

## Subjective Illness Theory and Antipsychotic Medication Compliance by Patients with Schizophrenia

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This study investigates subjective illness theories of patients with schizophrenia, *i.e.*, how they define their health problem, what they assume causes their illness and which course of illness they expect. The predictive value of those theories for patients' compliance with antipsychotic medication is tested. A problem-centered interview was conducted with 77 schizophrenic patients at discharge from inpatient or day hospital treatment. All patients were on clozapine treatment. Interviews were analyzed by means of computer-assisted content analysis. In addition, potential determinants of compliance were assessed using the 9th version of the Present State Examination, the UKU side effect rating scale, a checklist for patients' evaluations of the effect of psychotropic drugs, and a helping alliance scale. Compliance with medication was assessed by interviewing patients at discharge and three months later. Only slightly more than one half of the patients considered themselves mentally ill. They tended to endorse psychosocial causes more frequently as compared with biological causes. Slightly more than 25% of the patients each expected an improvement of the illness, a reoccurrence of the acute psychosis, or a chronic course. Whereas the quality of the helping alliance, delusion of grandiosity, and attitude toward psychotropic drugs proved to have an influence on patients' compliance with antipsychotic treatment, the three components of subjective illness theory (definition as mental illness, assumed etiology, and prognosis) did not have a statistically significant influence. Subjective illness theories vary in patients with schizophrenia. Although they might reflect different styles of coping with the illness, there is no evidence that they directly determine compliance with medication. Patients' views of the helping alliance and attitudes toward drugs should be considered in predicting compliance with antipsychotic medication.

—*J Nerv Ment Dis* 190:597–603, 2002

According to Groeben and Scheele (1982), subjective theories are to be understood as a “cognitive aggregate of the view of the self and of the world, which allows (at the very least) a partial explication, or rather, a reconstruction parallel to structures of scientific theories.” Subjective theories contribute to the definition of situations and impart orientational assurance (Laucken, 1974). They allow an additional explication of events that arise, partially with justificational characteristics (Wahl, 1979) as well as the prediction of future incidents, and contribute to stability, or rather, an optimum sense of self-worth. Subjective theories of illness deal with the search

for an explanation of the illness through the eyes of the sufferer. They deal with the questions of whether the sufferers actually view themselves as ill, how they describe their situation, which ideas they have of the origin and ensuing course of their illness, and which measures appear to them to be appropriate in order to improve their condition (Greenfeld et al., 1989). Subjective illness theories are to be considered against a backdrop of predominantly culturally formed models of interpretation that are dominant in a society (Moscovici, 1984). It is not a matter of whether the perceptions of the sufferer are “right” or “wrong”; rather, it is a question of exploring the coping methods of the sufferer.

Although the expression “subjective illness theory” originates in medical psychology, the term “insight into illness” comes from psychiatry. In the literature, this term has many varying definitions. Perhaps the simplest definition is the recognition that one has an illness or the awareness of symptoms (Bartko et al., 1988; Dittmann and Schuttler,

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1990; Hankoff et al., 1960; Heinrichs et al., 1985; McEvoy et al., 1981; Van Putten et al., 1976). Other authors have interpreted insight to be an understanding of the need for treatment (Amador et al., 1993; David et al., 1992; McEvoy et al., 1989a; Van Putten et al., 1976). A third approach to the definition of insight is to assess patients' explanations of their illnesses (Greenfeld et al., 1989; Linn, 1965; Townsend, 1975). A comprehensive definition has been proposed by Amador et al. (1993), who describe insight as a complex phenomenon with many components such as global awareness of mental disorder, awareness of effects of medications, and awareness of social consequences of mental disorder. Insight is a dynamic process and changes over time (Markova and Berrios, 1992). There is a clear distinction between the terms "insight" and "illness theory," with the difference being that insight is more heavily oriented around the medical disease model, and the patient's depiction is assessed against the backdrop of the current opinion of psychiatric experts.

