Neurol Ther (2024) 13:21–37
https://doi.org/10.1007/s40120-023-00573-7

REVIEW

Insights for Healthcare Providers on Shared Decision-Making in Multiple Sclerosis: A Narrative Review

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Received: September 6, 2023 / Accepted: December 7, 2023 / Published online: January 5, 2024

ABSTRACT

Shared decision-making (SDM) between the patient and their healthcare provider (HCP) in developing treatment plans is increasingly recognized as central to improving treatment adherence and, ultimately, patient outcomes. In multiple sclerosis (MS), SDM is particularly crucial for optimizing treatment in a landscape that has grown more complex with the availability of newer, high-efficacy MS therapies. However, little direct evidence on the effectiveness of SDM is available to guide practice. Multiple factors, including patient age, ethnic background, perceptions, invisible MS symptoms, and psychological comorbidities can influence a patient's willingness and ability to participate in SDM. HCPs need to appreciate these factors and ask the right questions to break down obstacles to SDM. The HCP has a responsibility to help patients feel adequately informed and comfortable in having an active role in their care. This review identifies potential barriers to SDM and provides a strategy for HCPs to overcome these obstacles through patient (and caregiver) discussions to ensure optimal patient satisfaction with treatment and thus the best possible outcomes for their patients.

Keywords: Adherence; Disease-modifying therapy; Multiple sclerosis; Patient experience; Shared decision-making

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Key Summary Points

Shared decision-making (SDM) describes an approach to healthcare decision-making where the patient and the healthcare provider (HCP) work collaboratively to develop and implement a personalized therapeutic pathway

The primary goal of SDM is to support patient experience and adherence to treatment, with the ultimate aim of improving patient outcomes

HCPs should engage patients in ongoing, meaningful, and individualized discussions along the patient journey, and be aware of any barriers that may impede the SDM process

To enable HCPs to deliver effective SDM, there is a need for robust evidence on the best SDM intervention(s) to use with patients with MS, methods for integration of SDM into clinical practice, and tools to educate HCPs

INTRODUCTION

Shared decision-making (SDM) describes an approach to healthcare decision-making where the patient and the healthcare provider (HCP) work collaboratively to develop and implement a personalized therapeutic pathway. Sharing decisions with their HCP empowers patients by supporting their autonomy, which is a key element of patient care [1]. Importantly, this approach contrasts with that of the traditional paternalistic medicine model, in which decisions are made solely by the HCP on behalf of the patient [2].

Treatment paradigms in multiple sclerosis (MS) evolved rapidly over the past decade with the availability of new disease-modifying therapies (DMTs) [3–5]. MS is a preference-sensitive condition, as multiple treatment options with different levels of benefit and risk are available to patients [2]. Thus, the views of the patient are an important consideration in treatment decisions [2]. In MS treatment, patient involvement in treatment decisions may improve patient satisfaction with their DMT [6], adherence [7, 8], and outcomes [9], thereby lessening treatment and disease burden. SDM is therefore particularly relevant in MS, with preference-sensitive decisions about treatment ideally made jointly by the patient and their HCP using an SDM process. SDM strategies should ideally incorporate treatment modalities beyond DMTs, such as self-management options, physical therapy, and symptom management.

This narrative review examines the current clinical experience of SDM in MS clinical practice and highlights how obstacles can be overcome to ensure HCPs and patients with MS are comfortable with the SDM process. We also propose a suggested set of questions developed on the basis of expert author opinion and best practices to facilitate SDM between HCPs and their patients with MS.

Compliance with Ethics Guidelines

This article does not contain any new studies with human participants or animals performed by any of the authors.

METHODS

Initially, PubMed was searched for relevant publications using the search terms “shared decision making” and “multiple sclerosis”, restricted to English language publications within the past 6 years, with further searches on references cited by relevant publications. No formal inclusion and exclusion criteria were applied. As a result of a relative paucity of research on SDM in MS, the search was widened to other conditions by omitting “multiple sclerosis” as a search term. Authors also used their experience and expertise to focus additional searches on areas of interest, such as demographics, SDM tools, financial aspects, patient preferences, patient knowledge, and comorbidities, in addition to publications already

known to authors. Articles were reviewed and included if they presented relevant information related to SDM.

This narrative review is based on previously published studies and does not contain any new studies involving human participants or animals. Approval by an ethics committee was not applicable.

CLINICAL EXPERIENCE OF SDM IN MS

Rationale for SDM

In therapeutic decision-making, taking the patient's values, goals, concerns, and preferences into account may improve their acceptance of and adherence to therapy [8]. Evidence shows poor adherence to treatment can lead to reduced treatment effectiveness and increased healthcare costs [8]. Patients with MS are more likely to adhere to a treatment they actively choose to take and are satisfied and comfortable with [7]. Indeed, there are moderate levels of evidence from observational studies, questionnaires, and surveys supporting a positive effect of SDM on treatment adherence in patients with MS. Randomized controlled trials have also shown positive impact of SDM on patient behavior, although evaluation and interpretation of the collective evidence is limited by heterogeneity in the assessment used in the trials [7]. SDM continues to be recommended by the American Academy of Neurology (AAN) practice guidelines [8] and expert opinion in MS [6, 7].

