

Want to Understand Delusions? Listen to the People Who Have Them

A small group of schizophrenia researchers thinks that personal narratives can tell us what test scores and brain scans can't

From Wired

Grace Huckins, June 7, 2022

For the first decades of Sohee Park's career in schizophrenia research, she rarely stopped to consider what life was like for her research subjects. Now a professor of psychology at Vanderbilt University, Park made a name for herself by studying working memory—the quick, scratch-pad-like memory that helps us keep track of what we're doing. By using simple tasks to deconstruct the workings of the schizophrenic brain, Park hoped to puzzle out the underlying causes of the condition's reality-bending symptoms—like delusions, false beliefs that are resistant to contradictory evidence, and hallucinations, which often take the form of imagined voices.

“We do symptom interviews all the time, where we ask set questions about symptoms—and these are very standardized, and that's what we're supposed to do,” she says. “We never really just chat about life, or their philosophy on life, or how they feel about their condition in general.”

Psychological research on schizophrenia typically looks something like this: A person who has been diagnosed with schizophrenia, or another condition that causes a similar psychosis, takes test after test. Usually, one of these is the PANSS, or “Positive and Negative Syndrome Scale.” Administering this test is generally the only time the researcher will ask their subject about their actual experience of psychosis—and anything the subject says will get distilled into numerical scores from 1 to 7. To the PANSS, a grandiose delusion (“I am the second coming of Jesus”) is the same as a persecutory delusion (“Someone is trying to kill me”) is the same as a referential delusion (“Everyone is talking about me”).

For the past several years, Park has taken a different approach: She asks her research subjects open-ended questions. She's heard about things far beyond the limits of the PANSS, such as out-of-body experiences; imagined presences; and profound, day-long flow states induced by painting. Now her research focuses primarily on how people with schizophrenia experience their own bodies.

Within psychiatry, Park's focus on personal experience is unusual. Academic psychologists have long preferred quantitative and neuroscientific methods, like

symptom checklists and brain scans, over hard-to-quantify personal narratives. But though they present analytical challenges, these narratives can still be studied. Last month, papers in widely read journals—one in *The Lancet Psychiatry* and the other in *World Psychiatry*—have analyzed first-person accounts of delusion and psychosis. To some, this sort of research, which deals in words and ideas rather than numbers and mathematical models, might seem unscientific. But Park, who was not involved in either of those studies, is among a small group of philosophers, psychologists, and neuroscientists who think that first-person accounts provide a better understanding of what psychosis is like and how it works. “In the rush toward wanting to be accepted by biological and physical scientists,” she says, “what we have left behind is, who is experiencing this stuff? Who are the people who actually have these experiences?”

This neglect starts at the point of diagnosis. In the Diagnostic and Statistical Manual (DSM), the so-called bible of psychiatric diagnosis, conditions are defined like scorecards: You must have X of these Y symptoms for Z months to have a particular mental illness. The original goal of this system was to facilitate research by providing some objective basis for deciding who had a mental illness and who did not. But these checklists leave little room for the complexities of real lives. “In my day-to-day encounter with patients, there was very little resonance between what I was listening to in terms of the lived experience—the complexity and the nuance and detail and the context, the life context that this person was describing—and these very reductive boxes that you’re ticking when you make a diagnosis or you think about treatment,” says Rosa Ritunnano, a psychiatrist and doctoral candidate in interdisciplinary mental health research at the University of Birmingham, and the lead author of the paper in *The Lancet Psychiatry*.

In their paper, Ritunnano and her colleagues quote people who describe experiences of newfound purpose, profound guilt, and oneness with the universe. The *World Psychiatry* study, which takes a capacious approach to characterizing psychosis across all its phases, highlights experiences that include childhood isolation, feelings of relief at the onset of delusions, and loss of a sense of self. None of these experiences appear in the DSM criteria for a schizophrenia diagnosis.

When it comes to understanding how delusions actually work, some researchers argue that lived experience is an invaluable tool. Even the idea that a delusion is a *belief* doesn’t necessarily hold up, according to Louis Sass, professor of clinical psychology at Rutgers University. Some individuals, he says, partially recognize that their delusions are false. Others may attest strong belief but hesitate to act on their delusions, which isn’t typical of a firmly held belief. Sass says this suggests that several distinct phenomena may be conflated under the label “delusion.” “If you want to pursue any kind of research, including neurobiological research, you need to bear that in mind,” he says. Distinct sorts of delusions could in principle have very different neural underpinnings—and those could be missed if all people with delusions are lumped into a single category for a brain scan study.