Studies already exist regarding the connection between insight of schizophrenic sufferers and their compliance with neuroleptic therapy (Bartko et al., 1988; Kasper et al., 1997; Lin et al., 1979; McEvoy et al., 1989b; Smith et al., 1997). Although some studies have failed to find any relationship between insight and compliance (Garavan et al., 1998; Van Putten et al., 1976), the majority of studies indicate that higher levels of awareness of having an illness and of benefiting from treatment bode well for positive clinical outcome and compliance with treatment (Bartko et al., 1988; Lin et al., 1979; McEvoy et al., 1989b). However, we are unaware of any previous studies investigating the connection between subjective illness theory and compliance. Here, we report the results of an explorative study, which dealt with the following questions:

1. How do schizophrenic patients' subjective illness theories take shape at discharge from the hospital? Or, more precisely, how large is the proportion of patients who describe themselves as being mentally ill? Which conceptions do they have of the causes of their illness? How do they imagine the future course of their illness?
2. Do subjective illness theories in combination with other variables predict compliance during hospital treatment and three months after discharge?

Whereas the first question is purely explorative, we formulated the following hypotheses regarding the second question:

1. Patients who describe themselves as mentally ill display greater compliance with antipsychotic treatment, compared with those who do not describe themselves as mentally ill.
2. Patients who attribute their illness to biological factors display greater compliance with antipsychotic treatment than those who explain their illness by psychosocial factors.
3. Patients who expect a chronic course of illness are less compliant than those who expect an improvement or fear relapse.

### Methods

This study was carried out simultaneously at the Department of Psychiatry at the University of Göttingen and the Lower-Saxon Regional Psychiatric Hospital in Göttingen, at the Psychiatric Hospital "Philippshospital" in Riedstadt, and the Department of Social Psychiatry at the Free University Berlin. The four sites were chosen with the aim of including a wide spectrum of patients with regard to treatment setting (university hospital *vs.* state hospital) and place of residence (urban *vs.* rural). All schizophrenic patients (ICD-10 F20) between 18 and 60 years of age who had been treated with clozapine during their inpatient or day-hospital treatment and were discharged with the recommendation to continue this medication on an outpatient basis were included in the study. Patients were asked to sign a written consent before inclusion in the study. In total, 102 patients consecutively discharged from the four hospitals participated. At discharge from hospital, the "Interview on Subjective Illness Theory," a problem-centered interview (Witzel, 1982; Holzinger et al., 2001b), was carried out with the patients. This form of interview is similar to the focused interview developed by Merton and Kendall (1945/46). The semi-structured interview is designed in such a way as to give respondents the opportunity to freely articulate their views (*i.e.*, it is intended to bear the maximum possible resemblance to an open conversation). However, it focuses on a particular problem introduced and continuously probed for by the interviewer. An interview guide was developed especially for the interview, which addresses the essential aspects of subjective illness theory such as labeling, causal attributions, perceptions of prognosis.

Interviews took between 35 and 55 minutes. They were tape-recorded and subsequently transcribed. The full set of transcripts was analyzed by means of structuring qualitative content analysis (Mayring, 1990). The method simultaneously allows the analysis of subjective concepts and the identification of structures in the qualitative material. It was de-

signed to facilitate the combination of qualitative methods with statistical analysis. Hence, it was particularly suited for our study, which aimed at assessing both subjective evaluations and the frequency and distribution of the judgments made. In a first step, texts were divided into units which were then given a code reflecting the original statements as closely as possible (paraphrasing). Paraphrases subsequently served as the basis for the formation of categories, which was carried out by means of an inductive method—new categories were formed and constantly revised until all relevant information from the interview transcripts was included. Coding was done independently by two researchers. Results were compared by an interdisciplinary research team consisting of psychiatrists and psychologists. The team resolved possible discrepancies and summarized similar codes in generic categories until the final coding system was arrived at. For content analysis, a computer-based approach was chosen, using the software package WinMax (Kuckartz, 1998). The program allows simultaneous access to the texts analyzed, the coded blocks of text, and the categories of the coding system relevant for the respective transcripts. It is further designed to facilitate the “quantification” of verbal data by defining variables from the categories and reading them into a statistics package without losing reference to the original data. In our study, data collected through the inductive procedure was thus converted into an SPSS file for statistical analysis.

