Schizophrenia and Other Psychotic Disorders

INTRODUCTION

We begin this book with the first person accounts (FPAs) written by people who have been diagnosed with or have experienced the symptoms of a psychotic disorder. The *Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text revision (DSM-IV-TR)* groups together under this category disorders that involve a variety of serious symptoms that have considerable impact on people’s daily lives. Of these disorders, schizophrenia is the prototype. Earlier versions of the *DSM* took a unitary approach that conceptualized psychopathology on a continuum; neurosis reflected a higher level of functioning and psychosis signified the greatest impairment in functioning. Arieti’s (1974) concept of a “break with reality” defined psychosis more narrowly and is why the first signs/symptoms or episode of schizophrenia has been termed a *first break*. Psychosis represented an inability to distinguish between internal and external stimuli. The break with reality referred to this loss of ability to reality test, or to tell whether, for example, the voices a person hears are real and are being heard by others or not. This way of thinking about psychosis has endured. In neurotic disorders as defined by
the first two DSMs, this capacity remained intact. Beginning with DSM-III, the manual abandoned the unitary approach and, instead, defined psychopathology as discrete or distinct categories of disorders and developed a core set of criteria for each disorder.

People who have been diagnosed with any of the psychotic disorders may experience problems in perception (hallucinations in any of the five sensory areas, but most often auditory or visual hallucinations), delusions or false beliefs, disorganized speech (and thought), and/or disorganized or catatonic behavior. While these psychotic symptoms are common across the disorders in this category, such symptoms are not thought of as the core parts of every disorder in this section, and there is variation in the symptoms that are considered psychotic for different disorders in this category. In schizophrenia, schizophreniform disorder, schizoaffective disorder, and brief psychotic disorder, the following are psychotic symptoms: delusions, any hallucinations (with or without accompanying insight) that are prominent, disorganized speech, and disorganized or catatonic behavior. In substance-induced psychotic disorder and psychotic disorder due to a general medical condition, only delusions and hallucinations with no insight are considered to be psychotic. In delusional disorder and shared psychotic disorder, the term psychotic is interchangeable with the term delusional.

It is important to note that some cognitive disorders, mood disorders, dissociative disorders, and substance withdrawal disorders may also involve more transient psychotic symptomatology. And, increasingly, there is no assumption of common etiology in the psychotic disorders. For example, current research posits that schizophrenia is thought to be etiologically more similar to schizotypal personality disorder than to the other psychotic disorders (Tsuang, 2002).

While certain symptoms were thought of as pathognomonic of schizophrenia in the past (e.g., Kurt Schneider’s first-rank symptoms of schizophrenia/1939), we now know that there is no one sign or symptom that defines or predicts the disorder. People with schizophrenia can experience a variety of cognitive and emotional difficulties that must, by definition, be related to social and/or occupational dysfunction. These include problems in perception, in communication and language, in the content and process of thought and speech, in attention, in volition and drive, in the ability to experience pleasure, in affect and mood, behavior, and inferential
thinking. Symptoms of schizophrenia are classified as either positive or negative. Positive symptoms represent an exaggeration or distortion of normal functions (e.g., delusions and hallucinations). Negative symptoms involve a reduction in or loss of normal functions (e.g., affective flattening and avolition).

The subjective experience of signs and symptoms has been viewed as especially critical to an understanding of schizophrenia (Estroff, 1989; Strauss, 1989). *Schizophrenia Bulletin* dedicated an entire issue to this topic (Strauss & Estroff, 1989). Viewing the illness through the eyes of those who have been diagnosed with it has contributed to a renewed focus on designing psychosocial treatment and services that will be more responsive to consumers’ needs, reduce stigma, and enhance their quality of life. Honoring the subjective experiences of those with schizophrenia (or any mental disorder) requires us to shift perspectives from thinking of ourselves as the experts to viewing those who experience symptoms of mental illness as experts in their own right. We can learn a great deal about the challenging aspects of their experiences from listening to their stories. Perhaps more important, we also learn about courage, persistence, and the strength to endure and even triumph.

The FPAs in this chapter describe individuals’ experiences with schizophrenia and with schizoaffective disorder in which there is an added mood component. People who meet criteria for schizoaffective disorder must first meet the symptoms criterion for schizophrenia (Criterion A), and then also meet criteria for a major mood episode (depressive, manic, or mixed) during a significant period of the course of the illness. For individuals who meet criteria for any of the psychotic disorders, the personal experience of signs/symptoms can and does vary greatly. These can be frightening and disabling, especially initially. Probably no two people with a diagnosis of schizophrenia have identical symptoms or the exact same course or trajectory of the illness. The onset of schizophrenia most often occurs in late adolescence to mid-twenties (18–25) for men and from 25 to mid-30s for women. There is a bimodal distribution for women, with an additional peak of onset after 40. But the timing and process of onset varies across individuals, too. The onset for schizoaffective disorder occurs typically in early adulthood, although it can range from adolescence to much later in life. Women have a higher incidence of schizoaffective disorder than men and more often experience the depressive than the bipolar type.
As you read the FPAs in this chapter, we think you will be struck by the contrast between the DSM’s portrayal of these disorders and the subjective, personal experience of living with schizophrenia or schizoaffective disorder that our authors provide. In focusing solely on the symptoms and the DSM diagnostic criteria as we have done as background in this introduction, we risk coming away with a limited understanding of these problems. We have found that by “listening” to what the personal narratives in this chapter tell us about the lived experience of psychotic disorders, our understanding is broadened and greatly enriched.

Susan Salsman wrote the FPA that begins this chapter. Her life with schizophrenia changed greatly when someone else with mental illness identified with her and said, “Yeah, that happened to me too.” In the next selection, Paolo Scotti describes his experience of having schizophrenia and talks about his recovery as a process of “discovery.” Leslie Greenblat’s account of hearing voices reveals not only the challenges she has faced but also the resourcefulness she has shown in developing a strategy to cope with them and move on with her life. Benjamin Gray draws on what he experienced during a 12-month involuntary hospitalization for schizophrenia to critique services based on a medical model. He advocates for patients’ rights, discusses the rise of democratic psychiatry, and tells the reader about several alternative approaches such as the hearing voices movement. In an account of how she uses her own experience of schizophrenia and her recovery to work with others, Corinna West discusses her role as a peer specialist in helping those who are struggling with the illness.

Kristen Fowler’s moving story of her “first symptoms of psychosis” portrays how her illness changed from serious depression to include symptoms of psychosis that eventually were diagnosed as schizoaffective disorder. She describes this process as a descent into suicidality and psychosis. The final FPA in this chapter, written by an anonymous author, highlights the differences in having and receiving treatment for a mental illness versus a physical illness. The author makes her point by comparing her experiences of having schizoaffective disorder to the experiences that someone with diabetes might have.

QUESTIONS FOR REFLECTION

What are some common strategies that these authors have used to cope with having a psychotic disorder? What strengths have they revealed in dealing with the symptoms and other challenges they experienced? Do these
accounts fit your stereotype of people with schizophrenia or schizoaffective disorder? Why or why not?

**REFERENCES**


Wouldn’t it be great if all mental health professionals were required to have a mental illness? I’m just talking about those who want to deal with people who have been diagnosed with a mental illness. If a professional wanted to work with neurotics then, no requirements necessary, because all people have neuroses! I think that’s an inborn trait. But to help the mentally ill, you must be mentally ill.

I have lived with schizophrenia since about age 15. I knew there was something wrong, so I sought help. I saw school counselors and even went to see a psychologist a few times. Had I kept going to him, I might have learned early on that I had a mental illness. I found out many years later, after my hospitalization and diagnosis, after many years of seeking counsel from this doctor or that, or this counselor or that, that that early psychologist had suspected psychosis.

I wonder sometimes if I would have been better off if I had caught it early. But I’m okay with the fact that I didn’t, because life is good. I am who I want to be today. I probably couldn’t get any closer to being normal than I am right now. I’m not 100 percent and it’s not perfect. But will it ever be for anyone? Everyone has something to deal with at some time. Mine just happens to be schizophrenia.

I can’t count the number of mental health professionals I have seen in my search for answers. I just know that there have been many. All of them were unique individuals, all of them were well educated, and all of them, I hoped, had the best reason for choosing the profession they did: to help people. I understand that that may not always have been the case, but the majority of them surely meant well, and I appreciate that.

I hopped from one mental health professional to the next, getting fixed up a little only to fall back into madness and return once again to a little office with a big desk and a new face. I would sit in desperation, longing to find the answers, longing for something to hold onto that would take away

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all of my pain. I was hoping to learn how to live, how to cope. I always wanted to be told what to do and how to do it.

After I realized that this would never happen, the mental health professionals just became sounding boards. If I babbled on enough, if I cried enough and complained enough, it would release some of the tension—at least for a while. And that’s all I could do because I knew then that nothing they said or did would ever help me beyond the little hour we shared—that little hour filled with hopelessness and good intentions.

Finally I was hospitalized in 1989 at the age of 24 and came to some important realizations. First, something was seriously wrong in my head. Second, medication could help to take away some of that craziness. And third, I was not alone.

Realizing that I was not alone was a revelation. To this day I hear that one sentence in my head spoken from a beautiful person sitting next to me who came from some other place, whose life I knew nothing about—a complete stranger whose face I caught only intermittent glimpses of as I faded in and out of reality the first few days. Seeing her clearly now, this perfect, beautiful stranger said to me, “Yeah, that happened to me too.”

The medicine helped, I became friends with a staff member, and I started to enjoy a little sanity for the first time in months. But nothing in that hospital experience mattered more than what happened in that one little fragment of time. And I still find it humorous how it was said so nonchalantly and almost matter-of-factly, in a manner that one could have as easily said, “Your hair is red.”

I don’t know this girl’s name. I wouldn’t recognize her if I saw her on the street. I don’t know who she is or where she came from or where she is now. But a part of her lives in me just as strongly today as it did in the moment we first spoke.

