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Review Article

Schizophrenia: Is it time to replace the term?

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Abstract The attitudes of Japanese psychiatrists toward their patients who suffer from schizophrenia were investigated. We were concerned specifically with whether the psychiatrists inform their patients of the suspected diagnosis. We discuss how the term 'schizophrenia' may influence a psychiatrist's decision to inform his patients of the diagnosis. A self-reported questionnaire was distributed to 150 executive board members of the Japanese Society of Psychiatry and Neurology and analysis of the data obtained from 110 respondents was carried out. The results showed that the concepts that psychiatrists use when they give a diagnosis of schizophrenia vary considerably. Fifty-nine per cent of the respondents informed their patients of a diagnosis of schizophrenia on a case-by-case basis, while 37% informed only the patients' families. A tree analysis showed that the most important predictors for informing the patients of the diagnosis were assumptions about the public image of schizophrenia and a negative impression of the term schizophrenia, translated as 'Seishin Bunretsu Byou' in Japanese. The results revealed that the Japanese term for schizophrenia influences a psychiatrist's decision to inform patients of the diagnosis and that, by changing the term to a less stigmatized one, the disclosure of information about schizophrenia to patients would be promoted.

Key words diagnostic term, informed consent, schizophrenia, stigma, tree analysis.

INTRODUCTION

In this study, we review the attitudes of Japanese psychiatrists about telling their patients, who have schizophrenia, that they suffer from this particular mental disorder. We surveyed a select, influential group of psychiatrists in Japan to try to understand the dynamics of the doctor–patient relationship when a patient is diagnosed with schizophrenia. We found that there is some reluctance on the part of psychiatrists in Japan to inform their patients of a diagnosis of schizophrenia. The reason Japanese psychiatrists are reluctant to give this diagnosis is because of their assumptions about the public image of the nature of the disorder and because the word used to categorize this illness, 'Seishin Bunretsu Byou', amplifies the negative impression and heightens the social stigma of the disorder. We conclude that since the term schizophrenia, and its Japanese counterpart, are perceived negatively, both by psychiatrists and the general public, and since this negative impression itself may perpetuate an unnecessary social stigma about the disorder, it is a good idea at this time to replace the term schizophrenia with a less negative and less stigmatized one. By making this change it will then be easier for clinicians to inform their patients of this disorder and easier for their patients to understand and come to terms with the disorder. Moreover, by using another term, patients and their families will not experience the sometimes

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devastating effects of the social stigma associated with the term 'schizophrenia'.

The source of the negative image of schizophrenia can be traced back to the creative work of Kraepelin. He was the first to introduce the idea that there are two classes of major psychoses; namely, manic-depressive psychosis and dementia praecox, the latter being the historical predecessor of the term 'schizophrenia'. Kraepelin thought that dementia praecox was a chronic, or progressive, brain disease. As he envisioned it, this disease causes patients to experience severe impairment in their cognitive and social functioning.[1] Bleuler, however, criticized this pessimistic viewpoint.[2] Instead, Bleuler focused on the splitting nature characteristic of this disorder and named it schizophrenia (deriving the term from Latin). This term is now used worldwide.

The introduction of the term 'schizophrenia' appears to make the clinical situation more confusing because it is broader than that of dementia praecox. The broader, more encompassing the concept, the more heterogeneous the pool of patients diagnosed as schizophrenic. Because the diagnostic term acts as shorthand to condense information, the concept tends to cause confusion in clinical settings. The well-known US/UK Diagnostic Project, for example, revealed the discrepancy between the American and British use of the term which suggests that the diagnosis of schizophrenia is strongly influenced by local tradition.[3]

When we shift to the present situation in psychiatry and look specifically at the Present State Examination, we see that it was developed by drawing on the operational criteria of DSM-IV[4] and ICD-10,[5] both of which were influenced by Kurt Schneider's work. Even though such modern descriptive criteria were introduced, the nature of this disorder is still unclear and its validity has been called into question.

Such conceptual vagueness could cause problems not only in diagnosis but also in treatment. The elusive and elastic nature of the diagnostic term tends to perpetuate the prognostic stigma that all schizophrenic patients are deteriorating and unlikely to recover from their illness. The reason for this pessimistic view of a schizophrenic's prognosis is because our view of schizophrenia is still strongly influenced by Kraepelin's concept. We still tend to think that schizophrenia is a disease in which the patient progressively deteriorates, despite the fact that the development of new treatment approaches, particularly the use of neuroleptic agents, has had a favourable impact on the prognosis of this disorder.[6]

The result of this stigma is that it is difficult for clinicians, patients, and relatives to discuss naturally and realistically how to deal with the disorder. Furthermore, the negative impression generated and amplified by the term distresses the individuals to such an extent that they hear very little of what is said to them. The clinician therefore finds it difficult to build a collaborative relationship.

