

The Impact of Diagnosis

Gareth Fenley

I have been slipping off the balance beam of my life as my routines are disrupted by mental illness. Some familiar and disturbing phenomena have reoccurred, with consequences both familiar and new. More unsettling to me than the symptoms themselves has been the fact that my diagnosis is up in the air.

A consulting psychiatrist examined me and concluded that I had schizoaffective disorder eleven years ago, but that opinion was brushed aside when my recovery from a psychotic break proceeded so well. My psychiatrist diagnosed me with bipolar disorder. I told him more than once during early days of treatment that I was worried about having schizophrenia—an illness I knew almost nothing about that rang like a great bell of doom in my mind. The doctor reassured me that I did not have it, because, he said, schizophrenia is a disease of lifelong progressive deterioration, and I had a good prognosis. He said that when he diagnoses a person with schizophrenia, “it’s time to call the family in.”

My relatives never did care for that doctor because he didn’t talk to them. I held him in high esteem. He was very good with me. He often talked me into following his medical advice when I didn’t want to. And at a critical moment when my therapist recommended that I apply for Social Security disability, my psychiatrist said, “You probably could qualify, but you shouldn’t. You always do best when you are working.” His few confident words inspired me to stay in the job market.

Over the years, my interests and career have led from journalism into mental health. I became well informed about psychiatry. I was eventually surprised to learn that a recovery-oriented outlook can be favorable in people diagnosed with schizophrenia. The more time I spent with these individuals in my new vocation, the farther I traveled from the time I met a young woman who was visiting my undergraduate college twenty-five years ago. She confided to me in a private conversation that she had a disability. “What kind of disability? You can tell me,” I said, with all the naive confidence of a sheltered teenager. “Schizophrenia,” she finally said in a low voice, and I found myself horrified and speechless. She soon left my presence and never returned.

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Informed and much humbled by the events of the subsequent quarter century, dutifully appearing to renew my own prescriptions for psychiatric drugs, I sat down in my psychiatrist’s office chair one day last year and announced, “I’d like to ask you about my diagnosis.”

He gave me one of his level-headed looks. “You have a dopamine problem with an underlying affective disorder,” he said. I tried to get him to put that in terms of something I could identify in the *DSM* and he refused. “You know how they write that book,” he said dismissively. I suppose I know a little about it, and I now work with one of the guys who is writing the next edition, but I didn’t want to waste my precious twenty minutes on an argument. “In psychiatry, you don’t treat the diagnosis, you treat the symptoms,” he said to me. “Don’t worry about your diagnosis.”

I am beginning to suspect that he believes I have schizoaffective disorder after all, but he wishes not to stir up my mind and is going along with one of his often repeated treatment philosophies: “Don’t rock the boat.” Or maybe that’s just my paranoia talking. In any case, I am left to speculate about his motives.

Insurance plans and geography conspired to make me switch psychiatrists. Two doctors down the line I’m working with someone new, and that in itself is enough to unnerve me. I met my latest doc several weeks ago for our initial appointment, and he spontaneously said he wants to explore whether my diagnosis is truly bipolar or schizoaffective. Although he is doing exactly what I had been asking for, the reality of it hit me like bricks. I tumbled into my old rut of imagining a catastrophe, foreseeing that my partner will dump me and I’ll end up homeless.

When I was trained as a certified peer specialist in 2004, the head trainer, Ike Powell of Appalachian Consulting Group, taught my class that “onset of illness” was the first of five stages in the process of recovery relevant to peer support. At a continuing education refresher in 2007, Ike had revised his curriculum. “Impact of diagnosis” is now stage one. He teaches that it’s the “disabling power of a psychiatric diagnosis” that peer support works to dispel.

Well, I took my own medicine by seeking support from several others in recovery. Then I began to see myself in a new way with a mood of better cheer. This past weekend, I was hanging out in my favorite chat room, where I enjoy debating religious and political controversies. Someone tossed a gratuitous insult into the fray, using the label “schizo.” “Hey, no bashing schizos,” I replied. “I work with them, I am friends with them, and maybe I am one myself.”

Within seconds, another participant typed, “Maybe you are hard to diagnose. It took them three years to diagnose me accurately with schizoaffective disorder.” He followed up later by explaining that his mental illness isn’t all bad “because I get to see and hear things other people have to pay a lot of money for.”

Walk a dog through a neighborhood and you will discover a lot of dogs. Call yourself schizo, and you meet other people living on the schizophrenia spectrum.

The main productive points of publicly identifying myself as someone living with mental illness are to establish rapport with peers who have it and dissipate stigma among those who don’t. For those who choose to do this and ride out what happens as a result, life can be full of meaning where there was only chaotic darkness before. That has been my experience.

But there are countless other ways to create meaning and purpose in a life with psychosis. That message came through when I spoke with a man named David last year. He was responding to my invitation for first-person stories of how to live well with schizophrenia. “Don’t tell people you have schizophrenia” was David’s first piece of advice.

He was diagnosed in 1989, began taking antipsychotics, and basically sat on the couch to stagnate. He told me that it took him years to make progress slowly after that. What helped him most, he said, were a supportive family, exercise, prayer, music, writing, and “being willing to believe that it could be different.”

In 1998, he started listening to personal development tapes while he took five-mile walks. He stopped eating junk food and drinking sodas. As time passed, he got involved in Schizophrenics Anonymous, and even went to a conference organized by the group. When I last spoke to him, he was keeping busy with writing plays and romantic dating. He told me it was hard to take risks and try new things like this, but he said he put things in perspective by thinking, “If I’ve been contemplating suicide, then I can take some big risks to stay alive. Now this is my life’s purpose, to recover from this. It is an adventure.”

The adventure of meeting tomorrow’s challenge beckons me. I plan to go to a mental health advocacy summit meeting, where I will represent a consumer perspective. But first, I need to follow my recovery routine and get a good night’s sleep.

Gareth Fenley is a Certified Peer Specialist within the Department of Psychiatry and Health Behavior, Medical College of Georgia. Ms. Fenley also serves as President of the National Alliance on Mental Illness (NAMI) affiliate based in Augusta, Georgia. She can be reached at gfenley@mcg.edu.

