

How I Perceive and Manage My Illness

by Esso Leete

Abstract

The article describes some of the ongoing problems psychiatric patients encounter on a daily basis as perceived by an individual who has lived with schizophrenia for more than 25 years. Specific carefully planned coping strategies which are seen as critical to the recovery process are presented.

More than by any other one thing, my life has been changed by schizophrenia. For the past 20 years I have lived with it and in spite of it-struggling to come to terms with it without giving in to it. Although I have fought a daily battle, it is only now that I have some sense of confidence that I will survive my ordeal. Taking responsibility for my life and developing coping mechanisms has been crucial to my recovery. I would like to share some of these with the reader now.

To maintain my mental health, I found I had to change my priorities and take better care of myself. I modified my attitudes, becoming more accepting and nonjudgmental of others. In addition, I altered my behavior and response to symptoms. I have also had to plan for the use of my time. When one has a chaotic inner existence, the structure of a predictable daily schedule makes life easier. Now, obviously structured activity can be anything, but for me it is work-a paying job, the ultimate goal. It gives me something to look forward to every day and a skill to learn and to improve. It is my motivation for getting up each morning. In addition, my hours are passed therapeutically as well as productively. As I work, I become increasingly self-confident, and my self-image is bolstered. I feel important and grownup, which

replaces my usual sense of vulnerability, weakness, and incompetence. Being a member of the work force decreases stigma and contributes to acceptance by my community, which in turn makes my life easier.

Research continues to show that one of the differences between the brain of a "normal" person and **one** who has schizophrenia is a major difficulty filtering or screening out background noises. I am hyperalert, acutely aware of every sound or movement in my environment. I am "often confused by repetitive noises or multiple stimuli and become nervous, impatient, and irritable. To deal with this, I make a deliberate effort to reduce distractions as much as possible.

I often have difficulty interacting with others socially and tend to withdraw. I have found I feel more comfortable, however, if I socialize with others who have similar interests or experiences to my own. To counteract my problem with poor eye contact, I force myself to look up from time to time, even if I have to look a little past the person with whom I am speaking. If I do become overwhelmed in a social situation, I may temporarily withdraw by going into another room (even the restroom) to be alone for a while.

I attempt to keep in touch with my feelings and to attend immediately to difficulties, including symptoms like paranoia. For example, instead of constantly worrying about the police surprising me, I always choose a seat where I can face the door, preferably with my back to a wall instead of to other

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people. In general, instead of **work-**ing myself up emotionally over some threatening possibility, I will check out reality by asking the people I am with questions like who they are calling, where they are going, or whatever. It clears the air immediately, and usually I am satisfied with their answer and can go on about my business. In other words, I cope by recognizing and confronting my paranoid fears immediately and then moving on with my life, freeing my mind for other things. Also, I have learned to suppress paranoid responses, and I make an effort not to talk to myself or to my voices when others are nearby. It can be done through self-discipline and practice.

In addition, I suffer from feelings of isolation, alienation, and loneliness. This is difficult to deal with because on the one hand I need to be with people, but on the other hand I am frightened of it. I have come to realize my own diminished capacity for really close friendships, but also my need for many acquaintances. An ongoing and reliable support system has been extremely important. I have gained much practical information, insight, and support **from** my peer-run support group, a very comfortable means of coming to accept and deal with mental illness. Also, it has been invaluable to have someone I trust (often my husband) with whom I can “test reality.” I let him know my perceptions and he gives me feedback. I am then able to consider the possibility that my perceptions may not be accurate, and I modify my response accordingly if I wish. In this way I can usually acknowledge more conventional ways of thinking, instead of automatically incorporating outside information into my delusional

system,

A common complaint from persons with a mental illness is that of impaired concentration and memory. This can make holding a job or even completing a thought very difficult. To overcome the effects of a poor memory, I make lists and write down all information of importance. Through years of effort I have managed to develop an incredible amount of concentration, although I am only able to sustain this for relatively brief periods of time.

