



Moment *of* Impact

A young person's first psychotic break often marks the beginning of a lifelong battle with schizophrenia. But new research heralds a radical shift in how psychosis might be treated in its early stage—and may help crack its mysteries.

by SABINE HEINLEIN
photographs by REINHARD HUNGER



ON A MIDWINTER NIGHT TWO YEARS AGO, Beatrice* saw a skull appear in the pattern of her bedroom curtain. A thick layer of snow blanketed the Long Island town where she lived with her parents and younger sister, Stephanie*. Everyone else in the house was asleep. The skull was silent, but Beatrice knew what its presence meant. She laced up her boots. It was time to run.

A 22-year-old college junior majoring in English literature, Beatrice had barely left her room in two weeks. At first, she'd had a gnawing sense that her friends were talking about her behind her back, privately hissing about what a terrible person she was. Soon, glances from family members telegraphed that they too were against her. She barricaded herself in her room. Her interest in food and sleep faded. She had a powerful urge to keep the television turned on. At one point, it was tuned to an episode of the '90s sitcom *Martin*, and she was overwhelmed by a need to watch it. The sitcom seemed to connect with her as no person could.

Stephanie—only 18 months younger and as close as a twin to Beatrice—desperately tried to understand what was going on with her sister. “At first she would say things that were just weird,” Stephanie recalled. “She came into my room looking a little off. I asked, ‘Are you OK?’ and her response was, ‘I’m fighting, I’m fighting,’ and she walked out. Eventually she was just lying there with her eyes open, looking up to the ceiling. When I came and sat by her bed, her responses would be very slow and wouldn’t make any sense. She’d stare at me, then look back up. It was as if she was there, but she wasn’t.”

Her family became distraught over her behavior, which seemed not only bizarre but entirely out of character. The Beatrice they knew was responsible, personable, and calm. She was always able to remain level-headed, even when passions around her ran high. As an ambitious daughter of Afro-Caribbean immigrants, she managed to balance being a commuter student at a private university in New York City with part-time work, family obligations, and a social life.

Beatrice’s parents became convinced that she was suffering from some kind of spiritual illness. Devout Christians, they gathered the members of their close-knit extended family to read from the Bible and pray for her. Surely, her mother thought, Psalm 27 would help her sick daughter as it had strengthened her during her difficult first years in the United States. “Deliver me not over unto the will of mine enemies, for false witnesses are risen up against me...”

Then Beatrice saw the skull. As she got ready to make her escape, the family awoke and implored her not to go. She was adamant, so her father insisted on at least driving her to a friend’s house. In the car, Beatrice felt gripped with fear

of her father, certain he was intent on harming her. She swung the door open, rolled out of the moving vehicle, and started running. She banged on a random door and begged for help from the startled stranger who answered. When police officers arrived and guided her into a waiting ambulance, she thought they were angels.

A doctor at the community hospital where she was taken that night suggested that Beatrice check herself into Zucker Hillside, a psychiatric hospital in nearby Queens. All Beatrice knew when she got to Zucker Hillside was that she had successfully escaped her menacing family. She could finally rest—after

nearly two weeks with little sleep, she was exhausted. Beatrice didn’t know that she was having a psychotic episode with symptoms of the earliest intimations of schizophrenia. Doctors established that she hadn’t been smoking marijuana, which is known to spark psychosis in some, nor was there any history of mental illness in her family, another risk factor. For all anyone could tell, Beatrice’s break with reality seemed to come from nowhere.

DOWN THE RABBIT HOLE

SCHIZOPHRENIA, AFFECTING ABOUT 1 percent of the population, is cruel and corrosive. It typically emerges in young people in their mid-teens to mid-20s, preceded by a prodromal phase—a period of weeks, months, even years when their grasp on reality seems to crack and slip away. They may perceive things that aren’t there, misinterpret social interactions, or struggle with abstract thought—feelings that many people experience at one time or another but that don’t always escalate. For some, though, the feelings bloom into active psychosis, a constellation of symptoms and behaviors that can include hallucinations, delusions, cognitive impairment, and disorganized speech. At least two symptoms must persist for at least six months for someone to meet the diagnostic criteria for schizophrenia, although the disabling effects of psychosis begin long before then.

There’s no tidy explanation for what causes schizophrenia. Genetics is a factor: 10 percent of those with a first-degree relative who’s schizophrenic develop the condition themselves, and among identical twins, one’s being schizophrenic puts the

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other's risk at 50 percent. But a genetic predisposition is neither a guarantee that someone will develop the disorder nor a requirement. Researchers increasingly believe that schizophrenia is provoked by a complex interplay of biological, social, and psychological factors; different people seem to be more or less vulnerable, and a variety of stressors mingle with the underlying vulnerabilities to incite symptoms. The clustering of psychotic episodes among adolescents and young adults is at least partially explained, experts say, by the intense developmental challenges at that age.

