

# Why Do Some Patients With Schizophrenia Want to Be Engaged in Medical Decision Making and Others Do Not?

Johannes Hamann, MD; Rosmarie Mendel, PhD; Sarah Reiter, MD; Rudolf Cohen, PhD; Markus Bühner, PhD; Matthias Schebitz, MD; Stefan Diplich, MD; Werner Kissling, MD; and Achim Berthele, MD

## ABSTRACT

**Objective:** Treatment guidelines for schizophrenia recommend that medical decisions should be shared between patients with schizophrenia and their physicians. Our goal was to determine why some patients want to participate in medical decision making and others do not.

**Method:** To identify determinants of participation preferences in schizophrenia patients (ICD-10 criteria) and in a nonpsychiatric comparison group (multiple sclerosis), we undertook a cross-sectional survey in 4 psychiatric and neurologic hospitals in Germany. Inpatients suffering from schizophrenia or multiple sclerosis (but not both) were consecutively recruited (2007–2008), and 203 patients participated in the study (101 with schizophrenia and 102 with multiple sclerosis). Predictors for patients' participation preferences were identified using a structural equation model.

**Results:** Patients' reports about their participation preferences in medical decisions can be predicted to a considerable extent (52% of the variance). For patients with schizophrenia, poor treatment satisfaction ( $P < .001$ ), negative attitudes toward medication ( $P < .05$ ), better perceived decision making skills ( $P < .001$ ), and higher education ( $P < .01$ ) were related to higher participation preferences. In the comparison group, drug attitudes ( $P < .05$ ) and education ( $P < .05$ ) were also shown to be related with participation preferences.

**Conclusions:** Patients with schizophrenia who want to participate in decision making are often dissatisfied with care or are skeptical toward medication. Patients who judge their decisional capacity as poor or who are poorly educated prefer not to participate in decision making. Future implementation strategies for shared decision making must address how dissatisfied patients can be included in decision making and how patients who currently do not want to share decisions can be enabled, empowered, and motivated for shared decision making.

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Corresponding author: Johannes Hamann, MD, Klinik und Poliklinik für Psychiatrie und Psychotherapie, Technische Universität München, München, Germany  
(j.hamann@lrz.tum.de).

An engagement of patients with schizophrenia into medical decision making (shared decision making) is now considered standard of care by medical literature and treatment guidelines.<sup>1,2</sup> It is argued that all patients have a right to self-determination,<sup>3</sup> an argument that gains even more importance for schizophrenia patients that have experienced some form of coercion.<sup>4</sup> In addition, an increased participation of patients with schizophrenia may improve treatment adherence and long-term outcomes.<sup>5</sup>

However, before shared decision making can be implemented in schizophrenia treatment, it is necessary to know why some patients want to participate in medical decision making while others don't; otherwise, it will not be possible to target different shared decision-making approaches (eg, decision aids, communication training for physicians) to patients' participation needs and also to the patients' competencies in decision making.

While research from somatic medicine has identified several determinants for participation preferences, including sociodemographic variables (age, gender, education),<sup>6</sup> trust in the physician,<sup>7</sup> drug attitudes,<sup>8</sup> or locus of control,<sup>9,10</sup> it remains unclear whether these predictors are transferable to patients with schizophrenia or whether the situation for schizophrenia is distinctly different from other illnesses (eg, due to lack of insight, possibility of coercive treatment, disturbances of thought).

It was thus the aim of the present study to undertake a comprehensive analysis of potential determinants of participation preferences in patients with schizophrenia. In order to test whether patients with schizophrenia behave uniquely with regard to participation preferences, we additionally included a comparison group of patients with a nonpsychiatric illness.

## METHOD

### Participants

Our cross-sectional study addressed the participation preferences of patients suffering from schizophrenia or schizoaffective disorder. To gain more insight into whether the patterns studied for schizophrenia patients are unique for this patient group, we added a comparison group with many analogous parameters (eg, sociodemography, onset and chronicity of illness).

We chose multiple sclerosis as a comparison group because both disorders are severe and chronic disorders, are characterized by many largely unpredictable phases of exacerbations and remissions, exhibit an early in life onset, have similar lifelong risks for serious relapses, and, in particular, require long-term pharmacotherapy (antipsychotics, immune modulation) associated with potentially severe side effects.

