice Laroni received grants or contracts from the Italian Ministry of Health, the Italian Ministry of University and IRCSS Ospedale San Martino; consulting fees from Novartis, the healthcare business of Merck KGaA, Darmstadt, Germany, Biogen and Roche; speaker honoraria from Novartis, Sanofi, the healthcare business of Merck KGaA, Darmstadt, Germany, Biogen, BMS and Roche; and support for attending meetings from Roche, the healthcare business of Merck KGaA, Darmstadt, Germany, Novartis and Biogen. Amanda Montague's institution (Multiple Sclerosis Association of America) received grants and contracts from Genentech, EMD Serono, Boston, MA, Novartis, TG Therapeutics, Sanofi, BMS and Biogen. Stanca Potra received support for meeting attendance from Roche, and the healthcare business of Merck KGaA, Darmstadt, Germany. Heidi Thompson received speaker honoraria from Novartis, Roche and the healthcare business of Merck KGaA, Darmstadt, Germany.

Ethical Approval. This study was performed in accordance with the Helsinki Declaration of 1964 and its later amendments. All participants provided informed consent and data were anonymised. The survey protocols were reviewed by an independent institutional review board, WCG Clinical (Cary, NC, USA), and determined to be exempt from full review (Protocol numbers 5653 and 5652 for the 'Patient Empowerment' and 'Needs at Diagnosis' surveys, respectively).

REFERENCES

1. Baskaran AB, Grebenciucova E, Shoemaker T, Graham EL. Current updates on the diagnosis and management of multiple sclerosis for the general neurologist. J Clin Neurol. 2023;19(3):217–29.

2. Yamout B. Update in Multiple Sclerosis. eNeurologicalSci. 2025;38:100553.

3. Ferguson B, Matyszak MK, Esiri MM, Perry VH. Axonal damage in acute multiple sclerosis lesions. Brain. 1997;120(Pt 3):393–9.

4. Petrova N, Nutma E, Carassiti D, et al. Synaptic loss in multiple sclerosis spinal cord. Ann Neurol. 2020;88(3):619–25.

5. Walton C, King R, Rechtman L, et al. Rising prevalence of multiple sclerosis worldwide: insights from the atlas of MS, third edition. Mult Scler. 2020;26(14):1816–21.

6. Zuroff L, Farkhondeh V, Bove R, Green AJ. The road to remyelination in multiple sclerosis: breakthroughs, challenges, and considerations for future trial design. Drugs. 2025;85(11):1337–62.

7. Ghasemi N, Razavi S, Nikzad E. Multiple Sclerosis: pathogenesis, symptoms, diagnoses and cell-based therapy. Cell J. 2017;19(1):1–10.

8. Lakin L, Davis BE, Binns CC, Currie KM, Rensel MR. Comprehensive approach to management of multiple sclerosis: addressing invisible symptoms—a narrative review. Neurol Ther. 2021;10(1):75–98.

9. Simoens S. Societal economic burden of multiple sclerosis and cost-effectiveness of disease-modifying therapies. Front Neurol. 2022;13:1015256.

10. Rodríguez-Sánchez B, Daugbjerg S, Peña-Longobardo LM, et al. Does the inclusion of societal costs change the economic evaluations recommendations? A systematic review for multiple sclerosis disease. Eur J Health Econ. 2023;24(2):247–77.

11. Edinger A, Habibi M. The evolution of multiple sclerosis disease-modifying therapies: an update for pharmacists. Am J Health Syst Pharm. 2023;81(2):37–55.

12. Goldschmidt C, McGinley MP. Advances in the treatment of multiple sclerosis. Neurol Clin. 2021;39(1):21–33.

13. Vollmer BL, Wolf AB, Sillau S, Corboy JR, Alvarez E. Evolution of disease modifying therapy benefits and risks: an argument for de-escalation as a treatment paradigm for patients with multiple sclerosis. Front Neurol. 2022;12:799138.