I have shelled out a lot of money over the years. All the time and effort I put into my career as a patient, all the hard work and sweat these people poured out to me from behind their tidy desks, all the little hopes and twists of starlight fading into dawn, left me disillusioned by the realization that in order for healing to begin, we need only to hold in our hearts the love, understanding, and compassion of a fellow sufferer.

I can tell a mental health professional what I am experiencing: how it feels, my perception of it. I can describe hallucinations, pouring out expressions like water. I can be as eloquent as possible, laying open my soul. I can take the time to try to explain, to find the right words, knowing there are none, and then
leave feeling more frustrated than before. I can do this. I can bang my head against a wall for hours too. The results are pretty much the same.

Unless I have a doctor who also lives with mental illness, the plain fact is, the doctor will never understand. The doctor cannot learn it from a book. No matter how strong the desire to learn, to feel, to know and understand—it will never happen.

Healing may begin with a simple sentence that may forever leave an impression on your soul. But it is a journey from that point on. I have learned a few things over the years that only experience can teach. And what I found to be true, at least in my life, is that there must be a desire to get well.

Intrinsically the answers are already there inside of us. Whether they exist in the head or heart or soul, they are there, and we are all aware of that. It’s this part of us that keeps us alive in times of total despair. It kept us sane long enough for us to begin our relationship with it, even if it was only sporadic in the beginning. It’s the source we tap into that gives us hope and insight. And it is the very part of us that allows us to lead normal, happy lives.

I’m so adamant about directing my own recovery not just because of my disillusionment and frustration with the mental health field. My desire is also based on the fact that we are all unique. My experiences are never exactly the same as someone else’s. It is this uniqueness that makes treatment so difficult. But this very thing has brought joy into my life and a deep appreciation of tiny little moments that take place between two people at a single point in time—moments that can lead to epiphanies. It’s this uniqueness that allows us to learn from one another and always leaves a little mystery lingering so we can appreciate that some things will always be sacred.

Hospitals are necessary. Meds are necessary. In the beginning, I needed them more than anything. Meds have become an extension of my mind. If I don’t take them, I will not survive.

In the beginning, denial became my defense. I was angry and resentful. I hated life and felt singled out because of all the people this thing could have chosen, it picked me. At the time my diagnosis was equal to the death sentence. Nothing could have been more devastating. Not even death itself. No matter how hard I fought—kicking and screaming—it would not go away. It was like a pit bull growling at me that would stop only if I fed it. After it gobbled down its food, it would corner me again, continuing to growl and threaten. I decided to keep feeding it. And after
awhile, the dog took on the role of man’s best friend. I learned to live with it the best I knew how.

This is what I know. I made an effort to open my eyes, to become very aware of myself. I made a decision to quit wallowing in self-pity and to become responsible for the course my life would take. I came to see the important truth that only I know what is best for me in my journey of recovery—that I have the answers in me and have learned to draw on them. Through trial and error, I have learned what works and what doesn’t.

Experience teaches us how to live well. In time, the mental illness diminishes in importance. And some days it’s not any more significant than a little bug bite. Some days, it seems to have disappeared. I have learned that reaching out to family and friends with mental illness and taking meds—striving to be the very best I can be—are essentials. If my eyes are open and my mind is clear, I can see what I need to do. If I can reach out and share what I know, it may be that everything I say means nothing at all. Or it could be too that I might say one thing that seems to be of little importance to me, yet opens a new door for someone I don’t even know.

So, in our fellowship with one another, friends in the struggle, always keep in mind that there is no better medicine in the world than for one person who has a mental illness to say to another, “Yeah, that happened to me too.”

Peace and good cheer.

Recovery as Discovery

PAOLO SCOTTI²

The story of my recovery-related journey begins in the fall of 1992, when I was doing my Masters in Organic Chemistry at the University of Toronto. Slowly, slowly, something terribly wrong began to occur in my life. I began missing important meetings. I began thinking that fellow graduate students were out to get me and sabotaging my research work. I became ambivalent and could not decide what research to conduct and which professor to work under.

Now, I was not a born chemist, and I had to work very hard at it to do well; but the stress of graduate school, along with other factors, triggered the beginning of my illness. I began fearing for my life because I thought that people wanted to harm or kill me. I became afraid to take the subway, believing that I was being followed, and withdrew from everyone thinking that they were plotting against me. I believed that my house was bugged, that people could read my mind, and that people were trying to insert evil/destructive thoughts in my mind. The television and radio began to send me secret messages and were referring directly to me in their broadcasts. I sometimes heard voices saying negative statements about my religious faith, and I felt that I was being persecuted religiously.

Eventually, things got to the point where I became so disabled by delusions and other psychotic symptoms (although no one in my family, including myself, knew it was this) that I was admitted into a psychiatric ward at a general hospital. And thus began my experience with the mental health system. I was in an inpatient unit twice within a period of 3 months, after which I spent over a year in day hospital.

The hospital experience was not particularly positive. No one ever explained mental illness except for depression to me or to my family while I was there, and I was made to feel responsible for my misfortune (or at least I felt that way). The staff was not always helpful. I will never forget one of my meetings with my hospital psychiatrist. In one of my weekly visits that lasted no more than 15 minutes, my psychiatrist was becoming annoyed and impatient with me as usual because I could not finish my sentence, and I would start to repeat the same thing over again (this was due to thought disorder caused by my illness, although I did not know it at the time). Rather than trying to help me, he told me quite coldly: “You are always saying the same thing over again, it’s so boring.” I could have died at that moment. Just because someone is ill does not mean that they are any less human without feelings. Reflecting back, I now think of Psychiatric/ Psychosocial Rehabilitation (PSR) Core Principle 7: All people are to be treated with respect and dignity and PSR Core Principle 8: PSR practitioners make conscious and consistent efforts to eliminate labeling and discrimination, particularly discrimination based on a disabling condition. I wish the mental health workers back then would have known and practiced such principles.

I thought that everything that was happening to me was my fault and that I was to blame because I had some “character flaw.” I thought that I
had lost everything, my life was over, and I was a failure. I became depressed, and although I did not actively think of suicide, my will to live had never been less.

I started seeing another psychiatrist outside the hospital who fortunately was very caring. He listened to me patiently, got me on the right dose of medication, and after 6 months diagnosed me with schizophrenia. He described to me what the illness was and gave me literature references to read to help me understand the illness. I remember sitting in the family room with my mom and spending hours reading everything I could get my hands on.

I never felt labeled or stigmatized by my diagnosis. In the beginning, it was a relief to know of it because now I had an understanding of what caused my precarious circumstances, and I realized that it was not my fault or anyone else’s fault. The guilt that haunted me disappeared, and I no longer felt so helpless because now there was a name to my enemy.

With understanding, however, came the overwhelming realization of the powerful force that was against me, and I felt devastated. The negative symptoms of the illness kicked in, and I felt incapacitated and depressed. I could do nothing, and I lost all hope in myself and in life. For several years, I lived in darkness and despair.

Fortunately, I had people in my life, like my mom, who genuinely loved me and who believed in me and never lost hope in me. With her steadfast support, along with that of my psychiatrist and the rest of my family and along with my faith that guided me through the darkest hours of my life, I very, very slowly began to recover.

Recovery was not some magic wave that swept over me. I had to learn to live life all over again, and it occurred in painstakingly small, tiny steps over long periods of time. In and of its own, each step may have seemed insignificant, but with a steady reinforcement of incremental growth, progress was miraculously achieved. It was incredible how disabled I had become. At first, I was unable to do anything. Something as basic as grocery shopping was both frightening and overwhelming for me. I remember my mom taking me along to do grocery shopping as a form of rehabilitation. Initially, I would just cling to the shopping cart too terrified to move while my mom began busily loading the shopping cart. I did this for the longest time until 1 day, after many observations, I actually decided to venture away from the cart and gather some apples. This was how small my steps were, and it may
sound silly, but then I was faced with the daunting task of deciding which apples to choose from the bunch. Everything seemed so difficult.

Eventually, I was well enough that I felt like working again. I thought I could try and return to the field of science, so I tried returning to graduate school; however, because 5 years had passed, they no longer would accept me. I enrolled in a program called Work on Track that helps people with mental illness prepare to reenter the work force, and at the end of the program I began to look for work. Although Work on Track had helped me to prepare a good resume, again I had a 5-year gap in my resume, which, I was to find out the hard way, worked sorely against me. Even when I did get an interview, the question of the gap would arise. I was told to say that it was due to a medical condition but that it was now under control and that it would not be a factor in my job. It was unbelievable how, after saying this, I immediately sensed that any hope of getting the job disappeared and that we then went only through the motions of a superficial interview with no chance to succeed. I never got a second interview. In one way, I felt discriminated against; however, I would never have been able to prove it even if I wanted to. This was my first “failure.” I became convinced that I would only be accepted to work as a janitor and spend the rest of my life cleaning other people’s toilets. Not that there is anything wrong with that. It is a noble and honest job, but I felt that I wanted to do something different.

After some time reflecting and regrouping, I was determined to find a meaningful job and to contribute positively and constructively to society. So I went back to college and got accepted into George Brown College’s Dental Technology Program in Toronto. I thought that if I worked with my hands and did something practical, I would be happy. I told no one about my illness, and I was terrified that someone would discover my “secret.” Returning to school full-time (and with no accommodations) was incredibly difficult; however, after 3 years, I graduated with my diploma in dental technology. Schooling was not, however, my most difficult step. After graduation, I found work in a dental laboratory and soon realized that this was an even more stressful, fiercely competitive, and productivity-oriented business. The law of the day seemed to be that if you were not better and faster than the next person, your days were numbered. After a very difficult year of working in the field, it was clear that I would not be able to work effectively in this field. Both my employer and I agreed that the situation was not working out, and I resigned. I told no one about my illness. Maybe, I erred;
However, I did not think that this was a field open to accommodations. This was my second failure.