A majority of patients prefer an active role in decision-making. Among 7009 patients from the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry, patients most commonly had a preference for patient-centered decision-making (i.e., the patient prefers to make final treatment selection; 47.9% of respondents), followed by SDM (i.e., patient and HCP share responsibility for deciding treatment; 42.8%) [10]. Similarly, in a survey of 379 patients with MS in Argentina, 47% preferred an active decision-making role with the patient making the decisions, and 27% preferred SDM, with the patient and HCP making the decisions jointly [11].

The emergence of higher-efficacy therapies (HETs; e.g., alemtuzumab, cladribine, natalizumab, ocrelizumab, and ofatumumab) for MS has expanded the number of treatment options, which increases the complexity of treatment decision-making, as HETs can differ in mechanism of action and benefit–risk profile [12]. Multiple European observational studies and a systematic review of 12 studies suggest that initiating HET early in the disease course could reduce the risks of disease and disability progression compared with starting treatment with a lower-efficacy DMT [13–16]. In this dynamic treatment landscape, it is important for patients to make informed decisions about HET, ideally using an SDM process. Given the available evidence available, it is prudent for HCPs to discuss HET with their patients with MS as part of SDM at the earliest opportunity, provided there are no extenuating circumstances or contraindications [3]. A thorough review of a patient's medical history is particularly important, as some HETs are not suitable for all patients, given their use may increase risk of some comorbidities, including progressive multifocal leukoencephalopathy [17], malignancies [18, 19], immune-mediated colitis [19], and pyoderma gangrenosum [19].

SDM is also important for patients who need to switch DMTs because this process can be emotionally demanding. Patients may have to adjust to different routines and manage potential risks associated with the new DMT. They may also experience anxiety associated with the underlying reasons for switching therapies and their concerns about disease prognosis and progression, and the effectiveness of DMTs [20].

MS affects more women than men, at a ratio of approximately 3:1; it is also on the rise among young women [21]. For women with MS in their child-bearing years and couples planning a pregnancy, SDM is a critical aspect of selecting a DMT because treatment selection must balance the benefit to the patient against potential risk to the fetus [22]. Additionally, many DMTs, including alemtuzumab, natalizumab, ocrelizumab, cladribine, teriflunomide, fingolimod, siponimod, ozanimod, and

ponesimod, are contraindicated or not recommended during breastfeeding, or only recommended if the benefit justifies the risk to the infant [22].

Evidence for SDM in MS

There is a notable lack of robust evidence on the benefits of SDM on patient outcomes in MS [7]; however, a review of observational studies, surveys, and questionnaires revealed a positive effect of SDM on treatment adherence in patients with MS [7]. Systematic reviews of between four and 35 predominantly USA-based studies reported positive benefits of SDM in other diseases, including asthma, diabetes, and cancer [23–25]. Nonetheless, there is limited research into the long-term consequences of SDM [26, 27], in part because SDM has not yet been widely implemented in routine care [26]. Further research into the wide-ranging and longer-term consequences of SDM on patients may help to demonstrate the value of SDM in clinical practice [7, 27].

Real-world data, which provide information on drug and disease outcomes beyond the tightly controlled parameters integral to randomized controlled trials, could provide evidence on the effect of SDM on patient outcomes; such data are essential to support truly data-driven decision-making in MS. Real-world evidence provides a comprehensive view of MS treatment patterns and outcomes and several registries now exist. Examples include the North American NARCOMS [28] and COVID-19 Infections in MS and Related Diseases (COViMS) registries [29]. Researchers use these data sets to assess patients' experiences with MS and COVID-19 in MS, respectively. The iConquerMS network has been used to evaluate patients' experiences with COVID-19 vaccines and the impact of the COVID-19 pandemic on MS care [30, 31]. The National African Americans with MS Registry (NAAMSR) [32] is collecting information on MS in African American patients. Lastly, information on Hispanic patients with MS is being collected by MS registries at the University of Southern California and the University of Miami [33]. These registries will provide a more complete picture of MS in a broad spectrum of patients, which can be used to inform SDM.

Effects of Demographic Factors on SDM

As a result of the limited evidence on SDM in MS, learnings from MS studies and those from other fields of medicine can provide insights into the role patient demographics can have on SDM preferences and perceptions.

There is conflicting evidence regarding the impact of patient gender. The previously mentioned NARCOMS Registry study of patients with MS, as well as two scoping reviews of 74 and eight articles in surgery and rheumatology, respectively, found women favored SDM more than men, who preferred physician-based decision-making (i.e., HCP makes final, or all, decisions on treatment) [10, 34, 35]. In contrast, a meta-analysis of 775 clinical encounters in seven USA-based randomized trials across several diseases found no significant difference in SDM between gender dyads, suggesting male gender may not act as a barrier to SDM [36]. A secondary analysis of a Cochrane review of 87 studies on SDM interventions found no studies collecting data on non-binary patients [37], so there remains a paucity of data on the SDM experiences of this patient population.

