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Psychotic Spectrum Disorders: A Conversation with Jane G. Tillman, PhD, ABPP

Part 1: What are Psychotic Spectrum Disorders?

“Psychotic” is a term that gets tossed around a lot in the culture. How would you frame it, as a clinician?

To start, psychosis represents a spectrum of disorders with many different etiologies or origins. People are most familiar with the term schizophrenia, but schizophrenia is probably going to turn out to be an umbrella diagnosis for many different conditions. People can be psychotic for all kinds of reasons, in the wake of substance abuse — with hallucinogens, for example— or because of schizophrenia. People who are bipolar can become psychotic, and so can people with various degenerative disorders. The interaction between biological and genetic vulnerabilities with family and cultural factors is known to be complex. At the Austen Riggs Center we appreciate the complexity of the etiology and treatment of psychosis, providing an integrative treatment approach using psychotherapy, family therapy, and medication along with intensive social engagement through the therapeutic community program.

What are the chief symptoms?

The symptoms most people are familiar with are what we call positive symptoms: hallucinations, delusions, paranoid beliefs, unusual behavioral or mood manifestations. Those are often treated acutely with medications and patients respond well to that.

Once you’ve treated the positive symptoms, people can enter what’s called the negative phase of a psychotic disorder: lack of motivation, lack of direction, flatness. There’s a quality of just being slowed down, and a withdrawal or social isolation. This can be debilitating. It is also much harder to identify and treat. Everyone is familiar with the worst-case psychotic disorder, which is the disheveled person in the street who makes everyone anxious. That’s the more obvious, positive symptom.

People in the negative phase don’t look so disorganized because they’re not having hallucinations or delusions, but they can be very isolated and shut down. They often don’t really know what they want to do. They may feel lost and ashamed. They’ve gotten help from medication, but they have a whole other road ahead of them. How are they going to pick up the pieces of their lives, go on and adapt?

One feature of these disorders is tremendous denial that a person is troubled, or needs treatment. It can be very hard to treat someone who other people think is impaired when that person doesn’t think so. Typically, you see problems with family members, problems in employment. These individuals see themselves in the world quite differently, and often aren’t interested in receiving any treatment. This creates a lot of frustration in attempting to offer help.



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Part 2: More About Psychotic Spectrum Disorders and Working with Psychosis

Let's take a step back for a moment. What does psychotic mean in the first place?

For a lay-person, it means an altered sense of reality, a lack of shared reality with other people. Of course, we all have our own slant on reality, but hopefully we have enough touch points or shared points where we can have what we call a consensual reality.

What's a test you use to identify consensual reality?

When someone is in treatment you are looking to see if there is some acknowledgment of the trouble they have in their lives. A patient who has been arrested by the police, taken to jail, may say, "None of this ever happened." They just hit someone yesterday, and you can point to documentation. They'll say, "It's a lie." This disagreement about fundamental shared experience is difficult for the patient, their family, and for those providing treatment.

Is violence often a component?

It can be, but not often. You hear about violence in the news a lot and this contributes to the stigma that comes with psychotic disorders and schizophrenia. But only a minority of psychotic individuals is violent. That's one of the great misconceptions that may keep people from admitting their trouble. The label "psychotic" segregates these individuals from the rest of humanity. People don't want to be segregated and written off. And this is a population that is vulnerable to segregation, because they commonly misread social cues and think other people are trying to harm them. It can happen--though it's rare--that patients become aggressive out of the fear of being harmed by others.

In the minority of cases where there is violence, that's usually where it starts?

There may be an idea that someone is trying to hurt them, out of fear, or suspicion, paranoia — a delusion that someone is trying to attack. Also, in some psychotic episodes associated with bipolar disorder, people get revved up to the point that their judgment is clouded.

What do you find most compelling about working with people suffering from psychosis?

