

# Impact of Shared Decision Making on Disease-Modifying Drug Adherence in Multiple Sclerosis

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## CME/CNE Information

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The target audience for this activity is physicians, physician assistants, nursing professionals, and other health-care providers involved in the management of patients with multiple sclerosis (MS).

### Learning Objectives:

- 1) Describe new approaches to optimize adherence through shared decision-making and patient engagement principles.
- 2) Integrate shared decision-making principles and models into clinical practice.

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**Background:** *Shared decision making (SDM) and adherence to treatment are an integral part of multiple sclerosis (MS) care. A collaborative process, SDM actively involves the patient, the health care provider, and an extended network in making treatment decisions. Adherence to disease-modifying drug therapies in patients with MS presents an ongoing challenge for patients and health care providers due to the chronic nature of this disease. This narrative review aims to explore the impact of SDM on adherence based on existing literature and to identify new approaches to optimizing adherence.*

**Methods:** *A search was conducted using medical subject heading terms, including decision-making, adherence, shared decision-making, compliance, and patient-centered care.*

**Results:** *Shared decision making between patients and clinicians promotes adherence to the treatment plan in MS. A proactive SDM approach is based on patient preferences, education, and engagement. Providing credible and accurate sources of information is essential for improving patient engagement. Home monitoring, computerized models, and active patient engagement are a few new approaches to improve adherence in patients with MS.*

**Conclusions:** *Shared decision-making interventions can have a positive effect on patient adherence to disease-modifying drug therapy in MS care. A range of new strategies is emerging that may help promote optimal disease management. Int J MS Care. 2018;20:287-297.*

**M**ultiple sclerosis (MS) is a chronic, heterogeneous, inflammatory, neurodegenerative autoimmune disease that leads to physical, emotional, and cognitive disability. Although there is no cure for MS, there have been remarkable advances in the treatment of MS during the past 20 years. The goals

of MS treatment are to reduce disease activity and delay disability. Several disease-modifying drugs (DMDs) are approved for the treatment of relapsing forms of MS, and recently a DMD has also been approved for primary progressive MS. The approved DMD landscape includes medications with various routes of administration (injectable, oral, and infusion), frequencies, mechanisms of action, and safety and tolerability profiles.<sup>1</sup> These drug-related factors—combined with patient preference, lifestyle, disease course, disability, and motivation, as well as insurance status and cost of DMDs—can potentially affect treatment adherence. In general, rates of adherence in MS range from 49% to 88%, with variations reported across studies.<sup>2,3</sup>

The efficacy of DMDs in MS depends on high levels of adherence. Data from managed care databases show

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that the incidence of relapses and relapse-associated hospitalizations increased in patients who were nonadherent or discontinued treatment with DMDs.<sup>4</sup> In addition, data from an observational, multinational, postmarketing study of 2566 patients with relapsing-remitting MS demonstrated that adherent patients had a better Multiple Sclerosis International Quality of Life Questionnaire score compared with nonadherent patients.<sup>5</sup> Studies have also shown that higher rates of adherence are linked with a lower risk of severe relapses. Longer gaps in DMD therapy (>90 days) may be associated with a higher risk of relapse.<sup>2,6</sup> Because adherence to DMD therapy is critical for the treatments to be fully effective in MS, maximizing adherence is essential. Interdisciplinary expertise and services in a treatment plan may facilitate treatment adherence.

In a survey of patients with mild-to-moderate MS, patient-centered care and shared decision making (SDM) were significantly associated with better adherence rates.<sup>7</sup> Shared decision making is a collaborative approach that actively involves the patient, the health care provider, and possibly an extended network in the decision-making process. Throughout the disease course of MS, there are many points where decisions are required, including if and when to initiate DMD therapy and which DMD therapy to initiate. These are issues in which the patient's values and preferences should contribute to the final decision.<sup>8</sup> The purpose of this narrative review is to explore the impact of SDM on adherence to DMDs in MS and to present new and emerging approaches to optimize adherence through enhanced patient support and engagement.

