



LESSONS LEARNED ABOUT **DENIAL** in Persons with

SERIOUS MENTAL ILLNESS

■ What we are dealing with here is anosognosia—a neurological syndrome that leaves patients unaware that they are ill. ■

By Xavier Amador, PhD

When I was a child, my older brother Henry was my hero. Our father died when I was just shy of 3 years old, and Henry—though only eight years older than me—did a lot to fill his shoes. We were very close and he taught me many important lessons in life, including the importance of being honest with yourself. Henry was always very insightful and responsible. But all that seemed to change after his first hospitalization for schizophrenia. He seemed suddenly to become defensive, in denial, and irresponsible.

After that first hospitalization, and many more that followed in the first few years of his illness, I learned an important lesson: My natural instinct to confront denial head-on didn't help and more often led to disaster. Whenever I discovered that he had once again stopped taking his medication—he never saw it as “his” back then—I would ask him why. Our conversations went something like this:

“I’m okay now. I don’t need it anymore,” he explained.
“But the doctor said you’re probably going to have to take this medicine for the rest of your life. You can’t stop taking it!”
“He didn’t say that.”
“Sure he did! I was at the family meeting, remember?”
“No. He said I had to take it while I was in the hospital.”
“Then why did he give you a supply of medicine to take home?” I argued, trying to prove him wrong.
“That was just in case I got sick again. I’m fine now.”
“No. That’s not what he said.”
“Yes, it is.”
“Why are you being so stubborn? You know I’m right!” I said.
“You’re the one who needs help, not me!”

With every dose of “reality”—*my* reality, not his—I tried to give him, Henry countered with more denials. And with every go-round we both became angrier and angrier. Our once trusting and respectful relationship became one marked by distrust and a surprising lack of respect on both our parts. As you will read below, for professionals working with persons with all kinds of serious mental illnesses (SMI) a relationship characterized by mutual respect and trust is key to many things including the person’s attitudes about treatment, their satisfaction with their healthcare provider, and their ability/willingness to take medicine reliably. Although there is not nearly as much research on family members, my personal experience is the same holds true for family relationships (Amador, 2012; Day, et al, 2005).

Before I turn to that research and other relevant findings, one more comment about my relationships with my brother is in order. Because I didn’t understand the root cause of his longstanding denial I thought he was being stubborn and immature. My accusations and threats to prove him wrong made him angry and defensive. My natural instinct to confront his denial was completely ineffective and made things worse between us. The end result was that he usually walked away from such arguments.

In 1989, when I first started doing research on the problem of poor insight into having a mental illness, there were fewer than 10 studies in the research literature. Today, there are close to 300! There has been an explosion of new research on this problem, and we have learned a great deal. I would like to share the two most important lessons that I—and the field—have learned in that time.

It's Not Denial

Research shows that about 50% of persons with schizophrenia (about 1.5 million in the U.S.) do not know they have an illness, and this unawareness does not improve with education, time, or treatment (Amador, Strauss, Yale, & Gorman, 1991; Amador & Andreasen, 1994; DSM-IV-TR, 2000; DSM-V, 2013). I purposely did not use the term “denial” in the previous sentence because this problem is not denial. Denial is a coping strategy, a way we deal with painful knowledge. People in denial know something deep down inside (unconsciously), but they lie to themselves about it. But the research indicates that this is not what we are dealing with when, after months and years of evidence, the person still does not believe she or he is ill. What we are dealing with here is anosognosia (AH-no-sog-NO-sia)—a neurological syndrome that leaves patients unaware that they are ill (Amador, Strauss, Yale, & Gorman, 1991; DSM-IV-TR, 2000; DSM-V, 2013).

