To Tell or Not to Tell

by Brian F. Hoffman

The three articles in this *At Issue* section all deal with important aspects of patient education. In the article below, B.F. Hoffman discusses the problem of telling the patient his diagnosis, and the therapeutic issues that must be considered in this process. In the second article, M. Linden and R. Chaskel focus on issues of informed consent in patients undergoing long-term pharmacotherapy, and present results of a study that assesses how much patients really know about the benefits and risks of their treatment program. Finally, C. Pilsecker describes his experiences in teaching a class about schizophrenia to hospitalized patients, and their understandable difficulties in accepting the fact that even the best, most recent research studies provide few certain answers about this puzzling disorder.

Bulletin readers who would like to respond to these articles, or to share experiences not touched upon here, should address their comments to At Issue, Center for Studies of Schizophrenia, NIMH, Rm. 10-95, 5600 Fishers Lane, Rockville, MD 20857.—The Editors.

"Truth without charity is often intolerant and even persecuting."

J. Swartz, as quoted in Edward’s *New Dictionary of Thoughts* (1977)

It is never easy to tell a patient his diagnosis. If the diagnosis is minor, then the patient may feel affronted and insulted; if serious, he may feel devastated and demoralized. In a single word, a diagnosis may imply real and tragic difficulties for the patient and his family (e.g., leukemia, stroke, or schizophrenia). These are compounded by irrational fears and guilt that may overwhelm and destroy the patient’s hope for his present and his future. The patient or his family may question the findings, the knowledge, the training, the qualifications, or the competence of the physician and his staff. Emotions can run high. The patient feels helpless, dehumanized, angry, and hurt; the doctor feels defensive, harried, knowledgeable, and superior—yet helpless in the face of his patient’s and his own vulnerability.

**Why Do You Tell the Patient?**

This is an age of consumerism and public education. The patient has a right to know as much about his illness and treatment as he wants to know, and more. For instance, a patient who has had a serious drinking problem may deny his problems and may need to be confronted with his physical, social, and marital difficulties if any treatment is to proceed. If a patient is to be responsible for his treatment plan, then he must have the knowledge on which he can base his treatment decisions. However, we must avoid fads and temporary trends. The role of the physician, using the art of the ancient healer, is to bring hope, to do what is best for the patient no matter what artificial roles or rules society may try...
to impose on this therapeutic relationship.

Nevertheless, the physician’s diagnosis and formulation, in words that the patient can understand, are the facts that a patient should expect to receive from his physician. In the absence of these facts and a clear statement of the physician’s opinion, the patient could enter a vicious cycle of blaming himself, his parents, or society. Denial of illness and indiscriminate accusations by the patient can perpetuate nonadaptive, alienating behavior and jeopardize his long-term rehabilitation. The question is not whether to tell or not to tell, but what, when, and how to tell the patient.

**What Do You Tell the Patient?**

A physician is the patient’s consultant, his advocate. He helps the patient to understand and live with his physical and emotional problems. He offers understanding, hope, and advice as well as medicine to treat, cure, or cope with disease and symptoms. The patient accepts or rejects these recommendations. The diagnosis and formulation represent a concise statement of the physician’s understanding. In physical medicine, the patient’s understanding may be similar to the physician’s. Even with physical illness, however, the physician may be concerned that his understanding is incomplete and may later be proved to be in error. With emotional problems, the physician’s and the patient’s understanding may be widely divergent. The physician is often afraid of alienating his patient or of giving an incomplete or erroneous diagnosis.

It is interesting that a physician seeing a neurotic patient in consultation will likely reassure him that there is no evidence for organic brain damage or psychosis. However, some physicians will not tell a patient their diagnostic impression when they know that a more serious problem exists—for instance, a psychosis.

The patient is entitled to the physician’s opinion. Is there a psychosis present? Are there organic features? Are there genetic, predisposing, or precipitating factors? What are the recommended treatment alternatives?

Schizophrenia is a term that most patients have heard and thought about. They do not know what it means, and they fear the worst. If the physician is considering the diagnosis of schizophrenia, or if such a diagnosis has been ruled out, the patient and family should be told. When the diagnosis has been made, the patient and his family can be told that he has schizophrenia and this means that the patient has had a psychotic episode in which he lived in a fantasy world for a period of time. The diagnosis is reserved for illnesses that are likely to remain or recur. The condition is treatable by medications which control the symptoms so that the psychosocial treatments can help the patient cope with life’s problems. Misconceptions must be corrected. The etiology of schizophrenia is neither simple nor clearly understood, although both genetic and psychological factors play some role. Neither is the treatment simple, but the prognosis does improve with treatment.