In addition to the three components of subjective illness theory (labeling, causal attributions, perceptions of prognosis), a number of factors were studied which the literature suggests have an influence on medication compliance of schizophrenic patients (Fenton et al., 1997; Kampman and Lethinen, 1999): gender, living arrangement, duration of illness, grandiose delusions, unpleasant side effects of medication, attitudes towards medication and patient's satisfaction with his or her psychiatrist. For the assessment of psychopathology, patients were interviewed with the 9th version of Present State Examination (Wing et al., 1974). Side effects of antipsychotic medication were assessed by means of the UKU side effect rating scale (Lingjaerde et al., 1987). For patients' evaluation of the positive and negative effects of medication a checklist with ten 5-point Likert-scaled items (Holzinger et al., 2001a) was used. Patients rated the therapeutic relationship on three items of the Helping Alliance Scale (HAS; Priebe and Gruyters, 1993). The mean score of three analogue scales assessing the feeling to be understood by the psychiatrist and perceived commitment of the psychiatrist and how right the patient felt the

received treatment was, was taken as a global indicator of the quality of the therapeutic relationship.

For the assessment of compliance with antipsychotic treatment, patients were asked whether during the last month they had taken their medication regularly and whether they had adhered to the prescribed dosage. The answers to these two questions were rated using a scale ranging from 0 (no compliance at all) to 3 (maximum compliance). The two scores were then combined to a sum score. Compliance was assessed at discharge from hospital and three months later. Sixty significant others were asked the same questions. There was a high agreement with regard to patients' and significant others' reports on medication compliance (Cohen's kappa = .76).

In total, transcripts of the interview that were able to be analyzed were available for 77 patients. Of the 102 patients originally recruited, 19 did not consent to the taping of the interview. In six cases the quality of tape recording was too poor to allow transcription. Of the remaining 77 patients, 60% were male. One third of the sample consisted of the following age groups: younger than 30, between 30 and 40, and older than 40 years of age. Of the sample, 74% were single, 37.5% lived on their own, 20% lived with their parents, and 17.5% lived with their spouses or partners. With regard to education, 32.5% of the respondents had completed fewer than 9 years of school, 32.5% completed between 9 and 12 years, and 26% had completed 13 years. Nine percent did not answer the question. Among the subtypes of schizophrenia, the paranoid type (ICD-10 F 20.0) was most frequently represented (42.5%). On average, patients had been admitted to inpatient treatment on five previous occasions. The median length of cumulative stay at a psychiatric hospital was 15 months. At the time of the interview, patients displayed fewer positive symptoms and about as many negative symptoms as the representative sample of first admitted schizophrenic patients studied in the ABC project (Häfner et al., 1992). Before being switched to clozapine, patients had been treated with up to 13 different traditional neuroleptics (median = 4). On average, patients had been on clozapine for almost 3 years.

## Results

### *Subjective Illness Theory of Schizophrenic Patients*

When asked whether they considered themselves to be mentally ill, 56.4% of patients responded “yes”; 21.8% denied that they were mentally ill, 14.1% believed that they had been mentally ill, although they were not ill at present, and 7.7% felt unable to an-

swer the question. The degree of decisiveness also varied. Some patients agreed decisively that they were ill. Others clarified their answers with additional explanations, for example with statements such as "yes, but not too extreme" or "I'd say that I'm slightly mentally ill." This is also true of the patients who did not consider themselves mentally ill. Some rejected the notion that they were ill and described themselves as healthy. Others described themselves as "very sensitive" or "perhaps delicate."