## Methods

A narrative literature search was conducted using the CINAHL, Embase, MEDLINE, and PsycINFO databases, including publications from 1946 to present. We applied the search to the earliest limits of the databases to track the evolution of patient participation in their own care. Medical subject heading terms used were *multiple sclerosis, multiple sclerosis – psychology, patient compliance, adherence, personal autonomy, risk factors, physician-patient relations, decision-making, shared decision-making, patient participation, patient participation – psychology, motivation, patient-centered care, quality of life, and chronic disease*. Initial searches were performed using each term, and subsequent searches used different combinations of the terms. Inclusion criteria consisted of

peer-reviewed articles written in English, with no limitations on publication date or country. Exclusion criteria included focus on adherence responses related to specific DMDs. Final results yielded 156 publications, 62 of which were determined to be relevant to the review.

## Results

### Adherence, SDM, and Patient Preference

The World Health Organization<sup>9</sup> defines patient adherence to long-term therapy as “the extent to which a person's behavior—taking medication, following a diet, and/or executing lifestyle changes—corresponds with agreed recommendation from a healthcare provider.”<sup>(p18)</sup> This definition puts the responsibility of continuously taking treatment on the patient but does not consider the collaborative network involved in the treatment paradigm. Continued vigilance of patient adherence to DMD therapy requires an interdisciplinary approach that involves the patient, health care providers, and caregivers (eg, physician, family, MS center staff).

Shared decision making is a process in which patients, health care professionals, and caregivers work together and collaborate to select appropriate diagnostic tests, treatment, and disease management strategies based on clinical evidence and the values and preferences of patients.<sup>8,10,11</sup> It represents a distinct departure from the conventional paternalistic model, which assumed a passive role for the patient in the treatment decision-making process.<sup>12</sup> As reported by Charles et al.,<sup>12</sup> “shared decision making is seen as a mechanism to decrease the informational and power asymmetry between doctors and patients by increasing patients' information, sense of autonomy and/or control over treatment decisions that affect their well-being.”<sup>(p682)</sup>

An SDM model has been shown to be valuable in preference-sensitive conditions, in which several treatment options of similar efficacy but with differences in risks and benefits are available.<sup>8</sup> Moreover, a study that assessed decision-making preferences in 283 patients with MS who were considering starting DMD treatment or reconsidering their current DMD treatment revealed that 90% of patients preferred to make an autonomous or shared decision, compared with 10% of patients who preferred to have the physician alone make the decision.<sup>13</sup> These findings have also been borne out in a survey of nearly 7000 respondents conducted by the North American Research Committee on Multiple Sclerosis investigators in which most participants taking a DMD

preferred patient-centered decision making or SDM.<sup>14</sup> This further illustrates that an overall collaborative network may be an important factor for treatment success and optimal health and wellness (Figure 1).

It is worth noting that challenges associated with defining these concepts have been identified in the literature. Trenaman et al.<sup>15</sup> identified variation in how adherence has been defined and measured in clinical trials, distinguishing trials measuring adherence to medication choice from those measuring adherence to treatment. The authors concluded that further study is warranted to help standardize how adherence is conceptualized, measured, and reported.<sup>15</sup> Furthermore, Charles et al.<sup>12</sup> recognized that the concept of SDM has not been clearly and consistently defined and that challenges in measuring the effects of SDM result from the wide range of interpretations of the type and degree of characteristics required for SDM models.<sup>12</sup>

### Assessment of Adherence and SDM

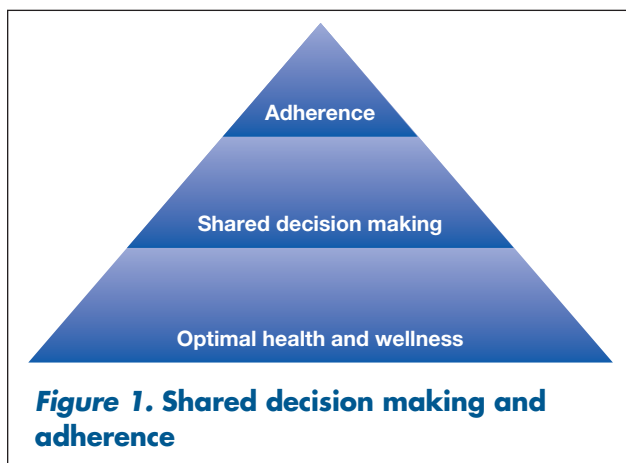
In patients with chronic diseases, including MS, health care providers are faced with the challenge of accurately assessing the degree of adherence. There is minimal guidance for health care providers in selecting the most appropriate adherence measures.<sup>16</sup> In clinical trials of DMDs in patients with relapsing MS, adherence is determined by the amount of drug returned on each visit and may not reflect the actual amount of DMD received.<sup>17</sup> In a real-world setting, estimating adherence rates in patients with MS is difficult due to the lack of standardized measures. Scanning a bar code before dosing of injectable therapy, checking whether a pill was dispensed, or even checking whether prescriptions were filled can serve as potential measures of adherence. Medication possession ratio, defined as the number of days' supply of dispensed medication divided by either