Sometimes I still find it difficult to keep my thoughts together. I therefore request that communication be simple, clear, and unambiguous. It helps me if the information is specific, as vague or diffuse responses only confuse me. When speaking to someone, I may need more time to think and understand before responding, and I take this time. Likewise, I have learned when working **on** a task to be careful, perhaps taking more time than others, and to concentrate fiercely on what I am doing. And I must be persistent.

Many times when becoming acutely ill, I am frightened of everything, feeling small and vulnerable. When I am in distress, I do whatever makes me feel better. This may be pacing, curling up into a ball, or rocking back and forth. I have found that most of these behaviors can be accomplished without appearing too strange, believe it or not. For example, I can pace by taking a walk, I can curl up when I sleep, and I can rock in a rocking chair or hammock or even by going to an amusement park. I am often able to relax by physically exercising, reading, or watching a movie. In general, then, I think I am discovering how to appear less bizarre.

I find it crucial to schedule time between events rigidly. For example, I will not agree to give two talks on the same day. I find I must also give myself as much time as I can in which to make decisions; I have an enormous amount of ambivalence, and pressure to come to a decision **quickly** can immobilize **me**. (It is not a pretty picture.) Too much free time is also detrimental. Therefore, I find it useful to structure my leisure time and to limit it. Perhaps some day I will be able to handle it in greater increments, but for now I find it best to keep very busy, with minimal amounts of leisure time.

Perhaps the coping strategy I use the most is compulsive organizing. I think a controlled environment is probably so important to me because my brain is not always manageable. Making lists organizes **my** thoughts. It also increases self-esteem, because when I have accomplished something and crossed it off my list, it is a very concrete indication to me that I am capable of setting a goal, working toward it, and actually accomplishing it. These “small” successes build my confidence to go out and try other things. As a part of this process, I break down tasks into small steps, taking them one at a time. Perhaps organizing and giving speeches about my illness is another coping skill—and the audience response is a type of reality-testing.

In general, then, I believe I do have an irritable brain. I am super-sensitive to any stimulus. My behavior is sometimes erratic, and I am easily frustrated and extremely impulsive. I regret that I still have times of uncontrollable angry outbursts. I cope with these and other symptoms by taking low doses of

medication. Before I came to realize the role medications could play in my illness, I was caught in a vicious circle. When I was off the medication, I couldn't remember how much better I had felt on it, and when I was taking the medication, I felt so good that I was convinced I did not need it. Fortunately, through many years of trial and error, I have learned what medication works best for me and when to take it to minimize side effects based on my daily schedule.

Increasing my medication periodically is one means I often use for stabilization during a particularly stressful period.

I want to emphasize that stress does play a major role in my illness. There are enormous pressures that come with any new experience or new environment, and any change, positive or negative, is extremely-difficult. Whatever I can do to decrease or avoid high-stress situations or environments is helpful in controlling my symptoms. In general terms, all of my coping strategies largely consist of four steps: (1) recognizing when I am feeling stressed, which is harder than it may sound; (2) identifying the stressor; (3) remembering from past experience what action helped in the same situation or a similar one; and (4) taking that action as quickly as possible. After I have identified a potential source of stress, I prepare mentally for the situation by anticipating problems. Knowing what to expect in a new situation considerably lowers my anxiety about it. In addition, I try to recognize my own particular limitations and plan in advance, setting reasonable goals.

Please understand that these are the kinds of obstacles that confront individuals with a psychiatric disorder

every day. Yet we are perceived as weak. On the contrary, I believe we are among the most courageous. We struggle constantly with our raging fears and the brutality of our thoughts, and then we are subjected as well to the misunderstanding, distrust, and ongoing stigma we experience from the community. Believe me, there is nothing more devastating, discrediting, and disabling to an individual recovering from mental illness than stigma.

