

Subjective Meaning of Taking Antipsychotic Medication for Patients with Schizophrenia in Japan

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Abstract *The patient's adherence to the antipsychotic medication regimen is a critical issue in the treatment of schizophrenia, because non-adherence is one of the main causes of relapse. 'Objective' factors including lack of insight and uncomfortable adverse effects are reported to contribute to non-adherence. It is also important to explore the 'subjective' meaning of taking antipsychotic medication from the patient's point of view, as medical anthropology has revealed the importance of subjective meaning of illness for the individual. In the current study, 11 schizophrenic and schizo-affective patients were interviewed to elicit the participants' subjective opinions about their medicines. The narratives contained negative and positive aspects of taking medicine from the patient's perspective. Antipsychotics are viewed as an unwelcome reminder of the stigmatized condition and as a threat to social life by potentially damaging the brain or creating drug dependency. On the other hand, patients recognized that antipsychotics effectively reduced uncomfortable symptoms, facilitated sound sleep, or stabilized the condition. Many patients do not take their medications; even the patients who accepted and adhered to the medication regimen expressed anxiety, worry, and reluctance to take medications. However, adherent patients tried to make sense of taking antipsychotics by covering negative meanings with positive ones. It is clinically important to explore subjective meaning of taking antipsychotic medication from the patient's perspectives.*

Key words: Schizophrenia, antipsychotic, adherence, narrative, subjective meaning, stigma

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INTRODUCTION Patient adherence to the antipsychotic medication regimen is a critical issue in the treatment of schizophrenia, particularly as non-adherence is a main cause of relapse. Approximately, 40-50% of patients do not follow their medication regimen (Lacro et al., 2002). Non-adherence is reported to be related to a lack of insight, adverse effects of antipsychotic drugs, and a limited doctor-patient relationship.

Medical literature has revealed important contributing factors to non-adherence; however, there are still other areas that need investigation. Research from medical anthropology and psychology has revealed that illness has a subjective meaning as well as an 'objective' biomedical process. Taking medication is not purely a physiological or biochemical matter. Rather, as Whyte et al. (2002) noted, giving and taking medication is also communication through symbols. As a result, it is important to explore the subjective or symbolic meaning of taking antipsychotic medication from the patient's perspective. Such an investigation would promote better understanding of non-adherence. Psychiatrists need this understanding to negotiate with patients and to appreciate what makes it possible for patients to accept medication. Previous research has focused on non-adherence. The implicit premise would be that adherence is the norm while non-adherence is a deviation from the expected behavior. However, it is unclear whether adherence is based on 'correct' understanding of the purpose and therapeutic action of psychiatric medication. Thus, the investigation must include adherent and non-adherent patients.

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The purpose of this study was to explore the subjective meaning of medication that allows schizophrenic patients to accept or reject their antipsychotic medication.

SUBJECTS AND METHODS In this study, 11 schizophrenic and schizoaffective patients who had been treated for at least 1 year were recruited from Hospital X in Japan. All patients were being treated by the author on an outpatient basis. After briefing the subjects on the purpose of this research, written informed consent was obtained.

The interviews were conducted in the outpatient clinic of Hospital X. The author made notes on the patient's responses in a similar way that psychiatrists do when interviewing a patient during a clinic appointment. Each interview lasted 30-60 minutes and each subject had 1 to 3 sessions. Clinical records were used to obtain demographic information and clinical history of each patient.

The interview questions were designed by the author and based on Kleinman's (1980) 'patients' explanatory model' as follows:

1. *What do you think your illness is?*
2. *What do you think caused your illness?*
3. *What do you think about your current condition?*
4. *What do you think about the effect of your medicine?*
5. *What kind of medication side effects do you experience?*
6. *What do you do in addition to taking medication in order to manage or improve your condition?*
7. *Do you modify your medication regimen? Of so, in what cases do you make modifications and how do you make those changes?*
8. *What do you expect will happen with your illness in the future?*
9. *What do you expect your medication regimen to be like in the future?*

Non-structured interviews were conducted and the questions were intended to solicit the participants' subjective opinions regarding their medication.

Table 1 shows the patients' demographic characteristics and an outline of the patients' attitudes toward medication based on the categorization by Pound et al. (2005).

