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Selection of Disease Modifying Treatment (DMT) Relates to Patient's Decision-Making Competence in MS

Hoffmann JA*[1], Dettmers C[2], Hedwig A[3], Jöbges M[2]

[1]Department of Psychology, University of Bath, Bath, Somerset, United Kingdom
[2] Kliniken Schmieder Konstanz, Konstanz, Germany
[3]University of Konstanz, Konstanz, Germany

***Corresponding author:** Hoffmann JA, Department of Psychology, University of Bath, 10W Claverton Campus, BA27AY, Bath, United Kingdom. Tel: +441225383367, Email: j.a.hoffmann@bath.ac.uk

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Abstract

Background: In Multiple Sclerosis, more efficient disease modifying treatment (DMT) are often accompanied by higher risks and side effects. Selecting the optimal DMT demands from patients and doctors therefore a complex decision-making process weighing risks and benefits. Patients and doctors often prefer to share responsibility when making these treatment decisions, but this shared decision-making model requests decision-making competence on both sides. The aim of our online study was to investigate whether patients' decision-making competence relates to DMT selection.

Method: 197 patients participated in the online survey, advertised by two patient organizations. Patients reported their DMT and who decided for or against a DMT: their neurologist, themselves, or both. We measured decision-making competence with two tasks from the Adult Decision-Making Competence Battery (A-DMC), the ability to follow decision rules and the consistency of risk perception. Perceived impairment of the disease was measured with Patient Determined Disease Steps (PDDS).

Results: The ability to follow decision rules varied with the potency of the DMT. Patients receiving basic DMT were better able to follow decision rules compared to patients receiving medium DMT. Patients who did not take any DMT stated more frequently that this decision was their own choice and independent of their doctor's advice.

Conclusions: If patients without DMT decided against this treatment on their own behalf, doctors and caregivers potentially have to strengthen their effort to reach out to the patient and to ensure the decision is well taken.

Keywords: Decision-Making Competence, Shared Decision Making, Disease Modifying Treatment, Immunomodulation, Multiple Sclerosis

List of Abbreviations

ADMC - Adult Decision-Making Competence Battery

AMSEL - Aktion Multiple Sklerose Erkrankter, Landesverband der DMSG in Baden-Württemberg e.V. (Action of Multiple Sclerosis Diseased, county organization of the DMSG in Baden-Württemberg)

ANOVA - Analysis of Variance

DMSG - Deutsche Multiple Sklerose Gesellschaft (the German Multiple Sclerosis Society)

DMT - Disease Modifying Treatment

MS - Multiple Sclerosis

GRiPS - General Risk Propensity Scale

PDDS - Patient Determined Disease Steps

Introduction

Selecting the best disease modifying treatment (DMT) in Multiple Sclerosis (MS) patients depends on a careful consideration in each case. To reach a treatment decision in chronic disease, the patient-centered view favors a shared decision-making process that assigns equal responsibilities to doctors and patients [1]. From the medical standpoint, doctors should recommend the most effective DMT based on the predicted course of the disease and current disease activity while considering side effects and comorbidities. From the patient's perspective, side effects might be more relevant, but preferences for DMT can be influenced by disease-irrelevant factors ranging from the mode of administration (injection, tablets) to the time interval (daily, monthly, every 6 month or every 12 month) to options to combine the DMT with family planning. Shared decision-making aims to combine those medical aspects with patients' treatment preferences and personal values [2] and preliminary evidence indicates its effectiveness for long-term decisions [3,4].

Yet, shared decision making necessitates that both doctors and patients possess the capacity to take informed decisions, that is decision making competence [5]. DMT decisions are particularly complex because DMT vary strongly in their benefit-risk profile [6] and more potent DMT are typically associated with higher risks to experience serious side effects [7,8]. Accurately perceiving these risks and appropriately integrating benefits and risks are trademarks of decision-making competence [5], but heavily depend on memory abilities in healthy samples and MS patients [9-11]. Since memory is often affected in MS [12-14], the question arises if MS patients still possess the capacity to make a good DMT choice. Beyond patients' cognitive ability to take informed decisions, patients may also differ in their willingness to take risks. In line with this idea, studies have demonstrated that MS patients have a lower risk tolerance or increased risk aversion compared to healthy control groups [15,16]. Our online survey investigated if DMT choices are linked to MS patients' decision-making competence and risk preferences, in particularly the ability to follow and integrate decision rules and the ability to perceive risk consistently.

