

BMJ Open What matters to patients with multiple sclerosis? Identifying patient-relevant attributes using a ranking exercise with open-ended answers from an online survey in Italy

Karin Schölin Bywall ^{1,2} Ulrik Kihlbom,³ Jennifer Viberg Johansson,^{2,4} Guido Pasquini,⁵ Filippo Gerli,⁵ Claudia Niccolai,⁵ Sara Della Bella,⁵ Emilio Portaccio,⁶ Matteo Betti,⁶ Maria Pia Amato,⁷ Sylvia Martin⁸

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ABSTRACT

Objectives This study aimed to explore what intervention specificities or attributes newly diagnosed individuals with multiple sclerosis (MS) find important and to explore possible reasons behind their evaluations.

Design A stepwise approach began with a systematic literature review to identify significant attributes. Patients with MS then assessed these attributes through an online survey, which included a ranking exercise and open-ended questions. Finally, the results were evaluated by the clinical team to select the most relevant factors for personalised care.

Setting and participants From June 2023 to December 2023, all consecutive patients referred to the MS Center of Careggi University Hospital were screened for inclusion. Following recruitment, cognitive and physical assessments were administered at the Don Gnocchi Centre. All participants were interviewed by an experienced neuropsychologist.

Procedures Participants were enrolled in the RELIABLE clinical trial, which included a ranking exercise and open-ended question. In the ranking exercise, patients prioritised levels of treatment attributes: treatment effects, methods of intervention, type of monitoring, monitoring, mode and mental support. The open-ended questions addressed the reasons behind the level rankings.

Results Participants' rankings revealed the most important levels of each attribute. The highest-ranked method of intervention was disease-modifying treatment, which received 164 points. For mental support, individual psychotherapy was deemed most important with 149 points. Preservation of cognitive function, a key treatment effect, received 144 points. Clinical check-ups were the top type of monitoring with 129 points. Lastly, the hybrid mode of monitoring (half remote/half in-person) was ranked with 77 points. Open-ended responses provided insights into the reasons behind these preferences, emphasising the importance of maintaining mobility, cognitive function and emotional well-being. The clinical team evaluated these findings, confirming that the selected attributes were both clinically relevant and aligned with patient priorities. This evaluation process

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The study used a stepwise approach, combining a systematic literature review, quantitative ranking and qualitative insights, ensuring a thorough exploration of treatment attributes.
- ⇒ The evaluation of results by the clinical team ensured that the selected treatment attributes were both clinically relevant and aligned with patient priorities.
- ⇒ Open-ended responses provided valuable insights into the reasons behind patient preferences, highlighting the importance of maintaining mobility, cognitive function and emotional well-being.
- ⇒ A limited number of patients with multiple sclerosis participated in the ranking exercise, potentially affecting the generalisability of the results.

ensured that the treatment specificities chosen for individualised care were comprehensive and reflective of patient needs.

Conclusions By identifying and prioritising key treatment attributes, this research highlights the multifaceted nature of MS management and emphasises the importance of aligning treatment options with patient preferences. Addressing these factors through further quantitative preference assessments is essential for preventative MS care, improving patient outcomes and promoting a more patient-centred approach to treatment.

INTRODUCTION

Multiple sclerosis (MS) is a chronic neurological disease that impacts the central nervous system.¹ It is one of the most common neurological conditions among young adults (aged 18–40 years), with a prevalence of approximately 2.8 million people worldwide and an incidence that varies geographically.² Characterised by its unpredictable nature and a wide range of symptoms, MS poses a substantial



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For numbered affiliations see end of article.

Correspondence to

Karin Schölin Bywall;
karin.bywall@crb.uu.se

challenge for both patients and healthcare providers.³ MS is an inflammatory disease where immune cells attack and damage the myelin sheath and nerve fibres in the brain and spinal cord.⁴ Initially, the inflammation can heal, causing symptoms to come and go. However, over time, the damage becomes more extensive and permanent, leading to a gradual increase in disability. MRI scans are fundamental for establishing diagnosis and for evaluating treatment response.

