First Person Account: Where Did I Go?

by Mary E. McGrath

The article that follows is part of the Schizophrenia Bulletin’s ongoing First Person Accounts series. We hope that mental health professionals—the Bulletin’s primary audience—will take this opportunity to learn about the issues and difficulties confronted by consumers of mental health care. In addition, we hope that these accounts will give patients and families a better sense of not being alone in confronting the problems that can be anticipated by persons with serious emotional difficulties. We welcome other contributions from patients, ex-patients, or family members. Our major editorial requirement is that such contributions be clearly written and organized, and that a novel or unique aspect of schizophrenia be described, with special emphasis on points that will be important for professionals. Clinicians who see articulate patients, with experiences they believe should be shared, might encourage these patients to submit their articles to First Person Accounts, Center for Studies of Schizophrenia, NIMH, 5600 Fishers Lane, Rm. 10C-16, Rockville, MD 20857.—The Editors.

The reflection in the store window—it’s me, isn’t it? I know it is, but it’s hard to tell. Glassy shadows, polished pastels, a jigsaw puzzle of my body, face, and clothes, with pieces disappearing whenever I move. And, if I want to reach out to touch me, I feel nothing but a slippery coldness. Yet I sense that it’s me. I just know.

I know I’m a 37-year-old woman, a sculptor, a writer, a worker. I live alone. I know all of this, but, like the reflection in the glass, my existence seems undefined—more a mirage that I keep reaching for, but never can touch.

I’ve been feeling this way for almost a year now, ever since I was diagnosed a paranoid schizophrenic. Sometimes, though, I wonder if I ever knew myself, or merely played the parts that were acceptable, just so that I could fit in somewhere. But the illness has certainly stripped me of any pretense now, leaving me, instead, feeling hollow, yet hurting. I twist and turn, hoping to find a comfortable position in which to be just me.

There are still occasional episodes of hallucinations, delusions, and terrible fears, and I have medication for these times. It relieves my mental stress, but I hate my bodily responses to it and the dulling of my healthy emotions. Therefore, I stop using the drug as soon as the storms in my mind subside. And I keep wondering why there isn’t more emphasis on alternative therapies, such as the holistic programs used now by people with physical illnesses.

So I’ve searched, in library books and in articles about schizophrenia, hoping to find other solutions and answers to my whys, how longs, what’s the cure. Some of the information is frightening—the case histories of patients, the descriptions of symptoms. Some of it is confusing, reaming with speculations, yet with every author being certain that his written word is better than the last answer in print. Schizophrenia is genetic—no, no, it’s surely biochemical—definitely nutritional—sorry, but it’s caused by family interactions, maybe stress, etc. Now, with the worship of the technological gods, the explanation is that schizophrenia is a brain disease colorfully mapped out by the PET scanner. I suddenly feel that my humanity has been sacrificed to a computer printout, that the researchers have

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dissected me without realizing that I'm still alive. I'm not comfortable or safe in all their certain uncertainties—I feel they're losing me, the person, more and more.

In the most recently published book I've read, a doctor writes that psychotherapy is useless with schizophrenics. How could he even suggest that without knowing me, the one over here in this corner, who finds a lot of support, understanding, and acceptance with my therapist? Marianne is not afraid to travel with me in my fearful times. She listens when I need to release some of the "poisons" in my mind. She offers advice when I'm having difficulty with just daily living. She sees me as a human being and not only a body to shovel pills into or a cerebral mass in some laboratory. Psychotherapy is important to me, and it does help.

I sound angry—I guess I am—at the illness for invading my life and making me feel so unsure of myself . . . at the medical researchers who now only want to pick and probe into brains or wherever so they can program measurements into their computers while ignoring me, the person . . . at all the literature which shrouds schizophrenia in negativity, making any experience connected with it crazy and unacceptable . . . at the pharmaceutical industry for being satisfied that their pills keep me "functional" when all the while I feel drugged and unreal to myself. And I'm angry at me for believing and trusting too much in all this information and becoming nothing more than a patient, a victim of some intangible illness. It's no wonder to me anymore why I feel I've lost my self, why my existence seems a waning reflection.

But I'm still searching, questioning—looking inside now rather than on the library shelves—just wanting to feel a little comfortable. I know all the negatives: Schizophrenia is painful, and it is craziness when I hear voices, when I believe that people are following me, wanting to snatch my very soul. I am frightened too when every whisper, every laugh is about me; when newspapers suddenly contain curses, four-letter words shouting at me; when sparkles of light are demon eyes. Schizophrenia is frustrating when I can't hold onto thoughts; when conversation is projected on my mind but won't come out of my mouth; when I can't write sentences but only senseless rhymes; when my eyes and ears drown in a flood of sights and sounds . . . and on and on, always more . . .

But I know I'm still me in the experience. And I'm creative, sensitive. I believe in mysteries, magic, rainbows, and full moons. I wonder why it's expected that I be quieted, medicated whenever it seems I'm stepping out of the boundaries of "reality." Should I let anyone know that there are moments, just moments, in the schizophrenia that are "special"? When I feel that I'm traveling to someplace I can't go to "normally"? Where there's an awareness, a different sort of vision allowed me? Moments which I can't make myself believe are just symptoms of craziness and nothing more.

What's so "special"? Well, the times when colors appear brighter, alluring almost, and my attention is drawn into the shadows, the lights, the intricate patterns of textures, the bold outlines of objects around me. It's as if all things have more of an existence than I do, that I've gone around the corner of humanity to witness another world where my seeing, hearing, and touching are intensified, and everything is a wonder.

Music, especially if I listen through headphones, envelops me and becomes alive, breathing high and low notes, and I'm floating on the movement.

Sometimes, in my schizophrenia, I go to the library, feeling like an explorer in a jungle of words and pictures. It can be frustrating because I capture nothing—not even one book chosen and checked out—but I scan the photos, the copied art works, even focus on a paragraph or two, as I venture along the shelves, my eyes jumping from book to book. I soon leave, emptyhanded, yet satisfied by having seen so much.

My illness is a journey of fear, often paralyzing, mostly painful. If only someone could put a bandaid on the wound . . . but where? Sometimes I feel I can't stand it any longer. It hurts too much, and I'm desperate to feel safe, comforted. It seems, at these times, when I reach bottom, that I'm given a message and I feel mystical, spiritual, and like a prophet who must tell anyone that there's really nothing to fear. A white light often appears, branding this message on my very soul, and those who are most afraid will see it in me and be at peace. And I somehow feel better for being the courier.

These "special" moments of mine—there are so few, but I look for them and use them to help me pass through the schizophrenic episodes. And I can't even predict when or if these moments will come. But I won't deny their existence; I won't tell myself it's all craziness.

I'm hopeful about the ongoing research to find an answer to schizophrenia, and I'm grateful for all the caring and the help of those in the mental health profession. But I know that I'm the schizophrenic living the experience, and I must look inside myself also for some ways to handle
it. I have to be able to see me again as a real person and not a fading reflection.

The Author

Mary E. McGrath is a sculptor who has been working with wood for the past 7 years. She has just begun to exhibit her pieces in area galleries and shows. In addition, she also works as a full-time employee of the Federal government.

Available From NIMH

Free single copies of Special Report: Schizophrenia 1980 are available to requesters. The report summarizes recent results of schizophrenia-related research. Topics covered include diagnosis, genetics, biology, psychophysiology, perception and cognition, family studies, and treatment.

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