Compared to schizophrenia patients,<sup>11</sup> multiple sclerosis patients are generally considered competent partners in shared decision making, with no or only little doubt about their decision-making capacity.<sup>12</sup>

All patients had to fulfill ICD-10 diagnostic criteria either for schizophrenia/schizoaffective disorder or for multiple sclerosis according to their clinical files; they had to be aged between 18 and 65 years and had to speak German fluently. Patients were inpatients of the selected clinics and were

recruited (2007–2008) in the week before discharge from their hospital stay. Two investigators were in regular contact with the psychiatrists/neurologists from 2 psychiatric and 2 neurologic hospitals, comprising several wards, to identify patients suitable for the study. Such candidates were then approached by the investigators and asked to participate.

After written informed consent was obtained, the patients, and afterward their physicians in charge, were individually contacted for the study by one of the two investigators. During the survey, questionnaires were handed out one by one by the investigators who also assisted patients if they had difficulties understanding any of the items. Investigators were also instructed to pause for some minutes when patients showed any sign of tiredness or lack of motivation.

The study was approved by the institutional review board (Ethics Committee) of the Technical University Munich.

### Data Obtained

Patients' age, gender, and years of education were registered. Earlier studies have repeatedly found younger age, female gender, and higher education to be associated with higher participation preferences.<sup>6,13</sup>

### Questionnaires

The 2 instruments used to examine participation preferences are among the most frequently used questionnaires in the context of shared decision making: the Autonomy Preference Index (API) decision making subscale,<sup>14</sup> a 6-item scale addressing the patient's general wish to participate in medical decisions, and the decision-making subscales chest pain and current health of the Problem Solving Decision Making Scale (PSDM), two 2-item scales addressing the patient's wish for participation in two scenarios (chest pain vignette, current health vignette).<sup>15</sup>

Since participation preferences had been found to be particularly high in patients expressing poor satisfaction with their treatment,<sup>5</sup> the Questionnaire on Patients' Treatment Satisfaction (ZUF8), an 8-item questionnaire addressing general satisfaction with hospital care,<sup>16</sup> was added.

Since lower participation preferences were found in patients who express trust in their physicians, we included the Trust in Physician Scale,<sup>17,18</sup> an 11-item questionnaire.

It has been shown that for patients with chronic mental illness and with experiences of clinical coercion, irrespective of the current clinical situation, their judgment of personnel in regards to fairness (eg, procedural fairness) may play a critical role in their acceptance of psychiatric treatment (eg, drug treatment).<sup>4,19</sup> Therefore, 3 subscales from the Questionnaire on Organizational Justice<sup>20,21</sup> (procedural justice, informational justice, interpersonal justice) were included.

The concept of locus of control has been linked with participation preferences,<sup>9,10</sup> but results were inconsistent. We applied the Multidimensional Health Locus of Control Scales.<sup>22,23</sup> This questionnaire consists of four 3-item subscales: self-responsibility, self-blame, chance, and powerful others. According to the concept of health locus of control, patients with low external and high internal locus of control

are assumed to prefer more active problem solution strategies leading to a pronounced wish for participation in medical decisions.<sup>9,24</sup>

Attitudes toward medication have been shown to be related to participation preferences in patients with schizophrenia,<sup>25</sup> with more negative attitudes correlating with more expressed participation preferences. The Beliefs about Medicines Questionnaire<sup>26</sup> contains 4 subscales, each comprising 4–5 items. It distinguishes between beliefs about medication in general and beliefs about the specific medication prescribed.<sup>27</sup> Furthermore, it distinguishes between the perceived need for the medication (necessity) and the perceived potential for the medication to cause problems (concerns).

Patient participation in treatment decisions requires that patients are competent partners in decision making, which implies a certain level of information about the disease. We asked the patients (1) whether they feel well informed about their disease (5-point scale) and (2) what they have done to inform themselves about their illness (5 items, eg, attendance to patient seminars, internet research, and visits to self-help institutions).