MS is triggered by environmental factors in individuals with certain genetic risks.⁵ Current medications reduce the frequency of new episodes but cannot repair existing damage and partially fail to stop progression independent from relapse activity.⁶ Future research aims to improve treatment by focusing on the underlying mechanisms of the disease.⁷ As a lifelong condition, MS necessitates ongoing medical supervision and treatment, tailored to the individual's specific needs and the progression of the disease.⁸ The interventions for MS are diverse, encompassing disease-modifying therapies, symptomatic treatments, rehabilitation and lifestyle modifications.⁹

Given the chronic and unpredictable nature of MS, it is crucial to thoroughly assess and comprehend the treatment specifics (also called attributes) that are most important for individuals living with the condition.¹⁰ In preference studies, an attribute is a characteristic or feature of something being evaluated; it is a specific aspect that can vary and influence a person's choices. For example, it can be viewed as a quality that helps to compare different options, such as the price or colour of a product. Researchers use these attributes to understand how people weigh different factors when making decisions. These attributes considered in one's decision making can vary significantly from person to person, influenced by their symptoms, disease progression, personal preferences and lifestyle.¹¹ Recognising these critical factors is essential for tailoring a more personalised and patient-centred approach to MS care.¹² This approach not only enhances treatment effectiveness but also enables collaborative decision-making between patients and healthcare providers regarding the most suitable treatment options at each stage of the disease. Such collaboration is vital for fostering patient ownership and adherence to the treatment regimen.¹³

Furthermore, early prevention strategies play a crucial role in mitigating the risk of MS development.¹⁴ By identifying and addressing risk factors and promoting healthy lifestyle choices, it is possible to reduce the likelihood of MS onset or delay its progression. Therefore, incorporating preventive measures into MS care plans is imperative for improving long-term outcomes and the overall quality of care.

This study was part of the RELIABLE project (Vinnova (ERA-permed project) 2022–00564), which aimed to assess the subclinical burden of neurological impairments in early relapsing-remitting MS patients with no evident neurological disability (Expanded Disability Status Scale (EDSS) score of 2.0 points or less). This comprehensive

assessment includes comorbidities, lifestyle, imaging, neuropsychological, gait and balance analyses. Additionally, the RELIABLE project seeks to understand patient preferences, which serves as motivation for this study. A clinical trial part of the project is dedicated to the definition of risk-based classification for newly diagnosed patients, integrating patients' preferences in the research. This study aimed to explore what intervention specificities or attributes newly diagnosed individuals with MS find important and to explore possible reasons behind their evaluations.

METHODS

Participants and recruitment

Patients referred to the MS Center of Careggi University Hospital were consecutively recruited for the RELIABLE project. Cognitive and physical assessments, as well as interviews, were conducted at the Don Gnocchi Centre. Screening for inclusion took place from June 2023 to December 2023. The inclusion criteria were based on a diagnosis of relapsing-remitting multiple sclerosis (RRMS) according to the 2017 McDonald criteria, age of 18 years or older, an EDSS score of 2.0 or lower and a disease duration of 5 years or less. Verification of the MS subtype, disease duration and EDSS were accomplished by obtaining a signed consent form for the release of medical information from the treating neurologist. Psychiatric and substance abuse histories were obtained via interviews and verified by medical records.

Exclusion criteria included a history of relevant psychiatric comorbidities that might compromise understanding of the test and clinical scales, relapses or corticosteroid treatment within 30 days before inclusion, a history of substance abuse and the presence of non-MS related physical or cognitive impairments that could prevent completion of the study assessments. Participants were selected from patients referred for diagnosis and/or treatment at Careggi University Hospital. Enrolment was based on consecutive recruitment at the centre for the RELIABLE clinical trial. The estimated sample size needed to observe a relevant effect in the clinical trial was 70 patients. Therefore, the targeted sample size for this side study, which included the ranking exercise and open-ended questions, was set to include all 70 patients. We used the Checklist for Reporting Of Survey Studies to guide reporting of the survey results (online supplemental file 1).