According to the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revision (DSM-IV-TR), “A majority of individuals with schizophrenia lack insight ... Evidence suggests that poor insight is a manifestation of the illness itself, rather than a coping strategy ... comparable to the lack of awareness of neurological deficits seen in stroke, termed anosognosia.” (DSM-IV-TR, 2000, p. 304)

As cochair of the last revision of the *DSM-IV* text on schizophrenia, I was asked to propose changes that would better reflect scientific consensus. Every change considered had to be peer-reviewed by other scientists. The quote above reflects scientific consensus in the field (as of 1999) that poor insight is common in schizophrenia and is linked to executive (or frontal lobe) dysfunction. In the seven years since this update in the *DSM*, many new studies have replicated this finding.

The workgroup on *DSM-V* (our current diagnostic manual in psychiatry) asked me to review the literature again and submit the text for the same section. Here is what the research tells us today:

Unawareness of illness is typically a symptom rather than a coping strategy. It is comparable to the lack of awareness of neurological deficits following brain damage, termed anosognosia...This symptom is the most common predictor of nonadherence to treatment. It has been found to predict higher relapse rates, increased number of involuntary treatments, poorer psychosocial functioning, aggression, and a poorer course of illness. (DSM-V, 2013, p. 101)

If you believe that the person you are trying to help has anosognosia for schizophrenia, rather than denial, then you should not say that this person “refuses to acknowledge he is ill.” That would be like accusing someone of refusing to stop being delusional or hallucinating. We don't do that because we understand that these are symptoms of the disorder and not the person's choice. Armed with this knowledge and some additional research, you can become much more effective at convincing someone who has anosognosia—someone with poor insight—to accept treatment and services.

Relationships are the Key

Too often, people with anosognosia for schizophrenia feel that we (I am speaking here both as a therapist and as a family member) are their enemies. From their perspective we are not allies because we keep trying to convince them of something that they know, with certainty, is not true. In this context it is not surprising that the relationship often deteriorates and becomes adversarial. However, once you understand that the mentally ill person's refusal to accept treatment typically results from a brain dysfunction that is beyond his control, you will see why you shouldn't take it personally or blame him for what appears to be deliberate denial. In fact, from this person's point of view it is common sense to refuse treatment. If we take the psychoeducational, or medical model, approach and tell the person (again and again) that they are ill, we will only drive them further from the people and help we believe is needed.

Research on the “therapeutic alliance” across a wide range of disorders finds that it predicts the effectiveness of treatment and positive treatment outcomes (Amador, 2012; Day et al, 2005). In one study published in the *Archives of General Psychiatry* the investigators studied 228 patients with either schizophrenia or schizoaffective disorder and found that “the quality of the relationships during acute admission [was] an important determinant of patients' attitudes toward treatment [more positive] and [better] adherence to medication” (Day, et al, 2005). This is one of many studies that find the same thing: the therapeutic alliance is a powerful predictor of who will accept treatment and stay in treatment. It is more important than the experience of side effects or many other factors studied. And relationships matter in this way even when the patient has anosognosia for mental illness.

This research begs the question: How does one develop a strong therapeutic alliance? One way to answer that question is to look at studies of interpersonal techniques that have been found to improve treatment adherence. Motivational interviewing, developed more than 30 years ago to help people with substance abuse problems accept treatment, has been well studied and can be very effective in helping people who do not understand they have a mental illness accept treatment and stay the course. In fact, in their review of 20 years of research aimed at improving medication adherence in persons with schizophrenia, a Columbia University psychologist and her colleagues found that “although programs utilizing family therapy and psychoeducation were common in clinical practice, they were typically ineffective [at improving medication adherence, or compliance].” Instead “those programs that utilized [elements] of motivational techniques were effective...” (Zygmunt, Olfson, Boyer, Mechanic (2002); (Paillot, 2009)

In 1998, in collaboration with Aaron T. Beck, I developed a six-session inpatient intervention aimed at improving insight into illness and medication adherence in patients with schizophrenia. This therapy based on motivational interviewing and cognitive therapy did not appear to improve insight as we had hoped at the time, but it did improve the therapeutic alliance. From this experience I pulled together a more simple intervention which added elements of Carl Roger's client centered therapy into the program which was then boiled down to its core communication tools aimed at improving the alliance, turning adversaries into

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allies and helping persons with SMI accept treatment and stay the course (Amador, 2012).

