Shared Decision-Making and Satisfaction with the Treatment Decision-Making Process in Multiple Sclerosis

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Abstract

Background

Multiple sclerosis is a chronic, demyelinating disease that requires treatment decisions at multiple points in the disease course. Shared Decision-Making (SDM) is an approach to treatment decision-making that actively involves the patient and physician in reaching a treatment choice and may be ideally suited to treatment decisions in MS.

Methods

We sent 500 patients with a diagnosis of MS seen at a specialty MS center and participating in the Comprehensive Longitudinal Investigation of Multiple Sclerosis at the Brigham and Women's Hospital a questionnaire to assess SDM, satisfaction with the treatment decision-making process, and patient and disease characteristics. The questionnaire also asked patients to identify any additional information or decision aids that would have been helpful in treatment decision-making.

Results

161 patients completed the questionnaire and 134 were currently treated. Treated patients reported high levels of SDM and satisfaction with the treatment decision-making process. There were no differences in patients treated with high versus low efficacy treatments, relapsing vs. progressive disease, high vs. low disability, high vs. low risk propensity, and high vs. low expectations of disease worsening. Approximately 65% of patients indicated that they would have liked additional information at the time of their last treatment decision including information regarding the likelihood of serious side effects and disability worsening.

Conclusions

MS patients treated at an MS specialty clinic reported high levels of SDM and satisfaction with the treatment decision-making process. Additional studies are needed to determine if SDM leads to better clinical outcomes and to assess the role of decision aids in supporting SDM.

Keywords: Shared decision-making • Patient satisfaction • Multiple Sclerosis• Disease Modifying Therapy (DMT) • Decision aids

Introduction

Multiple Sclerosis (MS) is a chronic demyelinating disease of the central nervous system with a usual onset between the ages of 20 and 40 years. Persons with MS (pwMS) have wide-ranging physical, emotional, and cognitive symptoms and a variable disease course typically characterized by early relapsing and remitting disease with a risk of gradual disease progression in the later stages [1,2]. Today, there are more than 20 Disease-Modifying Therapies (DMTs) approved by the US Food and Drug Administration which have shown efficacy in reducing disease activity in MS, primarily in the relapsing-remitting form of the disease [3]. Increasingly, DMTs for progressive forms of MS are also available, although these are comparatively less effective, and the treatment of progressive MS remains a challenge [4,5]. While there are clear benefits of treatment in reducing relapses and clinical disability, DMTs also have potentially serious side effects [1,4-6]. Additionally, there are multiple approaches to treatment and many points in the disease course when treatment decisions need to be made; however, there is no indicated single best course of treatment [6-8]. While the consensus among physicians seems to be that early intervention is crucial in disease management, the array of treatment options available and potential risks involved in using high-efficacy medications require that pwMS establish long-term relationships with their healthcare providers who can adapt strategies based on disease and individual factors or preferences to optimize the management of the disease [9].

Shared Decision-Making (SDM) is a method of medical decision-making distinguished by its emphasis on patient knowledge, flow of information between patient and physician, and a shared responsibility between patient and physician regarding the final treatment choice [10,11]. SDM has been characterized as an ethically imperative approach to treatment decision-making given its focus and impact on patient satisfaction with care compared with previous models of patient-physician relationships such as paternalism and physician-as-expert [11-13]. SDM can also be viewed as a practical approach for balancing the potentially conflicting ethical principles of patient autonomy and beneficence, with the ultimate aim of improving patient outcomes and patient satisfaction [14]. While SDM is not feasible in every medical encounter, such as in acute emergency situations where there is often a single agreed-upon action that needs to be taken by a physician, it is ideally suited for conditions where long-term care is necessary, particularly in chronic conditions where there are multiple courses of action available to the physician and patient which rely heavily on preference and information [11]. This framework makes it well-suited for MS, a disease often diagnosed in early adulthood with a lifelong variable course that requires treatment decisions at different points using treatments that carry wide ranging risks [7,8,12,15].