Stepwise approach

Starting with a literature review (step 1) to identify important treatment attributes for newly diagnosed patients with MS. The literature review revealed key themes: (1) differences emerged between healthcare professionals' and patients' perspectives, (2) interventions for MS outside disease-modifying therapies (DMTs), (3) severe side effects, (4) communication, information and knowledge and (5) psychological and emotional

factors.^{1 5 8 10 11 15–23} This specific literature review and its methods have been published separately.²⁴

Thereafter, in step 2, a list of possibly patient-relevant attributes was further assessed by patients diagnosed with MS. In this step, patients who were enrolled in the RELIABLE project were invited to sit together with a health-care professional and answer an online questionnaire (see all survey items in online supplemental file 2). The questionnaire was developed in English by the whole team and then translated to Italian in order to be coded in the secure data collection system RedCap (pretesting was performed by native Italian speakers at Don Gnocchi). The questionnaire was filled in to the RedCap system (verbatim) by the researcher after the patient responded to the questions in the questionnaire to protect anonymity and avoid data extraction from general records from the patient's information in the general record system. The questionnaire included both a quantitative ranking exercise to assess the most important treatment aspects of the ones identified in step 1 and open-ended questions for patients to present the reasons behind their choices. Participants answered the questions via a sheet of paper when visiting the Don Gnocchi Foundation outpatient clinic, and the interviewer transcribed verbatim their 'open comment' on the final section of each item. Finally, in step 3, the results were discussed and evaluated within the clinical team of the RELIABLE project to select the most clinically and patient-relevant treatment attribute to individualise treatment for newly diagnosed patients with MS. As the preferences are designed here to be eliciting

preferences (based on the current situation) and not exploring (potential scenarios), health care professionals (HCPs) were asked to define the current situation for the Italian setting and the most realistic treatment option that an MS patient will face in the clinic.

Quantitative ranking exercise of potential aspect level

Individuals diagnosed with MS (n=70) were asked to answer five different ranking questions. Each question with a theme representing a potential treatment attribute. The potential attributes included were treatment effects, methods of intervention, type of intervention, monitoring mode and mental support. Each question included three to four different potential levels of attributes to be ranked by its importance by the respondents (table 1).

Before disseminating the survey, experts' interviews were used to refine the content and exact working through two workshops and two rounds of written reviews.

Qualitative open-ended questions

During the primary data collection stage of the RELIABLE project, when newly diagnosed patients with MS were enrolled, they participated in several clinical tests for their physical condition. They were also assessed regarding their cognitive and psychological state. During these interviews with the neuropsychologist, participants were asked to perform a ranking task, and the neuropsychologist entered their answer in a specially designed digital platform. The platform was used to collect data

Table 1 Ranking exercise of potential attribute levels

Potential attribute	Questions asked to patients	Potential attribute levels that were ranked
Treatment effects	Which effects are the most important for you?	► Prevention of disability progression (chance of reducing the progression of MS, symptom progression) ► Preservation of cognitive function (memory, processing speed, verbal fluency and executive functions) ► Preservation of mobility abilities (motor functions and autonomy) ► Preservation of psychosocial engagement (go to work, family time, love life and social interaction)
Methods of intervention	Which method of intervention are you willing to try first?	► Treatment with disease modifying drugs (DMDs, pills, injection...) ► Lifestyle changes (diet, better sleep, stress management, smoking interruption and alcohol interruption) ► Exercise (physiotherapy, walking and sports)
Type of monitoring	Which type of monitoring would you like the most?	► Self-monitoring ► Clinical check-ups ► Caregivers monitoring (family member, partner...)
Monitoring mode	Which monitoring mode would you like best?	► Remote (App/online and phone call/SMS) ► In-person (clinical centre, GP) ► Hybrid (in person+online)
Mental support	What type of mental support is more important for you?	► Individual psychotherapy (with a psychologist) ► Group psychotherapy ► Psychological support (other healthcare professional) ► Neuropsychology (brain training)
GP, General Practitioner; MS, multiple sclerosis.		

for both the ranking exercise and open-ended questions, which the neuropsychologist was tasked with recoding verbatim while interacting with the participant.