the refill interval (where the last refill is the end point) or a preset specific fixed refill period, is a common way to measure adherence; however, this ratio does not account for whether the treatment is being taken as prescribed.<sup>16,18</sup> Understanding the behavioral reasons for nonadherence may help to select an appropriate DMD for each patient. Behavioral measures that focus on the underlying reasons for being adherent (eg, the Morisky Medication Adherence Scale,<sup>19</sup> the Multiple Sclerosis Treatment Adherence Questionnaire<sup>20</sup>), combined with patient preferences and lifestyles, are useful self-reporting tools that assess the potential for DMD adherence. Although self-report studies are important for patient behavioral assessment, these studies are open to methodological limitations, such as overestimating or underestimating adherence.<sup>16,17</sup> Because there is no ideal medication adherence measure, health care providers should consider using more than one measure to assess adherence.

Although SDM is increasingly recognized as the ideal model of communication between patients and health care practitioners, especially in chronic conditions with partially effective treatments such as MS,<sup>21</sup> its empirical impact has been difficult to evaluate in clinical trials. Recent systematic reviews of clinical trials evaluating SDM and information provision have found marked heterogeneity in the number and extent of interventions used and in the quality of evidence. This has made comparisons and examination of the effects of collaborative provider–patient interventions difficult.<sup>22,23</sup>

In two randomized controlled trials, nurse-led information provision and counseling were shown to have the potential to increase informed choices.<sup>24,25</sup> However, a systematic review of randomized controlled trials and quasi-randomized trials evaluating the effectiveness of information-sharing approaches between providers and patients with MS found mixed results. Interventions studied included decision aids, educational programs, self-care interventions, and personal interviews with physicians. The authors concluded that providing information to people with MS seems to increase disease-related knowledge, although the effect on decision making and quality of life was less clear. However, the authors noted that interpretation of study results remains challenging due to the diversity of the interventions and outcome measures investigated.<sup>23</sup>

Although SDM is conceptualized as a process involving the patient and the health care provider, only a few