This *communication program*, called LEAP—for Listen-Empathize-Agree-Partner—can be learned by nearly anyone interested in helping someone with poor insight, or anosognosia, accept treatment (Amador, 2012; Paillot, 2009; Ihm, 2009). In fact it has been taught to tens of thousands of healthcare professionals, family caregivers and even law enforcement personnel worldwide (see www.LEAPinstitute.org).

The first step when using LEAP is to stop trying to convince the person he or she is ill. Instead, the goal is listen and respect the person's point of view by actively reflecting it back to them. The importance of listening without judging or reacting to what the person says cannot be overstated. So when a person with schizophrenia talks about the alien transmitter in his brain as the reason he does not need medication, the experience is respected and not contradicted. And the person's feelings about how they have been treated and misunderstood—the anger, depression, loneliness and fear are empathized with. “I would feel angry too if I were in your shoes and people kept telling me I needed medicine when what I really need is surgery to have the transmitter removed. Did I understand you correctly?” When you listen in this way, the person feels respected and befriended. The decision to accept treatment will have nothing to do with being ill but instead will hinge on his relationship with you. The research is clear: The key is to build a relationship in which the ill person feels listened to and respected, and trusts you. Consequently, you almost never give your opinion about the illness or treatment unless it is asked for. You learn how to listen to delusional beliefs (e.g., there's a CIA conspiracy against me) with respect and without telling the person it could not possibly be true.

When asked whether you believe such things to be true, you do not rush to give your answer because you know it will be hurtful; instead you try and respectfully delay giving your opinion. “I promise I will answer your question, but with your permission I would like to talk more about how to help you stay out of the hospital and find that job you told me you wanted. Would that be okay? When you finally do give your opinion, you use what I call the “Three A-tools” (Apologize, Acknowledge you could be wrong, and Agree to disagree). Start with an apology—because it will likely feel disappointing to the person—and a great deal of respect for the other person's point of view. For example: “You keep asking me whether or not I think the CIA is following you. I will tell you, since you asked, but I want to apologize because this will probably feel hurtful. I want you to know I could be wrong, I don't know everything and I just hope we can agree to disagree. I just don't see it the way you do. But I respect your opinion—I will not try and talk you out of it—and I hope you can respect mine.”

After listening respectfully, refraining from giving your opinion, and then when you do give it you use the “A-tools,” you look for areas where you agree, and partner on those. Perhaps it is to help the person stay out of the hospital, get a job, deal with the stress he is experiencing from the conspiracy, or get a full night's sleep. You partner on those things you can agree to work on together.

Your goal is to become a true ally (who thinks treatment might help with a range of problems, not just mental illness) and not get mired in the impasse that begins with your saying “You're ill and need treatment!” and ends with “I am not sick, I don't need help!” (Amador, 2012; Paillot, 2009; Ihm, 2009)

...YOU WIN ON THE STRENGTH OF YOUR
RELATIONSHIPS, NOT ON THE STRENGTH
OF YOUR ARGUMENT

The explosion of research on the problem of insight has taught me many things in the years since Henry first became ill. But mostly it has helped me to have a better relationship with my brother and to help him, and others like him, to accept treatment. By taking the LEAP approach we became friends and allies again. By not arguing and instead listening to him with genuine respect, I learned a great deal about my brother: I learned that he was never being stubborn or irresponsible when he refused treatment—he was suffering from anosognosia and simply following his common sense, which told him he shouldn't take medicine for an illness he didn't have. Among the lessons learned was that I would have done the same thing if I were in his shoes. Most important, by listening instead of arguing I learned that he never stopped being my hero. Today, I feel as proud and lucky to have had him as my brother as I did when I was a little boy. ▼

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