Some authors have found participation preferences in the medical context to be relatively stable over time,<sup>14</sup> but there is hardly any information about the link between these preferences and the person's perceived decision-making skills in daily life (decisions other than health care decisions). To gain more insight into this issue, we applied 3 subscales with 6 items each from the Melbourne Decision Making Questionnaire (MDMQ).<sup>28,29</sup> The 3 subscales applied were self-esteem (eg, "I feel confident about my ability to make decisions"), buck passing (eg, "I prefer to leave decisions to others"), and vigilance ("When making decisions, I like to collect lots of information").<sup>28,29</sup>

### Analysis of the Data

It was the aim of the study to perform (1) multivariate analyses separately for the schizophrenia and the multiple sclerosis group, allowing to control for interactions between different variables and (2) a comparison of the findings between the 2 patient groups.

Missing values ( $n=6$ ) were estimated for all items with the expectation-maximization algorithm from SPSS 16 (SPSS Inc, Chicago, Illinois). This procedure provides maximum likelihood estimates for missing data.

Frequencies, means, and standard deviations were calculated to describe the patient groups. The 2 patient groups were compared using *t* tests.

To reduce the number of potential predictors of participation preferences, we entered the sum scores of the questionnaires applied into an explorative principal component analysis (eigenvalue greater than 1 rule). We used the oblique Promax rotation and analyzed the factor structure separately for the 2 patient groups. Promax rotation was chosen because we expected correlated scales. The Kaiser-Meyer-Olkin coefficient was 0.80 for the schizophrenia group and 0.69 for the multiple sclerosis group, which can

**Table 1. Patient Characteristics**

Characteristic	Schizophrenia <sup>a</sup>	Multiple Sclerosis	P Value
No. of patients	101	102	
Female gender, n (%)	54 (54)	67 (66)	.09
Education > 10 years, n (%)	69 (68)	64 (63)	.46
Married, n (%)	9 (9)	42 (41)	<.001
No. of patients employed, n (%)	23 (23)	54 (53)	<.001
Involuntary admission, n (%)	16 (16)	0	<.001
Age, mean (SD), y	36.3 (11.3)	38.5 (8.4)	.11
Illness duration, mean (SD), y	9.8 (9.1)	9.9 (8.5)	.94
No. of hospitalizations, mean (SD)	4.7 (3.3)	5.9 (6.0)	.07
Duration of hospital stay, mean (SD), d	65.0 (46.7)	9.8 (7.2)	<.001
Illness severity, mean (SD)			
CGI score (range of scale, 1–7)	3.5 (1.2)		
EDSS score (range of scale, 0–10)		3.7 (1.6)	

<sup>a</sup>Schizophrenia (n = 83), schizoaffective disorder (n = 18).

Abbreviations: CGI = Clinical Global Impressions scale, EDSS = Expanded Disability Status Scale, NS = not significant.

**Table 2. Participation Preferences in Medical Decision Making by Patient Group**

Diagnostic Group	n	Mean	SD	P Value <sup>a</sup>
PSDM score (chest pain) <sup>b</sup>				
Schizophrenia	101	5.0	1.8	.003
Multiple sclerosis	102	5.8	1.8	
PSDM score (current health) <sup>b</sup>				
Schizophrenia	101	5.4	1.6	.001
Multiple sclerosis	102	6.1	1.6	
API score <sup>c</sup>				
Schizophrenia	101	16.7	4.4	.002
Multiple sclerosis	102	18.6	4.0	

<sup>a</sup>t Test.

<sup>b</sup>PSDM scores range from 2 (doctor should decide) to 10 (patient should decide).

<sup>c</sup>API scores range from 6 (doctor should decide) to 30 (patient should decide).

Abbreviations: API = Autonomy Preference Index, PSDM = Problem Solving Decision Making Scale.

be regarded as good/modest and indicates that the data are suitable for the analyses.

Since the scales differed considerably in length, we standardized each scale and calculated mean *z* scores of the scales constituting a given factor in each sample. This was necessary because the scales differed in the number of items or number of categories that would have resulted in a biased sum score, with more weight being given to scales with more items. These sum scores of standardized scales, as well as the control variables (age, gender, education, duration of illness), were then entered into a structural equation model. This assures that all scales are used with the same weight in both samples.