There are several validated methods of assessing SDM in medical encounters. The nine-item Shared Decision Making Questionnaire (SDM-Q-9) is a patient-reported measure synthesized from the full Shared Decision

making Questionnaire [16]. The SDM-Q-9 has been shown to be a reliable, brief, well-accepted instrument to measure the process of SDM [17]. Further, the SDM-Q-9 has demonstrated good psychometric properties and therefore may be appropriate in assessing SDM in pwMS [18]. In this study, we sought to characterize SDM among pwMS followed at a specialty MS Center using the SDM-Q-9. In addition, we examined whether experiences related to the treatment decision-making process differed based on individual and/or disease characteristics. Finally, we asked pwMS to identify additional information that they would have liked to have had available at the time of a treatment decision (in retrospect), and what kinds of decision aids they believe would have been most helpful.

Treatment decision-making questionnaire for climb study participants

1. What treatment are you currently taking for your multiple sclerosis? (Tick the box)

❑$_1$ Aubagio
❑$_2$ Avonex
❑$_3$ Betaseron
❑$_4$ Copaxone
❑$_5$ Gilenya
❑$_6$ Ocrevus
❑$_7$ Plegridy
❑$_8$ Rebif
❑$_9$ Rituxan
❑$_{10}$ Tecfidera
❑$_{11}$ Tysabri
❑$_{12}$ Other: _____

2. Please think back to your most recent treatment decision making process.

My doctor made it clear that a decision needed to be made.					
Completely Disagree ❑$_1$	Strongly Disagree ❑$_2$	Somewhat Disagree ❑$_3$	Somewhat Agree ❑$_4$	Strongly Agree ❑$_5$	Completely Agree ❑$_6$
My doctor wanted to know exactly how I want to be involved in making the decision.					
Completely Disagree ❑$_1$	Strongly Disagree ❑$_2$	Somewhat Disagree ❑$_3$	Somewhat Agree ❑$_4$	Strongly Agree ❑$_5$	Completely Agree ❑$_6$
My doctor told me that there are different options for treating my medical condition.					
Completely Disagree ❑$_1$	Strongly Disagree ❑$_2$	Somewhat Disagree ❑$_3$	Somewhat Agree ❑$_4$	Strongly Agree ❑$_5$	Completely Agree ❑$_6$
My doctor precisely explained the advantages and disadvantages of the treatment options.					
Completely Disagree ❑$_1$	Strongly Disagree ❑$_2$	Somewhat Disagree ❑$_3$	Somewhat Agree ❑$_4$	Strongly Agree ❑$_5$	Completely Agree ❑$_6$
My doctor helped me understand all the information.					
Completely Disagree ❑$_1$	Strongly Disagree ❑$_2$	Somewhat Disagree ❑$_3$	Somewhat Agree ❑$_4$	Strongly Agree ❑$_5$	Completely Agree ❑$_6$
My doctor asked me which treatment option I prefer.					
Completely Disagree ❑$_1$	Strongly Disagree ❑$_2$	Somewhat Disagree ❑$_3$	Somewhat Agree ❑$_4$	Strongly Agree ❑$_5$	Completely Agree ❑$_6$
My doctor and I thoroughly weighed the different treatment options.					
Completely Disagree ❑$_1$	Strongly Disagree ❑$_2$	Somewhat Disagree ❑$_3$	Somewhat Agree ❑$_4$	Strongly Agree ❑$_5$	Completely Agree ❑$_6$
My doctor and I selected a treatment option together.					
Completely Disagree ❑$_1$	Strongly Disagree ❑$_2$	Somewhat Disagree ❑$_3$	Somewhat Agree ❑$_4$	Strongly Agree ❑$_5$	Completely Agree ❑$_6$
My doctor and I reached an agreement on how to proceed.					
Completely Disagree ❑$_1$	Strongly Disagree ❑$_2$	Somewhat Disagree ❑$_3$	Somewhat Agree ❑$_4$	Strongly Agree ❑$_5$	Completely Agree ❑$_6$

3. How satisfied are you with your most recent treatment decision making process?

Extremely Satisfied			Neutral			Extremely Dissatisfied
1	2	3	4	5	6	7

4. When you made your most recent treatment decision, what additional information would you have liked? (Check all that apply)