It was now 2004, and I was in my early 40s. I was afraid that my life would amount to nothing and that I had little purpose in this life. Then, my psychiatrist suggested one day that I consider shadowing a peer support worker on an Assertive Community Treatment (ACT) Team. Up until now, I wanted nothing to do with the mental health system or its users, and I was still unwilling to disclose my illness. I found the experience, however, to be very interesting and positive. It was encouraging to see the dedication and the care that the ACT Team demonstrated in improving the quality of life for people who suffer from mental illness, and I wanted to contribute to this dedication and caring. After some thought, I enrolled in the PSR Certificate Program at Humber College in Toronto. I found the PSR courses to be totally amazing. They were also a double blessing in that they taught me how to work with and care about people with a mental illness, but I could also apply the teachings to my own life. Recovery took on a totally new meaning for me. I joined the PSR/Réadaptation Psychosociale Canada Ontario Chapter Board of Directors (of which I am still a board member), and I began volunteering at a drop-in for a case management organization. My life seemed to take on new meaning and purpose. Things came to me naturally, and I really enjoyed what I was doing.

Then I lucked out. While I was doing my PSR Field Experience Course in Toronto East General Hospital’s ACT Team, an opening for a peer support worker arose on Canadian Mental Health Association’s West Metro ACT Team in Toronto. I applied, and in February 2006, I was hired as their peer support worker. I still work there, and I love my job. I am even happier now than I was before my illness started.

They say that recovery is knowing oneself under new circumstances, redefining one’s role, and reevaluating oneself to develop a new sense of respect for oneself. After living in darkness for many years and having died to my old self, thinking that my life was over and futile, a new birth emerged from within me that has made my life more meaningful and purposeful than before. Whereas before I was a “thing” person, I now discovered a part of me that is a “people” person. I treasure relationships, everything from my relationship with our Creator, family, service users, coworkers, fellow peers, and friends.

They also say that the goal of recovery is to be more human. All the pain and suffering of the past was not a waste because it has helped me to be more
human in that now I feel I am a more compassionate and empathic person, and I can use that new enlightenment to help others. Thus, my recovery has been a precious discovery for me and hopefully for others, which I happily share here.

Acknowledgments
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Understanding Health as a Continuum
Leslie Greenblat3

“That’s enough cherries.”

That sounds like Pat. But Pat, sitting across from me, said I could have as many cherries as I like. It’s a hot July night, they’re tart and smooth, and I like them.

“You’ll feel it in the morning. That’s enough cherries.”

These are good cherries. Just one more. I promise this will be the last one.

“You’re making a pig of yourself.”

Yes, the seeds and stems are piling up. But Pat said I could have as many cherries as I like, and I’m the one who’s going to feel it in the morning. Besides, she told me she won’t eat them. She doesn’t like sour cherries.

This is what my summer evening was like. Chatting with a friend, eating cherries, and trying to filter out a constant commentary from the vocalized thoughts in my mind. My ability to screen out the “free advice” is hard won. For many years I responded to the constant commentary as if it were coming from someone powerful—sometimes smarter, healthier, and more active.

than I was, or sometimes dark and cruel. Even when I was told that I was contaminating everything I touched, I still listened. Family and friends told me to ignore the thought-voices. I couldn’t.

Ten years ago I was diagnosed with schizophrenia, and for the first three years I lived the revolving door syndrome: I was hospitalized 13 times. On May 24, 1999, I graduated magna cum laude with a degree in women’s studies from the University of Maryland. I’m now enrolled in a master’s program in the Johns Hopkins School of Public Health.

Before, I’d take the meds, I’d start to feel better, and then I’d think I didn’t need them anymore. Other times I’d convince myself that I could rise up out of the psychosis faster by not being on meds. Regardless of my reasons, I’d still end up hospitalized. Somewhere along the line—I still can’t say when or exactly how—I came to realize that I had to stay on the meds and that I needed to trust someone else’s perceptions. As I write this, it’s hard for me to think about walking on the Verrazano Bridge, believing that because I wanted to go south for the winter, going over the bridge was the quickest way to get to Florida. Three women stopped and gently restrained me from walking off the sidewalk. I regret to this day that I don’t know their names to thank them. They saved my life. I wish I could tell them who and what I am today.

Surrounded by boxes of books and household items to be moved, I am struck by how far I’ve come.

Hearing voices is a lot like having a child pulling at your skirt, asking questions 24 hours a day. Yelling and screaming at the child doesn’t stop the barrage of questioning and does little to calm yourself. On the other hand, patience and respect works with children and thought-voices. I’ve tried both—screaming and calm intervention—and calm works better. Even learning that much, though, took time and energy. While driving, I may hear that child ask, “What are you doing?” and I think, “I’m driving.” If that doesn’t satisfy her, I’ll visualize the engine. I don’t know much about combustion engines, you understand, but I know enough to soothe a child.

I had to learn to manage what I constantly heard if I was ever going to be healthy and independent. One of the hardest things is privacy. Am I as transparent to others as they sometimes seem to me? I miss the feeling of solitude. While I intellectually know that I am alone, it doesn’t diminish the fact that I still feel as if my head is full of other people.
My thought-voices come up with some very intense perspectives. When I think of my voices as external or separate entities, I find myself feeling demoralized, asking, “Why didn’t I think of that?” Sometimes I have a very hard time thinking of these thoughts as mine. When I find myself in this situation, I can be very critical of myself, constantly pushing to be creative and clever. I am, however, coming to understand that what sounds to me like an outside commentary is from my own thinking. So even if I “hear” someone saying, “Look, she’s at the computer writing,” I can rephrase it to myself, “I am at the computer writing.” I shift from third person to first person.

Sometimes it’s hard to accept that I generated these seemingly external observations. I avoid the use of “voice” to describe what occurs in my thinking. Instead, I prefer to conceptualize these occurrences by saying it is as if I hear “voices.” As I move along in my recovery, I am better able to own what I think as belonging to me.

Ironically, I am learning to talk to myself. But this time I know to whom I am directing my ideas—myself. I used to think that I could project telepathically—that someone else could hear me. I remind myself that everyone processes and deliberates before sharing with others.

One of the most effective tools I have for coping is sharing. I have an excellent working relationship with my psychiatrist. All of my close friends know I was very ill, and as I continue to make new friends, they, too, learn of my struggle. My illness is not a dirty little secret. This given, I have to be careful about what I share and with whom. The concept of “voices” can be frightening and difficult to understand. My friends and family are enormously supportive, but I had to be willing to recognize that a trained professional is better equipped to untangle my distorted thinking.

Asking for help in appropriate ways and not letting a situation get out of control are critical processes. Being willing to let go of your ego and ask for and accept feedback are part of the healing process. Even so, I believe that “the patient is the expert.” The idea that a doctor knows all the answers doesn’t click with me. This isn’t to say that professionals don’t have valuable input, but I know my illness better than anyone.

I attribute much of my recovery to my hard work. I have been on many medications, including clozapine, but I have had the same doctor now for nearly 10 years. Dr. Ann Alaoglu is the person I feel had the greatest impact on my return to health. Before I met her, I didn’t trust doctors. Doctors doped me up, locked me in, and were generally distant.
Dr. Alaoglu, unlike so many of my past therapists, was willing to put herself on the line, sharing with me her sense of my progress and lapses. One of her greatest strengths is her ability to paraphrase. When I was stressed or unhappy, she may have said, “You seem really down today. What’s going on?” I remember psyching myself up for a flight home but telling Dr. Alaoglu that the trees were warning me not to go. Dr. Alaoglu responded by saying, “You seem a bit nervous about your trip.” If I had said that to a former therapist of mine she would have suspended my visit and told me (yes, told me!) I was crazy. I think paraphrasing is critical: Hearing how others interpreted what I said gave me a sense of how I was communicating. Later in my treatment, Dr. Alaoglu gave me more rein in my recovery, listening to my input about the level of medication I was on and taking me seriously when I asked for a decrease or even an increase in my medications. I felt empowered in my recovery.

I can remember one doctor who never said a word to me during therapy except to say, “Please sit down, Ms. Greenblat. Tell me about your day.” He would take notes, nodding occasionally, and then at the end of a session say, “Thank you, Ms. Greenblat. I will see you later this week.” He completely lacked warmth or affection.

There is one more person I must mention: my mother, Dr. Cathy S. Greenblat. She is among the most energetic, positive, determined persons I know. That drive was evident throughout the course of my illness. She searched out the best hospitals and investigated alternative therapies like megavitamins (which, by the way, are very helpful) and visual therapy. As psychotic as I was, within 2 weeks of my discharge she had me pounding the pavement, looking for a job. She supported my decision to go back to school. It was her perpetual optimism that kept me afloat, swimming with me until I was able to swim on my own.

I am fortunate to live in a community with a strong commitment to vocational rehabilitation. The community college I attended before the University of Maryland—Montgomery Community College—had tuition breaks for disabled students. Scholarships to the University of Maryland that would have been unavailable to me because of the credit minimum (a minimum of 12 credits was considered full-time and determined eligibility for the scholarship) were negotiated through the Department of Disability Services. Being treated as a human and not an illness is critical to recovery. I am increasingly accepting that I may think this way for the rest of my life—that
I think differently. Sometimes my thoughts-voices (I still haven’t found a good way to describe them) are a real pain in the ass. I have found numerous ways to cope, but still they can/I can be very draining.

What I can say about my recovery is that I had to accept that I played a role in my wellness. It no longer was satisfying to defy or protest treatment—I knew I had to have a working relationship with a therapist and accept my part of the job. I carry with me today the question I was asked several years ago: “Are you ready to be well?” I wasn’t then. I am now.