Studies suggest that patient age could influence SDM preferences. Two scoping reviews, one of 74 studies in surgery and one of 12 studies in rheumatology, found younger patients had higher SDM preference or satisfaction, although a threshold for "younger" was not provided by these reviews [34, 35]. Analyses of data from the NARCOMS Registry showed younger patients preferred patient-centered decision-making, whereas older patients preferred SDM or physician-centered decision-making [10], suggesting a gradual decline in desired autonomy over a patient's life span, generational differences in older patients accustomed to the paternalistic approach to medicine, or a greater propensity for younger patients to research their disease and treatment options online.

A patient's ethnic background can influence their involvement in SDM. A systematic literature review of 23 cancer studies primarily in USA-based patients from underrepresented groups (e.g., Latinx, African American, East Asian) with low acculturation were less involved in decision-making than those with high acculturation, which was potentially due to language barriers [38]. The systematic review also revealed a patient's spiritual beliefs and cultural or community norms could also impact the patient's participation in decision-making, especially in situations where a religious or cultural authority figure made the treatment decision for the patient [38]. An analysis of data from 63,931 participants in the USA-based Medical Expenditure Panel Survey (MEPS) revealed higher percentages of Hispanic, Asian/Pacific Islander, and Black/African American patients had poor SDM satisfaction scores compared with White patients [39]. In rheumatology studies, more non-White patients reported a lack of active participation in SDM (such as HCPs inviting patients to participate in SDM and developing treatment plans together), lower physician trust, and lower active participation in patient–physician communications compared with White patients [40–42]. The MEPS surveys also found that a lower education level was associated with poor perceived SDM (defined as a final composite SDM score of 4–8 on a 12-point scale) [39]. Furthermore, patients with lower education levels and socioeconomic status (in 17 studies), language barriers (in seven studies), or health literacy (in six studies) reported suboptimal communication between patients and HCPs, less involvement in decision-making, and more decisional conflict in the rheumatology scoping review [35].

HCPs should be aware of these factors and ensure that patients have the opportunity to participate in SDM if they wish by eliciting and integrating their preferences into treatment, as patients may not understand that they are allowed to do so [35]. It should also be recognized that some patients may prefer not to participate in SDM [10]. To aid HCPs in discussions with their patients with MS around SDM, we propose a set of questions (Figs. 1 and 2). In addition to general questions, we also suggest including questions that consider patient-specific factors that can impact effective SDM (Fig. 2).

HCPs and SDM

Successful SDM relies on buy-in from both patients and HCPs. However, some HCP approaches can impact SDM. As previously mentioned, MS has been traditionally paternalistic in nature, whereby the HCP would make treatment decisions without taking patient preference into account [9]. Although there is a shift toward patient engagement [9], a consensus paper from Argentinian neurologists revealed that one of the main barriers for applying SDM in MS is the paternalistic and authoritarian role traditionally exhibited by many physicians [43]. Although a paternalist approach may be appropriate for some patients with MS, patients should have the choice to delegate the decision-making to their HCP [9]. Furthermore, studies on SDM in MS have highlighted the importance of educating HCPs with the communication skills needed for effective SDM [44–46].

A study of 96 neurologists in Spain identified a rate of therapeutic inertia (i.e., the absence of treatment initiation or intensification when there is evidence of disease activity) of nearly seven in 10 non-MS-specialist neurologists, which was linked to aversion to ambiguity (when the probability of events is unknown) [47]. In addition, concerns around legal liability in cases of serious adverse events can result in HCPs being risk averse and hesitant when considering DMTs with potentially serious side effects, such as HETs [48, 49]. These factors could affect HCP decision-making and, consequently, impact the treatment discussion with patients, with less information provided by HCPs on HETs.

