Expectations and the Recovery Process

by Marcia Lovejoy

Abstract

Personal experience is used to illustrate the effects of expectations on a patient's self-esteem and hope. The author, who was diagnosed as having chronic schizophrenia, points to the self-fulfilling nature of expecting a poor outcome. Project Overcome is one attempt to provide patients, families, mental health professionals, and the general public with models of successful patients. Former patients are available to lecture about their past experiences, thereby demonstrating through their actions that there is always hope.

Even a cursory examination of the current literature (see Schizophrenia Bulletin, Vol. 5, No. 3, 1979) reveals that the debate over the classification of various subtypes of schizophrenia still rages. Biochemical, genetic, and environmental theories compete with symptomatic categorizations, only to be challenged by premorbid case histories as the parameters within which schizophrenia is viewed. A primary goal of this search is prognosis, the discovery of predictive indicators that will enable clinicians to determine which clients can be expected to improve. The other, inevitable side of the coin is that they will also be able to predict which clients will probably not improve. And therein lies the danger of categorical labeling. The effects of such an emphasis, and its resulting expectations, upon the clients with the "wrong" (i.e., poor prognosis) subtype are immeasurably damaging, compounding the overwhelming social stigma clients face in attempting to overcome their illness.

I speak with some authority about the effects that professional expectations and community attitudes have upon the recovery process because my own label, since 1965, has been "chronic schizophrenic." And although I may not be qualified to speak about the etiology of my illness or the legitimacy of the various subtypes (e.g., chronic, paranoid, poor premorbid) under which that illness was classified, my experiences have taught me valuable lessons about the human consequences of such a self-fulfilling prophecy. I have also learned that there are ways in which clients and professionals can combat the stereotypes and accompanying hopelessness that stand in the way of recovery.

I began to hallucinate at the age of 9. My classmates quickly noticed that I was "different," and reacted to me "differently." Due to brain damage that would not be detected for another 17 years, my physical abilities lagged far behind those of other children. Simple skills such as balancing in hopscotch, catching a ball, or running into a twirling jump rope were extremely difficult for me. The more I tried and practiced at home, the more difficulty I experienced. My classmates ridiculed my efforts and I reacted to their rejection by isolating myself from them, knowing that I did not belong. I learned at an early age that I was not like other children, and that I must conceal my difference.

The 1950s were not an enlightened period, and my teachers saw my difference as the result of my being a recalcitrant daydreamer. I

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would giggle at odd times as I would "see" a troop of elves jump merrily from desk to desk and tweak the teacher's nose. At other times I would cry out at the sight of my desk biting my dress like a hungry animal. My behavior was annoying, and my explanations were seen as fanciful lies to cover up my disruptive behavior. When I was 12 years old, the family doctor prescribed medication for my "nerves." In high school, my mother gave me the phenobarbital that had been prescribed for her. By late adolescence I had learned that I could trust no one with the truth, and after two unsuccessful suicide attempts had decided stoically to see my life through to the bitter end.

My sophomore year of college was interrupted by increased hallucinations. I believed everyone was looking at me and I began sneaking down back stairways to avoid their piercing looks. I could hear the low growl of a tiger following me. Eventually I believed my room to be electronically monitored and that my thoughts were being recorded. Finally I was hospitalized.

In the hospital I was given medication, which ended the whirling in my head and banished the tiger's growl. I still feared others looking at me and I searched my room for hidden microphones. Even though I could not see them, I was sure the FBI was taking pictures of my every move. I was frightened: frightened of the FBI, frightened by others' critical gazes, and very frightened of this strange hospital.

The hospital itself was a kaleidoscope of images and emotions. Here were "sick" people dressed in street clothes, playing pool, and making billfolds. The rooms were large and clean, but the air was stale. There were no phones or televisions. There were a great many rules, which were not written anywhere, and apparently changed frequently. Receiving letters or telephone calls, and even private bathing were "privileges" that I must somehow earn. Being basically fearful already, I did well by quietly obeying everyone. I had seen what happened to those who did not conform to the rules. Several staff members would suddenly surround the offender with the phrase, "Are you going to cooperate, or do you want to go to 'South'?" South was the locked ward, and every day several patients were forcibly taken from my ward to South. Few returned from that ward, and those who did were unrecognizable. They did little but lie in bed, and when they walked, it was an odd, shuffling gait. Some even drooled. I was afraid of them, and of the staff, but my greatest fear was that this was where I belonged, and that this place would be my future.