"The experience of transitioning to adulthood is tremendously stressful," said Patrick McGorry, a psychiatrist and professor of youth mental health at the University of Melbourne in Australia.

"There are a lot of major tasks you have to master during this transition, and there's also often exposure to drugs, especially

cannabis and stimulants. I suspect that the interaction between those environmental factors and epigenetics, which affects the expression of genes, is the main factors that trigger psychosis."

For more than half a century, the troubling symptoms of psychosis have been treated primarily with antipsychotics, a class of psychiatric drugs that block dopamine, the neurotransmitter that regulates the brain's motor and cognitive control as well as its motivation-and-reward system. Antipsychotics were first developed in the 1950s, and their effectiveness in bandaging symptoms led to a still prominent theory that psychosis is related to a problem with dopamine regulation. But even as they successfully relieve some disabling symptoms, the drugs are often accompanied by side effects so unbearable, including sluggishness, tremors, and extreme weight gain, that many patients stop taking them. The reliance on heavy doses of drugs, along with patients' non-adherence to treatment, has led many on a progressive downward spiral of relapse and recurrent hospitalization. As such, a first psychotic episode often marks a fast track to lifelong disability.

"It's wonderful that we have them, but it's not enough just to give patients pills and cross our fingers that they continue to take them," says Joel Gold, the former director of psychiatric emergency services at Bellevue Hospital Center in New York City. "There've been a lot of failures over the last 50 years with that model."

During the past three decades, however, an alternative method of dealing with psychosis has been making its way around the world, based on work McGorry pioneered in Australia beginning in the 1980s. He recognized that although young patients experiencing their first psychotic break were quite different from the typical middle-aged patients with full-blown schizophrenia, they were often treated the same way—with heavy doses of antipsychotics to lessen the symptoms and not much else. McGorry took a more proactive and optimistic approach to young people's recovery, inspired by the staging sys-

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metric, research has repeatedly shown, is how early the care begins after psychotic symptoms commence, although it is not entirely clear why.

"One theory is that a delay in treatment is biologically toxic, as it is with cancer, where the illness spreads during the delay," McGorry says. "There's a lot of research now underway to see if the active psychotic process changes the brain in an adverse way over time and whether that may lead to a less robust treatment response. We know there's a loss of gray matter in parts of the brain, but the changes are quite subtle on scanning. And while there's some evidence that medications are neuroprotective, other evidence says medication actually accelerates the gray matter loss."

Regardless of whether researchers can pinpoint a biological risk in delaying treatment, "there's a much more obvious process that happens, and that's psychological and social toxicity," McGorry says. "A 17-year-old becoming psychotic while her peer group is moving out of the house, going to college, and becoming independent is missing all these milestones in development. What's very difficult to repair is the tremendous psychosocial and functional damage to people and their families, unless you prevent it from happening in the first place or tackle it comprehensively in the critical early phase."

In Australia, just such an approach has led to the creation and expansion over the past 10 years of a program called Headspace, a national network of mental health facilities oriented toward young people. Headspace is located in ordinary places such as shopping malls and are designed in some ways like youth cafes or community centers to reinforce the normalcy of seeking help. Further, they operate on a primary care model, inviting young people who experience any psychological challenge of any severity, so as to effectively reach those in the nascent stages of psychosis and ideally avert hospitalization.

Early intervention services for first-episode psychosis

tem that guides cancer care. Taking aim at first-episode psychosis, he and his colleagues offered a range of treatments, including cognitive behavioral therapy, vocational help, family support, and substance-abuse intervention, as well as traditional antipsychotic drugs, although administered at a much lower level than was typical.

What McGorry found, and which has since been successfully replicated elsewhere, is that young patients who receive such multifaceted care are more likely to go back to school or work and resume a functional life and less likely to develop chronic, debilitating schizophrenia than those who get treatment-as-usual. In one study, researchers at the University of Manchester found that the risk of developing a full-blown psychotic disorder was lowered by over half in patients who received cognitive behavioral therapy for two years. A key





have also become the norm in parts of Canada and Europe. In the United Kingdom, they were instituted by the National Health Service in 2004. But in the United States, adoption of the care prototype has lagged—until recently. In 2009, Congress apportioned \$35 million for the development of evidence-based treatment for first-episode psychosis and for proof that the treatment can be feasibly implemented in existing community clinics. In 2014, it followed up with another \$25 million in block grants for states to develop early-intervention programs. The results of the most significant and comprehensive study to date of these programs captured national headlines when they were published last fall in the *American Journal of Psychiatry*. Based on data from 34 clinics in 21 states, the study found that first-episode psychosis patients who receive team treatment, including talk therapy and low doses of antipsychotics, fare better than those who receive conventional care—and that the sooner they start treatment after symptoms begin, the better they do.