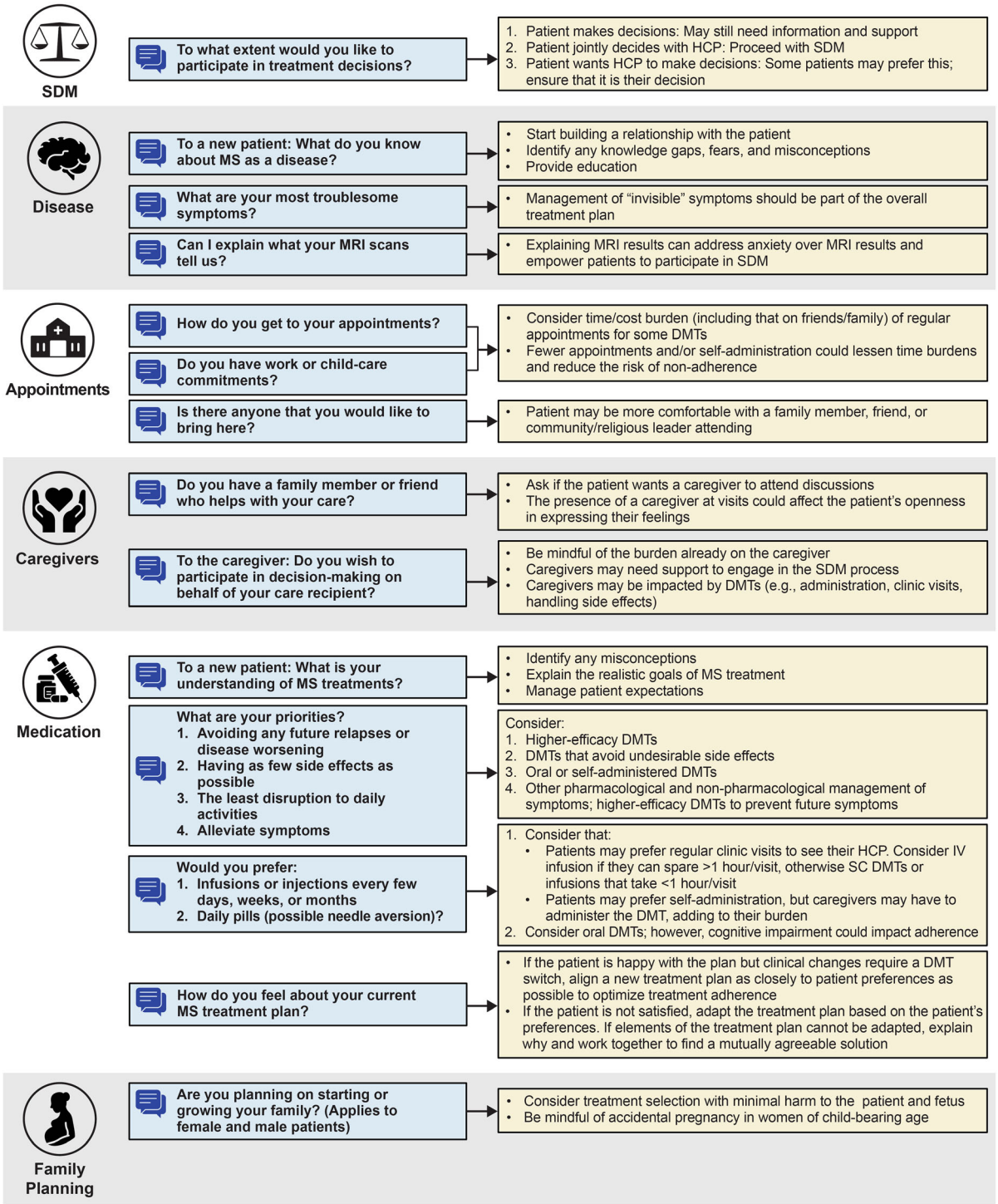

Fig. 1 Suggested general patient questions to assist HCPs and patients with MS navigate treatment decisions using SDM. *DMT* disease-modifying therapy, *HCP* healthcare provider, *IV* intravenous, *MRI* magnetic resonance imaging, *MS* multiple sclerosis, *SC* subcutaneous, *SDM* shared decision-making