14. Col NF, Solomon AJ, Alvarez E, et al. Implementing shared decision-making for multiple sclerosis: the MS-SUPPORT tool. Multiple Scler Relat Disord. 2023;80:105092.

15. Ubbink DT, Damman OC, de Jong BA. Shared decision-making in patients with multiple sclerosis. Front Neurol. 2022;13:1063904.

16. Tortorella C, Solaro C, Annovazzi P, et al. Informing MS patients on treatment options: a consensus on the process of consent taking. Neurol Sci. 2020;41(8):2249–53.

17. Topcu G, Mhizha-Murira JR, Griffiths H, et al. Experiences of receiving a diagnosis of multiple sclerosis: a meta-synthesis of qualitative studies. Disabil Rehabil. 2023;45(5):772–83.

18. Savio M, Kearney H, Giunti G. Evaluating the evidence behind multidisciplinary roles for a multiple sclerosis unit: a systematic literature review. Mult Scler Relat Disord. 2025;95:106342.

19. University of California SFMSET, Cree BAC, Hollenbach JA, et al. Silent progression in disease activity-free relapsing multiple sclerosis. Ann Neurol. 2019;85(5):653–66.

20. Kappos L, Wolinsky JS, Giovannoni G, et al. Contribution of relapse-independent progression vs relapse-associated worsening to overall confirmed disability accumulation in typical relapsing multiple sclerosis in a pooled analysis of 2 randomized clinical trials. JAMA Neurol. 2020;77(9):1132–40.

21. PIF TICK. https://piftick.org.uk/. Accessed Dec 2025.

22. Bayat F, Negarandeh R, Pashaeypoor S. The effect of patient-centered empowerment program through telenursing on self-management in people with multiple sclerosis: a double-blinded randomized clinical trial. BMC Neurol. 2025;25(1):138.

23. Appleton D, Robertson N, Mitchell L, Lesley R. Our disease: a qualitative meta-synthesis of the experiences of spousal/partner caregivers of people with multiple sclerosis. Scand J Caring Sci. 2018;32(4):1262–78.

24. Kesselring J, Boyko A, Laroni A, Bharadia T, van Galen P, Alexandri N. Caregiver involvement in MS: duty or disruption? Neurol Ther. 2022;11(1):9–20.

25. Parker LS, Topcu G, De Boos D, das Nair R. The notion of "invisibility" in people's experiences of the symptoms of multiple sclerosis: a systematic meta-synthesis. Disabil Rehabil. 2021;43(23):3276–90.

26. Celius EG, Thompson H, Pontaga M, et al. Disease progression in multiple sclerosis: a literature review exploring patient perspectives. Patient Prefer Adherence. 2021;15:15–27.

27. Guardado S, Tripathi N, Isomursu M, Giunti G. Adoption of mHealth apps in chronic care: healthcare professionals' views. Stud Health Technol Inform. 2025;328:496–500.

28. Jaworski M 3rd, Balconi J, Santivasci C, et al. Improving conscientiousness through a smartphone app and telecoaching intervention: insights from multiple sclerosis and healthy aging samples. J Neurol. 2025;272(9):580.

29. Fragkiadaki E, Nizza IE, Starr R, Smith JA, Rice C, Cotterill N. Trajectories of change in experiences of multiple sclerosis: insights from an online group psychological intervention. Disabil Rehabil. 2026;48(8):2362–78.

30. Hobart J, Bowen A, Pepper G, et al. International consensus on quality standards for brain health-focused care in multiple sclerosis. Mult Scler. 2019;25(13):1809–18.

31. Tindall T, Topcu G, Thomas S, et al. Developing a patient care pathway for emotional support around the point of multiple sclerosis diagnosis: a stakeholder engagement study. Health Expect. 2023;26(2):858–68.

32. Schmierer K, Mathews J, Stennett A, et al. Coaching newly diagnosed people with multiple sclerosis. J Neurol Neurosurg Psychiatry. 2024;95(Suppl 2):A76–A76.