About Poor Insight and Diagnosis

By Xavier Amador, PhD

The Diagnostic and Statistical Manual for Mental Disorders, 5th Edition (DSM-V) is in the works and will likely be published in 2012. I worked on the last two editions and was co-chair of the last revision of the Schizophrenia and Related Disorders section. My co-chair, Michael Flaum, MD, and I were asked by the American Psychiatric Association (APA) to revise the text to insure that it was based on scientific consensus rather than on the views of a single expert. To accomplish this we brought together experts from around the United States and overseas to review the research and independently review the text we proposed so that it would accurately reflect the scientific evidence available at the time. After our text revision (TR) and peer review process, the text was independently reviewed again by experts on the APA Task Force for the DSM-V-TR.

At that time (10 years ago), our peer-reviewers and the APA Task Force agreed that “a majority of individuals with schizophrenia lacked insight into having a psychotic illness” and that this problem was “a manifestation of the illness itself rather than a coping strategy” (page 304, DSM-IV-TR, APA Press, 2000). It was a symptom of the brain disorder rather than denial. It was compared to anosognosia—an unawareness syndrome seen in stroke patients and others with frontal lobe lesions.

I speak frequently all over the United States and overseas (see www.LEAPInstitute.org) and for the past 10 years I have been asking my audiences if they have heard of anosognosia and whether they believe this unawareness syndrome exists in schizophrenia and related disorders (e.g. schizoaffective disorder and other psychotic illnesses). In the early years, only one or two hands went up. Today, between one-half to two-thirds of my audiences raise their hands.

However, many mental health professionals and family members still have trouble believing it.

For this reason—because of the continuing gap between science and practice—I will briefly review the research that has convinced me and most other experts on schizophrenia that when a patient (who has received a reliable diagnosis) with this disorder persists (for years) in saying “I am not sick, I don’t need help!” he is giving voice to a symptom of the illness (similar to a delusion) rather than to denial.

Studies using neuropsychological tests
Numerous studies consistently report that low performance on the Wisconsin Card Sorting Test (WCST) is significantly correlated with insight deficits in patients with schizophrenia (e.g. Shad et. al., 2006; see also the relevant review chapter in Amador and David, Insight and Psychosis, edited volume, Oxford University Press, 2004). The WCST test measures, among other things, executive functions (anterior cortical function, a.k.a. frontal lobe function) such as planning, rule acquisition, abstract thinking, and initiating appropriate action/inhibiting inappropriate actions and self-reflection. Frontal lobe lesions have been found to be a common cause of anosognosia in neurological disorders (see: Alexander and Struss, 2006; see also the relevant review chapter in: Amador et. al., Schizophrenia Bulletin, 1991; and in Amador, I am Not Sick, I Don’t Need Help! Vida Press, 2007).

Structural brain imaging studies
Although far fewer in number, studies of the neurobiological underpinnings of poor insight in schizophrenia generally find that anosognosia in schizophrenia is correlated with a range of frontal lobe abnormalities (see: Alexander and Struss, 2006; see also the relevant review chapter in: Amador and David, Insight and Psychosis, edited volume, Oxford University Press, 2004). Additional structural and functional brain imaging studies and post-mortem brain studies are currently underway and should help to shed light on the pathophysiology of this common symptom of schizophrenia.
How research should influence the DSM-V

Psychiatric diagnoses are purely descriptive. To date, there is no blood test or brain scan that can diagnose mental illness. We look instead for diagnostic categories and dimensions that tell us something about what is likely to happen to the person (i.e. we ask, “What is the predicative value or validity?”). This also helps us to choose and recommend treatments and services that will be helpful to the individual.

The current subtypes of schizophrenia (e.g. catatonic, undifferentiated, disorganized, etc.) have limited predictive value. For that reason—and because the extensive research on poor insight in schizophrenia indicates that patients with this symptom have a poorer course of illness, are more prone to violence, homelessness, and poor adherence to treatments—the time to use the level of “awareness of illness” as a subtype and/or dimension in the DSM is long overdue. This is especially true when we look at the research on motivational interviewing (MI) and cognitive behavioral therapy (CBT) (see my first column on LEAP (Listen-Empathize-Agree-Partner)) which, along with long-acting injectable medications, are clearly the treatments of choice for such individuals.

When a psychiatrist or other mental health professional meets someone with schizophrenia and does the initial evaluation, the question of whether the individual understands he is ill, is aware of symptoms of the disorder, and is aware of previous success with treatment (if applicable) needs to be assessed and documented. This information is critical to planning treatment. For example, if the patient does not understand he is ill and has never seen any benefit to medication and supported housing despite evidence that such interventions have clearly been helpful, then the clinician must recommend a realistic treatment plan as described above rather than one based on misconceptions or false hope: e.g., hand over a prescription (that will never be filled) and arrange a follow-up appointment (that will be ignored). Instead, active engagement with strategies like MI, CBT, LEAP, and long-acting injectable medications would arguably, based on science, be the treatments indicated. Approximately one-half of all persons with schizophrenia and related disorders have long-term problems understanding they are ill and, as a consequence, refuse treatment and services. They fight with well-meaning clinicians and family members who are trying to engage them in the interventions that can give them a chance at recovery. They (understandably, because they are certain nothing is wrong with them) toss out prescriptions, appointment cards, and advice regarding their disorder and treatments. We know how to engage such persons in treatment—the science exists. The first step after making a diagnosis is to do a careful assessment of insight into illness and identify whether the person being evaluated has anosognosia. Once we do that, we can then choose a different path toward stabilization and recovery—one that employs science-proven communication skills and medications designed to help persons with poor insight and poor adherence to treatment. ⭐

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Xavier Amador, PhD, (www.DrAmador.com) an adjunct professor at Columbia University and the author of numerous scholarly and trade publications, including the national bestseller I am Not Sick, I Don’t Need Help (Vida, 2000) is a regular columnist for SZ Magazine.

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