Further, if patient and doctor agree jointly upon the DMT decision, one would expect that DMT choice systematically varies with the major determinant of the doctors' recommendation, that is a higher disease activity should be observed for patients taking more potent drugs. We used here a self-reported measure of MS disease severity and impairment, Patient Determined Disease Steps (PDDS) [17]. Finally, we studied if preference for shared decision making is linked to DMT and if this relation can be explained by decision competence.

Materials and Methods

Patients: 197 MS patients (50 men, 146 women, 1 non-binary; M_{Age} - 45.8 years, SD_{Age} - 11.6) completed the online survey between 12.4.2021 and 01.07.2021. The survey was advertised on the homepage of two German professional patient organizations (Deutsche Multiple Sklerose Gesellschaft, the German MS Society, DMSG, and its regional equivalent within the county Baden-Württemberg AMSEL). The survey link was also published on the homepage of Kliniken Schmieder Konstanz. The study was approved by the Ethical Board of the University Konstanz.

Disease Modifying Treatment (DMT): We categorized the DMT into four groups following the German guideline for diagnostics and treatment of Multiple Sclerosis from 2021 [18], no DMT, basic drugs with little efficacy and little risks (interferons, glatiramer acetate, teriflunomide, and dimethyfumarate), medium-potent drugs with medium efficacy and medium risks (fingolimod, cladribine, and ozanimod), and highly potent drugs (alemtuzumab, CD20 antibodies like ocrelizumab and rituximab, and natalizumab). 39 (19.8%) patients did not take any immunomodulatory drug. 77 (39.1%) patients received a basic drug of group 1, 28 (14.2%) a medium-potent drug and 53 (26.9%) a highly-potent drug.

Patient Determined Disease Steps (PDDS): Patients rated their perceived degree of impairment caused by MS [17]. Patient indicated his or her subjective experienced level of impairment on a scale from 0-normal to 8 - bedridden.

Decision Making Competence*:* We measured patients' decision-making competence with two tasks from the Adult Decision-Making Competence battery (A-DMC) [5]. In the Decision Rules (DR) tasks, patients were asked to choose between different fictitious DVD players based on predefined decision rules. The complexity of the decision rules varied between decision rules that required consideration of only one or all presented attributes. The ability to successfully complete the task was determined by the number of correctly selected DVD players. In the consistency of risk perception task, patients were asked to determine the probability of 10 events (e.g., death by terrorist attack) occurring within the next year or the next 5 years. Subsequently, the probability estimates were evaluated using the laws of probability. For instance, patients should judge the likelihood of an event occurring within the next year lower than its likelihood of occurring within the next 5 years.

Risk-Taking: Risk preferences may also influence the choice of immunomodulation. Therefore, patients completed the General Risk Propensity Scale (GRiPS) [19]. They indicated for 8 questions how much they agreed or disagreed with a statement related to personal risk-taking behavior (e.g., "Taking risks is an important part of my life") on a 5-point Likert scale.

Shared Decision Making*:* We assessed the degree to which patients and their neurologists shared the responsibility for taking the DMT. This question asked if the patient took the decision alone, the neurologist took the decision alone, or the decision was made together.

