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Separating the illness from the person

By Xavier Amador, PhD

As a health care provider and brother of someone with schizophrenia, I am repeatedly struck by how valuable and healing it is to be able to separate the person from the illness.

This is vital to understand because when we confuse symptoms for the person’s true beliefs or core personality, we make terrible mistakes in our communications, interactions, and expectations.

To help with this task I often use analogies such as: “Would you take it personally if your grandmother, sick with Alzheimer’s disease, forgot who you were?” It would still be very painful, but you would understand it was not personal. She was not forgetting your name because she didn’t love you.

Separating the person from the illness has many benefits. The task sounds simple if you educate yourself about the symptoms of schizophrenia, but answering the question with any certainty becomes a lot harder when “negative” symptoms (involving a loss of functions such as the ability to express emotion, feel pleasure, or have motivation) are blurring the line between the person and the schizophrenia.

The illness posing as the person

“He doesn’t do anything. He won’t even try,” I complained about my brother, Henry, to my stepfather during my first visit

home from college. “He hasn’t worked in a year and won’t apply for jobs.”

My stepfather agreed and said he had tried to motivate him too, but nothing seemed to work.

“He doesn’t seem to care when I’ve tried to talk with him about it! It’s so selfish—his living here with you and Mom and not contributing anything,” I added.

My stepfather was more kind and patient than I was as an 18-year-old know-it-all who was working his way through college. I am glad that some of his example wore off on me and I learned to be more patient with Henry, because what we didn’t know at the time was that he was already ill with schizophrenia.

I found out several years later that he was experiencing hallucinations and delusions. He wasn’t telling anyone about them; in fact, we didn’t learn about these “positive” symptoms (symptoms that involve an overactivation of brain functions) for another three years when he had his first full-blown psychotic episode. When that happened, it was obvious that he was sick. He was hearing voices telling him that our mother was trying to kill him and he had paranoid and grandiose delusions. Antipsychotic medicine helped with those positive symptoms, but not the negative ones.

The negative symptoms were visible—vividly obvious—but we didn’t recognize them for

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what they were. I thought that quitting numerous jobs, dropping out of college, and then refusing to apply for jobs was "Henry" and had nothing to do with his illness. In retrospect, I regret my youthful impatience and judgmental proclamations: He's "lazy," "immature," and "irresponsible."

But at the time I was making the same natural mistake that millions of families around the world have been making for as long as schizophrenia has existed: I was confusing the illness for the person.

The person

Whether the person with schizophrenia has positive symptoms or not, negative symptoms are common. Some patients have prominent negative symptoms with few or no positive symptoms. Their ability to express emotion is nearly lost, their affect is flat—appearing to the uninformed as if nothing fazes them; they care about no one, not even themselves.

Even more troubling is another negative symptom that involves loss of motivation. "Amotivation" is a common negative symptom of schizophrenia. Because antipsychotic medications do little, if anything, to improve this symptom, even patients who are engaged in treatment (and are adherent to their medication and "responding well") continue to exhibit amotivation for years and decades after the positive symptoms have diminished or remitted completely.

My brother had a tremendous amount of motivation throughout

his childhood, adolescence, and early years in college before he dropped out. In fact, he worked from the time he was 12 years old and contributed every penny he had to our mother who had been widowed with four children after we fled Cuba in 1962. Henry was someone she relied on: to fill in for my father, to contribute to the family finances, and, when he turned 16, to drive us to the grocery store, doctor's appointments, and all the other places we needed to go.

Henry had many good friends, was an outstanding pitcher on his high school baseball team, he had girlfriends, jobs, and did well enough in school. He was a highly motivated student, worker, athlete, and friend. When my mother remarried, many of the burdens were lifted from Henry's young shoulders, but that didn't mean he felt less responsible. At the age of 22, he took responsibility for driving our blended family (six out of the eight brothers and sisters he had) cross-country when we moved from Ohio to Tucson. Our parents had gone ahead because of my father's new job and to buy a house. Henry was delivering us and all our earthly belongings in a rented truck. When I look back on what he was like before he became ill I asked myself: Does this really sound like a person who was selfish, immature, and irresponsible?

Hindsight is 20-20. I suggest that if you have this illness and find yourself saying negative things about your own character—like I said about my brother's when he first became ill—take a careful look

at how you were before you were diagnosed. And if you are a loved one or health care provider, make sure you remember how this person behaved before he or she became ill. Because it not only helps to stop the criticism—which is extremely important—but also because it can change our expectations and the ways in which we help.

My brother's positive symptoms were largely under control. But he hit a glass ceiling. He never returned to school or found paid employment. I believe the symptom that kept him from breaking through this barrier was the loss of motivation. He didn't have the ability to easily start difficult tasks and when he did, he rarely had the ability to persist. That is what amotivation looks like.

Over the years I learned to separate the illness from the person and to help others to do the same. It made me less critical, more encouraging, and ultimately more effective. It also helped me to not join the ugly chorus in my brother's head—the one that told him he was a failure and lazy.

The lesson I learned was to look to the past to be clear about the person I was looking at today. With that clarity of vision, I was able to help him rather than participate in bringing him down. ★

Xavier Amador, PhD, is an adjunct professor at Columbia University and the author of numerous scholarly and trade publications, including the best selling book I Am Not Sick, I Don't Need Help! How to help someone with mental illness accept treatment (Vida Press, 2007).