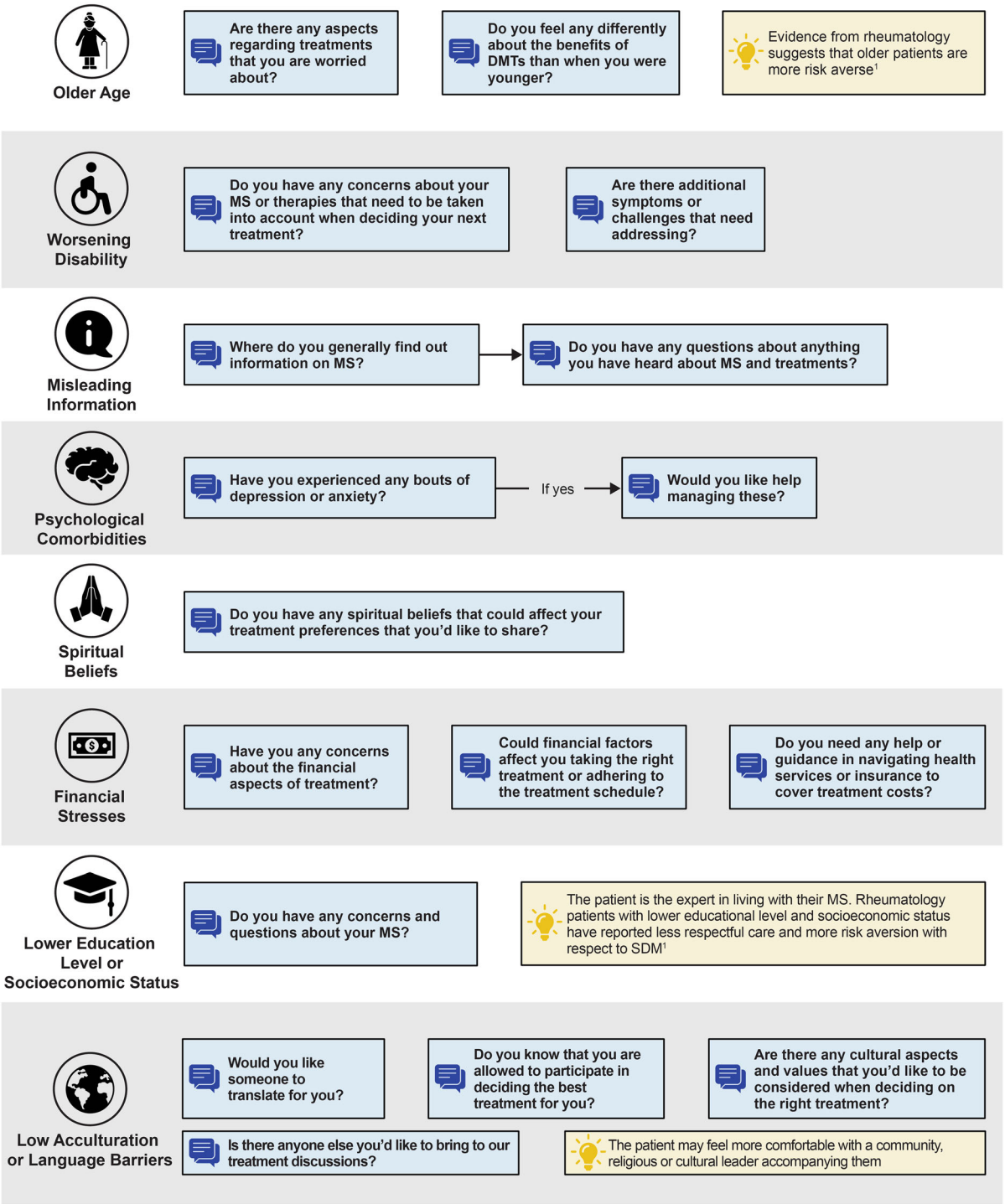

Fig. 2 Suggested questions based on patient-specific factors and SDM preferences. *DMT* disease-modifying therapy, *MS* multiple sclerosis, *SDM* shared decision-making

OVERCOMING BARRIERS TO SDM

Recognizing Differences in Patient and HCP Perceptions

Patients and HCPs may have different perceptions of the value of physical and mental functions and, therefore, of how MS symptoms are prioritized for treatment. A multicenter cohort study of 171 patients with relapsing–remitting MS (RRMS) in Germany found that vision and swallowing were rated more highly by patients, but hand function was rated more highly by HCPs [50]. Patients often experience invisible MS symptoms not detected by standard neurological examination, such as fatigue, depression/mood symptoms, pain, cognitive impairment, sleep problems, and sexual dysfunction [49]. Consequently, if HCPs focus on treating detectable symptoms and disease progression, the true burden of MS on patients can be overlooked [49]. Although the HCP, particularly the MS specialist, is the expert on the disease and DMTs, the patient is the expert on their experience of MS and their goals, fears, risk tolerance, and so on. By enabling patients to communicate their most troublesome symptoms to HCPs and explain their priorities for managing their MS, both parties can bring their relative expertise to the SDM process to shape the overall treatment plan. This is particularly important given the limited time HCPs may have with patients because of constraints in medical systems. Moreover, as part of SDM, HCPs need to be proactive in asking questions and eliciting details from patients who may not be forthcoming about their symptoms.

When considering DMT treatment initiation, the attributes of efficacy, mode and frequency of administration, and side effect profiles are valued most by patients, according to a systematic review of 24 DMT studies in RRMS [51]. However, a USA-based survey of 150 patients and 154 neurologists, and a Dutch survey of 62 HCPs, found that HCPs may view logistical factors surrounding receipt of treatment as less important, and instead focus on prevention of disease (brain volume loss, relapse rate) and disability progression, as well as treatment safety, including risk of infection [48, 52]. The MS in the 21st Century initiative of 14 HCPs and 11 patients with MS from Europe and the USA revealed that HCPs were concerned about the level of risk patients were willing to accept with their therapy [49]. Patients may underestimate treatment safety risks and overestimate benefits, which can impact treatment adherence [53]. SDM for selecting a DMT, including HETs, should therefore include a number of topics, including safety, side effects (including management and risk mitigation strategies), vaccinations, practicality, convenience, and patient preferences [8].