Results

DMT and Decision-Making Skills: Table 1 summarizes how patients in each DMT group perceive their self-reported impairment (PDDS scores), how they vary in decision making competence and risk taking, and how they perceived shared decision making. As expected, PDDS scores systematically varied with the DMT they took, Welsh ANOVA $F(3, 78.9) - 15.0$, $p < .001$, $\omega^2 - .18$. Post-hoc tests revealed that patients receiving basic DMT reported the least impairments compared to patients without DMT, mean difference x - -1.95, 95%-CI - [-2.94; -0.96], patients receiving medium potent DMT, mean difference x - -1.30, 95%-CI - [-2.32; -0.28], or patients receiving highly potent DMT, mean difference x - -1.59, 95%-CI - [-2.43; -0.76]. Interestingly, taking DMT related also to one aspect of decision-making competence, the ability to follow decision rules, $F(3, 193) - 3.556$, $p - .015$, $\eta^2 - .052$. Post hoc tests suggested that patients who took basic DMT followed rules more accurately than patients who took medium potent DMT, mean difference x - .10, 95%-CI - [.01; .19]. However, DMT was not connected to either risk perception, $F(3, 193) - 0.7$, $p - .554$, $\eta^2 - .01$, or risk taking, $F(3, 193) - .4$, $p - .765$, $\eta^2 - .005$. (Figure 1)

	Disease Modifying Treatment			
Variable	None	Basic	Medium	High
N patients (%)	39 (19.8%)	77 (39.1%)	28 (14.2%)	53 (26.9%)
Age	52.5 (13.3)	44.0 (10.4)	48.1 (10.8)	42.3 (10.4)
PDDS	4.5 (2.1)	2.6 (1.4)	3.9 (1.8)	4.2 (2.0)
Decision Rules	.69 (.17)	.74 (.14)	.64 (.16)	.72 (.15)
Risk Perception	.84 (.17)	.82 (.15)	.84 (.11)	.86 (.11)
Risk Taking	2.3 (0.8)	2.2 (0.7)	2.3 (0.6)	2.3 (0.8)
Shared decisions				
Patient alone (%)	31 (79%)	32 (42%)	5 (18%)	23 (43%)
Shared (%)	6 (15%)	42 (55%)	20 (71%)	27 (51%)
Physician alone (%)	2 (5%)	3 (4%)	3 (11%)	3 (06%)

Table 1: PDDS score, decision making competence, and shared decision making varying with disease modifying treatment (standard deviation in brackets)

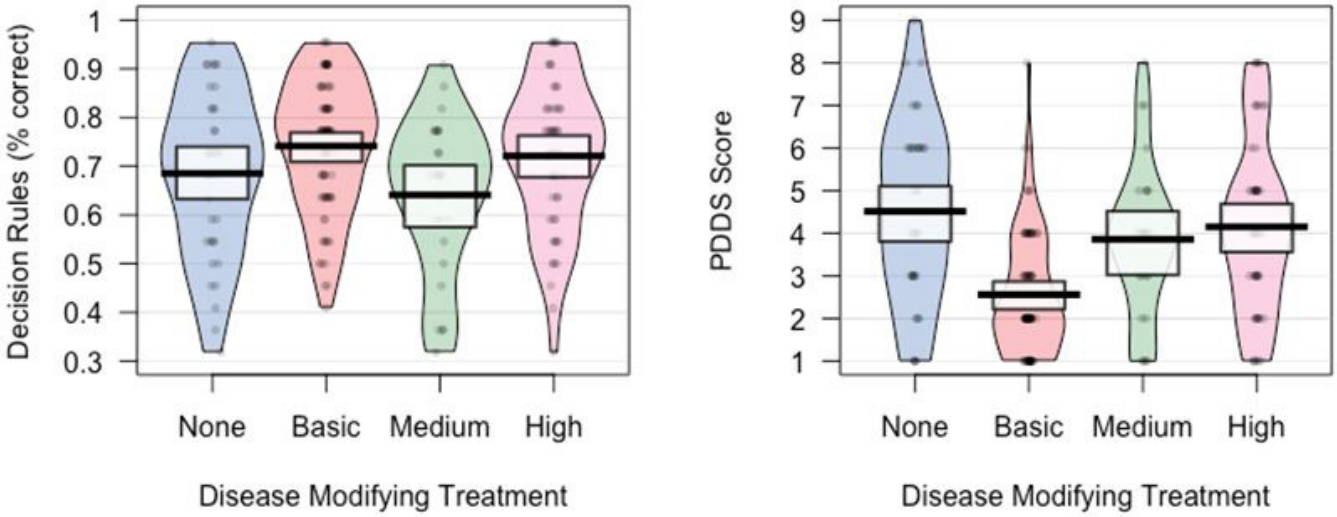

Figure 1: Decision Making Competence and PDDS as a function of Disease Modifying Treatment