❑$_1$ Ability of different treatments to reduce number of relapses
❑$_2$ Ability of different treatments to reduce disability worsening
❑$_3$ Likelihood of minor side effects on different treatments
❑$_4$ Likelihood of serious side effects on different treatments
❑$_5$ Impact of different treatment on fatigue or quality of life
❑$_6$ Cost of different treatments
❑$_7$ Convenience of different treatments
❑$_8$ Other: (Please specify) _____

5. If you wanted more information, what decision aids would have been most helpful?

❑$_1$ Additional time with my doctor
❑$_2$ Pamphlets at the Partners MS Center
❑$_3$ Monthly emails about treatments from the Partners MS Center
❑$_4$ Videos about treatments

❑5 Information on the Partners MS Center website

❑6 Other: (Please specify) _____

6. In general, people often face risks when making financial, career or other life decisions. Overall, how would you place yourself on the following scale from 1-7?

Extremely Comfortable Taking Risks			Neither Comfortable Nor Uncomfortable Taking Risks			Extremely Uncomfortable Taking Risks
1	2	3	4	5	6	7

7. Please estimate the risk of your MS worsening over the short- (2 years), medium- (5 years) and long-term (10 years).

	Extremely Unlikely	Unlikely	Neither Likely Nor Unlikely	Likely	Extremely Likely
2 years	1	2	3	4	5
5 years	1	2	3	4	5
10 years	1	2	3	4	5

8. What is your age?

❑1 18 years-24 years

❑2 25 years-34 years

❑3 35 years-44 years

❑4 45 years-54 years

❑5 55 years-64 years

❑6 Age 65 or older

9. What is your gender?

❑1 Female

❑2 Male

❑3 Other

10. Which of the following statements best describes your MS symptoms? Choose one.

❑1 I have had one episode of neurologic change (attack) suggestive of MS, but do not yet carry the diagnosis of MS.

❑2 I have changes on MRI suggestive of MS, but I have not had any neurologic symptoms and do not yet carry the diagnosis of MS.

❑3 I had flare ups (also called relapses, attacks, or exacerbations) when I first developed MS, and I continue to have flare ups of my MS.

❑4 I had flare ups (also called relapses, attacks, or exacerbations) when I first developed MS, but am currently stable.

❑5 I had flare ups (also called relapses, attacks, or exacerbations) when I first developed MS. My level of function is now getting steadily worse during and between flare ups, and I am having fewer and fewer (or none at all) flare ups.

❑6 I have never had flare ups (also called relapses, attacks, or exacerbations) of my MS. Instead, my level of function has gotten steadily worse since the onset of my disease.

11. Please select the one statement that best describes how much your MS has restricted your activity over the last 4 weeks. Choose only one.

❑1 I have no difficulty walking 25 feet (25 feet is approximately the length of two parking spaces on a city street) and I have no other neurologic symptoms due to my MS.

❑2 I have no difficulty walking 25 feet (25 feet is approximately the length of two parking spaces on a city street), but I have the following neurologic symptoms due to my MS… Check all that apply.

- ❑2a Vision problems
- ❑2b Weakness, numbness, or tingling in my arms or legs
- ❑2c Coordination or balance problems
- ❑2d Speech problems
- ❑2e Swallowing problems
- ❑2f Bladder problems
- ❑2g Bowel problems
- ❑2h Attention, memory, or thinking problems

❑3 I have difficulty walking 25 feet, but I do not use a cane or some other form of support (such as a splint, brace, or crutch) to help me walk (25 feet is approximately the length of two parking spaces on a city street.)

❑4 I can walk 25 feet without a cane or some other form of support (such as a splint, brace, or crutch) but I use this occasionally or for longer distances (25 feet is approximately the length of two parking spaces on a city street.)

❑5 To be able to walk 25 feet, I must use a cane or some other form of support on one side such as holding on to furniture or touching the wall. I may use a scooter or wheelchair for longer distances (25 feet is approximately the length of two parking spaces on a city street).

❑6 To be able to walk 25 feet, I must use two canes, a walker, or two crutches. I may use a scooter or wheelchair for longer distances (25 feet is approximately the length of two parking spaces on a city street).

❑7 My only form of mobility is a wheelchair or scooter.

