

Personal Insight into Serious Mental Illness

Summarized by Thomas T. Thomas

Many people with serious mental illness lack insight into their own disease. In his book *I Am Not Sick, I Don't Need Help*, **Xavier Amador, PhD**, explained this tendency. He made a presentation of “things we can do to engage with someone who doesn't think they're ill” to the Schizophrenia Society of Nova Scotia in December 2005. Our September 26 meeting featured a video of that presentation.

Xavier Amador is an adjunct professor in Clinical Psychology at Teacher's College, Columbia University in New York City and is on the Board of Directors of the National Alliance for the Mentally Ill. He is a clinical psychologist who treats adults, children, and adolescents in individual, couples, and family therapy. He has published over 100 peer-reviewed scientific papers and other publications, including five books. Dr. Amador was co-chair of the last text revision of the section on schizophrenia and related disorders in the Diagnostic and Statistical Manual (DSM IV-TR, often referred to as the “Psychiatrists' Bible”).



*XAVIER AMADOR,
PHD*

In the video, Dr. Amador asked by a show of hands how many in the audience were people with a mental illness, how many were people who loved someone with a mental illness, and how many were professionals caring for someone with a mental illness—and he raised his own hand each time, because in addition to clinical practice, Dr. Amador has a brother with schizophrenia and has himself suffered from clinical depression. He said that to solve the problem of engagement we need the help of all three groups.

He began with the example of Margaret Mary Ray, whose daughter helped him prepare the book *I Am Not Sick*. Ray believed she was David Letterman's wife—believed it so thoroughly that she stalked him, stole his car to drive around as her own, was brought repeatedly before a judge for trespass, and received multiple restraining orders. Even when confronted with her delusions—for example, that the car was demonstrably not “her husband's”—she maintained them and never understood that she was ill. She suffered from schizo-affective disorder, never got treatment, and eventually died by suicide.

Ted Kaczynski, the Harvard-trained mathematician and Unabomber, was not some diabolical monster but a sick, sad man who had schizophrenia and never understood his illness. His defense team, in an effort to save him from the death penalty, tried to show how ill he was, yet Kaczynski refused to participate and tried to fire them. He would rather be executed than portrayed as sick.

About six million people in the U.S. have psychotic disorders, Dr. Amador said, yet about half of them don't understand that they are ill. According to studies, awareness of the signs and symptoms of illness is fully present in about a quarter

of patients, moderately or intermittently present in another quarter, and missing in half of patients.

“Denial of illness does not in itself indicate bad judgment,” Dr. Amador said. “If you are not ill, then taking medications which have side effects and might harm you is not bad judgment but just common sense.” He noted that during the 1980s—before the revision of DSM IV-TR—schizophrenia was described as a degenerative illness that would only get worse over time. That was wrong then and wrong now, but with such a description hanging over a person, why would anyone who wasn’t ill accept that label and suffer the stigma it carries? The doctor’s brother with schizophrenia would not admit his own illness despite being confronted with the results of his own tantrums, delusions, and disappearances. Arguing with his brother about the illness strained their relationship.

To illustrate the point, Dr. Amador role-played with a member of the audience, Scott, who was married to Cheryl, had two children, and worked as executive director of a medical institute. After obtaining these facts, the doctor promptly told the man he was wrong. There was no such life. Cheryl had a restraining order on him. The institute had recently removed him for trespass. “We don’t think of ‘I am not sick’ as a strongly held belief—not as strong as Scott’s belief in his own life situation,” Dr. Amador said. “But it’s every bit as strong. The patient won’t be grateful, receptive, or compliant to be told this is all a delusion. He will be frustrated and angry. He will ‘cheek’ the meds you force on him in order not to swallow them.”

According to one study, 40% of people with schizophrenia are not aware that the voices in their heads are not real, he said. And the other 60% may be aware the voices aren’t real but have no understanding of their true origin. Dr. Amador called these “pockets of insight.” Similarly, in another study, people with the movement disorder tardive dyskinesia—which sometimes results in rolling the fingers and twisting the lips—were often unaware of any movement. Some who were shown videos that proved they were moving randomly might acknowledge their movements, but when asked two weeks later would deny it: “I had that then, but not now.”

When Dr. Amador himself began to suffer the symptoms of depression in the 1990s—ironically, while he was working on a book about deep depression—he also was unaware of his own condition. It took a colleague administering a common psychiatric test, which at first Dr. Amador dismissed as a joke, to bring him to an understanding of the fact that he was ill. However, unlike the psychotic patients described above, once he understood the situation, he was able to accept his illness, get treatment and medication, and continue functioning.