I think the quality of the thought-voices evolved as my health evolved. I no longer hear suggestions to run into traffic; if I did, I would refuse. I’m able to judge the appropriateness of the advice. More often than not, the thought-voices are reasonable—if nagging. Now they tell me not to eat too many cherries, for example. I hear advice to get enough sleep, eat sensibly, get my exercise. They really bug me about exercise, but I believe it’s me telling me to get my exercise. I’m a thinking, intelligent woman. I know I need to get exercise. But for some reason, I tend to hear it as coming from someone or somewhere else. It’s difficult to really concretely define “voices” for someone else. Sometimes it seems they serve as reminders of things I should or shouldn’t do—doubts vocalized.

What’s the magic cure? How did I go from being an angry, distrusting, “treatment-resistant schizophrenic” to a woman entering graduate school, who lives with schizophrenia? There’s no magic cure. All I offer to my fellow travelers is this: Be patient with yourself. Take time to have fun. Work hard. Be passionate. Be willing to trust yourself and others. Take your meds. If you have issues about your meds, negotiate with your doctor. Have courage. If you are in a difficult or stressful situation, plan your response. Have someone to call. Know your limits, and most important, be willing to grow beyond them, but know where to go for support. I am open to alternative health therapies, too. I’ve tried visual therapy and vitamin therapy and still practice meditation, controlled breathing, and visualization. I’m involved in a study on the effects of fish oil, and think it’s working for me. I am sharper and clearer and was able to reduce my neuroleptic medications.

Therapists will say that a move to another city to go to graduate school is about a 10 on the stressor scale. I know it all too well. I also know that I have tools to manage this life event. I know if I start being unable to sleep, I need to call my support network (my therapist, mom, sister, stepfather, and friends) and get feedback on what is happening. “Leslie, take a warm bath,
get in bed, shut your eyes, don’t open them. Or even take a PRN...” If my thought-voices become too overwhelming or frequent, I know I need to call for support. True, my phone bill is enormous, but think what hospitalization would cost. Final exam? Breathe slowly, hold it, push it all out of my mouth slowly, follow the breath.

A diploma is not a certification of mental health for anybody. I believe health is not an end point; health is an ongoing process of self-reflection and action. I now understand, too, that my illness exists as a continuum. I can find lots of ways to make myself totally crazy. I can now find as many ways to keep myself sane.

Emerson said, “There are voices which we hear in solitude, but they grow faint and inaudible as we enter into the world.” I wonder sometimes, as I grow even healthier, if the voices will fade away completely. Will I miss them? Having lived with them for so many years, I wonder if it will feel empty or lonely without them. Thought-voices are part of who I am, and what makes me unique. With what will I replace them? I believe I will find other ways to be unique.

Can I do it? I believe so. I am willing to try.

*Psychiatry and Oppression: A Personal Account of Compulsory Admission and Medical Treatment*

Benjamin Gray⁴

Hearing Voices: A Personal Story

Certainly, my negative conception of traditional psychiatry and compulsory treatment is colored by the 12 months that I spent in a psychiatric acute unit. Kept under Section 3 of the Mental Health Act of the United Kingdom, I was both obliged to stay in hospital and forced to take antipsychotic medication against my wishes, though physical force was never used against me.

My strange religious beliefs were perhaps quite rightly classified as delusions and discounted by my psychiatrist, nurses, and also my family, but

this left me with the impression that my experiences, however negative and painful, were also being discounted and that I was not being listened to in order to be more deeply and humanely understood. The famous line of Szasz (1973, p. 113) often came to my mind: “If you talk to God, you are praying; If God talks to you, you have schizophrenia.”

Among the people I met during my time in hospital was Rosemary. She was an unassuming, quietly spoken woman, unremarkable apart from an air of sadness. Rosemary had told me and many of the nurses that she would be better off dead than hearing any more of the terrible voices that kept her from sleeping. Better up there with her mother in heaven, she told me, than down in the hell of the psychiatric ward with her voices. Within a few days of being discharged, Rosemary was with her mother again. The nurses called a meeting in the communal lounge. There had been an accident. Rosemary had thrown herself in front of a train. The girl next to me at the meeting broke into tears.

Night after sleepless night and through the long, seemingly endless days in the ward, where smoking and television stood in place of any attempt of therapy, I and my fellow patients experienced similar feelings to those of Rosemary: feelings of loss, isolation, pain, sorrow, self-pity, confusion, and helplessness.

“You’re alone,” an insidious voice whispered to me. “You’re going to get what’s coming to you.” “You’re going down there!” it shouted. “You wait until you see what I’m going to do to you!”

When I heard my voices, which would often shout at me, no one around me moved or looked startled. It was just me hearing the voices. I tried not to answer them. Better to ignore the voices, repress them, and soldier on, I thought. I had seen others screaming back at their voices, and it had left me with mixed feelings of consternation, pity, and fear. I did not want to look mad, like them. Any symptoms of hearing voices would go on medical case notes, be raised as proof of insanity at my case reviews, and keep me locked up in the hell of the ward away from family, friends, and what seemed like a long-distant normal life.

I learned several important lessons too: never admit that you hear voices; certainly never answer them; do exactly as you are told by staff or concerned family or you will be seen as ill; never question your diagnosis or disagree with your psychiatrist; and be compliant and admit your mental illness or you will never be discharged.
All the time, the voices got worse. “Hot fire in your eyes!” shouted a voice to me in the hell of the ward. “That’s where you’re going. In the fire of the sun!”

Many of the people, and there have been hundreds, with mental illness who I have talked with both as a patient and as a researcher and academic, tell me that they have had to suppress and hide their voices in order to be considered well, stable, and healthy. Not only is this a suppression of symptoms, but it is also a suppression of people’s personhood. Traditional psychiatry, in this gloomy and pessimistic view, could be argued to be little more than an instrument of social control and of oppression and a system of scientific belief that perhaps unintentionally crushes people’s subjectivity, choices, human rights, and free will.

The majority of individuals with schizophrenia and mental illness that I have spoken with, and from my own personal experience in a psychiatric acute unit I have to agree, find meeting with their consultant psychiatrist threatening because any unusual thoughts or behavior can be taken out of context and construed as psychotic. Many people with mental health problems are genuinely afraid of meeting with their psychiatrist or other members of the mental health team. I remember a teenage boy in the ward literally shaking and wringing his hands with fear before his weekly case review with his psychiatrist, much to the concern of nurses, the boy’s mother, myself, and the boy’s mental health advocate.

Many people with mental health problems hide their symptoms, their aberrant beliefs, and their voices to stay out of hospital, but this means that they are ostracized and that there is a lack of dialogue between mental health professionals and people with mental health problems. This also means that there may be a lack of disclosure and of what is really going on in people’s lives and what voices they may be hearing. Because people with mental health problems fear the psychiatric encounter and are afraid of punitive intervention or compulsory treatment, psychiatrists and mental health professionals are not getting the full picture so as to agree a consensus on care plans and treatment. This is also true of family carers, who are increasingly being called upon to provide around the clock support for people with mental health problems in the community. Family carers are often little more than the unpaid workhorses of community care, who lack the skill and information necessary to provide adequate support to their family members with schizophrenia and mental health problems who may hear voices.
More worryingly, when in hospital, violence is sometimes used as a tool for getting noncompliant patients to take their medication, usually via depot injection. This violence is often conceived of as right, as just, and in the patient’s best interest. Certainly, many nurses I have spoken to have not only said that they do not like administering forcible injections but also say that they have a duty of care. Violence as care is an oxymoron and hides the institutionalized abuse of people with schizophrenia and mental health problems. I myself have witnessed 8 occasions where patients have had to be very violently restrained by staff and only 2 assaults by mental health patients on nurses. This is in line with evidence that people with mental health problems are more likely to experience violence on their person rather than attacking other people.

Psychiatry has taken a biomedical approach, with the prescription of powerful antipsychotic medication, including drugs such as olanzapine, risperidone, and clozaril, all of which I have been prescribed. These powerful antipsychotics have serious and debilitating side effects, are toxic, and have also been suggested to be harmful to those taking them in the long term. These antipsychotic medications have often been described as a “chemical cosh,” leaving people who take them passive, debilitated, and zombie like. This could be suggested to lead to the tranquilization of people’s personal beliefs, however irrational, and their thoughts, subjectivity, and feelings. Such an approach could certainly be argued to crush diversity and discount the diversity of people’s experience of life and the world, in the name of normalization and keeping a stable social and medical order.

Put very crudely, popping a pill is far less of a burden on a health service that has limited resources, a lack of money, severe pressures on beds, and a lack of inpatient provision, which often depends on family carers who lack the knowledge and expertise of dealing with people with mental health problems who may be in distress and where care in the community is limited in scope and often means no care in the community, leaving people with mental health problems with the feeling that they are alone, invisible, and ostracized.

All this means that there is little study of what schizophrenics’ voices say to them, which would make people’s experiences more valid and meaningful and also lend itself to a more human account of mental illness. People’s experiences of hearing voices are silenced, which can only augment
Schizophrenia and Other Psychotic Disorders

ignorance and fear, both in society and in the mental health-care system. Little attention has been given to what people with mental health problems think and feel and what treatments they would prefer. Psychiatry overrelies on powerful antipsychotic medications, and there are long waiting lists for less invasive treatments such as counseling and cognitive behavioral therapy.

To complicate and make matters worse, it is almost impossible to talk with other people and relate the pain that voices inflict when they are raging inside you and shouting you down. It is even harder to face the voices and achieve what psychiatrists and mental health professionals call “insight.” My voices, in particular, often sounded telepathic, as though people were speaking to me through their minds. My voices would often be racist or abusive about mental health staff and other patients. It is perhaps not surprising that voices like these, if dismissed as bizarre delusions and not discussed as at least phenomenologically or subjectively “real,” may sometimes lead to violent behavior toward staff and other patients or—as I have witnessed—the smashing of hospital furniture, equipment, and the television from which the voices emanated.