It's a great question because I love working with these patients even though it's heartbreaking sometimes. These are human beings at risk of becoming society's throwaways. They're often shuffled from one drug trial or one symptom management situation to another. And mental health professionals struggle to treat these people, because they can make you intensely uncomfortable. Patients with symptoms of psychosis can be oppositional and very negativistic. Imagine how painful it might feel to be isolated in a world of private belief without understanding others or feeling understood by them. In therapy, there may be long silences as patients struggle to put difficult thoughts and feelings into words. For most people there's a longing for dignity and a wish to be respected. Patients want to find a place where they don't feel exposed, ashamed, and humiliated. And often, patients are just grief stricken, asking, "Why me?" Often, on the surface, there may be delusions of grandeur, feelings of being omnipotent, of knowing better than everyone. But when that is stripped away, there's a profound grief. We have many patients who are insightful and say 'I would rather be crazy than face the sadness I have to face in my life,' with so many relationships lost, so many opportunities lost, and people who think their future is lost. This is why it's vital to get people into treatment as early as possible.



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Part 3: What Psychosis Looks Like

One source of dignity is work, but that must be challenging with people with symptoms of psychosis.

Yes, sadly, it is. Concentration and attention become very difficult. Certainly, if you have the negative symptoms, you're not likely to be motivated. Really it's a long, long process to get people rehabilitated to the point that they can consistently work in a job. It is quite demoralizing to be disabled by a serious illness. This frequently leads to shame and humiliation. Often people with psychosis are dependent on their families for ongoing financial and social support.

There also can be a lot of family strife about what is expected in return for that support. Families may feel angry because they see the symptoms of the disease — out of control drinking, say — as simply bad behavior. When parents find out they have a child with schizophrenia, you have to do a lot of education, and help them manage their grief—particularly when it looks like it's going to be impairing over the long-term.

What portion of the psychotic population will fall into this category of long-term struggle?

About a third of people diagnosed with psychosis will have one episode, recover, and that's it. Another third will have an episode, recover fairly well, though maybe not to baseline, and have recurrent episodes. So you'll see a pattern of remitting and relapsing over the course of their life. Another third of people will have a break, and never really recover. They may be paranoid or delusional in a very chronic or ongoing way. What I've seen is that when you tell people they have schizophrenia, they all assume they're in that last category. But a lot of people with schizophrenia do recover, and go on to lead productive and satisfying lives.

What do people suffering psychosis look like and talk like? In other words, how would they appear to a clinician or family member?

One sign would be serious disruption in social relationships, family relationships and a loss of overall functioning such as an inability to work, go to school, volunteer, really to function in the world.

We often encounter patients who have serious substance abuse symptoms, perhaps in an effort to treat their own symptoms via alcohol or other substances. The negative symptoms of schizophrenia likely have some relation to depression and patients following an acute psychotic episode often feel extremely depressed and defeated.

Many antipsychotic medications have significant weight gain as a side-effect, and that's one reason why the mortality rate is higher in this population. Smoking is also prevalent in patients with psychotic illnesses, contributing to ongoing health concerns.

What's it like on the inside? What do people psychotic people feel like and think like?

I think people can feel extremely lonely. People with psychotic disorders may push people away with odd, angry, scary behavior. And the patients themselves know something is not right and so they may avoid other people. Patients often have the feeling that no one understands them, because the reality of the psychotic person is often quite at odds with the perceptions of the people around them. So they can become angry, puzzled, and frightened by that.

Does it manifest physically?

I think people can be either cut off from their bodies, or very frightened that they don't look right. They might fear they're being stared at. They sometimes have odd ideas about illnesses, for example, or bodily delusions.



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When does psychosis typically manifest?

For males, probably between ages 16 and 30. And a little later in women, maybe around 24 to mid-30s.

There's also childhood schizophrenia, and there are older people who have late in life onset schizophrenia, but the predominant onset is around late adolescence early adulthood, right when people are making the move to leave home, go to school, and function independently.