Methods

PwMS enrolled in the Comprehensive Longitudinal Investigation of Multiple Sclerosis at the Brigham and Women's Hospital (CLIMB) were eligible to participate. CLIMB is an ongoing prospective observational cohort study that began following patients in 2000 [19]. More than 2000 participants have been enrolled. Additional inclusion/exclusion criteria for the study include diagnosis of MS according to the revised McDonald criteria, age 18 or older, and a patient visit to the Brigham MS Center in the last 24 months [20]. Recruitment letters and questionnaires were mailed to 500 randomly chosen CLIMB participants meeting inclusion/exclusion criteria for this study. Surveys could be completed and mailed back in postage paid envelopes. Surveys could also be completed online using a provided URL. Thirty-eight questionnaires were returned for having incorrect addresses and 161 were completed and returned for a response rate of 35%. Of the 161 participants who returned the questionnaire, 27 reported that they were not on treatment and did not contribute to our analysis, leading to a final sample size of 134 participants. This study was approved by the Mass General Brigham Human Research Committee (Protocol 2017P002814) as exempt human subjects research and consent was not required.

The Treatment Decision-Making Questionnaire for CLIMB Study Participants (see Supplementary Materials) was completed anonymously and included questions designed to measure SDM, satisfaction with the most recent treatment decision-making process, and patient and disease characteristics. First, participants were asked about their most recent treatment decision. Participants described the treatment chosen, completed the SDM-Q-9 to describe the process, and completed an additional question about satisfaction with the most recent treatment decision-making process. Satisfaction with the most recent treatment decision-making process was measured on a seven-point scale that ranged from extremely satisfied to extremely dissatisfied. Second, participants were asked about any additional information or decision aids that would have been helpful in the treatment decision-making process. Third, participants were asked about risk propensity and disease expectations in the short-, medium- and long-term. Risk propensity was measured using a single-item seven-point scale that ranged from extremely comfortable taking risks to extremely uncomfortable taking risks [21]. Disease expectations were measured by asking participants to estimate the likelihood of MS worsening in the short- (2 years), medium- (five years) and long-term (10 years) using a five-point scale that ranged from extremely unlikely to extremely likely. Finally, participants were asked demographic and clinical questions including patient-reported disease category and patient-reported disability [22].

Statistical methods

Summary statistics for each of the demographic and clinical questions were calculated as proportions because only categorical data were collected due to the anonymous nature of the questionnaire. For the SDM-Q-9 and the question about satisfaction with the treatment decision-making process, the proportions of participants who provided each answer were calculated. In addition to the descriptive statistics, the mean scores on the SDM-Q-9 questions and satisfaction with the treatment decision-making process question were examined in five separate two-group comparisons: high efficacy treatment vs. low efficacy treatment, relapsing MS vs. progressive MS, high disability vs. low disability, high risk propensity vs. low risk propensity, and high expectations of disease worsening vs. low expectations of disease worsening. The high efficacy treatments were ocrelizumab, fingolimod, rituximab, and natalizumab; the low efficacy treatments were all forms of interferon-beta, glatiramer acetate, dimethyl fumarate, and teriflunomide. Participants who reported being on other treatments were not included in this comparison. Participants were classified as progressive or relapsing using the patient-reported disease category question (Question 10). Participants were classified as high disability based on whether the score on the patient-reported disability question (Question 11) was greater than 2; participants were classified as low disability if the score was 2 or less. Participants were classified as having higher risk propensity if the participant was comfortable taking risk (score of 1-3 on the risk propensity measure) (Question 6), and participants were classified as having lower risk propensity if the participant was neither comfortable nor uncomfortable (score of 4-7 on the risk propensity measure). Participants were classified as having high expectations of disease worsening in the next five years if the participant thought they were likely or extremely likely to have disease worsening (score of 4-5 on the disease expectation question) (Question 7), and participants were classified as having low expectation of disease worsening in the next five years if the participant thought they were unlikely or neither likely or unlikely to have disease worsening (score of 1-3 on the disease expectation question). For each two-group comparison, the two sample t-test was used, and a 95% confidence interval for the estimated difference in group means was also calculated. All statistical analysis was completed in R version 3.6.3 (www.r-project.org).