The main point to reiterate is that these voices are silenced and dismissed as delusions and that they are managed mostly by medical treatment and thus not addressed in human and sympathetic terms that might begin to tackle the root cause of the problem, which in turn might help people cope more profoundly and insightfully with their voices.

Certainly, the overreliance on medication is perhaps not surprising, given that people who hear voices can be perceived as aggressive, irrational, and violent. My voices often took on a demonic or hellish quality: “You think you’ve been exploited and abused?” a demonic voice often shouted at me. “You wait until you see what I’m going to do to you! You wait until you see what I look like!”

But this is partly the point: other people cannot hear the schizophrenic’s voice. There needs to be a dialogue so as to treat the voice hearer’s experience as valid and meaningful (Foucault, 1992; Laing, 1967). A more democratic psychiatrist listens to people with mental health problems and is open to their experiences and voices, so not stigmatizing the voice hearer, which in turn may lead to more holistic, democratic, and sensitive packages of mental health care.
Discussion: The Rise of Democratic Psychiatry and the Hearing Voices Movement

What I have learnt as an academic and researcher, as well as a mental health patient labeled with schizophrenia, is that what people with mental health problems want is to be treated as equal citizens with equal human and medical rights. People with mental health problems who hear voices or hallucinate want to be valued, as we all do, not feared and ostracized. They want their views and opinions taken into account, especially as regards what sorts of treatment they have and in their care plans. They want a right to accept or refuse medication and not have it forced upon them supposedly for their own good. At the very least, people with mental health problems want their stories, narratives, and voices to be valued and taken into consideration. Such an approach would take people’s diversity, and their diverse experiences and beliefs, into consideration and not label people as mad or bad but value them as human beings, with all the faults and strengths that being a human being entails. Such an approach would give rise to a more democratic and person-centered psychiatry, which would also view mental health patients’ experiences as a form of expertise to be shared with professionals rather than discounted as delusions.

What is required is a balance of perspectives between traditional psychiatry and the diverse experiences of people with mental health problems, with the aim of achieving a consensus on pathways of treatment and new, innovative, and alternative methods of mental health practice (Stastny & Lehmann, 2007). Hearing voices groups and voice hearers’ Internet discussion forums are just 2 contemporary examples as is the use of advance agreements and directives.

Central to this process is the rise of democratic psychiatry and the hearing voices movement, headed by the eminent psychiatrist Marius Romme and organizations such as Intervoice (http://www.intervoiceonline.org/), Asylum (http://www.asylumonline.net/ and http://studymore.org.uk/mpuzasy.htm), MindFreedom (http://www.mindfreedom.org/), and the Hearing Voices Network (http://www.hearing-voices.org/andhttp://www.hvn-usa.org/).

Democratic psychiatry and the hearing voices movement do not ostracize and silence people who hear voices but create space for their voices, narratives, stories, personal thoughts, and experiences, which will lead to more humane and holistic approaches of understanding and treating
schizophrenia and mental illness in the future. This means that psychiatry rather than doing things “to” or “for” people must begin to work “with” them. According to Romme and Morris (2007):

The term ‘schizophrenia’ is not just stigmatising, but also fundamentally flawed. It is a label without scientific validity. Diagnosis ignores connections between life experiences and core illness experiences. We urge mental health professionals to listen to what their patients are telling them and help them understand their experiences. (p. 7)

References

*Powerful Choices: Peer Support and Individualized Medication Self-Determination*

**Corinna West**

Introduction

I am a certified peer specialist. I have helped homeless people and people with mental illnesses reclaim their lives by sharing my story of recovery from both homelessness and mental illness. I use many tools and creative talents each day at work: poetry, PowerPoint presentations, personal conversations,

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recovery research, and extensive social networking. I believe that the mental health system can change to provide recovery for every single person with mental illness. I think that 2 of the important science-to-service gaps in real-world schizophrenia treatment are the ability to inspire people to make changes in their own lives and to help people decide to take responsibility for important choices that will affect their recovery. As a peer specialist, I tackle both issues. I think that we need both more peer support and more medication self-determination and individualization of treatment.

My message is a story of hope that all people with mental illness can take control of their lives on the other side of a diagnosis. We can regain a productive and fulfilling membership in the community. By combining my life passions, my recovery story, my dreams, and my joys, I am able to create novel presentations and workshops. I perform these for day programs, support groups, consumer-run organizations, and staff trainings at community mental health centers. These are active and participatory learning experiences that incorporate performance or spoken word poetry, PowerPoint slides, and cutting-edge research that challenge how the current mental health system is being funded and operated. I am a storyteller, and I tell a tale of change: taking the power back to help oneself, taking risks, and finding new dreams. I create short or long workshops where people can become inspired by both giving and receiving peer support in order to learn the importance that mutual relationships can have. I believe that peer support is the future of the mental health system, and we will be some of the most powerful forces in transforming the mental health system to a “recovery-oriented community of hope” (Missouri Department of Mental Health, 2009).

My recovery involved finding a way to maximize my strengths and move beyond my weaknesses, and active transportation, including walking, running, and bicycling, is an important element in my daily routine. Patricia Deegan, PhD, a psychologist who has also recovered from schizophrenia, has come up with a term called “personal medicine,” which is what we do for ourselves. Pill medicine is what we take, and personal medicine is what we do, both how we stay well and the reasons we find for wanting to stay well (Deegan, 2005). I have incorporated my art, my work, and my life, in a way where many of the things I do will enhance my recovery. I ride a bicycle everywhere I go and advocate for the 8.3% of Missouri households that have no access to an automobile (Missouri Bicycle Federation, 2009). I use exercise as a positive coping tool for stress, I am out and involved in the community, and I have made a great group of
friends and supporters who enjoy my personality with or without mental illness. My plan, my power, and my way is to do what I can to be a positive, inspirational person who has immense potential to make the world a better place.

Reclaiming Dreams

A few years ago, when I was more ill, I read somewhere that when an initial diagnosis of mental illness is made, what should happen is that the doctor should give the diagnosis and give some basic information about the illness and the treatment. Then the doctor should walk out of the room, and a person with that diagnosis should walk in and say, “I have this illness, and I have a life. I have some really good things going for me on the other side of this diagnosis.”

When I first read that, I thought, “I’d like to be that person.” Now I am. I am a certified peer specialist working for Mental Health America of the Heartland, an information and advocacy organization in Kansas City. My last peer support assignment was at a local homeless shelter, where I gave my peers information on recovery, helped them look for jobs, helped advocate for their residential needs, taught people how to prepare an agenda for their medication appointments, assisted with transportation planning, and served as an example that recovery is possible. I also co-coordinate a warmline, a consumer-operated alternative to a crisis line where people with mental illnesses can call and just talk to someone else who is experiencing the process of recovery. Our warmline is all volunteer staffed with about 28 consumers who answer about 350 calls a month while learning employment skills, recovery information, assertiveness, and how to build their own personal peer support networks. My job is to help people rebuild their lives. What I try to communicate as a peer specialist is that it is worth digging a mile through stone. I try to give people the tiny hope of a baby dream that they can recover; however, they need to hear it. I try to help people connect and to learn to help themselves. My story, along with my joys and passions, is part of the peer support movement that is transforming the mental health system (Peebles et al., 2007). I advocate for clients’ larger possibilities in staff meetings, I challenge stigmatizing statements made in the back rooms, I share updated information about recovery, and I bring in creative client-centered solutions to my coworkers. Most important, I provide an example of productivity and recovery for every staff member with whom I interact.
This ability to change attitudes and perceptions for both clients and other staff is unique to the peer support role.

Spoken word poetry is one of the most powerful tools in my arsenal. This is a dense art form that can communicate emotion, ideas, and my ambitious personality in a brief amount of time using intonation, gestures, and choreography. I have a 7½-minute poem about being a member of the 1996 Olympic Judo team that contains the same important images, skills, character, and a lot more emotion than the original 60-minute PowerPoint presentation. After hearing this poem, people have said, “That is the most inspirational thing I have heard in a long time,” and “I was so hopeful that it brought tears to my eyes.” One of my poems was selected for publication in Mind Matters Monthly, a newsletter for people inside Oswatomie State Hospital, the biggest inpatient institution in the state of Kansas. A peer specialist who works in the hospital said, “When people read the poem, and saw all that you had accomplished, the light bulb went off for them. They just realized, ‘Yeah, I can do this.’ It was really powerful and amazing to watch.”

Peer Support as an Evidence-Based Practice

Peer support is qualitatively different than other mental health staff interactions. A client at the homeless shelter where I worked told the other peer support worker and me, “I really like working with you two because it seems like you understand where I am coming from. You two are the best part of this facility.” Paulson et al. (1999) compared practice patterns of consumer and nonconsumer providers of mental health services and found a much greater qualitative than quantitative difference. “While the activity log analyses showed that both teams had similar patterns in what they did, that is the type and distribution of time spent doing case manager activities, there were observable differences in how the teams carried out these same activities. In other words, there were differences in the practice ‘cultures’ operating in the two teams [italics and quote original].” The kind of differences included boundary issues such as a greater willingness to self-disclose, less expressions of fear of the clients, and less rigid issues of personal space like a friendly “goodbye” hug. The consumer team had less emphasis on adherence to rules and seemed to work more cooperatively rather than imposing sanctions. Perhaps, the most important difference observed was a more relaxed...
pace “where the case manager seemed to ‘be there’ for the client, where it was not the task but rather the relationship and being fully present with the consumer which was considered paramount in the recovery process” (Paulson et al., 1999).

Sells, Black, Davidson, and Rowe (2008) found that “clients with peer providers perceive that their providers’ communications are more validating compared with clients with traditional providers. Moreover, peer providers’ invalidating communication appeared to be linked to clients’ subsequent improvements in social relationships and health, whereas no corresponding associations were found for clients of traditional providers.” Often when I have had to disagree with a client, I have been able to bring in first hand experience. I remember one particular conversation discussing the merits of hospitalization with a person who was not really suicidal or a danger to others. I was able to bring in my own experience of multiple hospitalizations that not only kept me safe but also somewhat delayed me in the process of finding solutions to my primary problems of a job, friends, and housing.