The situation is more complicated in Japan because of the way schizophrenia was translated into Japanese. In Japanese, schizophrenia is translated as 'Seishin Bunretsu Byou' which means a disease (Byou) of the splitting (Bunretsu) of the mind (Seishin). The Chinese characters used for this term, however, could serve to strengthen the stigma associated with this disorder. Each Chinese character and/or combinations of them have their own meanings. The virtue of this feature of the language is that it helps us to easily speculate and understand the meaning of a term we encounter in daily life. In the case of 'Seishin Bunretsu Byou', the Chinese characters we use are in common usage. They have several meanings which Japanese people will readily understand or, at least, have a general sense. Such everyday words, however, could be misleading and cause the average Japanese to speculate about the nature of the disorder and lead them to conclusions which strengthen the negative image of this disorder. For example, 'Seishin' means not only mind but also spirit or soul. 'Bunretsu' means disorganization or fragmentation. Thus, 'Seishin Bunretsu Byou' means more than the splitting of mind. A Japanese reading these Chinese characters might also infer that it means the fragmentation of human spirit. This semantic nuance gives a Japanese person the impression that a patient suffering from 'Seishin Bunretsu Byou' is a human being whose spirit is fragmented. Needless to say, this linguistic nuance serves only to reinforce the devastating impression of this disorder. This observation goes beyond the borders of Japan. Since Chinese characters are used in China and Korea as well, a large portion of the world's population would have similar misleading negative impressions of this disorder.

Mental health professionals need to be sensitive to the fact that patients and their families might suffer from being told the diagnosis. Given the clinical importance of sharing information of a disorder with the patients and their families, it is disadvantageous to our clinical practice to use a term with which patients are uncomfortable. If the use of the term 'schizophrenia', and its Japanese counterpart 'Seishin Bunretsu Byou', is detrimental to the patient's

treatment and attitude toward the illness, it would be better not to use the term at all. The National Federation of Families with Mentally Ill in Japan proposed changing the term 'Seishin Bunretsu Byou' to a less stigmatized one in order to minimize the detrimental effects of this term. Currently, the Committee on the Concepts and Terminology of Psychiatric Disorders of the Japanese Society of Psychiatry and Neurology is investigating the problems associated with the term schizophrenia and is discussing the reasons for and against the changing of the name.

SUBJECTS AND METHOD

To understand the attitude of Japanese psychiatrists in informing a patient and patient's families about a diagnosis of schizophrenia, we sent out a questionnaire (Appendix 1) to the executive board members of the Japanese Society of Psychiatry and Neurology. Of the 150 board members, 110 (73%) responded to our questionnaire. The average number of years since the respondents started working as psychiatrists was 29 (10.1). Of all the respondents, 58 (52.7%) were working at university hospitals, 37 (33.6%) at mental hospitals, 10 (9.1%) at general hospitals, and 5 at other kinds of institutions.

The Chi-squared Automatic Interaction Detection (CHAID) was used to evaluate what kind of variables affect the psychiatrists' attitudes to inform the diagnosis of schizophrenia to a patient. The CHAID is a tree-based analytic model. The analysis offered by CHAID is similar to the Autonomic Interaction Detector (AID) except that at each stage, CHAID allows for multiple splits instead of only a bisection; moreover, the splitting is performed on the predictor which maximizes the significance of the Chi-squared statistic. CHAID partitions a set of data into mutually exclusive, exhaustive subsets of vectors that best describe dependent variables. This analysis can detect interactions and non-linear effects which tend to be easily missed by other traditional techniques. In our study, whether a clinician informs a patient of the diagnosis or not was treated as the dependent variable, and 34 predictor variables, presented in Appendix 1, were used to predict the dependent variables. In this procedure, the analysis was not allowed to split an independent variable if the resulting partition led to a new group with less than 10 respondents. Each partition was also required to explain at least 5% of the dependent variable's variance. For the analysis reported here, a package from SPSS (SPSS Inc., Chicago, USA) that can perform the analysis on a personal computer was used.[7–9] Two of the authors (K. Yamauchi and K. Yoshimura) conducted these analyses.