Results

Participants

The demographic characteristics of participants are provided in Table 1. Given that the questionnaire was completed anonymously, information from the clinical record could not be combined with the questionnaire responses. Therefore, all clinical information was based on self-report. Study participants were primarily relapsing-remitting MS (RRMS) and they reported some disability due to the disease. In terms of treatments, participants were on a variety of treatments, and Ocrelizumab was the most common (21%) (Table 1).

Table 1. Demographic and clinical characteristics of study participants.

N	134
Age group	
18 years-24 years	1
25 years-34 years	1
35 years-44 years	15
45 years-54 years	46
55 years-64 years	48
65 or older	19
Missing	4
Sex	
Female	91
Male	39
Missing	4
Patient-reported MS disease category	
1: Clinically isolated syndrome	3
2: Radiologically isolated syndrome	1
3: RRMS with relapses	11
4: RRMS stable	82
5: Secondary Progressive MS	18
6: Primary Progressive MS	11
Missing	8
Patient-reported disability	
1	32
2	63
3	7

4	3
5	13
6	6
7	5
Missing	5
Neurologic symptoms in patients who reported no difficulty walking	
Vision problems	19
Weakness, numbness, or tingling in my arms or legs	43
Coordination or balance problems	36
Speech problems	6
Swallowing problems	7
Bladder problems	23
Bowel problems	8
Attention, memory, or thinking problems	30
Treatment	
Aubagio	7
Avonex	7
Betaseron	1
Copaxone	12
Gilenya	19
Ocrevus	28
Plegridy	1
Rebif	4
Rituxan	12
Tecfidera	22
Tysabri	9
Other	12
Risk propensity	
1-Extremely comfortable taking risks	16
2	17
3	28
4-Neither comfortable nor uncomfortable taking risks	27
5	19
6	15
7-Extremely uncomfortable taking risks	6
Missing	6
Risk of MS worsening over 2 years	
Extremely unlikely	27
Unlikely	38
Neither likely nor unlikely	36
Likely	14
Extremely likely	4
Missing	15
Risk of MS worsening over 5 years	
Extremely unlikely	16
Unlikely	34
Neither likely nor unlikely	36
Likely	22
Extremely likely	10
Missing	16
Risk of MS worsening over 10 years	
Extremely unlikely	9
Unlikely	23
Neither likely nor unlikely	44
Likely	26
Extremely likely	18
Missing	14

SDM

The results from the SDM-Q-9 are presented in Table 2. Participants described their most recent treatment decision as SDM across all the questions and the two most common responses for each of the nine items was strongly agree or completely agree. The highest level of agreement was for the final question: "My doctor and I reached an agreement on how to proceed". Participants were also satisfied with their most recent treatment decision-making experience.

Table 2. SDM-Q-9 and satisfaction with the treatment decision-making process.

	Completely disagree	Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree	Completely agree	Missing
My doctor made it clear that a decision needed to be made	10 (7.5)	4 (3.0)	7 (5.2)	18 (13.4)	27 (20.1)	64 (47.8)	4 (3.0)
My doctor wanted to know exactly how I want to be involved in making the decision	3 (2.2)	1 (0.7)	5 (3.7)	21 (15.7)	36 (26.9)	63 (47.0)	5 (3.7)
My doctor told me that there are different options for treating my medical condition	2 (1.5)	2 (1.5)	4 (3.0)	10 (7.5)	35 (26.1)	79 (59.0)	2 (1.5)
My doctor precisely explained the advantages and disadvantages of the treatment options	1 (0.7)	5 (3.7)	7 (5.2)	12 (9.0)	33 (24.6)	74 (55.2)	2 (1.5)
My doctor helped me understand all the information	2 (1.5)	6 (4.5)	3 (2.2)	15 (11.2)	33 (24.6)	73 (54.5)	2 (1.5)
My doctor asked me which treatment option I prefer	5 (3.7)	2 (1.5)	2 (1.5)	15 (11.2)	32 (23.9)	76 (56.7)	2 (1.5)
My doctor and I thoroughly weighed the different treatment options	4 (3.0)	2 (1.5)	7 (5.2)	22 (16.4)	36 (26.9)	60 (44.8)	3 (2.2)