The open-ended answers were analysed by inductive qualitative content analysis of the open-ended questions.²⁵ All open-ended answers corresponded to the question 'Why did you choose this ranking?' for each attribute ranking task (Q1. Which effects are the most important attribute for you? Q2. Which method of intervention are you willing to try first? Q3. Which type of monitoring would you like the most? Q4. Which monitoring mode would you like best? Q5. What type of mental support is more important for you?). The answers were varying in lengths from the shortest being of three words ('Trust in therapy') to the largest being of 99 words (larger explanation about the participants' experiences with DMT motivating their choice for ranking DMT higher).

Each transcript was initially analysed independently. In qualitative content analysis, the process began with open coding, where SM and KSB read through the text, making notes and headings to capture the content. These headings were then categorised. Subsequently, categories were created by grouping related observations under higher-order headings to provide meaningful classification. Finally, the abstraction phase involved generating and naming categories, grouping similar subcategories together and continuing this process until a comprehensive understanding was achieved.

Evaluating clinical relevance

The first clinical evaluation was operationalised as a discussion at a digital RELIABLE project meeting. During the meeting, the results of the ranking exercise were presented. Thereafter, the clinical relevance of the top selected aspect levels was selected for further analysis. Additionally, the members of the meeting were asked to provide written feedback after the meeting to serve as input for further aspect and aspect level selection and framing.

Statistical analysis

All data were extracted in Excel, and the analysis was conducted using this software. For the analysis of the ranking exercise, the numbers were reversed. The most important level of an attribute received the highest score (ie, the top ranked attribute number 1 received the highest score 3 or 4, depending on the number of levels that were ranked). We present the normalised scores (total score for each level/max (total score)) $\times 100$ for each attribute.

Patient and public involvement

Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

RESULTS

Respondent characteristics

The quantitative ranking exercise of treatment aspect levels, along with the open-ended questions, was completed by 52 out of the targeted 70 respondents,

Table 2 Descriptive statistics of respondent's demographic characteristics

Demographics	Participants n=52
Age (years)	
Mean (SD)	36.2 (10.3)
Median (min, max)	36.5 (21, 63)
Gender	
Female	36 (72%)
Male	14 (28%)
Years of schooling	
8	4 (8.0%)
13	19 (38%)
14	1 (2%)
15	3 (6%)
16	9 (18%)
18	14 (28%)
Years since diagnosed with MS	
6 years with MS	1 (2%)
4 years with MS	8 (16%)
3 years with MS	11 (22%)
2 years with MS	15 (30%)
1 year with MS	10 (20%)
<1 year with MS	5 (10%)
MS, multiple sclerosis.	

resulting in a response rate of 74%. The mean age of the respondents was 36 years (SD 10.3). Most of the respondents were women (72%). All the respondents were clinically diagnosed with MS and received their MS diagnosis between the years 2017 and 2023 (table 2).

Attribute level rankings

The aspect level rankings were completed by 41 out of the 52 participants (79%) (figure 1). Three participants did not complete the ranking exercise as they were recruited before the implementation of the final design. One participant did not provide a ranking for one item, and the score for this item was not considered. One participant did not answer all the 'open-ended questions', but the ranking score was kept.

Levels of potential treatment attributes were ranked separately for each attribute. Within the potential attribute (1) mental support, individual psychotherapy was the highest ranked aspect level by 149 points, followed by neuropsychology with 134 points, psychological support with 107 points and group psychotherapy with 99 points. In aspect (2) monitoring mode, hybrid mode (half remote/half in person) was the most highly ranked level with 77 points, followed by in-person with 63 points and remote with 54 points. In aspect (3) type of monitoring, clinical check-ups were the highest ranked aspect level by 129 points. In aspect (4) methods of intervention, disease