RESULTS

The number of psychiatrists who gave an affirmative answer to each question is presented, in brackets, at the end of each question in Appendix 1.

Our data suggest that the definition of schizophrenia that psychiatrists use to formulate their diagnoses varied considerably. Among 110 respondents, 69.1% ($n = 76$) of them use Bleuler's concept, 63.6% ($n = 70$) use that of Schneider, 35.5% ($n = 39$) use the DSM criteria, and 30% ($n = 33$) use the ICD category.

Eight respondents reported that they always inform their patients of a diagnosis of schizophrenia (7.3%), while 51.9% (57) reported that they inform their patients of such a diagnosis only when they judge it as appropriate (i.e. on a case-by-case basis), 24.5% (27) said they always inform the family of the diagnosis while 12.7% (14) inform the family only when they judged it as appropriate.

Respondents reported that some of their patients experienced disadvantages because of being diagnosed with schizophrenia (65.5% (72)), 47.3% (52) of the respondents reported that their patients and/or families experienced considerable harm from the diagnosis, 27.3% (30) said that after diagnosing a patient with schizophrenia that patient subsequently experienced marital difficulties or divorce, and 15.5% (17) said that their patients lost their job.

Figure 1 shows the interaction effects between the predictors determined by the CHAID analysis. In this analysis, both psychiatrists who always inform their patients of the diagnosis of schizophrenia and those who tell the diagnosis on a case-by-case basis were put together and compared with those who inform the family of the diagnosis. Because 19 respondents checked both areas, the answers of only 91 respondents were analysed. As a result, the assumption about the general image of schizophrenia, at the top of the diagram, was selected as the most important predictor of the decision to inform patients and/or patients' family of the diagnosis. The next important predictor was the negative impression of the term 'schizophrenia'. In our study, the patients' competence explained little of the variance in the decision to inform the patient and/or their family of the diagnosis.

DISCUSSION

In order to offer effective treatment, it is important for clinicians to make a comprehensive assessment,

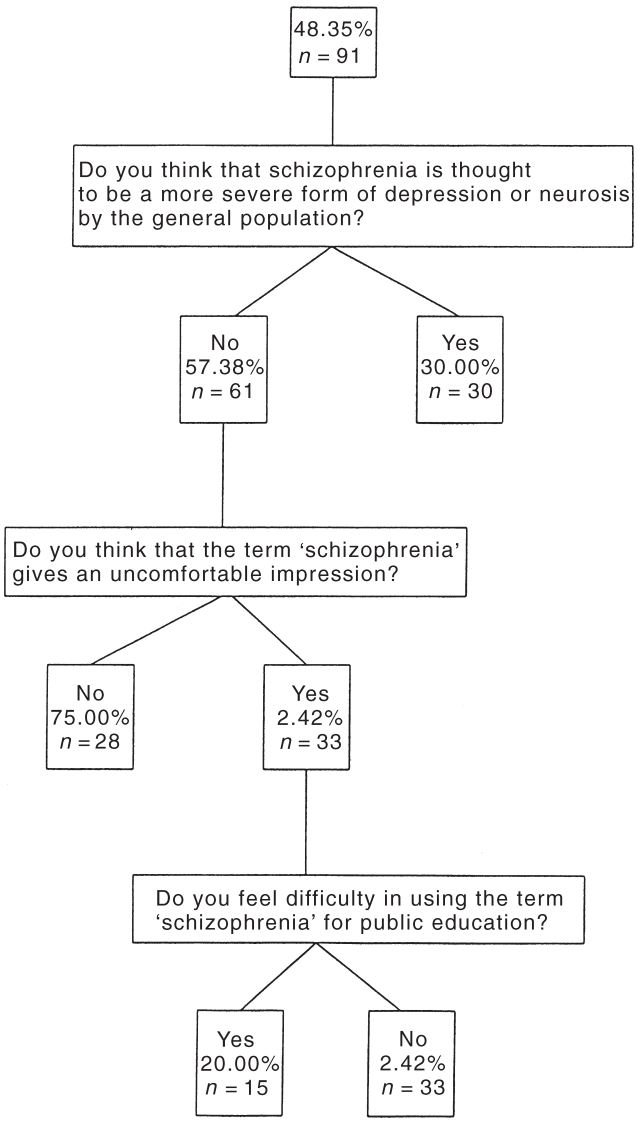

Figure 1. All percentages presented here are a rate of psychiatrists who inform the diagnosis of schizophrenia to a patient.

communicate the assessment to the patient and to obtain informed consent from the patient.[10] Diagnosis should be a process carried out by a clinician[11] and sharing information about the diagnosis during the process is beneficial in establishing satisfactory relationships between patients, relatives, and clinicians. This procedure is particularly important for the treatment of schizophrenia. Since a considerable number of patients with this disorder are treated and cared for over a long period of time, the participation of patients and their families in treating the illness is indispensable. Patients' perception of coercion in treatment may effect their attitude toward treatment, including their inclination to adhere to treatment.