DMT and Shared Decision-Making Preferences: Descriptively, most patients stated that they shared the treatment decision with the doctor or took the decision on their own and only a few patients stated that the doctor took the decision. Interestingly, patients without DMT stated that they more often took the decision by themselves. To understand this shift in shared decision making, we estimated four ordered logistic regression models that predicted shared decision making with DMT, PDDS, and the ability to follow decision rules (Table 2). Model comparison via AIC identifies a model with DMT only as predictor as the best model suggesting that patients who receive DMT more often perceive the decision for DMT as a joint decision between neurologist and patient, particularly patients with medium DMT. Perceived disease severity or a lower competence to follow decision rules does not alter preferences for shared decision making.

	Model			
Parameter	Baseline	DMT only	Covariates	DMT + Covariates
DMT: None vs. Basic	—	1.6 (0.5)	—	1.5 (0.5)
DMT: None vs. Medium	—	2.7 (0.6)	—	2.6 (0.6)
DMT: None vs. High	—	1.6 (0.5)	—	1.6 (0.5)
PDDS	—	—	-.26 (0.1)	-.16 (0.2)
Decision Rules	—	—	-.07 (0.1)	-0.0 (0.2)
Intercept: Patient | Shared	-0.2 (0.1)	1.3 (0.4)	-0.2 (0.1)	1.2 (0.4)
Intercept: Shared | Doctor	2.8 (0.3)	4.5 (0.5)	2.8 (0.3)	4.5 (0.5)
Deviance	343	316	339	315
AIC	347	327	347	329

Table 2: Ordered logistic regression models of DMT, PDDS score, and decision-making competence on shared decision making (standard errors in brackets)

Discussion

Involving patients actively in treatment choices has become more popular in the past decades and thus debates about the effectiveness of shared decision making have gained momentum [3,4,20]. In chronic diseases, such as MS, shared decision making may prove particularly advantageous because if patients have thoroughly considered and accepted risks and benefits of a medication, they may comply more with the selected treatment option [20]. In our study, the majority of patients actively participated in the medical decision-making process. Only 5.6% of patients reported that their treating neurologist took the treatment decision alone compared to 48.2% of patients who shared the decision with their neurologist and 46.2% who took the decision alone.
Interestingly, patients without DMT reported more frequently to have taken the decision alone. Possibly, neurologists initially promoted DMT less to this patient group and therefore patients opted more often against this treatment. For instance, patients without DMT were on average older than patients receiving DMT. Knowing that DMT are less effective in older age groups [21], physicians may have considered these treatment options less. However, our data does not allow any inference about the advice of the treating neurologist.

Risk avoidance does not seem to play a major role in selection of DMT as neither risk perception nor risk preferences varied with DMT treatment. However, the application of decision rules differed between DMT groups. Patients taking medium-potent DMT struggled the most to follow predefined decision rules. Those patients also often decided jointly with their neurologist about the DMT. These findings suggest that shared decision making and decision aids may prove particularly useful in supporting patients with lower decision-making competence to take a proactive role in the decision-making process [22].

Unfortunately, we collected only limited information about the course of the disease in this online study. For instance, the online questionnaire did not contain any question about disease course (relapsing remitting or slowly progressive) because many patients are uncertain about the classification of their disease course. As a result, we cannot infer if patients were treated according to national guidelines, especially the ones without DMT.

Patients' well-being should be the number one concern in any medical treatment decision. Knowing the patients' decision competence may aid doctors to engage patients actively in the decision-making process and prevent suboptimal treatment choices. If patients are not treated with DMT, doctors may want to consider whether this decision was based on sufficient medical information and a trustful exchange of opinions and preferences with the treating neurologist or GP.

Conclusion

Patients who decide not to take any disease modifying treatment in Multiple Sclerosis state that they rely on their own judgment and less on clinical advice. This indicates that the therapeutic alliance between doctor should be intensified when communicating information about DMT to patients.

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