Patient Preferences for SDM

Although it could be argued that, as patients choose to take their prescribed medication, they are actively participating in the decision-making process, some patients may be unwilling or feel unable to participate in SDM; the MS in the 21st Century initiative revealed that some HCPs identified an issue where patients are not engaged in their disease management plan [49]. This may be a result of the belief that the HCP is an expert and therefore knows best. In contrast, the NARCOMS Registry study found that only 9.2% had a preference for physician-centered decision-making [10].

Patient preference for SDM varies across patient characteristics and throughout the patient journey, which is a consideration for implementing effective SDM. For example, the NARCOMS study also noted preference for SDM over patient-centered decision-making rose with increasing disease duration [10]; patients with higher disability levels also had a reduced likelihood of preferring patient-centered decision-making and SDM vs physician-centered decision-making [10]. In addition, preference for SDM rather than patient-centered decision-making was significantly higher among patients receiving DMT [10].

Patient engagement in SDM can be achieved with HCP support. However, a French single-center qualitative study of 29 patients with MS revealed that patient preferences were often assumed by HCPs rather than elicited from the

patient and HCPs did not always value the patient's input regarding treatment decisions, leading to a negative impact on patient compliance [54]. In a survey of 97 parents of children with pediatric-onset MS recruited from a single US center and social media group, 88% of parents believed it was important for them to be involved in treatment decisions and 80% believed it was important for their child with MS to be involved in treatment decisions; however, less than half of parents reported that they were asked if their child wanted to be involved in SDM [55]. In this study, the majority of parents (88%) of children with MS who experienced good communication and support from the HCP reported high levels of satisfaction with the treatment decision process [55].

Patient Confidence in Their Knowledge and Understanding of MRI Results

From the HCP's perspective, magnetic resonance imaging (MRI) is a key prognostic tool to guide decision-making in MS, particularly at early stages of disease [56]; however, patients with MS may lack sufficient understanding of MRI to recognize and discuss the importance of these results in their care [57]. The detection of MRI lesions is widely used in clinical practice as a marker that, alongside other disease-related and demographic factors, is used to assess prognosis in MS and to inform decision-making [58]. An international cross-sectional study of 229 neurologists showed MRI activity to be the third-highest priority factor associated with MS treatment decisions (13% of neurologists), after relapses and Expanded Disability Status Scale score [59].

Patients can feel more control over their disease once shown their MRI scan [57]; however, one study questioned 457 patients with MS and found only 50% felt comfortable enough to discuss the results with their HCP, and a lack of understanding MRI results was a source of anxiety or fear for patients [57]. Another study of 92 patients with MS found that MRI results tended to cause anxiety for patients [60]. An online educational program was developed to educate patients with MS about MRI; a pilot study in 92 patients found that the program increased patients' knowledge of MRI, and patients felt empowered to discuss MRI findings with their HCPs. As such, the program had the potential to increase patients' MRI knowledge and enhance participation in MRI-based SDM [60].

An SDM process where the HCP describes the results and answers patient's questions regarding aspects of the MRI results that they do not understand can provide an environment in which patients feel more comfortable with how MRI results contribute to treatment decisions.

Addressing Psychological Comorbidities

The lifetime prevalence of depression among patients with MS is approximately 50%, which is about three times higher than the general population [61]. In a USA-based multicenter observational study in 183 patients with MS, 24% experienced depression and 22% experienced significant anxiety [62]. The study revealed a reduced sense of autonomy among patients with depressive symptoms with or without anxiety [62], potentially impacting a patient's self-reliance and self-efficacy over their MS and thus their decision-making ability [62]. In addition, depression was found to inversely correlate with active patient involvement in managing their healthcare in a single-center cross-sectional survey of 199 patients with MS in the USA [63], indicating that patients with depression would be less likely to engage in SDM.

AAN guidelines recognize that addressing any depression before initiating a DMT may improve the patient's decision-making and adherence to DMTs [8]. Moreover, understanding these psychological changes early in the disease course may help HCPs improve participation in treatment decisions at these crucial early stages of therapy [64].

Financial Stress

Health insurance policies and the financial situation of patients may play a contributing factor in treatment decisions. A survey of patients

in the NARCOMS Registry found that, of 2052 patients who did not take or stopped DMTs in the previous 12 months, approximately 6.1% stated this was due to insurance or financial reasons [65]. The survey also revealed that 8.1% of 3437 patients taking DMTs faced challenges to DMT use, including insurance denial in the first instance (3.3%) and when switching DMTs (2.3%) [65]. A patient's willingness to pay for DMTs can be influenced by patient-related factors, such as demographics, health status, comorbidities, and MS experience, as well as drug-related factors (DMT effectiveness, safety, mode of administration, out-of-pocket expenses) [66, 67]. A scoping review of 23 primarily US and European studies highlighted affordability of services could be a barrier to patients with MS, but having a dedicated HCP could ease the complexities of navigating the healthcare system for patients and identify possible funding sources [68]. Therefore, an SDM process should take into account any financial stress that could influence treatment choice and adherence.