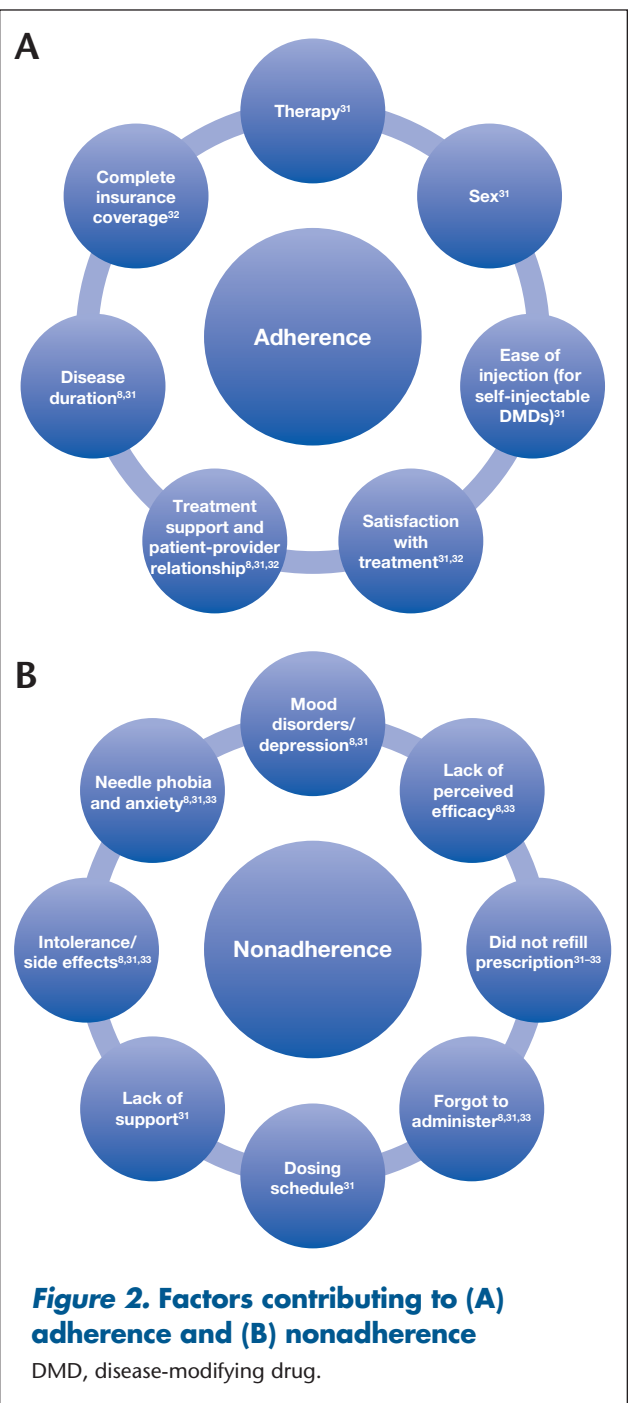


scales are available that assess the SDM process from the point of view of both participants, including the dyadic OPTION (“observing patient involvement”) scale,<sup>26</sup> the Multifocal Approach to Sharing in Shared Decision Making measure,<sup>27</sup> and the 9-item Shared Decision Making Questionnaire (SDM-Q-9), published in 2010.<sup>28</sup> The SDM-Q-9, in which patients evaluate the quality of nine aspects of the decision-making process,<sup>28</sup> is the most frequently used of the three scales.<sup>22</sup> However, a systematic review of studies evaluating the SDM-Q-9 revealed poor quality of evidence, suggesting that its value as an assessment tool may be limited.<sup>22</sup>

### Barriers to Adherence and SDM

A better understanding of barriers to adherence and SDM, whether related to the patient, provider, or health care environment, could improve clinical outcomes.<sup>29</sup> Factors that have been shown to be predictors of adherence include ease of injection, satisfaction with treatment, treatment support, patient–provider relationships, and complete insurance coverage (Figure 2A).<sup>2,30,31</sup> A survey performed in the United States in 2012, which evaluated data from the Pacific Northwest Registry of DMD-treated patients with relapsing forms of MS, found that the most common reasons for nonadherence were forgetfulness, injection-site pain, and other adverse effects (Figure 2B).<sup>2,30-32</sup> Whereas clinicians generally attribute patient nonadherence to adverse effects (82%), patients have a variety of reasons for nonadherence to a particular DMD, including adverse effects from treatment (42%), treatment fatigue (13%), practical issues relating to self-injection (9%), and perceived lack of efficacy (9%).<sup>1,33</sup> Patient behavior-specific factors associated with nonadherence include forgetfulness, perceived lack of DMD effectiveness, lack of realistic expectations (eg, DMD not addressing symptoms but preventing disability accumulation), and adverse effects and tolerability issues (Figure 2B).<sup>2,30-32</sup>

Patient clinical characteristics that may influence adherence and SDM include depression or other mood disorders, cognitive dysfunction and decline, fatigue, physical disability or limitations, social limitations, and absence of social support/network (Figure 2B).<sup>2,30-32</sup> Fatigue is one of the most common symptoms of MS, occurring in approximately 80% of patients.<sup>34</sup> More than half of all patients with MS will develop cognitive problems, including deficits in information processing, memory, attention and concentration, and executive functions (eg, planning and organizing).<sup>35</sup> Considering



that most MS therapies require continuous administration, fatigue, impaired cognitive function, or depression or other mood disorders may reduce the likelihood of accurate administration, thus affecting treatment adherence.<sup>6,30,36</sup>