FINDINGS The patients' narratives regarding taking antipsychotic medication are grouped into positive and negative meanings and relevant sub-themes as follows:

NEGATIVE MEANINGS

1. Stigma toward psychiatric medication
2. Worry about adverse effects

POSITIVE MEANINGS

1. Recognition of improvement
2. Comparison to somatic medicine
3. Hope for future reduction and termination of medication
4. Meaningful social life and acceptance of medicine

Table 1 Demography of subjects

Case #	Diagnosis	Gender	Age at interview (years)	Age at onset (years)	Duration of observation	Educational years (years)	Number of admission	Cumulative years of admission (month)	Attitudes toward medication
1	Schizophrenia	M	25	23	2	15	1	4	Ambivalent
2	Schizophrenia	M	39	23	16	12	3	3	Accept
3	Schizophrenia	M	42	26	15	14	3	48	Accept
4	Schizophrenia	M	33	21	12	9	5	7	Accept
5	Schizophrenia	M	45	41	3	12	0	0	Reject
6	Schizophrenia	M	24	22	2	16	1	3	Accept
7	Schizophrenia	F	44	26	18	12	1	1	Accept
8	Schizophrenia	F	35	34	1	14	0	0	Accept
9	Schizophrenia	F	71	58	2	12	0	0	Accept
10	Schizophrenia	F	40	18	22	11	3	3	Ambivalent
11	Schizoaffective disorder	F	50	48	2	14	0	0	Ambivalent
Average									6.27
			40.73	30.91	8.64	12.82	1.55		

NEGATIVE MEANING

1. Stigma toward psychiatric medication

All patients expressed serious concern about the stigma attached to taking psychiatric medication.

"I want to keep my psychiatric consultations secret, because it's shameful" (Male, aged 45 years).

"I would be ashamed if I had to take pills in front of others. It would make it difficult for me to find jobs" (Female, aged 40 years).

A great deal of research has reported that the stigma attached to schizophrenia is an internationally prevalent phenomenon. It is known that stigma exerts a major negative influence on a patient's perception of antipsychotics. Furthermore, stigma affects some patients' decision to cease their medication. Although psychiatrists regard cessation of medication as non-adherence, cessation could also be considered a form of de-stigmatization, that is, an effort of patients to counteract stigmatizing character of taking antipsychotics, as noted by Conrad (1985).

2. Worry about adverse effects

The patients expressed worry about various adverse effects of the antipsychotics they were taking. There are actual medically based adverse effects including extra-pyramidal symptoms, sleepiness, and increased thirst, which have been extensively documented. In addition, the patients worried about 'perceived' adverse effects that are not necessarily medically based.

"I am worried that I cannot live without pills in the future"
(Female, aged 40 years).

"I am nervous about taking pills. I worry that they are so strong that they are harmful to my brain" (Female, aged 35 years).

"I don't like psychiatric medicines because I feel that I am being controlled by them" (Female, aged 50 years).

These "perceived" effects include dependence on or addiction to medications, the medications being 'too strong', as well as a feeling of being controlled by the medication, as shown in the excerpts.

Though the 'perceived' adverse effects do not necessarily have a scientific basis, they still evoke strong concerns and contribute to the patients' negative evaluation of antipsychotics. Angermeyer et al. (2001) also reported similar perceptions among patients taking Clozapine in Germany.

POSITIVE MEANING

1. Recognition of improvement

The patients also displayed positive perceptions of antipsychotic medications. They reported a stabilizing effect of the medication. Many patients recognized this effect by retrospectively comparing their current condition to their previous psychotic exacerbation. This perception is exactly what psychiatrists emphasize and expect patients to appreciate. The positive perceptions also include the recognition of the immediate reduction of uncomfortable symptoms.

It is important to note that the effect of medication has a different meaning for patients than for psychiatrists as regarding adverse effects of antipsychotics. One patient (Male, aged 33 years) believed that antipsychotics were helpful to him because the medication effectively reduced his irritation, anxiety and nervousness. He did not mention the long-term stabilizing effect of his routine

antipsychotic. Instead, he often reduced his regular dose, because he seemingly considered it to be of little use.

“When I am overwhelmed by hallucinations, medicines readily improve these tough situations” (Male, aged 33 years).

Some patients emphasized the importance of sleeping well.

“Hypnotics produce a sound sleep. It is valuable to me because I don’t drink alcohol” (Male, aged 45 years).

This excerpt refers to the soporific effects of medication. This particular patient takes hypnotics to ensure a sound sleep, and refuses to take antipsychotics allegedly because he does not get the desired effect.

Therefore, the patients' measure of effectiveness appears to be in some cases much different from that of psychiatrists. Dowell and Hudson (1997) documented this discrepancy between patients and psychiatrists in the opinions regarding the effectiveness of medication, although the patients in that study were not schizophrenic.

2. Comparison to somatic medicine

Patients often compare antipsychotics to those medications used for somatic illnesses. However this comparison consists of two polarized tendencies.

One is focused on the distinction between medication for psychiatric illness and medication for somatic illness.

“Psychiatric medicines are so strong that they could have harmful effects on my brain, but supplements aren’t that strong” (Female, aged 40 years).

In this excerpt, the patient refers to supplements, and not directly to somatic medication. Of course, this focus is closely connected with the stigma attached to psychiatric illness.