Patient/Caregiver Knowledge and Expectations

Patient understanding of the role of treatment is important but can rely on the information patients receive from HCPs. A survey of 27 patients in the Finnish MS Society revealed that they wanted to be involved in decision-making, but they reported that the information provided by the HCP was seldom helpful and many preferred searching the internet or books for information instead [69]. Of concern, a single-center observational study in 137 Dutch patients with MS found the patients used misleading or unreliable information from the internet or television when considering treatment decisions [70]. As such, patients can be overloaded with information that has a marketing bias, which can skew patient judgment [9]. Furthermore, inconsistent information from HCPs, along with limited HCP support and patients feeling invalidated, may be a barrier to seeking support, especially in the event of a relapse, as demonstrated in a pilot survey of 1737 patients from an international online MS community, where information inconsistency had a negative impact on relapse self-identification [71]. Patients with MS need reliable, well-vetted resources to reduce the risk of finding incorrect or inappropriate information that influences their treatment decisions [49].

MS can impact the patient's family; as such, caregivers may need to be involved in the SDM process to aid mutual understanding, engagement, and education, and to facilitate the informed consent process [72]. This is particularly important in situations where the patient is a child [55], has cognitive impairment [73], or has reduced semantic memory that affects risk perception [74]. Caregivers may need encouragement or support to engage in the SDM process in partnership with or on behalf of the patient, taking into account the overall burden of caring for a patient with MS given the currently limited services available to caregivers [72]. In these situations, HCPs need to be mindful that the presence of a caregiver might also affect the patient's willingness to be open about their condition and feelings, and that any such involvement must be for the patient's benefit [72].

Several studies have highlighted a significant unmet need for patient or parent decision aids to facilitate SDM. A study involving 97 parents of children with pediatric-onset MS found a considerable proportion of parents had difficulty understanding how DMTs work, side effects, and monitoring, and nearly one-fifth felt unprepared for decision-making [55]. Another US multicenter study conducted in 290 patients with MS explored how DMT risks and benefits are weighed by patients; they discovered better patient knowledge was associated with an increased willingness to initiate DMT across a range of efficacies [75]. Therefore, increasing the level of MS-specific knowledge among patients and caregivers can enable them to make informed decisions, and thus assist in their participation in effective SDM [76, 77].

Recommendations and Tools in Overcoming Barriers to SDM

It is important for HCPs to engage patients in ongoing, meaningful, and individualized discussions along the patient journey as part of an SDM process. It is important for both parties to take responsibility for disease management, as highlighted by the MS in the 21st Century initiative [49].

The patient's treatment goals, values, concerns, preferences, and priorities should be identified for effective SDM. The treatment goals of patients and HCPs are generally aligned with the primary aims of reducing relapse frequency, slowing disability progression, and minimizing disease and treatment burden [6]. However, it is important to discuss these goals and consider treatment appropriately. For patients, life experiences, personal beliefs, and perceptions of risk play a substantial role in their contributions to SDM [78]. Each patient serves as an expert in their own perspective, symptoms, and experiences, which should be reflected in treatment decisions [79]. Accordingly, the AAN practice guideline (2018) recommendations advise, when planning to initiate a DMT, that patients should be counseled with respect to available treatment options at a dedicated visit and patient preferences need to be respected, as this may improve acceptance and adherence to therapy [8]. For instance, a patient may need to juggle their treatment regimen around family and work commitments, which might limit their ability to regularly attend clinics for treatment. Further, treatment priorities can differ between patients, with respect to lifestyle (e.g., starting a family or being able to work), disease management (relative importance of avoiding relapses, disease progression, or symptoms), and level of risk tolerance with respect to side effects. These can all impact suitable treatment options, so they need to be included in SDM. Ongoing dialogue around treatment decisions should continue throughout the disease course. Figure 1 presents suggested patient questions to aid HCPs in overcoming some of the barriers to SDM.

Information provision for patients with MS is important to increase their disease-related knowledge and potentially positively impact SDM, as highlighted in a systematic review of 10 studies with 1314 participants [80]. Evidence-based patient information handbooks on topics such as immunotherapy in MS have been published [81], which may improve the provision of information to patients and subsequently increase participation in SDM [81]. Interestingly, the way in which study results are communicated to patients is vital. Data from a repeated-measures study of 45 patients with MS from two centers in the UK showed patient understanding improved when clinical data were communicated in absolute terms that convey true differences, such as "X more patients taking this drug will experience a particular side effect than with this other drug," rather than relative terms that convey proportional differences or numbers needed to treat/harm, e.g., "twice as many patients taking this drug will experience this particular side effect" or "10 patients would need to take this drug before one patient experienced that side effect" [73].