To analyze the data, we used the structural equation approach with maximum likelihood estimation (variances and loadings) separately for the 2 patient samples. The model, shown in Figure 1, corresponds to a regression analysis with 11 independent variables (eg, mean standardized *z* scores for each factor derived in the principal component analysis) and 1 dependent variable, the latent variable participation preferences. This latent variable consists of 3 indicators (API and the 2 PSDM subscales) and corresponds to the common variance of these indicators.

To test differences in regression weights between the 2 groups for significance, we did an additional multigroup analysis: the loadings for variables of interest were set equal in both groups and the restricted model was compared with the unrestricted model. If this comparison was significant ( $P < .05$ ), then the loadings were significantly different.

Data analysis was undertaken using SPSS 16 and modeling was carried out using the AMOS 16.0 (SPSS Inc, Chicago, Illinois) structural equation modeling software.

## RESULTS

Of the 242 consecutively recruited patients who fulfilled our inclusion criteria, 39 (37 with schizophrenia and 2 with multiple sclerosis) refused to participate, resulting in 203 patients who participated in the study: 101 patients with the diagnosis of schizophrenia/schizoaffective disorder and 102 patients with multiple sclerosis. Patients in the 2 groups were largely comparable with respect to age, gender, duration of illness, and hospitalizations. However, patients with schizophrenia were less often married and less often employed and they had more involuntary admissions and a longer duration of hospital stay than patients with multiple sclerosis (Table 1). At the time of the study, the severity of illness in both groups was considered by their physicians as mild to moderate (schizophrenia: Clinical Global Impression Scale; multiple sclerosis: Expanded Disability Status Scale).

Patients' participation preferences scores on the 3 measures selected (API, PSDM chest pain, PSDM current health) showed small but statistically significant differences between the groups: patients with schizophrenia indicated lower participation preferences than patients with multiple sclerosis (Table 2).

In both groups, principal component analyses allowed extraction of 6 factors with eigenvalues greater than 1 from the set of questionnaires, which explained 72% of the variance in the schizophrenia and 67% of the variance in the multiple sclerosis group (Table 3): Factor 1 (satisfaction) covers the scales on satisfaction with care (ZUF8), on trust in physician (Trust in Physician Scale), and on fairness (Questionnaire on Organizational Justice subscales informational justice, procedural justice, interpersonal justice). Factor 2 (drug concerns) covers the 3 subscales from the Beliefs about Medicines Questionnaire related to concerns about medication (specific concerns, general overuse, and general harm). Factor 3 (decision-making skills) covers the 3 subscales from the Melbourne Decision Making Questionnaire (vigilance, buck passing, self-esteem). Factor 4 (internal control) covers the self-responsibility and the self-blame subscales of the Multidimensional Health Locus of Control scale. Factor 5 (information status) covers the patients' felt expertise about their disorder and their knowledge about treatment options as well as their attempts to increase their level of knowledge. Factor 6 (external

Table 3. Explorative Principal Component Analysis to Reduce the Number of Potential Predictors of Participation Preferences<sup>a</sup>

Scale	Multiple Sclerosis Group						Schizophrenia Group					
	Factor 1, Satisfaction	Factor 2, Drug Concerns	Factor 3, Decision-Making Skills	Factor 4, Internal Control	Factor 5, Information Status	Factor 6, External Control	Factor 1, Satisfaction	Factor 2, Drug Concerns	Factor 3, Decision-Making Skills	Factor 4, Internal Control	Factor 5, Information Status	Factor 6, External Control
Patient Satisfaction Questionnaire	<b>0.77</b>						<b>0.70</b>					
Questionnaire on Organizational Justice							<b>0.85</b>					
Procedural justice	<b>0.74</b>						<b>0.73</b>					
Interpersonal justice	<b>0.81</b>						<b>0.87</b>					
Informational justice	<b>0.71</b>						<b>0.82</b>					
Trust in Physician Scale	<b>0.65</b>						-0.41					
BMQ												
Specific concerns		<b>0.81</b>										
General overuse		<b>0.73</b>										
General harm		<b>0.79</b>										
MDMQ												
Self-esteem			<b>0.91</b>									
Vigilance			<b>0.57</b>									
Buck passing			<b>-0.86</b>									
Subjective expertise										<b>0.70</b>		
Expertise										<b>0.84</b>		
MHLC												
Self-responsibility									<b>0.83</b>			
Self-blame									<b>0.81</b>			
Powerful others										<b>0.31</b>		
Chance											<b>0.72</b>	
BMQ specific necessity											<b>0.61</b>	
% Variance explained (unrotated solution)	23	13	10	7	8	7	32	12	9	7	6	6
% Variance explained (rotated solution)	23	13	10	7	8	7	32	12	9	7	6	6