In affirming, with unprecedented authority and rigor, that the approach works, the study could fundamentally change how psychosis is viewed and approached in the United States, where the median duration of untreated psychosis is 74 weeks and the overall economic burden of schizophrenia is estimated to be \$63 billion a year, including costs related to law enforcement, homelessness, and loss of productivity due to family caregiving and to suicide.

“The message is that it’s important to do the right things, and it’s important to do them at the right time,” says Robert Heinssen, the director of the Division of Services and Intervention Research at the National Institute of Mental Health, who oversaw the study. “The really exciting thing here is that six years after this study started, it’s already being implemented very broadly. By the end of 2016, we should have one or more of these programs operating in every state. That’s a very rapid shift in capacity.”

LOST, THEN FOUND

THE FIRST TIME I met with Beatrice, we had pancakes and coffee at a Queens diner. A slender young woman with inquisitive brown eyes, wearing shiny oversized earrings and a colorful headscarf, she recalled how at Zucker Hillside she refused at first to take the antipsychotics she was offered, and then did so only reluctantly and with suspicion. “That was my paranoia,” she said. “I was always questioning and pestering the nurses about what I was taking and how much.” As the drugs took hold, they effectively blunted her symptoms, but they also made her so tired she

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could barely move, and so ravenous that she ate constantly, gaining 25 pounds in no time. In the psychiatric ward’s day room, she listened quietly to other patients. Some had cycled in and out of institutions for much of their adult lives. To Beatrice, they seemed far worse off than she, but they also signaled that a terrible future might be in store for her.

After about two weeks, her psychotic symptoms gone, she was discharged and enrolled in Zucker Hillside’s Early Treatment Program, an outpatient service for patients ages 15 to 35 that is modeled on the first-episode psychosis programs in Australia and elsewhere. Arriving for her first appointment, she found herself in a big, sunny room appointed with beanbags, a foosball table, a TV, and plenty of magazines. An adjacent space served as a thrift store manned by other patients, and flyers on the walls advertised an upcoming pizza

party. It seemed more like the common area of a college dorm than a psychiatric facility. Though skeptical, she was surprised by how much she liked being there.

She was introduced to her three-person team: a nurse practitioner she would meet with every other week to assess her medication and mental health, a vocational specialist who would help her manage her re-entry to work and school, and a social worker for one-on-one talk therapy sessions. The team emphasized that nothing was obligatory and that Beatrice was expected to actively participate in directing her care.

They also talked about involving her family, an important part of first-episode treatment, yet something that made Beatrice wary. There had been a lot of tension in the weeks after she came home from the hospital, and she harbored anger toward her parents. Out of ignorance, perhaps, or shame, they hadn’t fully acknowledged that what afflicted her was a real malady. “In my community, mental illness is not socially acceptable,” Beatrice said. “There’s an idea that a black woman shouldn’t go to therapy—she should just go to church.” Eventually, though, her mother came to the program, learned about psychosis, and was told what to watch out for and how to respond: If Beatrice seemed to feel scared or persecuted again, or if she said things that didn’t make sense or withdrew into her room for prolonged periods, don’t just pray—get in touch with the therapeutic team. Her mother began to understand.

Beatrice’s medication was slowly decreased to a low maintenance dose, and the unpleasant side effects subsided. Then the hardest piece of her recovery came into view. As she fully digested what had happened, she was beset by an overwhelming sadness. How could she move on if the parameters of her

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existence—her very conviction about what’s real and what’s not—could crumble at any time? How could she regain a solid sense of herself after having been so lost? She had always been averse to intimate sharing, but now it was required of her. Her therapist assured her that what had happened wasn’t her fault, and that their work together wasn’t about finding surefire factors that caused the illness but about identifying the stressors that could make it flare again.

Beatrice gradually opened up. After initially describing a happy childhood, she began to recall how unstable her family had felt during their first years in America. “The hardest thing for my mom was finding employment and people to trust,” she told me. “A new immigrant, she didn’t know how things worked. A lot of people took advantage of her. For my dad, the problem was safety. He was carjacked, and my uncle was robbed at gunpoint.”