The other tendency is to analogize psychiatric medication to somatic medication.

“Psychiatric drugs are not any different compared to medications for hypertension or medications for stomach pain” (Female, aged 35 years).

This reasoning is based on “somatic idioms of distress”, which are quite common in the non-western world (Kirmayer & Young, 1998). Somatic idioms of distress enable patients to express their symptoms without evoking the stigma that typically accompanies their psychiatric illness. This also seems to be the case in schizophrenic patients who adopt these idioms.

3. Hope for future reduction and termination of medication

Many patients expressed their hope for future reduction and termination of their medication, but they did not express how they would achieve these conditions. The reduction of medication represents the approach to full recovery from the illness. The patients dream that they can achieve such a healthy condition that they do not have to keep taking medication any more.

“I worry about what would happen to me if I stop taking medicines. Maybe I can stop after 2 or 3 years of treatment. But I need medicines as long as I have anxiety” (Female, aged 35 years).

This theme of hope introduces the process of “subjunctivizing” (Good, 1994) elements, which allow patients to have an openness to change for their perception about antipsychotics. The subjunctivizing elements ameliorate the negative aspects of antipsychotics, thus helping patients accept their medication.

4. **Meaningful social life and acceptance of medicine**

The excerpts presented here reveal that when patients have a meaningful social life that they want to maintain, they honestly recognize the relevance of their antipsychotic medication. They generally continue medication with minimal enforcement.

“I don’t want to stop taking the medicine. If I do, I would become ill again. I don’t think it’s good. I ‘m afraid I will be admitted to the hospital again. My job is really good and it is important to me” (Female, aged 44 years).

It is impressive that these patients were actively taking their medications, whereas previously they had been reluctant to follow the prescribed regimen.

DISCUSSION Analysis of the patients’ narratives has revealed various aspects of the subjective meaning of taking medication from the patient’s perspective.

On the one hand, medication has negative aspects. Antipsychotics are closely connected to the stigma of schizophrenia, and also evoke fear regarding extra-pyramidal side effects, as well as the fear that the medication may be so “strong” that it damages the brain. For some patients, medication is also a form of external control, or an imposed adherence to a certain regimen.

On the other hand, medication is also considered to have positive effects. Psychiatrists expect patients to perceive the medication as a useful and helpful therapeutic measure.

Thus, both positive and negative aspects of taking medication were identified, as clarified previously by Rogers et al. (1998). However, it is important to note that these aspects are not necessarily based on medically ‘correct’ concepts but on the patient’s subjective evaluation.

There is much hesitation, suspicion and anxiety regarding antipsychotic medication among schizophrenic patients. This is also prevalent among adherent patients. As Pound et al. (2005) summarized in their overview of the literature on medication-taking behavior, the layperson’s response to medication is best captured by the concept of “resisting medication”. They noted that patients adopted resistance to prescriptions as a strategy for the management of medication.

The “resisting” attitude is, however, only one aspect. The “accepting” patients, at least, tried to find positive meaning in taking their medication using various strategies, including recognizing the effectiveness of medication, analogizing antipsychotics to somatic medication and maintaining hope for future reduction and termination of medication. These strategies allowed patients to destigmatize their situation. It is also remarkable that some patients with satisfactory social lives accept their medication without serious resistance. When patients have something of value, they cease resisting the medication regimen and try to integrate it into their lives.

From a clinical perspective, it is important that psychiatrists do not rigidly impose medication adherence on schizophrenic patients, but rather seek to understand the patients’ point of view. It is essential to explore and discuss the patient’s subjective meaning in order to obtain cooperation regarding treatment and adherence to the medication regimen.

There are several limitations associated with this study. The number of subjects was limited. In addition, there were several methodological issues. The subjects knew the researcher was at the same time their attending psychiatrist. This may have distorted the objectivity or neutrality of the patients’ statements; however, the interviews were conducted in a setting that was typical of the

usual clinical encounter. As the patients were not accustomed to being tape-recorded, the author chose to write information rather than record interviews electronically. This may have resulted in a loss of precision in the recording of the patients' responses; however, the setting, atmosphere and familiarity of the patient-psychiatrist interaction were maintained.

In the future, it will be necessary to conduct future studies with a larger number of subjects with attention to patients' familiarity with data collection settings and methods. It would be also intriguing to conduct cross-cultural comparative studies on subjective meaning given to antipsychotic medication by schizophrenic patients.

CONCLUSIONS In summary, this study identified both negative and positive aspects of taking medication from the patients' perspectives.

Patients worry about possible negative consequences including stigma and adverse effects. Patients must find meaning in medication adherence in order to accept and comply to the recommended dosage and schedule. Still, these meanings are not necessarily medically correct, but subjectively evaluated. It is important to appreciate the patients' struggle to make sense of psychiatric medication in the context of their own personal world.

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