<sup>a</sup>Sum scores of questionnaires added to a factor for the later analyses are displayed in bold. Factor loading (absolute values) below 0.3 are not shown.

Abbreviations: BMQ = Beliefs about Medicines Questionnaire, MDMQ = Melbourne Decision Making Questionnaire, MHLC = Multidimensional Health Locus of Control.

control) covers the powerful others and chance subscales of the Multidimensional Health Locus of Control Scale.

The factor loadings (standardized regression weights  $a$ ) of the questionnaire measures were quite similar in the 2 groups, except for the Beliefs about Medicines Questionnaire subscale specific necessity, which loaded highly negative on drug concerns ( $a = -0.45$ ) in the schizophrenia group but on external control in the multiple sclerosis group ( $a = -0.65$ ). Accordingly, we took this score as a separate variable in the further analyses (Table 3).

Separately for the 2 groups, the standardized mean sum scores of all measures loading on the 6 factors extracted, the score on necessity of medication, and the epidemiologic variables age, gender, education, and duration of illness were finally entered into the structural equation model to predict the postulated latent variable participation preference, defined by the 3 scores API, PSDM chest pain, and PSDM current health.

As expected, there were significant intercorrelations ( $0.19 \leq r \leq 0.66$ ) among our measures for participation preferences and among the potential predictors for participation preferences (Table 4).

Figure 1 shows the (partially latent) regression models. In both groups, the model explained 52% of the variance but the weights of the various predictors differed to a certain degree between the groups. In the schizophrenia group, higher education, more negative drug attitudes, poorer satisfaction, and better decision-making skills predicted higher participation preferences.

In the multiple sclerosis group, higher education and more negative drug attitudes also predicted higher participation preferences. However, in contrast to the patients with schizophrenia, multiple sclerosis patients' satisfaction with treatment and their decision-making skills did not predict higher participation preferences, while lower external control attribution (ie, attributing less power to their physician to determine the further course of illness) and lower perceived necessity of the medication clearly did.

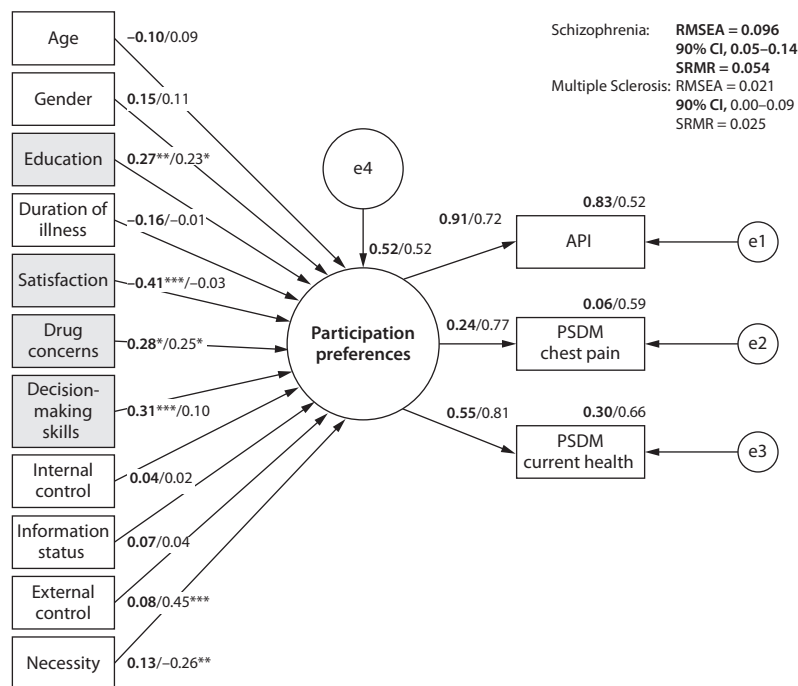
Multigroup comparisons revealed that the 2 groups differed with regard