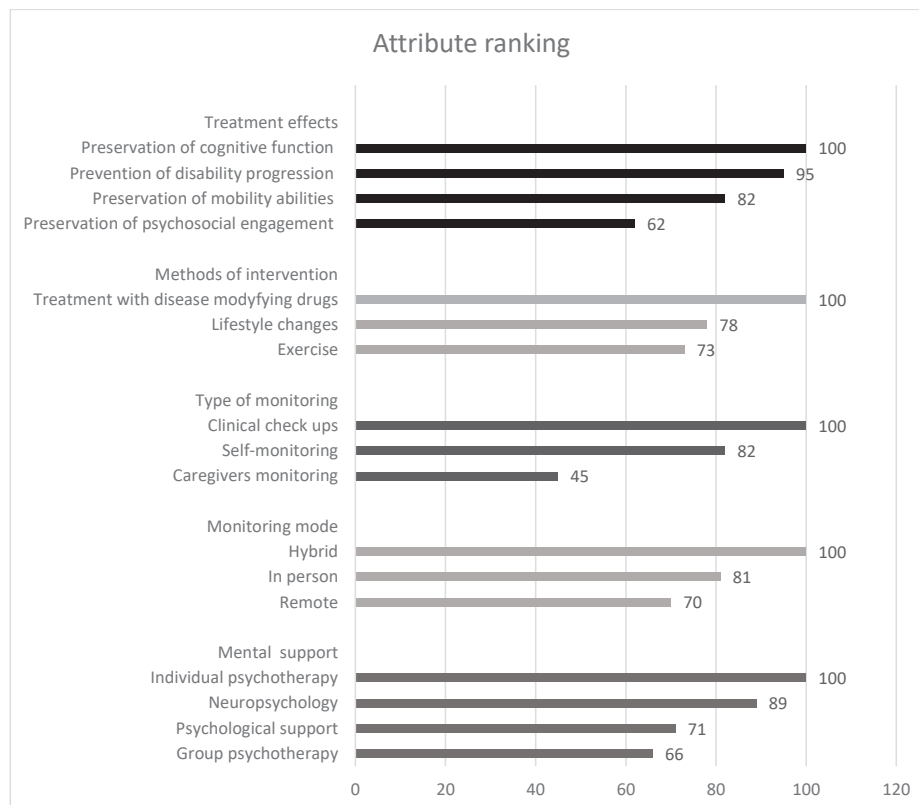


Figure 1 Attribute level ranking. Normalised scores (total score for each level/max (total score)) $\times 100$ for each attribute.

modifying treatment was the highest ranked aspect level by 164 points, followed by lifestyle modification with 128 points and, closely followed by exercise with 121 points. In aspect (5) treatment effects, the highest ranked aspect level was preservation of cognitive function with 144 points, then prevention of disability with 138 points and then preservation of psychosocial engagement with 89 points. For all points description, see [figure 1](#).

Reasons behind aspect rankings

Results of the qualitative content analysis revealed that respondents made their choices based on their right to impact treatment decisions, trust in the healthcare system, their self-image, side effects and psychosocial aspects ([table 3](#)).

Right to impact treatment decisions

In order to feel that quality of life is not impaired by MS, treatment needs to fit into the individual's current lifestyle and not depend on caregivers or family members to sustain their way of living.

Trust in the healthcare system

Individuals trust the HCPs expertise and guidance, relying on the fact that offered treatments or medication are accurate and efficient. Medical and scientific advice are considered first as elements to address the severity and produce the best benefits.

Side effects

Individuals want to avoid harm and suffering.

Self-image

During the course of illness or course of treatment, individuals want to maintain their identity (self) and still be themselves internally.

Psychosocial aspects

Individuals express emotions and need for support or social connection to talk about MS and their experience.

Clinical evaluation

The results from the ranking exercise and open-ended questions to explore treatment attributes important to patients and reasons behind their evaluations were discussed among the research team of the RELIABLE project for clinical evaluation. The clinical evaluation consisted of the authors, that is, persons working with patients with MS as healthcare professionals (medical doctor, physiotherapists and neuropsychologist), and researchers specialised in preferences studies (psychologist, ethicist and health scientist).

The clinical evaluation resulted in four new attributes with associated levels. Each aspect was selected based on being both clinically and patient relevant ([table 4](#)).