Patient social and cultural factors must also be taken into account. In today’s multicultural environment, language differences may present a barrier to both SDM and adherence, and cultural-specific attitudes and values may also influence patients’ expectations as to how their

health should best be managed. By learning about their patients' social and cultural beliefs, staying nonjudgmental when differences arise, and being alert for signs of discontent or lack of engagement, physicians can help mitigate these differences.<sup>37</sup>

Misinformation and lack of education may further affect patient ability and willingness to engage in their own care. Patients with MS frequently report difficulties in finding useful information on the internet.<sup>38</sup> This access to information that may be inappropriate, inaccurate, or overwhelming can negatively affect patient motivation and self-reliance.<sup>38</sup> Lower educational levels may prevent understanding of health information, compromising effective participation in decision making.<sup>38</sup>

Barriers to adherence and SDM may also be related to the health care provider. A more paternalistic approach from a clinician does not take patient perspective into account and alienates the patient from the decision-making process. This may result in the patient being prescribed a DMD to which they have difficulty adhering. The medical professional's manner of interaction can affect the patient's level of participation in their care. Patients whose health care providers respond positively and provide feedback about their needs, views, and concerns are more likely to participate in SDM than patients who feel that their physician is dismissive of their concerns.<sup>39</sup> Time constraints limiting the length of clinical consultations are also recognized as a major obstacle to effective communication.<sup>38</sup> In an international study of neurologists and nurses caring for patients with MS, two-thirds of participants recognized engaging patients in SDM as an essential skill. However, the same participants self-reported significant deficits in their abilities to engage patients and/or caregivers in SDM due to insufficiencies in knowledge, skill, and confidence. These results suggest that continuing medical education and performance improvement initiatives should be implemented and would be welcomed by practitioners caring for patients with MS.<sup>40</sup> However, the additional time and resources required for training may be an impediment to implementation of such programs.<sup>37</sup>

Nonclinical factors, including costs and health care barriers, can also affect adherence and SDM. The costs of all DMDs in MS are high, and the level of coverage varies for each of these treatments.<sup>30,41</sup> The health care system can create barriers to treatment adherence by limiting access to health care, using a restricted formulary, or switching to a different formulary, in addition

to high costs or copayments.<sup>42</sup> For newly diagnosed patients, insurance companies may require that patients take DMDs in a certain sequence rather than allowing them to start with the agreed-on regimen. A change in a formulary, which may or may not be based on effectiveness of a particular therapy, can require a patient to discontinue a preferred treatment. Addressing other potential contributors to nonadherence, such as drug cost or availability, should involve the collaborative network (eg, social workers, insurance companies, MS patient advocacy societies, and DMD manufacturers) for the patient and health care provider to choose an optimal treatment.

### **SDM and Patient–Provider Relationship**

The success of the SDM is based on a positive patient–provider relationship,<sup>7</sup> and the development of this relationship begins at the initial visit and diagnosis. Data from the MS Choices Survey across seven countries demonstrated that there are several differences between patient and physician responses to questions exploring reasons for poor treatment adherence.<sup>1,33</sup> These findings illustrate the importance of establishing a strong patient–provider relationship and more active communication to combat nonadherence. It is imperative for both the patient and the provider to clearly understand their role, responsibilities, and goals. In particular, the health care provider should adequately weigh the benefits and risks of each DMD based on patient treatment preference (eg, route of administration), tolerance, work environment, and other lifestyle factors. Ultimately, these efforts will lead to choosing an optimal DMD for a patient.