**Table 4. Intercorrelations Between the Independent Variables Used to Predict Patients' Participation Preferences (*r*)<sup>a</sup>**

	Age	Gender	Education	Duration of Illness	Satisfaction	Drug Concerns	Decision-Making Skills	Internal Control	Information Status	External Control	Necessity
Age		-0.04	-0.03	0.58**	0.20*	-0.02	0.06	-0.13	0.08	0.04	0.07
Gender	0.25*			-0.04	0.00	0.04	-0.08	0.04	-0.08	0.03	0.14
Education	0.00	0.13		0.12	0.15	-0.09	0.06	-0.02	0.07	0.23*	-0.22*
Duration of illness	0.56**	0.05	0.01		0.12	-0.02	0.00	-0.16	0.23*	0.18	0.08
Satisfaction	0.12	-0.04	0.07	0.16		-0.43**	0.10	0.02	0.31**	0.03	0.23*
Drug concerns	-0.08	0.18	-0.14	-0.23	-0.59**		-0.12	-0.15	-0.34**	-0.18	-0.19
Decision-making skills	0.13	-0.02	0.11	0.04	0.15	-0.21*		-0.02	0.12	0.25*	-0.11
Internal control	0.16	0.05	-0.04	0.20	0.23*	-0.34**	0.06		0.04	0.24*	0.16
Information status	-0.14	-0.05	0.06	0.13	0.26**	-0.30**	0.19	0.14		0.16	0.06
External control	0.15	-0.05	0.24*	-0.07	-0.09	-0.01	0.10	0.01	0.03		-0.18
Necessity	0.19	0.06	0.02	0.27**	0.56**	-0.54**	0.06	0.24*	0.32**	-0.16	

<sup>a</sup>Data in the upper half of table body (gray shaded area) are from the multiple sclerosis group; data in lower half of table body (unshaded area) are from the schizophrenia group.

\**P* < .05. \*\**P* < .01.

**Figure 1. Analysis of the Data Using Structural Equation Approach With Maximum Likelihood Estimation (variances and loadings)<sup>a,b</sup>**

<sup>a</sup>Data for the schizophrenia group are displayed in bold, data for the multiple sclerosis group in nonbold. Gray shaded boxes indicate significant predictor in the schizophrenia sample. For reasons of clarity, we omitted the correlations between the predictors, although, in the analysis, these correlations were specified. The table of correlations is presented in Table 4.

<sup>b</sup>The model displayed in the figure corresponds to a regression analysis with 11 independent variables on the left side (age, gender, education, duration of illness, and the standardized *z* scores for each of the factors derived in the principal component analysis) and 1 dependent variable (in the center), the latent variable participation preferences. This latent variable consists of 3 indicators, shown on the right side (Autonomy Preference Index [API] and the 2 Problem Solving Decision Making [PSDM] subscales) and corresponds to the common variance of these indicators. On the left side, the standardized regression weights ( $\beta$ ) of the predictors of the latent variable are displayed, and, on the right side, regression weights ( $\beta$ ) of the scales on the latent variable participation preferences are shown. The latter ones indicate how well the latent variable is able to explain differences in the participation preference scales. The model was calculated separately for the 2 patient groups.

\**P* < .05. \*\**P* < .01. \*\*\**P* < .001.

Abbreviations: e1 = error 1, e2 = error 2, e3 = error 3, e4 = error 4, RMSEA = root square error of approximation, SRMR = standardized root mean square residual.

to the following predictors: satisfaction ( $\chi^2_1 = 7.16$ , *P* < .01), external control ( $\chi^2_1 = 4.36$ , *P* < .05), necessity ( $\chi^2_1 = 5.88$ , *P* < .05), and, to some extent, patients' perceived general decision-making skills ( $\chi^2_1 = 3.63$ , *P* = .057). There was no significant difference (*P* > .05) with regard to education ( $\chi^2 = 0.22$ ) and negative drug attitudes ( $\chi^2 = 0.23$ ).

