On Educating Schizophrenics About Schizophrenia

by Carleton Pilsecker

Abstract

Hospitalized schizophrenics attended a class on schizophrenia (1) to learn about their illness; (2) to try to understand why they are sometimes labeled schizophrenic and sometimes not; and (3) to try to determine the validity of their diagnosis. Many attendees appreciated the class while others, by not attending the second of two sessions, raised questions about its appropriateness for them.

For over a year I have been teaching a class for schizophrenic inpatients at the Veterans Administration Medical Center in Long Beach, California. The class is offered once a month, and consists of two 1-hour sessions. The first session explores the meaning of schizophrenia and how it is diagnosed. The second session, which is held the next day, reviews ideas about etiology and the types of treatment methods available. (See the course outline.) Attendance is voluntary.

Whether or not they later attended, many patients responded favorably to the announcement of the class’s formation. Some expressed surprise: “I’ve been in and out of hospitals for 16 years, and no one has ever offered to tell me about my illness.” Only one patient objected: “It should be left to the doctors.”

A total of 116 patients have now attended one or both sessions of the class; the number of patients attending each session has averaged 8, with a range of 1 to 19. Not included in these figures are a very small number of patients who appeared for the class but left before it began or a few minutes thereafter. A few patients left during the first hour, but most remained the full time.

Some patients were still in poor remission when the class was held and asked questions or made comments reflecting their thought disorder. At times it was necessary to limit their contributions severely, but most uncomplainingly accepted my statement: “We can’t deal with that.” Two schizophrenic patients persisted in being disruptive—one through schizophrenic verbal productions, the other through continual lengthy challenge to what I was saying. Both were reprimanded by other members of the class with the result that one left the class and the other stopped challenging me.

Some patients were in very good remission and appropriately articulate. Most patients were in fair remission and offered generally relevant commentary with occasional loose commentary interjected. A number of patients appeared frightened, sat very still, and said nothing; some stared at me; some tried to avoid eye contact. Although a few patients have dozed on and off (but no snoring), the most common characteristic of the patients has been attentiveness.

Knowledge about schizophrenia has seemed at a relatively low level. A few patients had read a great deal about their illness, and were able to express their opinions cogently. Most of the patients were interested to see how their personal experience fit into a generalized description of schizo-

Reprint requests should be sent to C. Pilsecker, 11232 Hornet Pl., Lakewood, CA 90715.
phrenia. It appeared that they had either not been exposed to such a description before (as some stated) or that their exposure had not resulted in useful learning.

Patients seldom challenged the idea that certain behavior indicates illness. However, one dramatic challenge did occur during a discussion of paranoid delusions. "I don't have a delusion," said a patient. "I know that other people are out to get me." "OK," I replied, "but you're going to have a difficult time getting the rest of the world to believe you." His response was unanswerable: "Some things are not settled by democracy."

For one patient the discussion of hallucinations and delusions proved distressing—not because of his own personal experiences, but because it suggested to him that important people in the Bible were mentally ill rather than inspired.

There has been very little levity in the class; patients seem to take their situation seriously. Even moments that have been humorous to me have usually not provoked smiles or laughs from the patients. For example, in one class a manic patient frequently interrupted before falling asleep. When he awoke, he would again begin interrupting until finally he declared, "This schizophrenia doesn't apply to me," and abruptly departed—prompting another patient to remark: "I'd rather have schizophrenia than whatever he's got." Other patients solemnly agreed. Most smiles seemed to come from patients who were embarrassed or incredulous as they described the crazy behavior they sometimes exhibited.

Although concrete thinking is said to be a characteristic of the schizophrenic person, patients had no difficulty grasping two simple analogies. In one, schizophrenia was compared to a house (a collection of many building materials) and, in the other, the idea that heredity and environment could combine to bring about schizophrenia was illustrated by drawings of two trees with different "tilts" toward the illness.

Most patients were prompted to attend the class by one or another of three major questions:
1. As a schizophrenic, what am I?
2. As a mentally distressed person, why am I considered schizophrenic at one time and something else at another?
3. As a person having some life difficulties, why must I be called schizophrenic by mental health professionals?

**Question 1**

Most patients either explicitly acknowledged their identity as schizophrenics or implicitly did so by linking themselves, through questions or comments, to schizophrenic symptomatology. They came to the class to learn more about themselves by learning about their illness. Personal experiences were sometimes described to illustrate a concept being discussed; perhaps as often, however, an experience was mentioned as a way of checking whether the concept applied to them.

The patients reported verbally and through evaluation forms at the end of the class that much of what was taught was useful. Occasionally, there was an expression of the burdensome nature of the reality that had been described. One section of the evaluation form asked for a response to the statement: "One thing I wish we hadn't talked about was:" Although this section was almost always left blank, there were occasional poignant responses: "Once you get schizophrenia you usually don't get back to a high level." "Schizophrenia being a lifetime struggle. (Maybe it is, maybe it's not a lifetime struggle.)"