When health care providers and patients disagree on treatment choice, both are faced with the challenge of evaluating the decision from the other's perspective.<sup>43</sup> Data from a survey to analyze patient preferences for risk-benefit trade-offs for hypothetical DMDs can help providers understand patient perspectives.<sup>11</sup> Although the provider and patient have the same goals for a positive outcome, it is important to reevaluate these goals. There needs to be a conversation between the patient and provider to explain the rationale for a treatment choice and the associated risks and benefits. A patient may be willing to take a significant risk, but the health care provider should advocate for the patient's best interests based on the provider's knowledge and experience with various MS therapies.<sup>43</sup>

The health care provider is critical in presenting and mobilizing a treatment plan. The provider's ideas and plans are not effective unless matched appropriately

with patient expectations and goals. The accessibility of information on the internet and social media creates a wealth of information easily obtained by patients. Patients are often misinformed about MS from these resources; therefore, the role of the health care provider is to educate patients with reliable and valid data, correcting any misconceptions about the disease or treatment options. In addition, it is important for providers to educate patients on the disease process, rationale for DMD choice, and expectations for treatment. A study of newly diagnosed patients with MS demonstrated that patients preferred knowing the benefits and risks associated with first-line treatment; in particular, patients with higher disability preferred to take a more active role in the decision-making process.<sup>44</sup> Clearly discussing the impact of treatment on quality of life and potential long-term outcomes while having open lines of communication with the patient will improve the relationship and foster treatment adherence.<sup>45</sup> When patients understand the reasoning for treatment, they are more likely to remain adherent. In a small sample of patients surveyed about their perceptions of MS and treatment, it was found that a greater number of patients were nonadherent to treatment if they did not feel well informed about the disease or treatment by their neurologist.<sup>45</sup> In addition, having a greater degree of information about the disease<sup>45,46</sup> and greater autonomy in treatment options have been shown to be associated with a greater likelihood of patient adherence.<sup>47</sup> Patients are also seeking more active involvement and more regular interaction with their clinicians,<sup>45</sup> which indicates a greater need for more communication with patients with MS. By having more interaction with health care providers, the relationship remains more dynamic and may lead to improved adherence rates. The options for treatment may change throughout the course of an individual's disease process, and it is important to be able to develop that dynamic treatment plan in an effective manner. When there is an SDM process, patients are well educated and offered the information to guide them in the direction of optimal disease management (Table 1).

### Role of SDM in DMD Selection and Adherence

A thorough understanding of available DMDs for the treatment of MS is imperative for both the patient and the clinician. Behavioral, clinical, social, and financial factors should be considered when selecting a DMD. Furthermore, proper understanding of these factors may help promote adherence in patients with MS. Although

**Table 1. Key factors associated with shared decision making<sup>3,43-46</sup>**

- Patients who are well informed about their disease and the rationale for treatment may be more likely to be adherent
- Active, dynamic communication may reduce gaps between clinician and patient expectations and goals
- Taking patient preference into account (route of administration, tolerance, work environment, lifestyle) may optimize disease-modifying drug selection and adherence
- Sharing patient preference and clinician experience may help evaluate risk-benefit trade-offs associated with medications
- The health care team can correct patient misconceptions about disease and treatment (widely accessible on internet/social media)

each of the approved treatments reduces clinical exacerbations, delays disability, and improves radiologic outcomes, DMD efficacy and response to treatment vary among patients with MS.<sup>4,29,48,49</sup> The differences in responses among patients may be due to individual patient characteristics, pathophysiology and patterns of the disease, and mechanism of action of a given DMD. When initiating or switching therapies, differences in drug mechanisms of action, as well as the risks and benefits of each, should be discussed with patients. Before switching to a different DMD due to breakthrough disease and suboptimal response, discussion with patients and their families should focus on patient preferences (eg, route and frequency of administration). As new, more potent, immunologically active substances become available for MS treatment, individualized risk aversion and tolerance of risk should be considered by the prescribing health care provider and the patient. Currently, there are no biomarkers available to determine which therapy will be most beneficial clinically; therefore, a principle of partnership that considers both clinical expertise and patient preference can be valuable in addressing the challenge of choosing the right DMD.