When asked about the causes of their illness, most patients (48.4%) mentioned psychosocial stress factors. At the forefront was chronic burden, and above all strain or great pressure to achieve at work or in school. This was followed by relationship problems, both in conflicts in existing relationships and in damaged relationships that had been of some importance until present. Furthermore, seclusion, loneliness, and social isolation were also given as causes for the occurrence of the disease. Critical life events, for example, change of location, divorce, birth, and death, were rarely cited.

The second most frequently given cause of the illness (32.1%) was that of the conditions during childhood or in the parental home. The most frequently cited cause within this category was the aggressive atmosphere one was brought up in, and the fact that one was ill-treated as a child. Furthermore, a bad upbringing and a lack of parental acceptance were also put forward as having led to "identity problems" and "mental deformation." Finally, reasons such as lack of security, lack of affection, and a feeling of parental neglect were given, as was, in contrast, being spoiled by parents.

Of the patients, 24.3% ascribed the cause of their illness to personality factors, making this the third most frequently cited explanation of illness. Most frequently, patients assumed they were more sensitive than others. In addition to this, patients described themselves as having an "inferiority complex," "fear of new things," and "social difficulties with other people."

Relatively few (16.7% of patients) put the occurrence of the illness down to hereditary characteristics, which usually is taken into account only when another member of the family is mentally ill or receiving psychiatric treatment. Similarly, few (15.4%) accept it as an illness of the central nervous system. In several cases, patients spoke about a metabolic disorder in the brain, often without knowing exactly what this meant. Finally, 14.1% of patients report alcohol and drug consumption as causes of their disease.

The three stated categories (psychosocial stress, parental home and childhood, personality factors)

can be summarized by the overall category "psychosocial factors." Hereditary characteristics, disease of the central nervous system, and abuse of alcohol and drugs come under the overall category of "biological factors." Of the patients questioned, 38.5% saw their illness in terms of psychosocial factors, 32.1% saw their illness in terms of both psychosocial and biological factors, and 12.8% put their illness down to biological factors; 16.7% could not give a possible cause of their illness.

Similar to clinical usage, patients' expectations concerning the further course of the illness were grouped into three categories: recovery, intermittent course, and chronic course. Over a quarter of the patients (28.2%) expressed optimism. They counted on an improvement in their mental health, dependent on the fulfillment of certain conditions, where adequate treatment (in particular psychopharmacologic therapy and rarely psychotherapy) was most frequently quoted. Sometimes patients stated that the course of the illness was dependent on their having a partner or if they were working. Another quarter (26.9%) was aware of the risk of relapse, with only a few patients considering a reoccurrence of the acute psychosis as unavoidable. Likewise, approximately one quarter of patients (28.2%) had a more pessimistic outlook on their condition and were convinced that their illness would continue to proceed in a chronic manner or that their condition would deteriorate. Many justified their opinion as their illness had taken the same course and remained unchanged for a while. The rest of the patients (16.7%) were unable to deliver a prognosis for the future course of their illness.

#### *Relationship Between Subjective Illness Theory and Patient Compliance*

To what extent do subjective illness theories predict compliance during hospital treatment and three months after discharge from hospital? At discharge, 33.7% of the patients reported that they had not been taking their medication regularly, and 16.9% had changed the dosage. We carried out a multiple regression analysis, in which we introduced in the first step a set of variables, which according to previous research may have an influence on compliance. As can be seen in Table 1, in the case of delusions of grandiosity compliance was lower. By contrast, compliance increased with a more positive helping alliance. Gender, living arrangement, number of hospital admissions, side effects of antipsychotic medication, and attitude toward psychotropic drugs had no statistically significant influence. When these variables are taken into account, 20% of the variance

TABLE 1  
*Determinants of Compliance with Clozapine at Discharge from Hospital (n = 77)*