**How Do You Tell the Patient?**

Before a patient can be told his diagnosis, the physician and other staff must first formulate their own differential diagnosis and later their working diagnosis. In most cases the relevant staff should resolve their differences of opinion before a patient is told the diagnosis. A second rule is that the patient’s questions should be answered honestly and as completely as possible when they are asked. If the physician and the treatment team have reached their working diagnosis and the patient is not yet asking about their conclusions, then it is important to ask the patient why he is not asking about his diagnosis. Sometimes a patient will say that he expects his parents to tell him his diagnosis or that he doesn’t believe that the therapist has any special expertise. Such responses point to special problems that must be dealt with before any treatment will be accepted by the patient.

The physician and staff should tell as much to the patient as they know, but no more. A diagnosis is often reached in stages and may have to be communicated in this way, as the investigation unfolds. Broader diagnoses should be given until more specific diagnoses are arrived at (e.g., a diagnosis of functional psychosis may be used for some time before a diagnosis of schizophrenia is made).

**When Do You Tell the Patient?**

The patient should always be given his diagnosis in a one-to-one interview, in a supportive, gentle, and nonpunitive manner. An ongoing dialogue with his therapist must be encouraged. The diagnosis is to be given with hope and encouragement, and the inevitable fear that schizophrenia is incurable must be counteracted. The patient
can then be encouraged to discuss the diagnosis with other staff, and later in therapy groups with other patients. He can be encouraged to attend didactic groups on the psychiatric syndromes or on medications. With the patient's permission, the diagnosis can be discussed within a family session. The family also has a right to some of this information if the patient is expected to be an involuntary patient for a prolonged period of time. If a voluntary patient refuses to consent to information being released to his next of kin, then that decision should be thoroughly discussed and frequently confronted in therapy. Allowing the patient to scapegoat or overprotect his family is generally countertherapeutic. Nevertheless, if a voluntary competent patient does not give his consent for the discussion of the diagnosis and treatment plan with his family, the patient's right to privacy and confidentiality must be respected. This privacy, this trust is the cornerstone of all psychiatric treatment.

However, the process of giving a patient his diagnosis takes time, and the pace is set by the patient. Several interviews are generally required before the patient can understand and accept the diagnosis of schizophrenia. It is more important to use the patient's words (e.g., hearing voices or living in a fantasy world) than to use official psychiatric labels. Controlling those symptoms that the patient acknowledges becomes the important treatment goal. Later the patient can be educated to understand more technical terminology and nomenclature. The different recommended treatment choices can be given, as well as the success and relapse rates with various methods of treatment. It must be pointed out to the patient that medications are meant to control symptoms so that he can then start to cope with life. A patient must be told that medications are not a panacea; they do not remove any of life's problems, nor do they make a patient happy. The patient must still learn to solve problems and find happiness in his own unique way. Although the ultimate responsibility of continuing treatment remains with the patient, it is the treatment team that gives the patient and the family both the knowledge and hope to want to continue treatment.

The Author

Brian F. Hoffman, M.D., F.R.C.P. (C), is Staff Psychiatrist, Clarke Institute of Psychiatry, and Assistant Professor, Faculty of Medicine, University of Toronto, Toronto, Ont., Canada.

An Invitation to Readers

Providing a forum for a lively exchange of ideas ranks high among the Schizophrenia Bulletin's objectives. In the section At Issue, readers are asked to comment on specific controversial subjects that merit wide discussion. But remarks need not be confined to the issues we have identified. At Issue is open to any schizophrenia-related topic that needs airing. It is a place for readers to discuss articles that appear in the Bulletin or elsewhere in the professional literature, to report informally on experiences in the clinic, laboratory, or community, and to share ideas—including those that might seem to be radical notions. We welcome all comments.—The Editors.

Send your remarks to:

At Issue
Center for Studies of Schizophrenia
National Institute of Mental Health
Alcohol, Drug Abuse, and Mental Health Administration
5600 Fishers Lane, Rm. 10-95
Rockville, MD 20857