Part 4: Treatment of Psychotic Spectrum Disorders at Riggs

Tell us about the treatment for this condition in psychotherapy and in the therapeutic community at Riggs? How is this different from treatment in other contexts?

Certainly one of the things we do at Riggs that patients won't get in other settings is 4-times a week individual psychotherapy. Some of the more biologically-based people might say that's a waste of resources on these people, or that can make them worse. There is controversy in the field about the value of insight oriented psychotherapy with psychotic people. The thinking is that, it is an illness to be managed, rather than a person to be understood. The research in this country is very much biological and behavioral. Psychotherapy can include crucial learning, for example, when someone speaks to you, what do you say back? You know, basic training for how to live in the world. That can be extremely helpful to patients

The research in Europe is very different. Americans often are not well-versed in the research from Scandinavian and Finnish treatment studies, but they have substantial positive outcome data on integrative treatment approaches using biological, psychological, family and social-based treatment interventions delivered in a cohesive system.

Our treatment at Riggs closely parallels what the Finnish researcher Yrjö Alanen calls, "need-adapted treatment." The idea is that you work with the needs of the individual with schizophrenia using psychodynamic psychotherapy, family systems work, medication, and community support. That's basically what we do at Riggs. His research used a treatment model very similar to ours, though our residential treatment is longer term. Their treatment is both in the hospital and in the home.

I should say that psychoanalysis has a tarnished reputation in the history of diagnosing and caring for schizophrenia. In the late 1940s, the term of the "schizophrenogenic mother" came into the psychoanalytic literature. This was unfortunate, and it put families on the defensive. Groups mobilized to fight what was perceived as "mother-blaming" or family blaming, insisting that these disorders were purely biological. What we now know about mental illness is that the etiology and phenomenology is extremely complex with many variables interacting to produce the symptom picture and the meaning structure of the experience. At this point, it is not possible to simplify these illnesses in terms of cause or treatment.

What we know from research, particularly from Scandinavia, is that family environment does play a role. If people have the genetic makeup or markers for schizophrenia, environment does make a difference in whether it's expressed or not. The research is clear that there's an interaction.

We need to take these people and their lives seriously. They not only have problems with their brain receptors, but also problems with meaning. Even if the trouble begins in an organic dysfunction, they still need to learn to manage their lives. By loose analogy, if you have diabetes, you have to reconfigure your life to take care of yourself and make some recalibrations. It is not optimal to surrender your life to the disease but some changes are necessary. People have to live



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a life that has purpose and meaning and need a lot of help to understand what's happened in order to put together a life that works.

So we provide the opportunity for social interaction and feedback, medication, and skills acquisition — but also, four times weekly psychotherapy. That's radical in this day and age. Many mainstream psychiatrists would think it's unwise to engage in intensive psychotherapy with severely disturbed patients. I think that's a shame. Why would you designate a category of people not to talk to the way you would talk to anyone about the symptoms in their lives and to assist in the development of insight to facilitate adaptation or change?

The therapeutic community program at Riggs is also unusual because our patients have such a range of psychopathology and difficulty. We have very high functioning patients and some very low functioning patients, and we don't segregate them by diagnosis or symptoms. What is remarkable to me is the humanity that the patients show each other; even the most crazy acting schizophrenic person gets feedback. They will hear, "That's not okay." Or, "You're scaring other people." Or, "I think you're doing that because you're scared." Individuals get a lot of engagement around their social presentation, and this is helpful.

It's also helpful that they can determine their own course. In many treatment programs, patients are required to go to groups. At Riggs, patients have freedom to choose their level of involvement, which will differ from others. Our patients with Borderline Personality Disorder are often very smart, savvy, and highly engaged in their interpersonal environment. They benefit from interpersonal contact and may have, (as well as generate in others) intense emotions. For schizophrenic patients, that's often too much stimulation. We have an environment where patients may have as much contact with others as they can tolerate. Then, when they've had enough, patients aren't pressured to remain in groups if it is over stimulating. They are free to self-regulate and titrate their stimulation, which is useful self-knowledge and self-management.