My doctor and I selected a treatment option together	3 (2.2)	3 (2.2)	3 (2.2)	19 (14.2)	39 (29.1)		65 (48.5)	2 (1.5)
My doctor and I reached an agreement on how to proceed	1 (0.7)	1 (0.7)	2 (1.5)	9 (6.7)	41 (30.6)		77 (57.5)	3 (2.2)
	7- Extremely dissatisfied	6	5	4-Neutral	3	2	1- Extremely satisfied	Missing
Satisfaction with the treatment decision-making process	11 (8.2)	7 (5.2)	3 (2.2)	5 (3.7)	3 (2.2)	26 (19.4)	73 (54.5)	6 (4.5)
Number (%) of participants who chose each option is provided								

Comparisons of SDM-Q-9 and satisfaction with the most recent treatment decision across groups are provided in Table 3. There were no differences between the high efficacy and low efficacy treatments in terms of the SDM process or the satisfaction with the treatment decision-making process. Similarly, in participants with relapsing and progressive disease and low and high disability, there were no differences in SDM or satisfaction with the treatment decision-making process. In terms of risk propensity and disease expectations, there were also no differences in the decision-making process with the exception of a difference on question 2 of the SDM-Q-9, "My doctor wanted to know exactly how I want to be involved in making the decision." For this question, participants with higher risk propensity had higher satisfaction, but this result should be interpreted cautiously given the number of multiple comparisons.

Table 3. Comparison of treatment decision-making questions by high efficacy vs low efficacy, progressive vs relapsing, high disability vs low disability, high risk propensity vs low risk propensity, and high risk of worsening vs low risk of worsening.

	High efficacy -low efficacy	**Progressive - relapsing**	**High disability – low disability**	**High risk propensity – low risk propensity**	**High risk of worsening – low risk of worsening**
My doctor made it clear that a decision needed to be made	-0.07; 95%: -0.6, 0.46; p=0.799	-0.15; 95%: -0.8, 0.51; p=0.654	-0.3; 95%: -0.9, 0.3; p=0.33	0.26; 95%: -0.29, 0.81; p=0.348	-0.3; 95%: -0.95, 0.35; p=0.37
My doctor wanted to know exactly how I want to be involved in making the decision	0.04; 95%: -0.38, 0.46; p=0.848	0.17; 95%: -0.31, 0.64; p=0.492	0.01; 95%: -0.43, 0.46; p=0.952	0.46; 95%: 0.07, 0.86; p=0.021	0.05; 95%: -0.41, 0.51; p=0.818
My doctor told me that there are different options for treating my medical condition	-0.12; 95%: -0.5, 0.26; p=0.519	-0.19; 95%: -0.63, 0.25; p=0.394	-0.09; 95%: -0.5, 0.32; p=0.661	0.1; 95%: -0.25, 0.44; p=0.584	-0.03; 95%: -0.43, 0.36; p=0.865
My doctor precisely explained the advantages and disadvantages of the treatment options	-0.13; 95%: -0.53, 0.28; p=0.539	-0.08; 95%: -0.57, 0.4; p=0.736	-0.28; 95%: -0.72, 0.16; p=0.208	0.01; 95%: -0.4, 0.41; p=0.977	0.05; 95%: -0.4, 0.51; p=0.826
My doctor helped me understand all the information	0.03; 95%: -0.39, 0.45; p=0.896	-0.03; 95%: -0.54, 0.48; p=0.905	-0.18; 95%: -0.64, 0.28; p=0.443	0.15; 95%: -0.27, 0.57; p=0.487	0.17; 95%: -0.28, 0.63; p=0.453
My doctor asked me which treatment option I prefer	-0.16; 95%: -0.59, 0.27; p=0.462	-0.09; 95%: -0.61, 0.42; p=0.72	-0.07; 95%: -0.56, 0.41; p=0.773	0.04; 5%: -0.39, 0.47; p=0.85	0.03; 95%: -0.44, 0.49; p=0.909
My doctor and I thoroughly weighed the different treatment options	-0.01; 95%: -0.44, 0.42; p=0.971	-0.02; 95%: -0.54, 0.49; p=0.927	-0.17; 95%: -0.65, 0.32; p=0.499	0.13; 95%: -0.31, 0.56; p=0.562	0.13; 95%: -0.34, 0.6; p=0.58
My doctor and I selected a treatment option together	-0.01; 95%: -0.4, 0.38; p=0.968	-0.02; 95%: -0.51, 0.46; p=0.926	-0.04; 95%: -0.5, 0.42; p=0.86	0.06; 95%: -0.34, 0.47; p=0.761	-0.03; 95%: -0.49, 0.42; p=0.881
My doctor and I reached an agreement on how to proceed	-0.19; 95%: -0.5, 0.13; p=0.242	-0.15; 95%: -0.51, 0.21; p=0.403	-0.07; 95%: -0.41, 0.28; p=0.705	0.05; 95%: -0.25, 0.36; p=0.721	-0.14; 95%: -0.46, 0.18; p=0.378
Satisfaction with the treatment decision- making process	0.18; 95%: -0.56, 0.93; p=0.626	0.49; 95%: -0.36, 1.34; p=0.253	0.25; 95%: -0.56, 1.06; p=0.541	-0.39; 95%: -1.11, 0.33; p=0.285	0.01; 95%: -0.81, 0.83; p=0.976