Physical activity

Physical activity was selected on the basis that it was a real option for MS patients enrolled in the RELIABLE project. Physical activity will be recommended to all patients to prevent the progression of MS. The selected levels were (1) resistance training, (2) stretching (eg, yoga,

Table 3 Results of the qualitative content analysis of the reasons behind respondents' rankings

Quotes from participants	Subcategory	Categories	Reasons behind choices
"I would prefer to do everything independently and always be followed up through clinical checkups."	Maintaining autonomy	Right to impact treatment decisions	I want the right to impact treatment decisions
"I chose this sequence because it corresponds more or less to what I already do"	Habits Convenience		
"I would not want to burden my loved ones"	Protect others		
"The most important thing is that the disease does not progress. Then it's all together, a whole sequence of things."	Time		
"Family monitoring sees situations but is not objective; there is too much involvement, because sometimes we tend to be influenced by some feelings that have nothing to do with the issue"	Objectivity	Trust in healthcare system	I trust the healthcare system
"Doctors are the ones you have to trust the most" "The doctor is the best person who can perform these kinds of checks"	Trust		
"Medical monitoring is the most authoritative"	Believe		
"The important thing for me is to feel as little as possible the presence of this disease in my life and the difference between me and anyone else who does not have multiple sclerosis"	Identity	Self-image	I want to stay the same as before my MS diagnosis
"Because I don't want to lose myself and not be able to do the things I always do. The progression of the disease is inevitable, but I would like to be able to remain the person I am for as long as possible"	Protect self-image		
"Because the safeguarding of cognitive functioning is the safeguarding of my personality"	Self-perception		
"This order is the best for me"	Self-confidence		
"I can't stand the pains"	Fear of pain	Side effects	I want to avoid side effects
"These are all side effects that I am not willing to accept. The multiple sclerosis already seems to me to be enough."	Avoiding side effects		
"a group discussion would help me better understand my problem by comparing myself with other people who can understand my discomforts without perhaps judging me" "It is important for me to see and talk to people without the filter of a computer unless it is necessary"	Warmth	Psychosocial aspects	I want to maintain my social life
"I would look for comparison with those around me in this area, because they are already in it."	Group belonging		
"Because I am not afraid of the psychosocial aspect of which I feel very calm and secure the rest yes" "They are all important, however with medication I am calmer" "Based on my fears"	Emotions		
MS, multiple sclerosis.			

pilates) and (3) aerobic training. Physical activity was also selected on the basis of being an accepted alternative by MS patients. As the results from the ranking exercise by MS patients revealed, physical activity (ie, exercise) was preferred over both lifestyle changes (ie, diet, better sleep, stress management, smoking interruption and alcohol interruption) and disease modifying drugs.

Cognitive training

The selection of cognitive training as an aspect was based on available treatment options for newly diagnosed

patients with MS in RELIABLE. The aspect levels were specified as (1) individual home-based computerised training, (2) group exercise together with other MS patients and (3) individual neuropsychology with therapist (cognitive rehabilitation), even if 'preservation of cognitive function' was the lowest ranked aspect level out of the different levels of treatment effects. The reasons behind respondents' choices in the ranking exercise were based on self-image and the desire to stay the same as before the MS diagnosis. Therefore, cognitive training

Table 4 Final list of attributes and attribute levels

Final attributes after expert evaluation	Final levels
Physical activity	▶ Resistance training. ▶ Stretching (eg, yoga, pilates). ▶ Aerobic training.
Cognitive training	▶ Individual home-based computerised training. ▶ Group exercise together with other MS patients. ▶ Individual neuropsychology with therapist (cognitive rehabilitation).
Disease modifying drugs	▶ Disease modifying drug (everyday pill). ▶ Short course of pills (eg, 2 weeks per year). ▶ In-hospital infusions (every month or every 6 months). ▶ Wait to start with disease-modifying drugs, to follow-up with new assessment after 6 months.
Emotional support	▶ Individual psychotherapy. ▶ Group psychotherapy. ▶ Psychological counselling (other healthcare professional).
Treatment effects	▶ Preservation of cognitive function. ▶ Preservation of mobility abilities. ▶ Preservation of quality of life.
MS, multiple sclerosis.	

was selected on the basis of being both clinically relevant and relevant by the patients.

Disease modifying drugs

Aspect levels selected were (1) disease modifying drug (everyday pill), (2) short course of pills (eg, 2 weeks per year), (3) in hospital infusions (every month or every 6 months) and (4) wait to start with disease modifying drugs, to follow-up with new assessment after 6 months. This decision was based on the alternatives provided to patients that were enrolled in the RELIABLE study.