Peer support was designated as an evidence-based practice by the Centers for Medicare and Medicaid Services (CMS) in August 15, 2007, letter to State Medicaid Directors that said, “CMS recognizes that the experiences of peer support providers, as consumers of mental health and substance use services, can be an important component in a State’s delivery of effective treatment.” The letter emphasized that plans and goals must be individualized and person centered (SMDL, 2007).

[sic] Report of Eiken and Campbell (2008) on Medicaid coverage concluded that “1) when provided in addition to other mental health services, a majority of studies suggest peer support helps participants improve psychological outcomes and reduce hospitalization; and 2) a majority of studies suggest peer providers perform as well as non-peers when peer-delivered services are an alternative to traditional mental health services.” Gates and Akabas (2007) found that barriers to integrating peer staff include attitudes toward recovery among nonpeer staff, role conflict and confusion, lack of clarity around confidentiality, poorly defined peer jobs, and lack of opportunity for networking and support. The authors suggest workplace strategies to respond to each of these issues. The agency I work for, Mental Health America of the Heartland, employs 9 peer specialists who work in collaborating nonprofit agencies throughout our bistate metro Kansas City area. Although we are one of the largest groups of peer specialists in our region, we have
barely scratched the surface of the demand. Many other states have yet to make the effort to create a certification process so that they can bill Medicaid for providing peer support. Increasing the amount of peer support would remedy an important science-to-service gap in the real-world treatment of schizophrenia.

The Importance of Choices

I think that the science-to-service gap can be summed up in one word: choices. In an ideal world, all people with schizophrenia would have access to available evidence-based treatments. The power of choices is summarized in Patricia Deegan’s article “Recovery as a Journey of the Heart” that explains how those of us with psychiatric disabilities can choose to become helpless rather than hopeless when our efforts feel futile. Deegan explains that choices are essential to help someone come out of this place and says “… the staff must not fall into despair, feel like their efforts are futile, grow hard of heart, and stop caring themselves. If they do this, they are doing exactly what the person with the psychiatric disability is doing” (Deegan, 1996).

Role modeling of hope is one of my most important jobs as a peer specialist. By sharing my recovery story, I can help staff avoid the trap of feeling that their efforts are wasted by pointing out that people do indeed recover. At the homeless shelter, I started a process of collecting success stories of clients so that they could be used to inspire other clients for grant writing, to reassure staff, and to reward the clients who were so recognized. One of the clients I approached said, “Well, I didn’t really consider myself a success, but I guess I have made a lot of progress.” I help both the clients and the other staff recognize small milestones. I learned in a support group that I helped to facilitate that recovery is best understood in hindsight—just as it is possible to travel most of the way from Miami to California without seeing a single sign for over 1500 miles that you are on your way to California (Crowley, 2000). I help both clients and staff to see the signs and keep hope alive. Fisher and Ahern (2002) have described how the role modeling of hope works by providing hope, social connection, and a belief that people can regain control of their life.

When I was going through the certification training to become a peer specialist, Beth Filson, also a certified peer specialist and one of the trainers,
told us, “In no other field could I take those ten years of my life that were so much misery and pure hell, and turn all that negativity into something positive. All those experiences that were so terrible when I lived through them have now become valuable and have the potential to help someone else, and it’s like, ‘Wow, those years weren’t wasted.’” Hearing people respond to my recovery story with a new sense of encouragement is incredibly powerful for both me and the person with whom I am working.

The Choice of Medication

Nowhere does the importance of choices have such a social and emotional impact as in the area of medication. Article of Roe and Swarbick (2007) on “A Recovery Oriented Approach to Psychiatric Medication” mentions that efforts to develop and integrate concepts such as shared decision making, self-determination, and informed consent are transforming the mental health system. The authors suggest that supporters can help by empowering consumers to ask questions, to help consumers prepare ahead of time for a meeting or to be present as an advocate, by role-playing aspects of the medication meeting, and by teaching consumers to ask for the drug prescribing information. As a peer support specialist, I have never once advocated medication discontinuance. Instead, I try to ask effective questions like, “How is that working for you?” or “What is your biggest barrier to reaching that goal?” or “Is there a way you can tell your doctor what you really need next time?”

Because I was first diagnosed with a psychotic illness relatively recently (2001), I was able to participate in a mental health system that allowed me some degree of choice. My initial symptoms of visual hallucinations were met with a prescription of an atypical antipsychotic, which worked for me. Later, a different doctor diagnosed me with a nonpsychotic mood disorder and abruptly took me off the antipsychotic with my consent. After about 2 months, I became floridly psychotic, with visual, tactile, and olfactory hallucinations. I remember vividly one time when I was trying to drive home and the hallucinations were so frequent that I was afraid to drive off the road or run into something that may or may not have been there. I finally pulled over and called a friend who is a mental health consumer. “Do you have any Thorazine?” I asked her. “I don’t care if it’s a bad drug, I’ll take anything at this point.” I was well aware at that time that atypicals were supposedly
superior, although that assertion has come into dispute more recently (Geddes, Freemantle, Harrison, & Bebbington, 2000). My friend did not have any meds for me but did talk to me about how to calm down and try to separate the real from the unreal enough to get myself home that evening. I got back on atypicals, and after a rough 2 or 3 more months including one more hospitalization, the psychotic symptoms were abated enough that I could live independently and work again. In fact, the job and the house I found to share were also very important steps as I learned to take responsibility for my own life and to build a new life instead of trying to get back to the life I had before I was ill.

As a peer support specialist, I can use my personal experience with medication to reinforce both the benefits and the disadvantages to medications, and I can help the clients weigh their goals in order to make a more informed decisions. This helps to create the individualized plan of care necessary for each person. I often have more time available than do my nonpeer clinicians, and I can try to work out the important values for the choice. I never tell people to discontinue medication, and in fact, when I do presentations, when people ask me about my medications, I tell them about Lance Armstrong, the cyclist. He is often asked about medications by people with the same kind of testicular cancer, and he tells them that medications and their effects are incredibly individual and have to be handled on a case-by-case basis, so what meds work for one person is irrelevant to another person’s treatment.

Medication Issues, Peer Support, and Self-Determination

There are people in the consumer movement who say, “I couldn’t have recovered without my medications,” and when I was more ill I was definitely in that category, although not so much anymore. Some people even advocate for a greater role of medication decisions made on behalf of consumers who may not see the need for medications (Frese, Stanley, Kress, & Vogel-Scibilia, 2001). However, there are also people who say, “If I had stayed on my medication, I don’t think there’s any way my life would be as together as it is now” (Carey, 2006). All these positions need to be recognized and validated. Bola and Mosher (2002) suggest that “An outright dismissal of antipsychotic medication use as well as an uncritical and universal prescription of these medications for all psychoses might be equally regarded as ideological positions.”
Ignoring the fact that some people do well off medications might be another large science-to-service gap in the real-world treatment of schizophrenia (Harding & Zahniser, 1994; Harrow & Jobe, 2007). I am aware that many of the studies showing greater rates of relapse for people on placebo (Beasley et al., 2006) are abrupt withdrawal studies, whereas gradual withdrawal, following sound pharmacological principles, has a much lower rate of relapse (Viguera, Baldessarini, Hegarty, van Kammen, & Tohen, 1997). I have found out that antipsychotics cause a discontinuation syndrome that can be confounded with relapse (Moncrieff, 2006). This may be based on the fact that antipsychotics increase the density of dopamine receptors and convert dopamine D2 receptors from the low-affinity state to the high-affinity state that is implicated in psychosis (Seeman et al., 2005). These increased numbers of high-affinity dopamine D2 receptors are invariably associated with behavioral supersensitivity to the brain's dopamine, the release of which is increased by stress, street drugs, and other factors. In addition, combinations of different genes in different people can be associated with such dopamine supersensitivity. No single gene is sufficient to account for behavioral supersensitivity and psychotic symptoms. For example, the removal or knockout of a particular gene will cause changes in the activity of other genes, which can converge to trigger dopamine supersensitivity and psychosis, so the race to find a single gene for schizophrenia is essentially futile (Seeman et al., 2006). This supersensitivity has been proposed to cause treatment failure over time (Samaha, Seeman, Stewart, Rajabi, & Kapur, 2007) and has been suggested, along with side effects, as an important reason for the high rate of discontinuation during the Clinical Antipsychotic Trials Of Intervention Effectiveness (CATIE) trial (Chouinard & Chouinard, 2008). It is possible that by medicating everyone, we are missing out on a group of people who are overrepresented in the best outcomes category (Kurihara, Kato, Reverger, & Yagi, 2002). More extreme detractors of medication have hypothesized that medications cause more harm than good and that lower use of medications explain the better outcomes found by the World Health Organization studies in the developing world (Whitaker, 2004).

Even though I understand these issues with medications, I still know from personal experience, from work observations, and from research data that medications do indeed have value. As a peer support worker, I have to try to avoid any dogmatic or judgmental characterization that would
be unhelpful to my clients. I am very aware that although I am a trained professional, I am not a doctor. Instead of giving any specific medication advice, I teach clients self-advocacy skills, negotiation strategies, and problem-solving techniques to address their concerns with their doctor. I teach self-determination so that people can optimize their medication regimes for themselves. My job is to model hope, as Patricia Deegan said, to keep offering options and choices, and to help the staff I work with to keep from falling into despair. I know recovery is possible, and I help people to see how they still do have the ability to impact the world and make changes. I teach them to ask themselves questions like, “What is stopping me from working?” or “Was it really true when that doctor told me that taking the bus would be too stressful for me?” or “Who else can I find to talk to about this problem?”