She also reflected on the evolution of her own identity. An overachiever and a good student at her racially diverse high school, at college she became increasingly self-conscious as she was often the only black woman in the room. “I felt that I had to constantly cross my T’s and dot my I’s so I wouldn’t be perceived as lazy or unworthy of being there,” Beatrice told me. It struck a nerve when she heard students from wealthy families make snide comments about those who depended on grants and loans for their education, as she did. In one class, she cowered when students remarked that black people relied on handouts and didn’t work as hard as white people, while the professor said nothing to dispute the claim.

Nobody can say for sure that Beatrice’s social identity triggered her psychosis. But a lengthy literature shows that immigration is a risk factor for many mental health problems, including schizophrenia. One recent study reported that Afro-Caribbean immigrants in London are nine times more likely to develop the illness than whites. Researchers point out that the stress of settling in a new society and feeling like an outsider, coupled with real experiences of hostility and racism, can fuel paranoia and delusional thinking among those who may be biologically vulnerable. Perhaps most interestingly, children of immigrants have even higher rates of psychosis than immigrants themselves.

“To deny the fact that people who are discriminated against have worse outcomes is naïve,” says Gold. “If someone is predisposed to psychosis, facing these kinds of daily hazards can be contributory. Many immigrants come over past the peak of biologic risk—schizophrenia develops most often in late adolescence or early adulthood. So the child of immigrants is going to be more susceptible to discrimination and bigotry.”

Just being able to identify and talk about the caustic effects of feeling judged was helpful to Beatrice. She also worked on developing techniques to calm herself when she felt stressed or dejected, and to distinguish her own self-image from the reductive image she sensed in the eyes of others. Her therapist encouraged her to paint, an activity that had always soothed her because it felt limitless and it put her in control. “You don’t have to talk,” Beatrice explained. “Shapes can mean anything. You can just put how you feel onto the canvas.”

TREATMENT AS AN ART

DESPITE THE RECENT landmark study, early treatment for psychosis is a long way from becoming commonplace in the United States. A team-treatment approach might work well in urban or academic centers, but it would be difficult to implement in places like Texas, where three out of four counties don’t have a psychiatrist, and an early-intervention “unit” might be staffed by a single overworked nurse-practitioner. Further, most insurance plans don’t cover the novel treatment. “The government backing this model is not the same as insurance companies embracing it,” Gold says.

Practitioners themselves constitute a barrier, especially psychiatrists doubtful of the approach’s scientific legitimacy. “For people who went to medical school, the idea of social intervention seems very squishy,” says Gold. “It’s not ‘clear medicine.’ In science, you have a hypothesis; you give 100 people a drug and 100 people no drug. Although their brains are different, the drug is the same for all. Social interventions are harder to assess. I’m a doctor, and I don’t have a problem with treatment being more of an art than a science. But most doctors aren’t comfortable with that. They’re not going to stop prescribing high doses of antipsychotics because someone talked to them about psychosocial intervention.”

Particularly in the United States, McGorry says, “there’s tremendous faith in the brain-disease model and a belief that the only way we’re going to have an impact on outcomes for schizophrenia, and really all mental disorders, is with breakthroughs in genetics or discoveries of new magic-bullet drugs. A more sophisticated way of thinking about it is biopsychosocial—with respect to the brain, the mind, and the environment. It’s an interaction between the stress of development and a person’s social environment, as well as the brain producing symptoms. The solution isn’t just about finding the gene or the killer drug. It’s much more complex than that.”

Like many patients, after the squall of her psychosis settled, Beatrice was eager to resume her old life as quickly as possible. The vocational counselor at Zucker Hillside promised to help her achieve her goals but also conveyed the need to sometimes slow down. Beatrice took a leave of absence from school but did accept an internship at an art gallery. She found herself sitting at home a lot, ruminating on her psychotic break, in shock that such a thing could have happened to her.

Beatrice returned to college the next fall, graduated the following spring, and celebrated the accomplishment by taking a vacation—her first ever—with her sister and four friends to a beach town where they explored caves, kayaked, and sunbathed. “I didn’t realize how much I needed it,” she told me. This past fall, she was working as a teacher’s assistant at a Manhattan preschool and thinking about applying to law school. She was still meeting regularly with her therapist and taking a low dose of medication, although she’d discussed discontinuing it with her nurse practitioner, who, she said, supported the decision.

“For a year, my issue was accepting that I ‘allowed’ myself to go so far,” she told me. “Looking back now, I think I needed that year. I was trying too hard to be the ‘old Beatrice,’ and I came to realize that that was wrong. I had to let go of old habits and start new ones, or this was going to happen again.” ■

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