## DISCUSSION

Patients with schizophrenia exhibited lower participation preferences than patients with multiple sclerosis. In both groups, participation preferences could be predicted to a large extent by several factors.

Patients with schizophrenia had higher participation preferences when they had negative attitudes toward drug treatment which, however, was also an important reason for patients in the comparison group. Other determinants for higher participation preferences in the schizophrenia group were higher level of education, better perceived decision-making skills, and poorer treatment satisfaction.

### What Determines Participation Preferences of Patients With Schizophrenia?

There was a clear association between drug concerns and participation preferences. Schizophrenia patients with negative experiences or expectancies with respect to their pharmacologic treatment want to have a greater say in medical decisions than patients who have more positive attitudes toward medication. Higher participation preferences also corresponded with poor satisfaction with different aspects of care, including general treatment satisfaction, trust in physician, and fairness (eg, interpersonal, procedural fairness). Thus, the wish to participate in medical decisions implies that there is some disagreement between patients and psychiatrists with respect to drug issues or satisfaction of care. In turn, patients who are convinced that they are in need of their medication and who express high satisfaction with care do see less necessity to participate in medical decisions.

A different aspect of participation preferences relates to the patients' education and perceived decision-making skills. Patients with poorer education prefer a more passive role in the medical encounter. Here, the patients' ability to access and understand medical information might affect their participation preferences.<sup>30</sup> The same might be true for perceived decision-making skills. Accordingly, mistrust in one's capacities (eg, due to disturbances of thought) may reduce the motivation to negotiate one's treatment with the psychiatrist.

### How Do Patients With Schizophrenia Compare to Patients With Multiple Sclerosis?

There were some similarities between the 2 distinctly different patient groups. Thus, the association of participation preferences with drug concerns and education was present in both groups, suggesting that this finding might be generalizable to other patient groups.

However, patients with schizophrenia also showed clear differences compared to the multiple sclerosis group with regard to the extent and the determinants of participation preferences. Earlier research has already shown that multiple sclerosis patients are more interested in participation than many other patient groups, a finding that is now replicated by our results.<sup>13</sup>

The relationship between poor satisfaction and higher participation preferences was present only in the schizophrenia group, probably because schizophrenia patients often do not have the chance to leave the hospital or change their doctor when they are dissatisfied. While dissatisfied multiple sclerosis patients might change their doctor, schizophrenia patients might try to gain more power over their treatment

process.<sup>11</sup> Moreover, many patients with schizophrenia have experienced their doctors using persuasion or even coercion. In such a relationship, issues like personal trust and confidence in the fairness of the other are of great importance,<sup>19</sup> and thus, trust and confidence are also related to participation preferences.<sup>25</sup>

Additionally, during acute stages of schizophrenia, most patients experience phases of impaired decisional capacity,<sup>31</sup> and, even in the more chronic phases, many patients might be limited in their cognitive capacities. This could lead to severely impaired self-esteem with regard to decision making. In fact, psychiatrists see impaired decisional capacity as the major obstacle to patient participation.<sup>32,33</sup>

Our findings also show that the patients themselves refrain from participating in decision making when they are unsure about their decision-making abilities. Looking at the results, we find this pattern is of greater impact in the schizophrenia group than in multiple sclerosis group because most multiple sclerosis patients are spared cognitive decline, whereas thought disorders are a common symptom of schizophrenia.

Finally, 2 predictors for higher participation preferences were found only in the multiple sclerosis group: the perceived necessity of medication and external control attributions.

The association of lower perceived necessity of medication with increased participation preferences might largely correspond to the association between participation preferences and drug concerns in the patients with schizophrenia. It might not have shown as a predictor in the schizophrenia group because of the high intercorrelation with negative drug attitudes (which was not present in the multiple sclerosis group).