Life is hard with a diagnosis of schizophrenia. I can talk, but I may not be heard. I can make suggestions, but they may not be taken seriously. I can report my thoughts, but they may be seen as delusions. I can recite experiences, but they may be interpreted as fantasies. To be a patient or even ex-client is to be discounted. Your label is a reality that never leaves you; it gradually shapes an identity that is hard to shed. We must transform public attitudes and current stereotypes. Until we eliminate stigma, we will have prejudice, which will inevitably be expressed as discrimination against, persons with mental illness.

We rarely read about people who have successfully dealt with their emotional problems and are making it, and they will not usually identify themselves to us because they are all too aware of the general attitude. The current image the public has of the mentally ill must be changed, not to mention that of the individual himself. We have grown up in the same society and have the same feelings about mental illness, but we must also live with the label.

Ultimately we must conquer stigma from within. As a first step—and a crucial one—it is

imperative for us as clients to look within ourselves for our strengths. These strengths are the tools for rebuilding our self-image and thus our self-esteem. I found that I first had to convince myself of my worthiness, then worry about others. Each time I am successful at a task it serves to reinforce my own capabilities and boost my confidence. Just this way, persons with mental illness can and must change the views and expectations of others.

Obviously, education about mental illness is critical for all parties involved, especially for the patient. I have made an extensive study of my disorder and have found education invaluable in understanding my illness, coming to terms with it, and dealing with it. We must conscientiously and continually study **our** illnesses and learn for ourselves what we can do to cope with the individual disabilities we experience.

Many of us have learned to monitor symptoms to determine the status of our illness, using our coping mechanisms to prevent psychotic relapse or to seek treatment earlier, thereby reducing the number of acute episodes and hospitalizations. My own personal warning signs of decompensation include fatigue or decreased sleep; difficulty with concentration and memory; increased paranoia, delusions, and hallucinations; tenseness and irritability; agitation; and being more easily overwhelmed by my surroundings. Coping mechanisms may include withdrawing and being alone for a while; obtaining support from a friend; socializing or otherwise distracting myself from stressor; organizing my thoughts through lists; problem-solving around specific issues; or tem-

porarily increasing my medication.

Yet too many times our efforts to cope go unnoticed or are seen as symptoms themselves. If others understood us better, perhaps they would be more tolerant. We did not choose to be ill, but we can choose to deal with it and learn to live with it. By learning to modulate stress, we will more effectively manage our illness, thus endowing ourselves with an ongoing sense of mastery and control. I find my vulnerability to stress, anxiety, and accompanying symptoms decreases the more I am in control of my own life. Unfortunately, our progress continues to be measured by professionals with concepts like “consent” and “cooperate” and “comply” instead of “choose,” insinuating that we are incapable of taking an active role as partners in our own recovery.

I see my schizophrenia as a mental disorder with a genetic predisposition, predictably expressing itself in times of extreme stress, but often exacerbated by rather ordinary fluctuations in my environment. Mental illness **is** a handicap with biological, psychological, and social ramifications, making it a formidable obstacle to

be overcome. I understand that life may be more difficult for me than for others and that I must preside over it more attentively for this reason. As with other chronic illnesses, it has demanded that I work harder than most. I know to expect good and bad times and to make the most of the good. I take my life very seriously and do as much with it as I can when I am feeling well, because I know that I will have difficult times again and will likely lose some of my gains.

Although there is no magic answer to the tragedy of mental illness, I contend that we need not be at its mercy. Appropriate treatment can help us understand our disease and we can learn to function in spite of it. We can overcome our illness and the myths surrounding it. We can successfully compensate for our disabilities. We can overcome the stigma, prejudice, discrimination, and rejection we have experienced and reclaim our personal validity, our dignity as individuals, and our autonomy. To do this, we must change the image of who we are and who we can become, first for ourselves and then for the public. If we do acknowledge and seriously study our

illnesses; if we build on our assets; if we work to minimize our vulnerabilities by developing coping skills; if we confront our illnesses with courage and struggle with our symptoms persistently—we will successfully **manage** our lives and bestow our talents on society, the society that has traditionally abandoned us.

The Author

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