It is, however, often difficult to inform schizophrenic patients of the nature of their illness and for them to understand the diagnosis, and it is especially difficult to obtain informed consent for treatment from the patient as they frequently lack insight into their illness. Our survey data show that only 7.3% of our respondents always informed their patients of a diagnosis of schizophrenia and that over half (51.9%) inform patients only when they judged it as appropriate. Conversely, 37.2% of the respondents inform family members of the diagnosis. The rate of psychiatrists who always or usually inform the patient of a diagnosis of schizophrenia is quite low compared to that reported by Green and Ganter (58%).[12] Such a low rate could contribute to the serious communication gap between the doctors, their patients and families as reported by Koishikawa *et al.*[13] in Japan, that is only 32% of patients who had been informed of the diagnosis could tell the true diagnosis.

The difficulty of telling patients and their families of a diagnosis of schizophrenia and obtaining informed consent has been discussed often. Frequently, people worry about whether or not the patient is competent to consent to or refuse psychiatric treatment. It has been thought that psychiatrists hesitate to inform patients of a diagnosis of schizophrenia because the patient is too impaired by the illness to understand the information and to give consent to the treatment.[14–17]

CONCLUSIONS

Our data suggest that the assumptions about the nature of schizophrenia held by psychiatrists and the negative impression of the term 'schizophrenia' held by the general population are the two main reasons why psychiatrists do not inform their patients of the diagnosis. It is certainly not unreasonable for a clinician to think that a stigma exists among the general population because, despite a prodigious effort to clarify the pathogenesis of schizophrenia, progress has been modest and definite answers to the most pressing questions remain elusive. This vague concept fosters both the psychiatric assumptions and the social stigma associated with this disorder.

Forcing psychiatrists to inform their patients of a diagnosis of schizophrenia, however, is not necessarily the answer to this problem. It is important to consider the patient's feelings and reaction to such a diagnosis as it may seriously harm the patient. Our data suggest that Japanese psychiatrists are cautious about informing patients and/or families about the

diagnosis of schizophrenia precisely because they think that it could seriously harm them. But it is also not desirable to rely on clinicians' personal opinions. If a clinician has to worry about the serious social consequences of giving a diagnosis, such as divorce or job loss, then such negative consequences might unfavourably influence his decision to tell the patient of the disorder. Such an attitude stems from a medical paternalism aimed at protecting the patient from harm, regardless of the patient's own preferences. It would be an over generalization, however, to think that a clinician sticks only to their limited experiences, but paternalism is a strong factor in the doctor–patient relationship which cannot be dismissed out of hand.

Our data also indicated that the psychiatrists' attitudes toward hesitating to inform the diagnosis comes not only from their paternalism but also from the general negative social impression of the term itself. Patients and relatives, as well as mental health professionals, feel uncomfortable when they hear the term 'schizophrenia'. One of the reasons for such a negative impression is due to the stigma associated with the diagnosis of schizophrenia. The concept of schizophrenia is still blurred despite the intensive research as mentioned before. The prognosis of patients diagnosed with schizophrenia varies considerably. Such prognostic vagueness also helps to foster the stigma that schizophrenia is an incurable disease. This stigma prevents clinicians from openly telling their patients the diagnosis and prevents them from discussing the disorder with patients.

Although the findings of our survey must be viewed with caution, because our sample was relatively small, they nonetheless have several important implications. Firstly, considering that our respondents are executive board members of the Japanese Society of Psychiatry and Neurology, their opinion could have a considerable influence on the overall opinion of Japanese psychiatrists. Secondly, to our knowledge, ours is the first survey to show the strong influence of the term schizophrenia on whether or not psychiatrists inform their patients of the diagnosis and our results point to the necessity of changing the term. Thirdly, clinicians were found to be still paternalistic and trying to protect their patients based on their own impressions of what was the correct judgment call in each individual case. Fourthly, these results suggest that further investigation of a larger number of clinicians and the general population, and an open discussion involving all factions of society, are necessary to attain a better understanding of this disorder. Moreover, our data suggest that replacing the term 'schizophrenia' with another more appropriate term would promote a better understanding of the diagnosis, one which patients could understand and accept, and one which would facilitate communication in both clinical and research settings.