Often, people with psychosis need an environment with low levels of expressed emotion, with less interpersonal stimulation and opportunities for quieter engagement. The Riggs community has enough people to provide a lot of life and spark and energy, but our psychotic patients can move in and out of that environment as they need to. They're not required to be overstimulated, or stay in a situation that's too overwhelming.

It's also important to get medication right. At the outset, we see some patients with positive, active symptoms — hallucinations, delusions, extreme paranoia. The thrust in these cases is toward identifying effective medications. It is extremely traumatic to lose your mind, and at some point, patients need a place to face and think about what's happened to them. Families need a similar opportunity.

The levels of medication used to treat positive psychotic symptoms can leave a person quite sedated in the beginning. It's hard to do psychotherapy with someone who is half asleep. So we try to find an effective dose that treats the symptoms but allows a person to engage in the therapy. Psychopharmacology is both an art and a science; it's very individualized. An effective drug for one person may cause intolerable side effects for another.



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Part 5: Psychotic Spectrum Disorder Outcomes, Recovery and Further Resources

What other activities have you seen help people with this condition?

Keeping patients engaged is really key—for example, learning to paint, or working in the greenhouse. Exercise is particularly important if you're going to be on antipsychotic medications because they cause weight gain. Also, informal activities with peers, such as going to the movies and going to dinner together are extremely important. The benefit of the open setting at Riggs is that people can be out in the world, not cloistered and locked up in a hospital. For schizophrenic people who are often so socially isolated, to be out in the world can be quite beneficial.

What positive outcomes have you seen from sufferers of this condition after treatment at Riggs?

There's a wide spectrum of outcome. These are often notoriously difficult conditions to treat. I have seen people do extremely well, and I've seen people get worse and deteriorate, so the outcome possibilities are hugely different. I've seen people go to school, work in a part-time job, and live independently in a community. I've also seen people who really couldn't manage in the open setting, and have left treatment here in a terrible way, sometimes going to locked settings. A major part of recovery is some supportive, social relationships. And if you can tap into people's creative potential, that's a huge boost to their self esteem and ability to express themselves. Certainly engaging the creative side of any person in this situation is very important. For our patients, to go the shop and take instruction from another person is a really big deal. Some people have a hard time allowing themselves to try something new and fail -- and then to try something else, which is what the creative process demands.

What do people who recover have in common?

A lot of our patients are very bright to start with, and they have good family support, so they can take their time and find their way. Many people who recover find a creative pursuit, something that engages them, or a kind of work they can tolerate that gives them a place in the world of dignity and self-respect.

One of the things that is astonishing to me is that the recovery rate for people with schizophrenia in third world countries is reported to be higher than in the U.S.--often these countries have no access to medication. This points to 'village mentality', where there is more social support, a place for people with psychosis in the community. They don't get shipped off or hidden from the to-and-fro of community life. The social environment may support persons with psychosis better in different cultures. In a fast-paced, so called "advanced" country, mentally ill people may become dehumanized problems to be managed rather than people to be understood. Our prisons are perhaps the largest mental health system in the country, full of people with psychotic disorders. And, of course, many sick people are living on the streets.

What books, or other resources, would you recommend for lay people who want to learn more about psychosis?

For an academic treatment of the history of psychotic disorders, I'd send people to Andrew Scull's book *Mad House: A Tragic Tale of Megalomania and Modern Medicine*. It's an historical account of what went on in the Trenton state hospital in the early 1900s. I'd recommend *The Center Cannot Hold: My Journey Through Madness*, by Elyn Saks, a professor, attorney, and MacArthur Grant recipient who has suffered from remitting and relapsing schizophrenia for a number of years. She recounts the experience of her symptoms, her various treatments including psychoanalysis and the important role of medication for helping her maintain her mental health. She does not romanticize schizophrenia and speaks to the profound effects of the course of her illness on her life and work.