Most patients seemed to understand and accept the fact that experts differ in their views on the definition, etiology, and treatment of schizophrenia. One patient, however, wrote on the evaluation form: "Let's talk about something with answers instead of something nobody knows about."

Patients with children have been concerned about the effect their illness may have upon their children both through heredity and the possibly adverse impact of their sometimes bizarre behavior. One patient told the class that he had definitely decided not to have children because of these concerns.

**Question 2**

A number of patients who attended were clearly manic in their behavior. (The few class disrupters usually came from their ranks.) They were interested in the class because they had at some time in the past received a diagnosis of schizophrenia. Another small group of patients had been labeled schizophrenic at times and not schizophrenic at other times (with or without a replacement diagnosis of which they were aware). A few patients realized that, at the same moment, one physician
Course Outline

Introduction
My information is secondhand (i.e., I have not been diagnosed schizophrenic)
Generalized concepts may not fully apply to a given individual
Each person is different regardless of label
There is much controversy among the experts about some aspects of schizophrenia

Meaning of schizophrenia
One form of mental illness
A collection of symptoms
  Feelings of unreality
  Difficulty in relationships
  Strange thinking and talking
  Feelings seem missing or inappropriate

Ambivalence
  Hallucinations
  Delusions
  Other
  Frequency of occurrence
  Acute episode vs. chronic illness

Means of diagnosis
No definitive physical test
Behavior, including reports of others
Psychological testing
Reasons for conflicting diagnoses

Ideas about causes
Proximate:
  Present focus on brain chemistry
Ultimate:
  Problem in utero (virus?)
  Heredity
  Environment
  Heredity plus environment

Ideas about treatment
Best to do nothing
Electroconvulsive therapy
Megavitamins
Hemodialysis
Psychotherapy
Pharmacotherapy
  Commonly used drugs
  Side effects
  Ways of dealing with side effects

Question 3
Some patients came to the class hoping to find out whether they were schizophrenic. "Tell people in future classes," one evaluation form read, "how a person can tell that he is schizophrenic." Not infrequently, this was framed in terms of a wish to find evidence that they were not schizophrenic. One patient, who was clear that schizophrenic was the appropriate label for himself, admitted that, over years of being sporadically hospitalized, he had never revealed all of his symptoms to his doctors for fear that they would give him the dreaded diagnosis. Another patient wrote that in future classes I should mention "the possibility that a person really doesn't have a mental disorder even though he has been labeled with a mental disorder."

Of the many ideas presented during the two sessions, one consistently provoked the greatest response. After making a blackboard illustration of a house to convey the notion that what looks like a house (schizophrenia) to one person may look like a barn (e.g., manic-depressive illness) to someone else, I would erase the window and door and comment: "It seems to me that being a schizophrenic may be like being inside this house, having great difficulty making contact with anybody on the outside, feeling trapped." Invariably most of the class assented.
with words or vigorous shakes of the head.

Both through the evaluation form and through comments at the end of the class, patients expressed appreciation for its being offered. Sometimes patients who encountered me many months later would spontaneously speak favorably of the class. Several indicators, then, suggest that patients welcome information about their illness. There is one contrary indicator, however. On the average, 45 percent of the patients who attended the first hour of the class did not return for the second hour. This figure is made slightly less stark by the fact that three patients came to the second session a month or two after attending the first session. Some of the dropout can be attributed to haphazard life/hospital circumstances: a very few patients were discharged between the first and second session; a very few were known to be attending other scheduled activities; a few later reported they "overslept" (which may not be haphazard). Some patients may have been disappointed in the quality of the presentation even though the written evaluations indicated that the evaluators almost universally felt it was well done. It is possible that some patients decided they were not schizophrenic and, therefore, had no need to attend the second hour. The uncertainty of the information may have bothered some patients, although it did not seem to trouble most of those who returned.

Even with these several explanations, there remains the possibility that a significant number of schizophrenic patients did not return for reasons relating to their schizophrenia. The unpredictability of the schizophrenic seemed at work in some instances. Several patients told me or someone else, shortly before the second session, that they were looking forward to coming but then did not appear. Perhaps the failure to return was a function of the anxiety of focusing on the source of one's distress; or of the intimacy of discussing a crucial element of one's nature with a small group of people; or of the hopelessness of being entrapped by schizophrenia.

Some staff members have asked if attending the class made a difference in the patients' behavior—for example, in medication compliance. However, the question has not been studied because the class is premised, not on the hope for behavior change, but on the right of the patient to know about his illness. Overall the class has demonstrated that some schizophrenic patients will take and appreciate the opportunity to exercise this right. It has also generated some yet unanswered questions about the limitations of some schizophrenics' tolerance for dealing with information about schizophrenia and/or for doing so in a small class setting.

The Author

Carleton Pilsecker, M.S.S.W., is Supervising Social Worker on Psychiatry, Veterans Administration Medical Center, Long Beach, CA.