



By Rachel Aviv

Ms. Aviv is the author of the book "Strangers to Ourselves: Unsettled Minds and the Stories That Make Us," from which this essay is adapted.

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Several years ago, when I was <u>reporting on clinics</u> for people in the earliest stages of psychosis, I met many young patients who were struggling to express what was happening to their minds. They described their condition as disabling, but it was still so new that it had not remade their identities or social worlds. When I asked one woman to describe her symptoms, she told me there was no language. She said, "It's like trying to explain what a bark sounds like to someone who's never heard of a dog."

Another woman, a graduate student who had just been diagnosed with schizophrenia, started keeping a journal when she realized she was having psychological experiences that she didn't know how to describe. She began making up phrases: She was struggling with "migrating electrical sensations" and the sense that "words were alive." She became preoccupied by what she described as the "overwhelming strangeness of the world."

The graduate student studied the definition of schizophrenia in the Diagnostic and Statistical Manual of Mental Disorders and, over time, worried that she was inadvertently bending her own behavior to better fit the bounds of that category. She became self-conscious about the experience of thinking and began to wonder if she heard a soft voice behind each thought, until she felt she was hearing voices, a symptom of the disorder. She was no longer sure what was her authentic experience and what had been suggested to her by experts.

Over the course of their treatment, the patients at these clinics learned new ways of explaining why their lives had changed. They began to use terms like "brain disease" and "chemical imbalance." Expert explanations replaced their idiosyncratic attempts to make sense of the world. One patient, who suffered from delusions about publicly humiliating himself, told me, "The hippocampus is firing too much and telling me to be afraid." Another said, "It's the adrenaline, the epinephrine, and the norepinephrine; and the amygdala can either heighten the anxiety or diminish it, depending on which direction I take with my thoughts."

When these patients could recognize that their unusual experiences were symptoms stemming from disorders in their brains, they were said to have "insight" — a pivotal, almost magical word in psychiatry. In a seminal 1934 paper in The British Journal of Medical Psychology, the psychiatrist Aubrey Lewis defined insight as the "correct attitude to a morbid change in oneself." A patient with the "correct attitude" understands, for instance, that the spirits of dead people are not suddenly talking to her, that the voices she hears are symptoms that medication can silence. Insight looms large in decisions about whether to hospitalize people against their will, and it is assessed nearly every time a patient enters a psychiatrist's office.

But the "correct attitude" may depend on culture, race, ethnicity and faith. <u>Studies show</u> that people of color tend to be rated as lacking in insight more than those who are white, perhaps because doctors find their modes of expressing distress unfamiliar, or because these patients have less reason to trust what their doctors say. In the starkest terms, insight measures the degree to which a patient agrees with her doctor.

The correct attitude is also historically contingent. Fifty years ago, at the height of the psychoanalytic era, a patient was said to have insight if she could recognize, say, her repressed hatred for her mother and the way that emotion had structured her life. But by the 1990s, psychoanalytic theories fell out of

favor and the correct attitude came to rest on a new body of knowledge: Mental illness was seen as a neurobiological problem, and people had insight if they understood that they had disorders of the brain. After the surgeon general's first ever report on mental health, in 1999, which was focused on reducing the stigma of mental illness, the surgeon general announced that there is "no longer any scientific justification for distinguishing between mental illness and other forms of illness," in part because both had biological causes.

But while a biological framework has alleviated some kinds of stigma, it has exacerbated others. A <u>recent meta-analysis</u> of 26 studies concluded that people who saw mental illness as fundamentally biological or genetic were less likely to blame mental conditions on weak character or to respond in punitive ways, but more likely to view a person's illness as uncontrollable, alienating and dangerous. The disease came to be seen as static and unyielding, a strike of lightning that couldn't be redirected. In her memoir "The Center Cannot Hold," Elyn Saks, a professor of law, psychology and psychiatry at the University of Southern California, wrote that when she was diagnosed with schizophrenia she felt as if she were "being told that whatever had gone wrong inside my head was permanent and, from all indications, unfixable. Repeatedly, I ran up against words like 'debilitating', 'baffling,' 'chronic,' 'catastrophic,' 'devastating' and 'loss.'"

In creating a shared language, contemporary psychiatry can alleviate people's loneliness and make frightening experiences legible and communicable, but we may take for granted the impact of its explanations, which are not neutral: They alter the kinds of explanations that count as "insight," and how we expect our lives to unfold. Psychiatrists still know little about why some people with mental illnesses can lead fulfilling, functional lives and others with the same diagnoses feel as if they are defined and disabled by illness. Answering the question, I think, requires paying more attention to the distance between the psychiatric explanations for illness and the individual stories and languages through which people find meaning themselves. Even if questions of interpretation are secondary to finding effective medical treatment, these stories change people's lives, sometimes in unpredictable ways, and bear heavily on a person's sense of self — and the desire to be treated at all. When newly diagnosed people lack insight, this might be because of the severity of the illness, but it may also be because they don't want to cede control over their identities. Though psychiatrists have worked to pay more attention to the perspectives of patients in recent years, they sometimes treat signs of mental illness without regard for whether they are the source of a person's distress.

Naomi Gaines-Young, who became a mother as a teenager and whom I interviewed for many months for my book, told me that when she developed psychosis she didn't accept that she had a mental illness, because the concept seemed so far removed from the substance of what she was going through. When she was in an unmedicated state, she said, "I felt I was being shown things that were being hidden from me all my life about the reality of me as a Black woman in America raising children." Ms. Gaines-Young wanted to talk with her doctors about the disapproving looks that people gave her and her babies on the street, but when her doctors reinterpreted these experiences as symptoms of bipolar disorder, it intensified her sense that reality could not be trusted. In her medical records, a doctor wrote, "insight is nonexistent." To have a new explanatory framework foisted onto one's life is not always healing or generative. It can also feel diminishing, a blow to one's sense of self. "Where is the sensitive side of psychiatry?" Ms. Gaines-Young said. "They missed the mark. The doctors' lack of knowledge about who I am and where I come from pushed me farther and farther away."

Ms. Gaines-Young ended up incarcerated for a crime she committed when she was psychotic, and she became close with a prison librarian with whom she discussed the books she was reading each week. She felt grounded by a deep connection to another person, and when she was sick, she trusted the librarian's assessment of her state of mind. When, after going off psychiatric drugs, the librarian told her, "I don't fully recognize you," Ms. Gaines-Young decided to start taking medications again. "She knew me intellectually, philosophically, and even on some level spiritually," she said. "She was a huge barometer to judge my wellness and non-wellness." Ms. Gaines-Young went on: "She wasn't treating me like a problem to be fixed only with medication. She understood the language I was speaking."

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https://www.nytimes.com/2022/09/20/opinion/us-mental-health-insight.html