	$\beta$	$p$	$\beta$	$p$
Gender (male)	-.111	.329	-.122	.295
Living arrangement (alone)	-.425	.672	-.049	.669
Number of hospital admissions	.027	.817	-.002	.984
Delusion of grandiosity <sup>a</sup>	-.262	.022	-.261	.025
Side effects of antipsychotic medication <sup>b</sup>	.127	.333	.132	.327
Helping alliance <sup>c</sup>	.361	.007	.378	.005
Attitude towards psychotropic drugs <sup>d</sup> (negative)	-.018	.888	-.002	.985
Labeling (mentally ill)			.047	.678
Beliefs about causes (biological causes)			.039	.739
Beliefs about prognosis (chronic course)			.140	.227
	$R^2 = .204; p = .023$		$R^2 = .222; p = .063$	
			Increment of $R^2 = .018$	
			$p = .673$	

<sup>a</sup> Assessed by 9<sup>th</sup> version of PSE

<sup>b</sup> Sum score of UKU side effect rating scale

<sup>c</sup> Mean score of Helping Alliance Scale

<sup>d</sup> Sum score of checklist for the assessment of patients' evaluation of positive and negative effects of medication

TABLE 2  
*Predictors of Compliance with Clozapine Three Months After Discharge from Hospital (n = 60)*

	$\beta$	$p$	$\beta$	$p$
Gender (male)	-.116	.376	-.102	.441
Living arrangement (alone)	.152	.247	.175	.192
Number of hospital admissions	-.083	.553	-.037	.801
Delusion of grandiosity <sup>a</sup>	-.095	.467	-.083	.534
Side effects of antipsychotic medication <sup>b</sup>	.180	.242	.122	.443
Helping alliance <sup>c</sup>	.288	.049	.250	.144
Attitude towards psychotropic drugs <sup>d</sup> (negative)	-.313	.024	-.318	.024
Labeling (mentally ill)			-.088	.508
Beliefs about causes (biological causes)			.046	.714
Beliefs about prognosis (chronic course)			-.170	.227
	$R^2 = .205; p = .086$		$R^2 = .245; p = .137$	
			Increment of $R^2 = .040$	
			$p = .460$	

<sup>a</sup> Assessed by 9<sup>th</sup> version of PSE

<sup>b</sup> Sum score of UKU side effect rating scale

<sup>c</sup> Mean score of Helping Alliance Scale

<sup>d</sup> Sum score of checklist for the assessment of patients' evaluation of positive and negative effects of medication

can be explained. When introducing the three components of subjective illness theory in the regression equation, the explained variance rises by only 2%. Neither the problem definition, the causal attribution, nor the assessment of the prognosis had a significant effect on compliance.

With regard to patients' compliance three months after discharge from hospital, 30% had not taken their medication regularly, and 18.3% had changed the dosage. With the same set of variables, this time 21% of the variance could be explained. Besides doctor satisfaction, patients' assessment of the effect of drug treatment had a significant influence on medication compliance. Again, through the inclusion of the three components of subjective illness theory, there was no increase of explained variance worth mentioning. None of the three components

had a significant influence on compliance (Table 2). Illness theory also did not show any association with other variables that are predictors of compliance in this study.

## Discussion

The study investigated subjective illness theory in a sample of schizophrenic patients that was homogeneous in several respects. All patients had recently been discharged from acute treatment in inpatient or day hospital settings and were on clozapine treatment. The latter implied that they consented to treatment with an atypical neuroleptic drug and the regular and frequent blood controls required. Additionally, all patients had consented to participate in a research study with repeated exten-

sive interviews. Thus, patients who are very difficult to engage with in treatment or research were not included. Despite this homogeneity of the sample, the qualitative method applied yielded a range of very different subjective illness theories.