Decision aids

Participants were asked to identify additional information that they would like to have known at the time of their treatment decision and the best approach to disseminating this information (Table 4).

Participants were most interested in additional information on the likelihood of serious side effects with different treatments, the impact of different treatments on fatigue or quality of life, and the ability of different treatments to reduce disability worsening, but at most 30% of participants expressed interest in each of these topics. Eighty-eight of 134 participants (65.7%) expressed interest in additional information on at least one topic. In terms of decision aids, additional information via email or a website were the most common responses, but all decision aids were chosen by fewer than 30% of participants.

Table 4. Additional information for treatment decision-making.

Additional information on treatment	
Ability of different treatments to reduce number of relapses	30 (22.4)
Ability of different treatments to reduce disability worsening	40 (29.9)
Likelihood of minor side effects on different treatments	29 (21.6)
Likelihood of serious side effects on different treatments	41 (30.6)
Impact of different treatment on fatigue or quality of life	41 (30.6)
Cost of different treatments	29 (21.6)
Convenience of different treatments	28 (20.9)

Decision aids	
Additional time with my doctor	31 (23.1)
Pamphlets at the Partners MS Center	22 (16.4)
Monthly emails about treatments from the Brigham MS Center	34 (25.4)
Videos about treatments	22 (16.4)
Information on the Brigham MS Center website	36 (26.9)
Number (%) of subjects who answered affirmatively for each option is provided. 134 subjects contributed to this table.	

Discussion

In this study, pwMS reported that nine previously identified practical steps of SDM are commonly used by providers at a specialty MS center. PwMS indicated that their providers made it clear that a treatment decision needed to be made and asked them how they wanted to be involved in the treatment decision-making process. Their providers told them that there were different treatment options, described the advantages and disadvantages of each treatment option, and helped them to understand the information. Their providers also asked them which treatment they preferred and weighed the options with them. Finally, PwMS and their providers selected a treatment together and reached an agreement on how to proceed. In addition, pwMS indicated that they were satisfied with the process used to make their most recent treatment decision. These findings suggest a shift away from the paternalistic style or physician-as-expert approaches previously used in healthcare. Instead, providers are combining their medical expertise and knowledge of DMTs with the personal preferences of the patient. Although we did not survey pwMS about treatment decision related to the management of relapses or physical symptoms, a recent systematic review found that pwMS demonstrate a strong preference for SDM in general, and particularly with respect to the management of MS-related physical symptoms including gait, balance, and fatigue [23].

Interestingly, we found that the SDM approach and individuals' satisfaction with the process were observed in pwMS with different treatment regimens (high efficacy *vs.* low efficacy), disease courses (relapsing *vs.* progressive), disability levels (high *vs.* low disability), risk propensity profiles (high *vs.* low risk propensity), and expectations of disease worsening (high *vs.* low expectation of worsening). These findings suggest that providers at an academic MS center are using SDM strategies broadly across the clinical spectrum of MS, taking into consideration clinical presentation and preferences in the decision-making process. This is in contrast to previous studies suggesting that physicians are not meeting the needs of pwMS in complex medical decision-making [9].