I have helped other mental health consumers to apply for the peer specialist training after not working for long periods of their life. One of them said, “I still believe I have a lot to contribute to the world and I would like to make a difference for someone else the way other people have done for me.” The choice of seeking employment is a powerful assist to recovery, yet a study on conformant care found that 52% of people had not been assessed for work potential. The same study found that 24% of people were undergoing polypharmacy with multiple antipsychotics, which the author defined as nonconformant to the Schizophrenia Patient Outcomes Research Team guidelines (Bollini et al., 2008). Because atypical antipsychotics cost $300–$600 a month, that could have bought quite a lot of peer support. In the wake of the CATIE trial results questioning the superiority of atypicals, Luchins (2006) says, “The decision to reduce resources for other interventions while enormously expanding the medication budget was not necessarily one that would have been supported by consumers, but it was a decision we made. In hindsight it was a mistake.”

As a peer supporter, my job is to challenge all the assumptions. The first assumptions I had to challenge were my own fears of never being able to work again at the same level and fears of not having friends or a family or a life worth living. I was very ill for a long time, and now I am not. I have a remarkable life with friends, passions, hobbies, and interesting and ever expanding opportunities. I have a practical and durable bicycle that gets me all over town while meeting amazing people and having interesting adventures along the way. Connecting with resources in the consumer movement helped me decide
to keep trying after I had given up numerous times. Now it is my turn to keep asking questions, to help people to find what works the best for them, and to keep pushing their limits. My role is unique with [sic] the mental health system because I affect both clients and the other staff as they provide services. I help both groups see that there are many powerful choices available.

Acknowledgments

To my compassionate ear co-coordinator, Lois Hohn, who is as dedicated as I am to consumer-provided services. To Randy Johnson, my boss, and the entire staff at Mental Health America of the Heartland, where I have been [sic] learned to harness my unique talents. To the countless leaders of the consumer movement who came before me and paved the way—we are the evidence.

References


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Episodes of significant depression have been a part of my life for as long as I can recall, but psychosis was unknown to me until I was in my mid-thirties, months after the birth of my second child. At first, all I recognized were the emerging symptoms of postpartum depression in the weeks after the birth: a familiar scenario, since it had also occurred with my first child. My OB/GYN immediately prescribed 50mg of Prozac daily. I took the medication, felt much better, and continued to breastfeed my second daughter with no apparent problems.

In fact, for about four months I felt better than I had in years. My therapist, an LCSW, was thrilled with my progress. She had been treating me with a technique called Eye Movement Desensitization and Reprocessing (EMDR) for about a year in order to abate the symptoms of depression, anxiety, and panic attacks I had suffered nearly all of my adult life. The therapy worked; I successfully overcame the anxiety and panic attacks, and the Prozac ameliorated the depression. I felt like I had been healed, cured, was a new person, for the first time truly enjoying the many blessings in my life: two beautiful daughters, a doting husband, a good income, and a teaching career I loved. But in the fifth postpartum month, and for no apparent reason, something went very, very wrong. The depressive mood returned—despite the Prozac—in a form it had never taken before, with a frighteningly self-destructive severity and a subtle but definite descent into psychosis. No one recognized it at first, although eventually it would be diagnosed by most professionals as schizo-affective disorder. The following essays are my recollections of some of these new, and very foreign, moments in the beginning of that process, as my mind gradually turned from sane to psychotic.

June 2002

Tim is away, traveling on business this week. I don't like it when he's gone. It's not the lack of conversation or sleeping in an empty bed that's the problem. The hard part is that time in the evening when the girls are in bed and the house is silent and dark. I know this sounds very strange, but I am sensing something awful in the shadows at night. In darkened spaces, I feel a presence is lurking; I fear that it is watching me. I don't like to think about what it might be, but I think it's something dead, something that is alive and yet shouldn't be alive. Something silent, stealthy, evil, made of bones, or bloody, decaying body parts. I am terrified to look in the closets, or behind doors, or in the garage. I am constantly turning my head to look behind me. Even a familiar sound such as the cat jumping off the counter startles me. My heart pounds while the water sprays over me in the shower, for fear that my eyes might be closed or my back turned and my body vulnerable as something advances toward me. I wish Tim would come home. The evil things keep hidden when he is around in the evening. They want me alone.

I told my therapist, Diane, about the evil things in the dark shadows. “I’m really embarrassed to tell you about this,” I said. “You’re going to think I’m schizophrenic or something.” I looked away, rubbing my finger over a small spot on my khaki pants. Even the closet in her office, dark behind folding doors, looked suspicious to me at the moment.

“No, no, it’s not that,” she said. “I’m not an expert on schizophrenia, but I would recognize it if I saw it. Besides, if you were schizophrenic, it would have developed in your teens and twenties.”

I breathed a sigh of relief.

“These might be some memories of childhood nightmares,” she continued. “We’ve been digging into your past while doing the EMDR, and all kinds of subconscious thoughts can resurface during the therapy.”

“I can’t tell you how glad I am to hear you say that,” I said.

“These creepy things have really been scaring me.” “More than likely, you’ll find that it will go away now that you’ve recognized the fear and discussed it with me,” Diane said. She smiled, and her clear green eyes looked relaxed.

She’s not worried, I thought.

I left her office feeling better, but the evil things in the shadows remained.
August 2002

It was late, past 10:00 p.m., when I went into the kitchen for a glass of water and realized the dishes hadn’t been done. Tim was hunched over his laptop in the family room, chuckling occasionally at the television. Frowning, I reached under the counter for the dishpan, squirted in some lemon-scented dish soap, and filled it with hot water.

The baby bottles got washed first, while the water was clean. All the pastel-colored plastic caps and bottles of various sizes clunked around in the dishpan as I inserted a bottle brush inside each one and twisted it. Gradually I became aware of a tapping sound on the screen sliding door. What is that? I peered over the counter to see if the dog was scratching to go out. She wasn’t there.

Tap. Tap-tap. Tap. I stacked the clean bottles to dry and moved on to the glasses and utensils, saving the messy pans for last. My gaze flicked back and forth between the dishpan and the screen door and the tapping sound. Suddenly I understood. Large moths were throwing themselves against the screen in an effort to get in. I could see them now. Tap, buzz. Tap. Tap.

But I was not entirely reassured. The tapping sound was creepy, and not just because I didn’t want the big brown moths to come in. I rinsed some cooking spoons and placed them in the dish drainer, not wanting to look at the screen anymore. What if those are fingers tapping on the screen? Long, crusty, brown fingers, not human. Alien. Trying to get in. Carefully I picked up a crystal wine glass and dunked it in the warm water. The dried purple residue of merlot colored a dimple at the bottom of the glass, just farther than the reach of my fingers.

Tap, tap. Buzz, tap. I had to look. It’s just moths, okay? It’s not fingers. It’s moths. Look, you can see them. They were ugly, fuzzy-looking things, some of them walking around on the gray screen that separated the yellow incandescent light inside from the charcoal darkness. I shuddered and felt that anxious tightening in my chest.

Crack. A stab of pain jerked my attention back to my hands. The wine glass had broken in my hands while I was washing it. A half-inch gash on my right hand started to bleed as I held it up, as though it had only just been cut with a scalpel. I stood there and watched the blood well up and run over my water-wrinkled hand; I turned it slightly so that it would drip into the dishwater and not run down my arm onto my clothes.
It was a very curious sensation, and one I had never felt before. I felt glad. Look at that. Fascinating, the blood dripping into the water and winding around, like drops of food coloring. This is a good thing, and you deserve such things. Very good. Well done. The sight of the blood swirling into the water captivated my attention and froze my body for many minutes. Yes.

In another moment, or perhaps many, I walked around the counter and closed the sliding door, locking out the moths and whatever else was out there. I forgot about the alien fingers, because I was busy looking at my own hand, which I had just cut wide open but seemed to have healed itself again. It took a few minutes of studying it before I realized, to my disappointment, that I had merely imagined the incident. I hadn’t really cut myself. But now I wanted to.

September 2002

For as literate as I am, I am having a terrible time coming up with the words to explain what this is like. At first I just thought that it was different moods, but now it’s more than that. I feel like my personality is somehow unraveling, and each mood takes on its own personality. There are no names for them, only descriptions: the fearful adult, the cold adult, the caring adult, the teenager, the child, the Others—those are the ones who are not me. They speak inside my head; I don’t hear them out loud, and I don’t “become” them—they are just there. The milder ones just talk about the way they see my world. The harsher ones, particularly the cold adult and the Other voices, shout and hiss a lot and order me to do things like cut myself. I can’t tell anymore if these are my own thoughts, or if they are something else. (But what?) Oh, boy—I told you this was confusing. If you understand this, you are way ahead of me.

Diane looked up after she finished reading the page. “Well, I admit that this seems unusual, and I can understand why you’re confused. Maybe we’ve uncovered some unconscious issues, and when you’ve worked through them, these ‘moods’ will disappear.”

“I certainly hope so,” I said. “They’re making me feel awfully strange. I’m still taking Prozac, so it couldn’t be depression, could it?”

“No, probably not.” She smoothed her dyed-blonde hair while she thought for a minute. “Let’s not get too discouraged about it, okay? You’re working very hard to get through these things, and I have no doubt in my mind that you’ll succeed. Just think what you accomplished while you were pregnant! You thought you would never get over those panic attacks, and
then one day you did.” She paused for a moment to take a drink of water. “I’ll bet, by the time I come back from my vacation, you and Liz will have all this figured out, and you’ll be just perfect.”

October 2002

The craft store had the exact paint set I wanted; it was a portfolio of watercolors in a box, instead of tubes. I opened the box and stared at the colors for what must have been ten or fifteen minutes, captivated by the luxurious sensory impact of each one. My confused, splitting mind was somehow drawn to, connected with colors, lines, and shapes in a very visceral way. Women wheeled their shopping carts past me, laden with eucalyptus-scented dried flowers, decorative pots, and wide cloth ribbons; they looked at me standing there studying the sixteen semi-moist paint squares, and no doubt wondered what I was doing.