Several studies have highlighted a significant unmet need for patient or caregiver decision aids to facilitate SDM [20, 55, 82]. Working groups of up to 47 patients, HCPs, researchers, funders, and policy makers have generated recommendations to increase adoption of SDM in clinical practice and highlighted the need to provide tools to support SDM [26]. Evidence from a range of conditions, including MS, has shown that patient decision aids can improve patient knowledge and satisfaction with the treatment decision and the decision-making process, have a positive effect on patient–HCP communication, and reduce decisional conflict and the proportion of people who are passive in their decision-making [82–84]. SDM tools, such as online patient-completed decision aids, can be extremely beneficial because they can help HCPs engage with patients to discuss unmet needs and preferences [85]. One interactive patient decision under development for MS comprises modules on patient medical history, DMT effectiveness and safety, attributes important to the individual patients, comparisons of

treatment options, and a tailored summary for HCPs to review with their patients [82]. SDM tools that can be used before clinic visits could also help address HCP concerns around time pressures in implementing SDM [35]. The use of such tools does not necessarily heavily impact consultations—a systematic review across multiple conditions found that decision aids only added a median of 2.6 min onto the length of a consultation [83].

CONCLUSIONS

The primary goal in SDM is to support patient experience and adherence to treatment, with the ultimate aim of improving patient outcomes. To enable HCPs to deliver effective SDM, there is a need for robust evidence on the best SDM intervention(s) to use with patients with MS, methods for integration of SDM into clinical practice, and tools to educate HCPs. Furthermore, there is a research gap around SDM experiences in non-binary populations, and more studies focusing on diverse ethnic groups of patients with MS are warranted to increase our understanding of how cultural, religious, and community factors can influence patient participation in SDM in MS.

ACKNOWLEDGEMENTS

Medical Writing/Editorial Assistance. Medical writing support, including assisting authors with the development of the manuscript drafts and incorporation of comments, was provided by Rebecca A. Jarvis, PhD, CMPP, of Envision Pharma Inc., and was funded by Novartis Pharmaceuticals Corporation. This manuscript was developed in accordance with Good Publication Practice (GPP4) guidelines. The authors had full control of the content and made the final decision on all aspects of this manuscript.

Author Contributions. Sharon Stoll, Kathleen Costello, Scott D. Newsome, Hollie Schmidt, Amy B. Sullivan, and Barry Hendin contributed equally to the development of this manuscript. All made substantial contributions to the conception of this manuscript, drafted the text or provided critical review of draft content, approved the submitted manuscript, and agree to be accountable for all aspects of the work.

Funding. Editorial and medical writing support of the manuscript and the journal's article processing charges were funded by Novartis Pharmaceuticals Corporation (East Hanover, NJ, USA). The authors received no honoraria related to the development of this publication.

Declarations

Conflict of Interest. Sharon Stoll has served on scientific advisory boards for Bristol Myers Squibb, F. Hoffmann-La Roche Ltd., Genentech, Forepont Capital Partners, Horizon, and TG Therapeutics; received research support from BeCare MS Link and MedDay Pharmaceuticals; received compensation for consulting services, served on scientific advisory boards, and received speaker honoraria for Alexion, Biogen, Bristol Myers Squibb, EMD Serono, Horizon, Novartis, Roche/Genentech, and Sanofi/Genzyme; is CEO of Global Consultant MD; and serves on the steering committee of Horizon and Roche/Genentech. Kathleen Costello has served on advisory boards for Bristol Myers Squibb, Genentech, Novartis, and Sanofi. Can Do MS has received support from Biogen, Bristol Myers Squibb, EMD Serono, Genentech, Novartis, Sanofi, Sandoz, TG Therapeutics, and Viatris. Scott D. Newsome reports consultant fees for scientific advisory boards from Biogen, Bristol Myers Squibb, EMD Serono, Genentech, Greenwich Biosciences, Horizon Therapeutics, Novartis, and TG Therapeutics; is an adviser for Autobahn; is the study lead principal investigator for a Roche clinical trial; was a clinical trial adjudication committee member for MedDay Pharmaceuticals; and has received research funding (paid directly to institution) from Biogen, Genentech, National Multiple Sclerosis Society (NMSS), Patient-Centered Outcomes Research Institute (PCORI), Roche, Stiff Person

Syndrome Research Foundation, and US Department of Defense. Hollie Schmidt works for the Accelerated Cure Project for MS (ACP), which has received grants, collaboration funding, payments for use of assets, or in-kind contributions from the following companies: AbbVie, AstraZeneca, BC Platforms, Biogen, Bristol Myers Squibb, Celgene, EMD Serono, Genentech, GlycoMinds, Mallinckrodt, MedDay Pharmaceuticals, MSDx, Novartis, Octave, Pfizer, Regeneron Genetics Center, Sandoz, Sanofi/Genzyme, and Teva. ACP has also received funding from PCORI and NMSS. Amy B. Sullivan has served as a consultant and speaker for Biogen, Bristol Myers Squibb, EMD Serono, Genentech, and Novartis. Barry Hendin has received research, advisory, or speaker's bureau support from Alexion, Biogen, EMD Serono, Genentech, Genzyme, Horizon, and Novartis.

Ethical Approval. This article does not contain any new studies with human participants or animals performed by any of the authors.

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