Even hallucination, an ostensibly simpler category, may cover multiple distinct experiences. Nev Jones, an assistant professor at the University of Pittsburgh School of Social Work who herself has direct experience of psychosis, has found in her research that “auditory” hallucinations aren’t necessarily as auditory as people assume. In a 2015 paper, she and her colleagues reported that under half of people with auditory hallucinations actually experience them as voices. For others, they more closely resemble thoughts than sounds. The mistaken assumption that these hallucinations involve sound, Jones says, could lead neuroscience awry. “You’re conceptualizing and operationalizing a phenomenon in a certain way, which would lead you to expect certain functional patterns in the brain,” she says. “And you’ve completely misunderstood and mischaracterized the underlying core phenomenon.”

These misunderstandings don’t just influence how delusions and hallucinations are conceptualized and studied—they affect how clinicians go about making people feel better. Often in psychiatry, the goal of treatment is just to bring down numbers on the PANSS, says Philip Corlett, an associate professor of psychiatry at Yale University. Reducing someone’s score may involve getting them to acknowledge that their delusions are false, but that might not always be the best step forward. Ritunnano and her colleagues argued in their article that, although some delusions may be terrifying or lonely experiences, others can create meaning, positive emotions, or a profound sense of wonder. The goal of treatment, says Corlett, should be “helping [patients] change or reconcile the things that are most bothersome about the experience, rather than making assumptions based on what we’ve read in the textbook.” And identifying those goals requires listening to what psychosis is like for each person.

Sarah Keedy, an associate professor of psychiatry and behavioral neuroscience at the University of Chicago, as well as a clinical psychologist, has found this approach essential to her therapeutic practice. She has worked with people who find their delusions so distressing that they barely leave the house—and rather than trying to resolve the delusion, she focuses on that distress. Treating these patients, she says, doesn’t involve convincing them that they are wrong—it involves listening, building trust, and then making small suggestions that might improve their quality of life, like taking a walk around the block.

In her neuroimaging research, however, it can be trickier to accommodate this nuance. While some types of delusions can feel very different—for example, grandiose and persecutory delusions seem almost antithetical—neuroscience studies often have to elide those differences for practical reasons. Finding differences between the brains of two groups of people is potentially possible in a small study; finding differences among 10 groups is not. “To get enough signal to rise from the noise, you’ve got to assume you can find the same thing in all those people that you’re looking to measure,” Keedy says.

But some scientists are working to incorporate first-person testimony into their research, despite the inherent challenges. Park asks study participants to report a

phenomenon called a “felt presence,” the sense that someone is there when they in fact are not, by using software to digitally “paint” a silhouette of a body to show the location of that presence. That way, she can directly compare different people’s experiences. Using this method, Park has found that people with schizophrenia often experience felt presences within, rather than outside of, their bodies. For his part, Corlett hopes to soon integrate first-person accounts into his research using machine learning. Algorithms can churn through pieces of text and transform their themes, emotions, and coherence, among other attributes, into numbers—and unlike the raw narratives, these numbers could be used for further statistical analysis.

Despite the methodological challenges, many researchers remain committed to this work for a simple reason: Centering lived experience seems more ethical, and more likely to benefit people with mental illness. But Jones also worries about psychosis being defined by neurotypical scientists who have never experienced it and are relying only on the testimonies of others. That harkens back, she says, “to the anthropologists of old.” Some insights into how psychosis works are only going to come from people who have experienced it. “What we are talking about is ineffable, logic-defying, bizarre, as some people would say, interior experiences that even the person themselves struggles to translate into language,” Jones says.

For Jones, there’s a simple solution—get more people with histories of psychosis into academia. Through mentorship and advocacy, Jones is working to counter the forces that keep people with histories of serious mental illness out of leadership positions in research. Ultimately, she hopes these experts are the ones writing about what delusions and hallucinations are like in academic journals—and neurotypical researchers are the ones listening. “It’s really more about bringing about humility in people, humility and interest in really hearing people’s stories, not in thinking they have the expertise and answers,” she says.