

Using a Psychiatry E-List to Develop a Model for Discussing a Schizophrenia Diagnosis

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Introduction by the column editors:

This is the third contribution to this column, which is based on the use of the electronic mailing list (e-list) of the Columbia University Public Psychiatry Fellowship (PPF) to generate a collaborative problem-solving process. Dr. Levin, a PPF graduate, questioned members of the e-list about how they discussed a schizophrenia diagnosis with a patient and compared their responses to a preliminary communication model that his group developed, resulting in important modifications to the model. Readers can submit management problems to Dr. Ranz at jmr1@columbia.edu for publication in future columns.

In the practice of oncology, transparent diagnostic communication is a widely accepted principle (1). However, such is not the case in psychiatry in communicating the diagnosis of schizophrenia. Only one-third of psychiatrists explicitly state the diagnosis of schizophrenia to patients,

referring instead to “psychosis” or “breakdown” (1). Low rates of communicating a schizophrenia diagnosis are found worldwide: United States, 46%; Japan, 30%; France, 34%; and Italy, 30% (2–4).

A number of factors contribute to the reluctance to communicate a schizophrenia diagnosis: uncertainty about diagnostic accuracy, pessimism regarding treatments, concern about stigma and the possibility that psychotic patients cannot process the diagnosis, and a lack of communication experience. Stereotypic views of people with schizophrenia often involve incompetence, dangerousness, unpredictability, and poor outcomes, and clinicians may not wish to cause distress or may fear being blamed.

People with psychiatric illnesses have an ethical right to know their diagnosis. Research suggests that they want to be informed and that a discussion improves shared decision making (5). Recently, two suggestions for renaming schizophrenia have been put forward, one from Japan, “loss of coordination disorder” (6), and another from the United States, “neuro-emotional-integration disorder” (NEID) (7). These proposals attempt to communicate more pertinent information; however, a recent study showed that a purely neurobiological perception of schizophrenia increased the likelihood of treatment referral without affecting stigma (8).

Communication skills research has shown that better doctor-patient communication results in improved patient symptom profiles (9), enhanced

satisfaction (10), and improved adherence to treatments (11). The fields of oncology and HIV offer many communication lessons in supporting patients during discussions of their diagnosis and treatment. Seeman (12) has proposed an oncology-based approach that emphasizes both the informational and emotional aspects of discussing a schizophrenia diagnosis.

In Australia, Brian Kelly proposed developing a communication training program to enhance the effectiveness of discussing the diagnosis of schizophrenia with patients and families. An international “Discussing a Schizophrenia Diagnosis” work group comprising schizophrenia researchers, educators, and communication training experts was established in 2010. The group’s aim is to develop a detailed, consensus-driven, and testable communication skills training model for discussing a schizophrenia diagnosis. It has chosen as its model “Breaking Bad News,” a communication skills training program at Memorial Sloan Kettering Cancer Center. This program uses a simulation methodology in which actors and physicians role-play standardized communication scenarios. Skill assessment is measured by video coding.

Obtaining feedback on the model

The group designed an initial set of goals and strategies and wanted to know whether other schizophrenia experts would agree with its approach. The group also hoped that these experts would point out any important elements of the conversation that might have been omitted. To ac-

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compish this task, the group approached the Public Psychiatry Fellowship at Columbia University, a leading national training program with 200 alumni on its electronic list manager (e-list). The group developed six questions that probed facets of its communication model, which were then posted on the e-list for on-line debate. In order not to bias the responses of the public psychiatrists, the group did not share its initial model with them. The following six questions were posted on the e-list:

1. How do you discuss the schizophrenia diagnosis?
2. Do you approach the conversation when the patient is still psychotic?
3. Do you deliver the diagnosis via a family meeting or alone with the patient?
4. What are the exact words you use to explain the nature of schizophrenia?
5. What are your thoughts on using euphemisms such as “psychotic break” or “mental breakdown” that imply reversibility, and how can we address resistance to using the word “schizophrenia”?
6. How do you discuss schizophrenia prognosis?

A vigorous online discussion supported many elements of the model but also offered significant additional suggestions. The work group summarized the responses thematically and debated the themes during three teleconferences. As a result of the on-line discussion and the work group’s teleconferences, the initial model was modified and expanded as described below.

Changes to the model resulting from e-list input

A synopsis of the goals and strategies in the updated model is presented in the box on this page to orient readers to the communication strategies. [A sample of doctor-patient dialogues is presented in an online appendix to this column at ps.psychiatryonline.org.]

The e-list responses pointed out that stigma reduction and maximizing adherence had not been included in the original goals. The group agreed and added them to the initial goals of education and empathy.

Strategy 1 (questions 1–3 above) deals with considerations before the

The Modified Model for Discussing a Schizophrenia Diagnosis

Goals: Empathic communication of a diagnosis of schizophrenia to patients and families; education about the illness, prognosis, and treatment to reduce stigma and maximize engagement in care

Strategies

1. Prepare for the meeting, which should occur within two weeks of the patient’s admission. The patient should meet diagnostic criteria for schizophrenia. Consider which multidisciplinary team members and which family members should attend. The meeting is led by the most appropriate senior clinician. Organize the meeting room, seating arrangements, and educational material in advance.
2. Negotiate the agenda collaboratively.
3. Review patient and family understanding of the psychiatric illness and discuss the schizophrenia diagnosis. Use a symptom checklist. Correct misperceptions and skepticism. Discuss precipitants, such as substance abuse, in the context of the stress-diathesis model, linking this to potential psychotherapeutic interventions that can ameliorate distressing thoughts and emotions.
4. Discuss the prognosis, including best, worst, and most likely outcomes. Link improved prognosis to adherence to treatments, better coping with stress, avoidance of substances, cohesive family functioning, and work rehabilitation. Discuss diagnostic certainty and uncertainty, addressing emotional cues.
5. Discuss meaning of “schizophrenia” for the patient and family: Use the “go around” skill to garner consensus, reduce stigma, and promote self-esteem. Consider disease attributions. Preserve trust and resolve conflict. Discuss barriers to adherence, emphasizing that engagement with a comprehensive treatment framework promotes recovery.
6. Discuss the follow-up plan. Encourage questions about work, dating, marriage, children, disclosure to others, relapse prevention, and ways family members can help. Motivate and inspire hope while giving practical guidance on steps to promote recovery. Praise family for cohesiveness. Acknowledge their distress. Summarize. Arrange follow-up.