External control attribution has been shown to influence participation preferences<sup>9,10</sup> but this correlation was present only in the multiple sclerosis group. Perhaps patients with multiple sclerosis are more aware of the highly unpredictable course of their illness than patients with schizophrenia. The acceptance of this unpredictability may have led some multiple sclerosis patients to assume more control over their treatment rather than pin their hopes on the physicians.

### What Do These Findings Mean for the Implementation of Shared Decision Making in Schizophrenia Treatment?

A better understanding of what influences patients' participation preferences is an essential premise for a successful implementation of shared decision making in schizophrenia treatment.

Drug concerns play a central role in both patient groups and possibly in many other chronic illnesses as well. Thus, psychiatrists may have to "accept that the patient has the right to decide not to take a medicine, even if [the physician does] not agree with the decision, as long as the patient has the capacity to make an informed decision and has been provided with the information needed to make such a decision."<sup>34(p4)</sup>

However, psychiatrists should emphasize an elaborate education about therapeutic options and the pros and

cons related with each option. In some cases, the offer of more than 1 treatment option (“equipose”)<sup>35</sup> might reduce patients’ reactance and lead to the acceptance of standard medical treatment.

Beyond drug concerns, patients with schizophrenia express high participation preferences if they are dissatisfied with their psychiatrists or their medical treatment. This pattern is in accordance with the findings from Kraetschmer et al<sup>7</sup> and suggests that physicians might have an additional eye on interpersonal or procedural aspects in order to meet their patients’ needs. For some patients, engaging them into the decision process might be sufficient to improve their perceptions of the interpersonal and procedural fairness.

Regarding those patients who have little interest in engaging in decision making, doctors should be aware that decisions made without these patients may not meet the individual patient’s specific needs and thus lead to poor adherence.

Doctors should therefore check whether such a lack of interest in shared decision making might be a result of poor education or low perceived decision-making skills. In these cases, it might well be possible to engage patients in decisions by allowing them to prepare well for the decision to be made. Decision aids and other interventions that aim at increasing patients’ participation have been found feasible and useful to empower patients to define and express their preferences.<sup>36,37</sup>

In addition, more efforts should be undertaken to motivate patients to engage in the decision process, even if patients believe that it should be the doctors who best make decisions. Here, patients should be informed that they might profit from a deeper engagement with respect to their health outcomes.<sup>38,39</sup>

Finally, psychiatrists might also keep in mind that markedly high participation preferences may have a kind of “signaling function” in some patients, indicating that these patients may be dissatisfied or prone to nonadherence.

### Limitations

Our study was confined to patients’ self-reported preferences. It is well established that attitudes do not immediately relate to behavior. Thus, for example, a patient who expresses high participation preferences in the questionnaire might behave passively during a consultation because his doctor behaves very authoritatively.

The cross-sectional and correlational design limits our ability to draw causal inferences, and the generalizability of our findings is limited to the two conditions studied. The focus on inpatients makes it difficult to generalize our results to outpatients. We, however, believe the issue of patient autonomy to be of exceptional importance for inpatients because inpatient treatment is associated with more powerful doctors (involuntary admission, no possibility to change the doctor, etc) than outpatient treatment. In addition, experiences patients make during inpatient treatment might have consequences for their behavior after discharge (eg, adherence). Finally, a selection bias might be present

since a considerable proportion of schizophrenia patients declined to participate in the study.

### CONCLUSION

Up-to-date patients with schizophrenia who want to participate in decision making are often dissatisfied with care or are skeptical toward medication. Patients who judge their decisional capacity as poor or who have poor education prefer not to participate in decision making.

Future implementation strategies for shared decision making must respect that patients’ reasons to participate in decision making may differ widely. It should be clarified how dissatisfied patients can be included in decision making and how patients who currently do not feel capable to share decisions can be enabled, empowered, and motivated for shared decision making.

**Author affiliations:** Departments of Psychiatry and Psychotherapy (Drs Hamann, Mendel, Reiter, Cohen, Schebitz, and Kissling) and Neurology (Dr Berthele), Technical University Munich, Munich; and Marianne-Strauss-Clinic, Berg (Dr Diplich), Germany; and Department of Psychology, University of Graz, Austria (Dr Bühner).

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