Adverse effects or safety concerns are important to consider in the process of DMD choice and adherence. Adverse effects associated with injectable DMDs may include injection-site reactions and flulike symptoms. As a result, adherence to injectable therapy is often a challenge for patients,<sup>6</sup> with more than 25% discontinuing therapy within 1 to 2 years.<sup>50</sup> As DMD treatment options have expanded to include oral therapies, studies are investigating whether adverse effects of oral medications (eg, gastrointestinal issues) are associated with non-adherence. Data from a real-world study demonstrated that discontinuation rates for the two most common

oral medications were driven by tolerability issues.<sup>51</sup> Studies are also investigating whether an oral route of administration is associated with improved treatment adherence. Data from a large US administrative claims data set demonstrated that DMD type, stratified by route of administration (self-injectable vs. oral DMDs), was not a significant predictor of DMD adherence.<sup>52</sup> Considering that intravenous administration of DMD occurs during a clinic visit, this may be the most reliable route of administration regarding adherence; however, the benefits and risks should be discussed with patients.<sup>6</sup>

### **New Approaches to Optimize Adherence Via SDM and Patient Engagement**

New strategies based on the principles of SDM are required to promote optimal patient involvement and treatment adherence. Given the chronic nature of MS, the importance of ongoing partnerships between patients, members of health care teams, and caregivers cannot be overstated. Home monitoring, computerized models, and active patient engagement are a few new approaches being applied to improve self-management and adherence in patients with MS.

Telephone-based home monitoring may represent an efficient method for assessment of medication adherence and early detection of individuals who may be at risk for nonadherence. Preliminary evidence from a longitudinal study of veterans with MS who completed monthly telephone-based interviews for 6 months demonstrated that adherence expectations predicted actual adherence after adjusting for demographic, illness-related, and psychosocial factors.<sup>53</sup> One-on-one pharmacist counseling/consultations from a patient's home can also be beneficial for patients and lead to improved adherence. For example, data from an analysis of patients new to DMD therapy who did and did not receive a one-on-one pharmacist counseling video conferencing session from a specialty pharmacy revealed that patients had significantly higher odds of being adherent if they had a video consultation.<sup>54</sup>

Computerization, electronic aids, and Web-based tools are other potential methods to assist with assessing and preserving adherence to DMDs. Computerization and the use of databases provide an opportunity to follow patients through the hospital pharmacy, where they receive the prescribed dose, and for clinicians to calculate key drug use parameters (eg, received daily dose, prescribed daily dose).<sup>55</sup> Electronic autoinjectors allow for individual injection settings and recording of

dose history, which can help patients who have cognitive deficits. Injection reminders such as telephone alerts or smartphone applications (apps) can help patients to remember to take their medications.<sup>1</sup> Smartphone apps may also be useful to track symptoms and medications using a treatment diary, which can be shared with the health care team.<sup>1</sup>

Interactive, Web-based, patient-focused programs may enhance self-management and allow for an integrated interdisciplinary approach. Examples include MSmonitor, a program for self-monitoring, self-management, and integrated, multidisciplinary care in MS,<sup>56</sup> and MSInvigor8, a cognitive behavioral therapy self-management program for MS fatigue.<sup>57,58</sup> MSmonitor comprises six validated questionnaires, two inventories (medication and adherence), two diaries, and two functionalities (e-consult and personal e-logbook).<sup>56</sup> A pilot study using this program suggested that repeated use of the short Modified Fatigue Impact Scale–5-item version and the 8-item Leeds Multiple Sclerosis Quality of Life questionnaire was associated with an increase in health-related quality of life.<sup>56</sup> MSInvigor8 consists of eight tailored, interactive sessions,<sup>57</sup> and a pilot randomized trial demonstrated that addition of e-mail-based support (MSInvigor8-Plus) significantly reduced fatigue severity.<sup>58</sup> In addition, patient-reported outcomes are starting to be recognized as an integral part of disease management, which can be collected using digital-based technology (eg, the Multiple Sclerosis Documentation System 3D) or identified from online community sites (eg, PatientsLikeMe.com).<sup>20</sup>

Patient engagement is essential for improving the quality, safety, and costs of health care interventions.<sup>37</sup> In 2011, the Multiple Sclerosis in the 21st Century initiative was established to define and update MS treatment and standards of care, develop a minimum international standard of care, and encourage the MS community to challenge the existing treatment paradigm. This group, composed of international experts in MS management and patient group representatives, recognized the importance of increasing patient engagement; they have identified five principles of active patient engagement (Table 2).<sup>37</sup> Given the complexity of MS pathology, the heterogeneity of the disease, and the variety of management options available, providing credible and accurate sources of information is essential for improving patient health literacy and engagement.<sup>37</sup> The responsibility for engagement is shared by the patient,