Emotional support

The initially assessed aspect levels for Mental support were revised into Emotional support after the qualitative analysis and evaluation round. The rationale for the change of the framing was the clinical relevance as it is more in line with the framing of the clinicians in Italy. The selected aspect levels were (1) individual psychotherapy, (2) group psychotherapy and (3) psychological counselling (with other healthcare professionals).

Treatment effects

The initial attribute Treatment effects was kept after the ranking exercise and the evaluation round. The aspect levels were revised from four to three by mainly focusing

on preservation, excluding prevention. The rationale for mainly focusing on preservation was due to the reasons behind respondents' choices to 'stay the same as before my MS diagnosis'. Therefore, the selected attribute levels were (1) preservation of cognitive function, (2) preservation of mobility abilities and (3) preservation of quality of life. For full description, see [table 4](#).

DISCUSSION

The aim of this study was to explore what intervention specificities or attributes newly diagnosed individuals with MS find important and to explore possible reasons behind their evaluations. This study outlined a stepwise approach that consisted of three steps. Step 1 was a literature review to identify important treatment specificities for newly diagnosed patients with MS. Step 2 was a quantitative ranking exercise, where patients with MS ranked a list of possibly patient-relevant factors. Finally, in step 3, the results of steps 1 and 2 were evaluated within the clinical team of the RELIABLE project to select the most clinically and patient-relevant treatment attributes for individualised treatment for newly diagnosed patients with MS. Within this procedure, five treatment aspects, with three to four levels each, were identified as being relevant for patients and clinicians.

The analysis revealed distinct preferences across five key treatment aspects. First, regarding mental support, individual psychotherapy was most highly valued. Second, for monitoring mode, a hybrid approach (half remote/half in-person) was preferred over in-person or remote-only options. Third, clinical check-ups were favoured. Fourth, disease-modifying treatment was the most desired intervention method, even at this early stage of the disease. Finally, preservation of cognitive function and prevention of disability were the most highly ranked treatment effects.

The final attributes selected were: physical activity, cognitive training, disease modifying drugs, emotional support and treatment effectiveness. The results from the ranking exercise were in line with previous research in the same field regarding preferences among patients with MS.^{10 11 13 26–29} This departure from solely quantifiable or directly comparable attributes acknowledges the complex interplay of clinical and psychosocial factors inherent in MS management. The MS field appeared to be conservative about drug-based and classical clinical checkups expectation by the patient even at early stages of the disease when it may not be clinically needed, showing that education and communication about MS are needed.

Indeed, qualitative research also showed similar views of patients who do not see the interest of the long-term vision of their disease, for example, struggling with advance care planning at later stages. Even if good options for remote care exist,³⁰ patients reported struggles, and when interrogated about the need for improvements, they clearly expressed the importance of getting more guidance and to ensure that they will get all the

needed information to be transferred to their clinician, that they will favour digital equipment that will help them monitor their health and maintain access to local clinic with online facilities linking them to their specific care team (first 3 out of 8 items).³¹ A suggestion for further research is to account for these specific attributes when offering remote or hybrid options to MS patients. It is also notable that patients themselves identified the need for cognitive function preservation to be a priority even at early stages,³² confirming the current rise of interest in refined evaluation of minimal changes.³³ But also the use of targeted interventions using different techniques, from therapy to exercise^{34 35} or different types of cognitive rehabilitation techniques (computer based, manual based or combined) was observed.³⁶

Recently, reviews about clinical outcomes in MS still did not include specific measures of social connectivity,³⁷ continuing the tradition of measuring optical, motor, balance, sensory or cognitive symptoms.³⁸ Further research could encourage the use of social connectedness measures like the revised Social Connectedness Scale.³⁹

The results for this study may be used for a future quantitative preference assessment in MS to assess the relative importance of treatment attributes and preference heterogeneity.⁴⁰ While previous preference studies in MS have mainly focused on drug development, such as the work by Lynd *et al*,⁴¹ the results of this study imply that patients consider treatment attributes related to preventative treatment, such as individual psychotherapy, preservation of cognitive function and clinical check-ups, to be important for their preferences of MS care. By integrating patient perspectives by assessing patient preferences and clinical insights, the research highlights the need for a personalised approach to MS care. This approach not only aligns treatment options with patient preferences but also addresses the multifaceted nature of MS management.