In the past ten years there have been more than 200 studies of people who don’t think they’re ill. This is a serious issue because such people do not take their medications or participate in programs that can help them, have a higher rate of involuntary commitment, have a more contact with the criminal justice system through misdemeanors and disorderly conduct, and have a lower quality of life. Awareness is one of the top two predictors of which patients will take their medication—the other being a social support system, friends and loved ones, who respect the patient’s point of view and work with them without anger or blame.

Research has shown that insight into a person's illness is not necessarily associated with the symptoms getting better. In fact, it's when people get better that they discard their medications, deny their illness, and then usually suffer a relapse. Instead, when the patient is in the hospital and demonstrably getting worse that he or she might suddenly "see the light" and acknowledge their illness to doctors and family members. This is not necessarily dishonest but it is suspicious. It is only common sense, Dr. Amador explained, for a person facing an unpleasant stay in the hospital to say whatever will obtain a release.

What causes poor insight into serious illness? The refusal of these patients to acknowledge their condition goes beyond denial and psychological defensiveness—although people with mental illness do get defensive. Dr. Amador recalled dealing with a man whom a stroke had rendered paralyzed on his left side and did not know it. When asked to move his left arm, the man at first agreed to do so and said that he was moving it. When the doctor said there was no movement, the man then acknowledged that he *could* move the arm but he didn't feel like it. When the doctor asked him to try really hard, the man said the doctor was somehow restraining the arm. These sorts of illogical explanations, desperate confabulations, are reminiscent of people with severe mental illness. Dr. Amador recalled in this connection a young man admitted to the psychiatric ward of a hospital, who had been restrained and stripped of his street clothes in the emergency room, insisting that he was in a locked ward only because there were no other rooms available, that he was only in for a checkup, and he was not ill.

The doctor compared this mental state to a psychological condition that was first described 120 years ago in relation to brain injuries and paralysis called "anosognosia." This condition is usually associated with dysfunction in the frontal lobes. There is a moderate to strong correlation, he said, between frontal lobe injury and lack of insight. This cognitive deficit is not a response to the illness, not a coping strategy, but a manifestation and a symptom of the illness, like delusions and hallucinations. The conviction that the patient is not ill is "self-confidence stranded in the time before he became ill."

As a way to engage with the patient who denies his or her own illness, Dr. Amador recommended motivational enhancement therapy (MET), sometimes called motivational conditioning. MET was originally developed for use with substance abuse patients. The goal is to develop a relationship with the person to the point at which he or she feels you respect his or her point of view. Only then will the patient reluctantly begin to agree with your point of view that therapy is needed. The process uses the mnemonic word LEAP, which stands for Listen, Empathize, Agree, and Partner.

Listening requires active listening, sometimes called reflective listening. In this process, the listener hears what the patient is saying and verifies the content by repeating back and restating what is said. It's important not to comment on or interpret what the patient is saying. To say "So you believe they are trying to kill you..." demonstrates the listener's own disbelief. Many friends and family members are made uncomfortable with this approach, because it feels like accepting and confirming the patient's delusions—"feeding the monster," as one audience member put it. But Dr. Amador noted that you can't make a person delusional or make the delusion worse by agreement. "You can't talk someone into

a delusion.” The point is not reality testing—which puts you on the other side of the argument—but gaining the patient’s trust.

Empathizing involves aligning yourself with the patient’s angers, fears, and frustrations. You ask, “How does that make you feel?” You show you understand, for example, that what the patient is going through is a scary experience.

Agreeing is the difficult point. The patient will ask in relation to the delusion or to his denial of being ill, “Do you believe me?” Of course, you must be honest, or trust will be lost. So the point is to delay answering that question. You say, “I will answer that, but first tell me more.” Or, “What I think isn’t important, I want to know what you believe.” Or, “Your opinion is the one that matters.” And finally, if the patient has memory problems, you can distract him or her and hope the question will go away. When you finally do answer that question, you can “agree to disagree” about the specific elements of delusion and whether the patient is or is not ill. In this discussion, you try to focus on the problems that the patient sees, not that you see.

Partnering is the last step. If the patient understands that you are trustworthy and feel there’s a need for medication, therapy, or hospitalization, then you can work together to begin planning the treatment.

To see the entire video, which is 111 minutes long and only available through Google Video, go to:

<http://video.google.com/videosearch?q=dr.+xavier+amador>.