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Appendix 1 Questionnaire on the term and concept of schizophrenia to the Committee on Concept and Terminology of Psychiatric Diseases

1. When did you start to work as a psychiatrist? 19( ). (69 + – 10.1)

2–1. Where would you mainly work?
- a. at a university hospital (58)
- b. at a general hospital excluding a. (10)
- c. at a psychiatric hospital (37)
- d. at a psychiatric clinic (0)
- e. at a research institute excluding a. (0)
- f. others (5)

2–2. Do you have any experience to treat patients suffering from schizophrenia in general practice?
a: yes (110); b: no (0)
If you chose 'no', you need not answer the questions no. 7–9.

3. When you make a diagnosis of schizophrenia, what kind of concept is it usually based on?
- a. DSM-III-R or DSM-IV (39)
- b. ICD-IO (33)
- c. any other operational diagnostic criteria (RDC, Feighner, etc.) (1)
- d. basic symptoms by Bleuler (76)
- e. the first rank symptoms by Schneider (70)
- f. other not specified (12)

4–1. How do you feel about the condition of schizophrenia, compared to when you became psychiatrist?
- a. becoming mild (74)
- b. be almost the same (22)
- c. gaining severe cases (0)
- d. others (0)

4–2. How do you feel about your own schizophrenia concept, compared to when you became psychiatrist?
- a. becoming global (you often diagnose as schizophrenia) (11)
- b. be almost the same (59)
- c. becoming strict (you rarely diagnose as schizophrenia) (34)
- d. others (6)

5. About prognosis of schizophrenia, how do you feel about rehabilitating probability?
About ( )% (58.1 + – 23.0)

6. What do you think the general public regards schizophrenia as?
- a. as disease for medical treatment (61)
- b. as being unknown what they would do (68)
- c. as negative as genetic or incurable disease (85)
- d. as severe case of depression or neurosis (39)
- e. others (9)

7–1. How do you inform your patients of schizophrenia?
- a. directly inform patient as a rule (8)
- b. inform a patient only when you judge as appropriate (57)
- c. only inform their family as a rule (27)
- d. inform their family only when you judge as appropriate (14)
- e. inform neither patient nor family as a rule (3)

7–2. Why don't you inform your patients of schizophrenia?
- a. because they cannot understand what it means (21)
- b. because it would throw them into despair (53)

c. because disease concept is indefinite (33)
d. because the name schizophrenia sounds negative (44)
e. because parties don't profit by knowing the name (37)
f. others (12)

8. When you need to serve patient diagnosed as schizophrenia with a medical certificate, do you manage the case in the following way?

8–1. With a medical certificate for handicapped annuity
a. record as schizophrenia regardless of the opinion of the patient or family (37)
b. record as schizophrenia as much as possible, with informed consent of the patient or family (65)
c. not record as schizophrenia as a rule (7)

8–2. With a medical certificate for a layoff
a. record as schizophrenia regardless of the opinion of the patient or family (5)
b. record as schizophrenia as much as possible, with informed consent of patient or family (45)
c. not record as schizophrenia as a rule (59)

9. Diagnosed as schizophrenia, do you have any experience against advantages of parties?
a: yes; b: no
a-1. any of them have got a great impact (52)
a-2. any of them have lost their job (17)
a-3. any of them have got divorced (30)
a-4. any of them have brought in a lawsuit against you on diagnosis (3)
a-5. others (7)

10. On using schizophrenia, do you feel inconvenient and problematic than other diagnosis, such as depression and epilepsy?
Chose one among the following a–d in each case. a: no; b: not very much; c: fairly yes; d: strongly yes

10–1. when you explain the third party the disease condition (a: 6; b: 19; c: 46; d: 38)
10–2. when you communicate with medical staff of other fields (a: 40; b: 49; c: 17; d: 3)
10–3. when you guide and educate medical nursing student (a: 72; b: 28; c: 8; d: 1)
10–4. when you educate the general public (a:37; b:34; c:27; d:10)

11. How do you think about changing the term schizophrenia?
a. the term, should be changed (51)
b. the term need not to be changed (42)
c. others (17)

12. Why do you think as item 11? Please show your any other ideas.