The main findings with regard to the subjective illness theory of schizophrenic patients can be summarized as follows: Although patients had recently been discharged from acute hospital treatment, only slightly more than 50% of them described themselves as being mentally ill. Patients might avoid labeling their distress and crisis as mental illness in order to reduce the risk of being stigmatized and discriminated against (Angermeyer and Schulze, 2001). This might also reflect an attempt of patients to get rid of their illness by "sealing it over" (McGlashan, 1987). There was a strong tendency toward endorsing psychosocial causes rather than biological causes—a finding which is in line with those of previous studies (Angermeyer and Klusmann, 1988; Hofer et al., 2001). About half of schizophrenia patients primarily believe in psychosocial causes of their illness in the above studies. The propensity to endorse psychosocial causes may result from a search for meaning by patients confronted with an illness which, in the end, may remain unexplainable to many of them and for which even experts do not provide explanations that are necessarily clear and plausible to the patients concerned. Besides that, attributing the occurrence of their illness to psychosocial stress may also help to avoid being blamed for it (Provencher and Fincham, 2000). Between 25% and 30% of the patients each expected an improvement of their illness, the reoccurrence of a psychotic episode, or a chronic course with further deterioration of mental health. The percentages are roughly in line with the probabilities for more or less positive outcomes of schizophrenia that current textbooks suggest. To some extent, patients' expectations may mirror the attitudes and prognoses of clinicians, and the concordance between clinicians' and patients' prognoses in individual cases may be tested in further studies.

The study failed to demonstrate a significant relationship between patients' subjective illness theory and their compliance with clozapine treatment. There are several possible explanations for this finding: the sample might have been too selective and homogeneous to capture the relevant variance in illness theories as the independent variable or in compliance as the dependent variable, so that a significant association was not detected. Both variables, however, did vary in the sample studied, and it seems unlikely that the selection process alone accounted for the absence of an association be-

tween illness theory and compliance. Another reason could be that our measurement of compliance relied on patients' self-reports, whose reliability is controversial. However, there was a satisfactory agreement with significant others' reports on medication compliance. Certainly, the measurement of clozapine blood levels would have been the most reliable method. However, this would have negatively affected patients' willingness to participate in the study. Patients' beliefs about the nature, causes, and prognosis of their illness may be of little or no direct significance for their decision as to which treatment should be chosen and, in consequence, be adhered to. The decision to continue or discontinue with clozapine treatment might be influenced by more practical aspects, such as the regular hassle to comply with blood controls. In this study, patients' assessment of the helping alliance was identified as the best single predictor of compliance, which underlines the central importance of the patients' views of treatment and a good therapeutic relationship for engaging patients in further treatment including their compliance with medication. In addition, delusions of grandiosity during inpatient treatment predicted lower compliance. This is in line with results of previous studies that also pointed at feelings of grandiosity and "the wish to be crazy" (Van Putten et al., 1976) as essential motives to discontinue with antipsychotic medication. Another predictor of compliance during the first three months after discharge from hospital was patients' assessment of the effects of drug treatment, which is a most plausible finding. All these predictors together explained approximately 25% of the variance of compliance with medication, which means that the greater part remained unexplained. Patients' decision-making processes may be complex and dynamic over time and cannot be sufficiently understood on the basis of a cross-sectional assessment of a limited number of predictive variables alone. Future studies may have to consider mediating and moderating factors in addition to baseline variables and may have to explore processes over time in more detail.

Subjective illness theory might, in our view, still be considered as a potential predictor of compliance in further research, despite the negative result in this study. However, the scope of studies should include clinicians' theories and the way patients feel understood and accepted with their theories by their clinicians. It might be assumed that a good match between beliefs of patient and clinician positively influences both the quality of the therapeutic relationship and patients' compliance with prescribed medication. When subjective illness theories of schizophrenic pa-

tients are investigated in research—to predict compliance or for other purposes—qualitative methods as applied in this study appear suitable to provide categories that can be subjected to quantitative analysis. Thus, the widespread call for qualitative methods to assess patients' views can be met in studies that test hypotheses using statistical procedures.

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