Although SDM may be preferred due to ethical considerations, there is little evidence to support other potential benefits [9,13,24]. A 2015 review of SDM for a variety of disorders including asthma, cancer, depression, diabetes, epilepsy and HIV found that SDM resulted in improved patient satisfaction, but there was no clear evidence that SDM resulted in improved behavioral outcomes such as adherence or health outcomes such as improved symptoms or quality of life [25]. In a narrative review of SDM in MS, Ben Zacharia *et al.* found that overall there was weak evidence supporting the benefits of SDM on DMT adherence [26]. Positive effects on adherence were mostly seen in observational studies that relied on surveys and questionnaires. There are several limitations associated with the use of self-report measures, including that they are subject to social desirability and memory biases that may result in an overestimation of DMT adherence. Ben Zacharia et al. stressed the difficulties inherent in studying the impact of SDM in chronic conditions with partially effective treatments and few standardized measures [26,27].

Our survey results demonstrate that many pwMS felt that they had adequate information needed to make a treatment decision, but about 65% of pwMS were interested in additional information about the treatments. The likelihood of serious side effects, the impact of DMTs on fatigue or quality of life, and the ability of treatments to reduce disability worsening were the most common areas pwMS wanted more information. This finding is consistent with previous reports of unmet information needs in MS [27]. Educational programs have been developed to address whether or not to initiate early treatment, pregnancy and injectable DMT choice, side-effects, and relapses [28-31]. Given the increasing number of FDA-approved therapies for the treatment of MS and the lack of studies showing head-to-head treatment comparisons, it is challenging to draw conclusions regarding relative efficacy or risk across DMTs. 9 Despite these challenges, this information is needed to fully satisfy the requirements of the SDM process.

Two groups recently published papers on the development of decision aids to promote SDM in pwMS. Col *et al.* described the development of an interactive online decision aid, MS-SUPPORT (Sharing and Understanding Personal Preferences and Objectives Regarding Treatment), to encourage patient-provider collaboration and improve SDM [32,33]. The decision aid guides users through a series of structured modules to gather information on the patient's goals, preferences, needs, situation, adherence, and health behaviors. A concise summary is then made available for patients to share with their providers. Col et al. compared the effects of MS-SUPPORT to usual care on DMT decisions, the SDM process, and quality of life in a multisite randomized controlled trial [33]. More than 80% of participants randomized to MS-SUPPORT reported that they would recommend it to others and that it helped them talk to their doctor and understand their options and the importance of taking the DMT as prescribed. Kremer et al. developed a prototype for a decision aid for pwMS to reduce the cognitive burden of considering treatment options [34]. The decision aid collects demographic and clinical data and asks pwMS to attach weights to characteristics such as reducing relapses, reducing progression, or safety that are most important to them. The decision aid then ranks treatment options according to patient preferences. Testing of the decision aid has not yet been completed. Future development and assessment of decision aids are important areas of investigation to aid in SDM for pwMS.

This study has several limitations. First, it was conducted at an MS specialty center with clinicians who focus primarily on the treatment of individuals with MS and may not be generalizable to other healthcare settings. Additional studies that include pwMS from different centers or regions are needed to improve the applicability of the findings. Second, the response rate was low which may indicate a response bias. It is possible that individuals who were happier with the treatment decision-making process were more likely to complete and return the questionnaire. This would mean that the missing data were not random. Third, the pwMS who participated in the study had a relatively mild disease course, and the findings may not reflect the larger population of MS patients with higher levels of disability.

In summary, pwMS treated at a specialty MS center reported high levels of SDM and satisfaction with the treatment decision-making process. Despite these findings, about 65% of pwMS were interested in receiving additional information about treatments. Additional research is needed to better understand the impact of SDM on behavioral and health measures in pwMS and to assess the role of decision aids in supporting and enabling pwMS to participate more fully in the SDM process.

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