**Table 2. Five principles of active patient engagement identified by multiple sclerosis experts<sup>37</sup>**

1. Setting and facilitating engagement by education and confidence building
2. Increasing the importance placed on quality of life and patient concerns through patient-reported outcomes
3. Providing credible sources of accurate information
4. Encouraging treatment adherence through engagement
5. Empowering through social activities, family involvement, and a sense of responsibility

Note: Data from Rieckmann P, Boyko A, Centonze D, et al. Achieving patient engagement in multiple sclerosis: a perspective from the Multiple Sclerosis in the 21st Century Steering Group. *Mult Scler Relat Disord*. 2015;4:202-218.

the health care team, and other support systems (eg, family). The ability to build on this sense of responsibility may empower a patient's engagement. The US Center for Advancing Disease has developed a national Engagement Behavior Framework to help patients understand how they can become involved in their own care. The framework includes a description of ten behaviors, such as how to communicate with health care professionals, make good treatment decisions, participate in treatment, promote health, and seek health knowledge. In addition, the framework highlights the challenges patients may face in managing their care.<sup>59</sup> Overall, engaging the patient is essential to achieve an SDM portfolio to maximize patient care and adherence. Additional studies are needed to demonstrate the role of these new approaches, such as home monitoring, computerized models, and patients' active engagement in optimizing DMD adherence.

## Discussion

There was consensus among the authors that a review of the existing literature was needed as a foundation on which to offer models of SDM in MS. This review of the evidence supporting SDM shows that a positive effect on adherence has primarily been reported by studies with moderate levels of evidence, such as observational studies, surveys, and questionnaires. Randomized controlled trials have been conducted to assess the impact of SDM on patient behavior, but there is a marked lack of standardization in definitions and measurements in these trials, making it difficult to draw conclusions with confidence. Although we acknowledge that the evidence base supporting the benefits of SDM on patient outcomes is not yet robust, we nonetheless endorse SDM as a promising approach to increase adherence. System-

atic reviews of the literature evaluating SDM interventions in other therapy areas, including type 2 diabetes mellitus, asthma, and adherence to cancer screening, underscore the importance of provider-patient communication in improving adherence.<sup>60-62</sup> Further study is warranted to standardize SDM models and produce evidence to conclusively determine the impact of SDM on adherence in MS.

Moreover, it is important to have multidimensional patient information and educational programs in place that take into account different aspects of the disease, therapeutic options (eg, immunotherapy, symptomatic therapy), barriers to adherence, natural evolution of the disease, encouragement of self-management, and emotional support systems.<sup>63</sup> Importantly, educational programs should include a lesson about SDM.<sup>63</sup> Studies have shown that a collaborative effort between patients and the health care team is essential for establishing clear communication and enhancing a patient's confidence with the health care process.<sup>37</sup> Given the wide-ranging effects of MS, patient quality of life can be significantly affected by psychological, physical, social, and financial factors throughout the course of the disease. The challenge for health care providers is to implement a management plan that addresses the full range of symptoms affecting each patient's quality of life.

In conclusion, SDM and adherence to DMDs are key principles in MS care. Use of DMDs reduces the frequency of relapses and radiologic disease activity and slows the progression of disability. However, it is critical that the patient with MS remains adherent to treatment over the course of their disease. Although

## PRACTICE POINTS

- Interventions aimed at optimizing medication adherence in patients with MS should incorporate a shared decision-making model that focuses on patient preferences, education, and engagement.
- A better understanding of patient characteristics and other factors contributing to disease-modifying drug nonadherence could improve clinical outcomes. New models and standardized approaches for adherence assessment and improvement are required to promote optimal efficacy of disease-modifying drugs and maintain a better quality of life in patients with MS.

multiple factors contribute to the success or lack of success with a particular treatment, an SDM process should be undertaken by the patient, the health care provider, and the extended collaborative network to maintain patient adherence and maximize beneficial outcomes. We conclude that the results of this narrative review support the concept that SDM interventions can have a positive effect on patient adherence to DMD therapy in MS care. Accordingly, we presented new and emerging collaborative strategies that may help promote optimal disease management. □

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