meeting with the patient. The group thought that a discussion to educate and reorient a psychotic patient was possible and should be similar to that with a delirious patient. The e-list agreed that sequential communications such as those with a delirious patient could be helpful at a time of psychotic bewilderment, but the timing would have to be tailored to the individual’s burden of psychotic symptoms and capacity to engage. The work group decided that a flexible window of “within two weeks from the date of admission” was a reasonable time frame to initiate the discussion. Strategy 1 was modified accordingly.

The work group’s initial model emphasized communicating the diagnosis within the framework of a family meeting. The e-list respondents pointed out that some patients value their autonomy or their privacy highly and might prefer to meet alone with their psychiatrist, although other patients would value the presence of their family in the meeting. In addi-

tion, the e-list differentiated between adolescent patients who require greater family involvement and more autonomous adults. As a result, the group decided that family involvement in this discussion should be decided on a case-by-case basis.

If family members ask how they can help, the e-list suggested that the psychiatrist consider this a communication cue to enlist the family’s support for the clinical goals of adherence and overcoming stigma. Also emerging from this discussion was the importance of strategies that help families solve practical problems, overcome helplessness and guilt, and maintain a sense of efficacy.

Strategy 3 (questions 1 and 4) deals with discussing the schizophrenia diagnosis. This strategy was modified significantly. An e-list respondent referred the group to a colleague who is an expert in cognitive-behavioral therapy for psychosis (CBTp), and she was invited to join the group. She suggested use of a checklist as an effi-

cient way to communicate the symptoms of schizophrenia. For example, a clinician might say, "I know that you may be skeptical of the diagnosis. Let's go through the symptoms of schizophrenia. Tell me which ones you think are applicable and which ones are less relevant."

The e-list respondents noted that resistance to the diagnostic discussion is normal (no one wants to hear that they have schizophrenia), but focusing on the "most worrisome" symptoms can facilitate engagement (question 5). These symptoms are then placed at the top of the "What is schizophrenia?" checklist. Finding this "common ground" is an important strategy that goes far beyond passive disease education.

Some respondents supported the old adage not to argue with patients about delusions or hallucinations. CBTp, however, regards gently correcting misperceptions about delusions and hallucinations by education, reframing, or Socratic questioning as an evidence-based strategy. The work group decided to retain this CBT principle as a component of strategy 3. The group also thought it legitimate to correct misperceptions about the cause of the illness.

The e-list considered it important to discuss both positive and negative symptoms. The work group concurred and decided that the checklist was the best way to address both.

Strategy 5 (questions 1, 4, and 5) considers the meaning of a schizophrenia diagnosis. The group expanded it to reflect "destigmatizing." The CBTp group member suggested "normalizing" stigma as an integral part of the discussion by pointing out that stigma is experienced by people with many other illnesses and even "foreign" accents. Antidotes to stigma include educating others about human differences and avoiding isolation. One respondent suggested medicalizing schizophrenia as a "neurochemical imbalance." The group disagreed because a neurochemical imbalance can also be stigmatizing and a way of framing schizophrenia as a temporary breakdown in "balance."

Strategies 3 and 5 (question 6) address the nature of schizophrenia and its prognosis. The group modified

these strategies to reflect the stress-diathesis model. In this model the clinician's formulation links the patient's perception of the illness to prognosis. For example, stress can intensify hallucinations, which in turn amplifies cognitions that "Voices have power over me," and "I can't function." Using alcohol as a way of coping further increases hallucinations and feeling powerless, making the process circular. The stress-vulnerability model provides a coherent way to explain susceptibility to psychotic exacerbation. Stopping the cycle of exposure to the stressor promotes improved self-efficacy. A better understanding of the nature of schizophrenia and its prognosis helps to build a realistically optimistic treatment framework, which includes medications, work rehabilitation, and psychotherapy.

The e-list discussion reflected the fact that prognostication in schizophrenia is less developed than in the field of oncology. One respondent pointed out that a "wait and watch" period that evaluates treatment response might provide a better prognostic indicator than the acute psychotic episode. If a patient who has diagnoses of drug abuse and schizophrenia is able to abstain from using, the prognosis may be more optimistic. This example illustrates how the "best, worst, and most likely outcome" framework chosen by the work group to discuss a schizophrenia prognosis can be used (strategy 4).

Strategy 6 (questions 1 and 4) focuses on summarizing and "next steps." This strategy was influenced by e-list suggestions about using motivational techniques to support treatment engagement. The e-list disavowed the therapeutic nihilism that often sets in with a diagnosis of schizophrenia. The respondents remained optimistic that when patients and families receive more information about the diagnosis, better collaborative decisions can be made.

Discussion

The online discussion facilitated development of a more detailed and nuanced approach. It supported utilizing a stress-diathesis perspective and discussing dual diagnoses, two

items that the group had not considered previously. It encouraged the group to adopt a more patient-centric view. Incorporating feedback from public psychiatrists and a CBTp researcher into the model will increase the likelihood of its successful dissemination to these influential groups.

The work group plans to use the model to investigate whether better communication about the diagnosis will reduce stigma.

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