After a while my attention broke away from the paint box and I walked down the next aisle, where the paintbrushes and colored pencils were stocked. Adjacent to the display of paintbrushes, there was a display of carving tools. I selected a detail brush and a mop brush for my watercolors, and across the aisle, several new Prismacolor pencils. That was all I really needed, but my mind turned back to the carving tools. *Just look.* You’ve got time.

Hanging there on the white pegboard racks were dozens of cutting and wood-carving tools, packaged separately and labeled with sizes and suggested uses. I was as fascinated by all these sharp little tools as I had been by the colors, but for a different purpose; I wanted these to cut *myself.* Instead of resorting to sharp scissors or broken glass shards (Tim had already locked up the kitchen knives), I could have my very own secret sharp tool.

There were all kinds of little knife tools; I only had to decide which one. Some had small blades, and some looked like chisels. One had a two-pronged point. *I could stab myself in the stomach with that one.* Another very tempting choice was a C-curved blade. *I could dig into my wrists and pull out the tendons with that one.* Finally, I decided on a more ordinary Exacto knife, which had a small, fine-pointed blade and a plastic cap that went over the top, so that I could carry it in my purse without cutting my fingers while I was rooting around for stuff. *Sharp, practical, easy to hide, easy to make an excuse for.* Oh, that? I need that for the building projects the kids are working on at school. *The one I had got lost.*
The knife and its sharp, triangular blade called to me from my purse like a chocolate bar. *I'm here, don't forget me. I'm so easy, so convenient.* The voice in my head, in its low, almost whispering tone so like my own voice, concurred. *Yes, yes, it's a lovely little knife, so simple for you to use. Get it out, why don't you? Cut that place on your hand where you burned yourself a couple years ago. You already have a scar there. It'll be quick; it won't even hurt much. There, see? Good girl. Just stick a Band-Aid on it and no one will know except us. Later you can do it again.*

I had never before allowed my personal problems to creep into the school day; in fact, I really didn't have time for them. I hardly had time to use the restroom. A fifteen-minute recess in the morning, forty minutes for lunch, and once a week an hour of prep time while the kids went to music or art; that was all I got. Five minutes, even three, or two, was enough time to get out supplies, set up a science project, or grade a few math tests. My prep time was golden, and there I was, using it to cut up my hands and arms. This was not a good sign, and I knew it. The voices were influencing me while I was at school, their commands taking precedence over my attention to the job that I loved and had been deeply involved with for years.

Not good. Not good at all. The knife reminded me constantly of its presence, like the One Ring to Frodo Baggins. The voices spoke softly, giving encouraging reminders. *Let's get out the knife. This is what we want you to do. Don't worry, we are on your side. Think how it will feel. Think of the warm, red blood inside you, and how much we like to see that. Look at your wrists, the inside, where the larger veins are. Think about how much you want to cut yourself there. Think. Think.* I could hear them out loud now, whispering in a chorus of voices. *We will be with you, whenever you are ready.*

*Why Having a Mental Illness Is Not Like Having Diabetes*

**Anonymous**

A number of times during the course of my illness I have been told by health professionals that it is useful to think of having a mental illness (in my case

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FIRST PERSON ACCOUNTS OF MENTAL ILLNESS AND RECOVERY

schizoaffective disorder) as having a lifelong disease that requires lifelong management and drug treatment—in fact, just like diabetes, a well-known disease affecting a large proportion of the population. Diabetics, so the story goes, need to accept that they have an illness that will require treatment for the rest of their lives; and if they continue the treatment, they will maintain their health insofar as this is possible, while if they discontinue treatment, they will suffer dire consequences, including blindness, loss of limbs, diabetic coma, and so on. Looked at in this light, treatment of a mental illness is just the same; if medication and other treatments are continued, the prospects are relatively good, and if not, the prospects are dire.

This story is common among health professionals who treat those with mental illness, but it also occurs in some medical research in which schizoaffective patients have been explicitly compared with diabetes patients. In a series of studies a team based in Lund, Sweden, took schizoaffective patients and compared their social networks and background factors (Nettelbladt, Svensson, & Serin, 1996; Nettelbladt, Svensson, Serin, & Öjehagen, 1995). The rationale for making a comparison between schizoaffectives and diabetics is as follows:

"From a medical and psychological point of view there are similarities between diabetes and schizoaffective disorder. In both diseases you may prevent a relapse by taking medication (insulin or lithium) and the risks of pregnancy and delivery are greater than for healthy women. Further, the chances that a child to a parent with diabetes or schizoaffective disorder will subsequently develop a diabetes or a schizoaffective disorder are considerable. Thus, the medical and mental strain caused by diabetes and schizoaffective disorder to some extent may be the same (Nettelbladt et al., 1995, p. 906).

I would like to spend the rest of this article showing why this parallel, so frequently made, is ill conceived and unhelpful.

Hospital Experience

A diabetes patient in hospital can expect a clean, hygienic ward peopled by staff who treat the patient with respect, as an equal, who explain the illness and the treatment regime, and who co-opt the patient as an important agent in his or her own recovery. A psychiatric patient, however, might well find a ward that is rundown and peopled by staff who do not seem to have the same expectations of respect for patients and of a generally good professional
working relationship between staff and patients. A psychiatric patient might instead, as I did in one of my hospitalizations, find staff who avoided talking to the patients as far as possible and whose only interaction with patients was to give commands.

As a diabetes patient, one would certainly not expect violence or abuse from fellow patients; and if this did occur, one could expect a swift reaction from the staff. However, as a psychiatric patient, violence from other patients is at times a real risk, and one that staff might seem to regard as inevitable.

A diabetes patient would certainly not expect to come out of the hospital experience feeling belittled and demeaned, whereas this is something that has been reported by psychiatric patients; and certainly it was my own experience in one hospital.

Finally, in a diabetes ward there is no sense of being in a prison, even though diabetic patients, just as much as schizoaffective patients, are necessarily confined to the ward for their health and safety. Mental patients in hospital, by contrast, frequently report feeling as though they were in prison; certainly during one of my hospitalizations I spent most of my time trying to devise ways to escape.

Attitude of Family and Friends

Schizoaffective disorder rips straight into the heart of the family, causing shame, anger, guilt, and self-blame from parents and siblings, as well as casting blame on the patient. Parents ask, where did I go wrong, and patients ask, if I had had a different upbringing could I have avoided this disease? With diabetes, however, there is no sense of blame, guilt, or shame; rather, people hear the diagnosis, learn (perhaps over time) about the condition, and come to accept the limitations of the condition.

After receiving a diagnosis of diabetes, a person could expect that their friends, on inviting them over for dinner, might inquire how they could best fit in with the patient’s new diet, if that were necessary. However, after receiving a diagnosis of schizoaffective disorder, a patient would be waiting a long time for someone to ask how he or she could fit in with the sickness. This is a pity because there are many very simple ways to make life easier for those who suffer from psychosis and other mental illness problems. In my own case, for purely psychotic reasons, I would love to be assured that there would be no electronic beeps in any house I was going to visit. However, I find it difficult to imagine asking even close friends to turn off any electronic
beeping machines when I am coming over; the request would be embarrass-
ing and weird. It is not confronting to conform to a diabetic diet, but it is
confronting to adapt to a psychotic patient’s needs.

With diabetes, there is no stigma. People are not afraid of a diabetes
patient. A diabetes patient would probably feel free to tell anyone that he or
she has diabetes, without expecting possible rejection or shunning. I have
frequently been warned by health professionals never to tell anyone, apart
from close family, the name of my sickness. Diabetes patients can even tell
an employer about their disease, whereas schizoaffective patients would be
most unwise to.

Even if the general public does not know the causes or exact effects
of diabetes, knowing only perhaps that it is something to do with sugar
in the blood, which means that someone with diabetes has to be careful
what they eat, their ignorance does not lead to fear and ridicule. Diabetes
is in fact quite easy to explain to a layperson. Schizoaffective disorder is
very hard to explain to a layperson. My own child is getting to be old
enough where she will soon need an explanation from me of what exactly
my sickness is and why I need to go to [sic] hospital now and then. Such
an explanation for a diabetes patient would be easy. For schizoaffective
patients it is very hard.

In the media diabetes generally receives an impartial, unemotive treat-
ment. I have never seen schizoaffective disorder referred to in the media
(another problem contributing to ignorance in the general public), but its
close relative schizophrenia is almost universally dealt with in simplistic, lu-
rid, and often violent terms—in any case generally with more hysteria than
information.

The Disease Course

The course, and consequences, of the 2 diseases are very different. Diabetes
does not get out of control and make a person do things for which they
could be civilly or criminally liable. Diabetes does not gradually erode a
person’s ability to think and reason or leave one unable to decide what is
true and what is not true in the world, crippling his or her ability to act as
an independent adult. Diabetes does not affect the very way people think,
who they are, and how they operate socially, professionally, and within their
family. Schizoaffective disorder does.
Treatment

Diabetes medicine does not change who a person is; it does not turn one into a zombie, negating the highs as it flattens out the lows; it does not change the way one operates or, in fact, change what it is to be that person. Medicine for schizoaffective disorder does.

Diabetes treatment does not require the same sacrifice of personal privacy that nonmedical treatment for schizoaffective disorder does.

These facts, each one perhaps small in itself, combine together in schizoaffective disorder to contribute toward an insidious erosion of the sense of self that is compounded by the action of the disease itself and the side effects of the medication. I therefore reject the analogy of schizoaffective disorder as being like diabetes. If I could choose a replacement analogy, I would say schizoaffective disorder is like a whirlwind: it comes out of nowhere, strips you naked and sucks you dry, and swiftly vanishes, leaving you empty and shaken but alive, wondering if it really did happen and whether, and how soon, it will come back again.

References