A strength of this study was the explorative stepwise approach that included a systematic literature review, patients with MS, healthcare professionals working with MS patients and preferences of researchers aligning with the stepwise method approach that expanded in the social sciences field, representing the excellence of preference studies across fields.^{42 43} A limitation of this study may have been the limited number of included patients with MS in the recruitment for the ranking exercise (n=41). Therefore, the results of this study may not be generalisable to the general MS population in Italy. However, we suggest further assessing patients' preferences for the identified MS treatment attributes in this study within a bigger patient sample and with a more robust preference elicitation method. Thereafter, it may be possible to draw conclusions on what treatment attributes MS patients in Italy prefer.

Additionally, the study also reveals gaps in current research, particularly in understanding how to effectively tailor treatments to individual needs and preferences, as most of the research focused on disease-modifying

treatment.^{11 44} These insights pave the way for further investigation into optimising MS care, ensuring that treatment plans are both patient-centred and evidence-based when literature showed the importance of different factors influencing patient preferences in MS.⁴⁵ Additionally, further research is required for the development of methods to quantitatively assess patient-relevant benefits and risks to support shared decision-making in treatment plans.²⁹

A key innovation lies in the study's explicit focus on a drug-centric paradigm, even if preventative measures are more and more emphasised and gaining more recognition as adequate intervention and most relevant personalised care in MS.⁴⁶ This is counterintuitive regarding the patient preferences for non-pharmacological interventions, such as lifestyle modifications and cognitive training.⁴⁷ The study's findings, particularly the low ranking of psychosocial engagement preservation, underscoring the lack of importance of quality-of-life considerations in MS care,⁴⁸ may be due to the fact that they are often overlooked in traditional clinical trials. For example, in a recent systematic review about quality of life aspects in MS, only two papers among 106 mentioned the importance of social aspects.⁴⁹

CONCLUSIONS

By identifying treatment attributes such as physical activity, cognitive training, disease-modifying drugs, emotional support and treatment effectiveness as key for patients, the research underscores the multifaceted nature of MS management. However, the study also reveals significant gaps in current research, particularly in tailoring treatments to individual needs and preferences, and developing quantitative methods to assess patient-relevant benefits and risks. Addressing these gaps through further research is essential for advancing MS care, improving patient outcomes and promoting a more patient-centred approach to treatment.

Author affiliations

¹Department of Public Health Sciences, Mälardalen University, Vasteras, Sweden

²Centre for Research Ethics & Bioethics, Uppsala University, Uppsala, Sweden

³Department of Learning, Informatics, Management and Ethics, Karolinska Institute, Stockholm, Sweden

⁴Department of Public Health and Caring Sciences, Uppsala University, Uppsala, Sweden

⁵IRCCS Don Gnocchi Hospital, Firenze, Italy

⁶AOU, Firenze, Italy

⁷Neuroscience, University of Florence, Firenze, Italy

⁸Uppsala University, Uppsala, Sweden

Contributors KSB is responsible for the overall content as guarantor. All authors have contributed to the planning, execution and reporting of the work. Specific contributions are as follows. KSB, UK, JVJ and SM: conceptualisation and design of the study. GP, FG, CN and SDB: data collection and analysis. EP, MB and MPA: clinical advice and validation of results. All authors have read and approved the final version of the manuscript.

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Patient and public involvement Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and the data sharing and handling of all tasks of the RELIABLE project regarding preferences and patient questionnaires have been granted to Uppsala University via the Swedish Ethical Review Authority (2023-05818-01), and Comitato Etico Regionale per la Sperimentazione Clinica della Regione Toscana (24121-PF-31_05_2023) approved the recruitment and clinical procedure for domestic experiments in Italy. All participants provided informed consent to participate in the RELIABLE project—including the survey with the ranking task.

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ORCID iD

Karin Schölin Bywall <http://orcid.org/0000-0002-5865-5590>

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