My psychiatrist seemed pleasant enough, and smiled as he stopped by for a couple of minutes twice a week to sign my chart. When I inquired about returning to school, he cautioned me to dismiss the idea of ever returning to academic pressures. He said I should realize that I was ill and had to take things easy. I asked about looking for work, and he stressed that this too was out of the question for me. Maybe in a few months a volunteer job might be a possibility. He said I should not to think about any of these things right now, and just to regard myself as retired and needing a long, long rest. I would later learn that during this first hospitalization the doctors had decided that because of my long history of problems and the results of testing, I had a poor prognosis. My first diagnosis would be chronic schizophrenia. Although I had just turned 19, the professionals expected me to be a back ward patient, and advised my parents to find facilities that were custodial in nature.

I saw myself as incurably ill, as someone who would always need to be taken care of by others. My parents disagreed with the doctor's recommendations and urged me to change doctors. The second and third doctors, however, said the same things. I left the hospital and tried to fit into my new role as sick and retired from active living, but I was overwhelmed by the emptiness of my future. I became increasingly afraid of myself and my feelings, which doctors said were further symptoms of my mysterious illness. Because I was sick, my feelings and perceptions could not be trusted by anyone, even myself. The weekly visits to my psychiatrist were only so he could watch me become sicker, and prescribe more medications, or hospitalize me for the safety of the community. I felt ashamed, helpless, useless, and frightened.

My experiences in the community only confirmed these feelings. At a bus stop once, I struck up a conversation with a woman. The inevitable question arose: "What do you do?" I hesitated, but finally said that I was "retired" and that I had been in a psychiatric hospital. The woman's reaction was immediate and unforgettable. She gasped, then looked quickly for an approaching bus; seeing none, she flagged down a passing cab. I tried getting a job and painfully discov-
ered the discrimination that surrounds mental illness. I eventually learned to lie and was hired. Applying for jobs far below my skills and intelligence, and fearful of discovery, I would become nervous and sleepless. If I complained to my doctor about my problems at work, he would suggest that perhaps I was not yet ready for work. If I then argued to continue working, he would increase my medication, and I would suffer from blurred vision and sleepiness, further compounding my work problem. If I hid my problems from the doctor and just kept them to myself, I also became worse. There seemed to be no solution. But I had to keep trying; at home, all I could do was watch myself and the hurt in my parents' eyes.

I had more hospitalizations. Most of them seemed the same. My life would go out of control and the doctor would suggest that I take a rest in the hospital. After the increased medication and sleep eased the roar in my head and I knew what was going on around me, I felt a deep sense of shame and failure. I spoke to a parade of doctors, nurses, psychology technicians, aides, and students, all of whom would ask me the same questions about my life and then jot notes in my chart. I would always be given the same advice: take your medications, follow the routine, and cooperate. I learned to measure my progress by external criteria, such as medication. If I was given less, I was doing better; if I received more, I was not doing well. Although I tried day treatment programs, medications, shock treatments, and hundreds of hours of one-to-one therapy with my doctors, nothing helped me to gain any more control over my life. No matter what combination of drugs, work, school, and therapy I tried, it would fail.

Some staff members did really try to help and would honestly offer advice or criticism. It was usually as a result of their friendship that I gained the courage to attempt a new job or to believe that I could really change and gain control of my life. There were always a few hospital or program staff members who helped me to try once again. However, the vast majority only succeeded in confirming my distrust of people and my feelings of worthlessness and hopelessness. The use of power which makes it possible for a handful of staff members to manage a ward also creates powerless victims, devoid of courage and self-respect. Power games create winners and losers; I was a loser.

The one comforting aspect of the hospital was my fellow patients. After I gave up the idea that they were the FBI in disguise, I found some companionship. At least it was easier to talk to them than to my doctors, nurses, or parents. Other patients especially understood my sense of shame, anger, and fear. Staff members always discouraged friendship between patients, saying that we were reinforcing each others' illnesses. They did not understand that we were also giving each other support and help. I could not confide my problems with hallucinations, or my fears about the FBI, to anyone who had not had similar experiences. Although it helped to share experiences with others who genuinely understood, there were answers we could not give each other: how to overcome it all; how to make it on the outside. We were all losers.

In 1972 I happened to end up in a drug and alcohol treatment unit. There I was treated quite differently. Staff members would be angry or smile because they honestly felt bad or good toward me, not for therapeutic reasons. They inspired me with the idea that I was responsible for changing my life, and that I could be sane in a crazy world, just as alcoholics could learn to stay sober in a drinking world. It would take time and effort, but it was possible. In this program, for the first time, I learned some things I could do to cope with living. Staff members called these ways of handling problems "tools." My tools would be unique for me as they needed to be individualized to fit each person's needs. I began to learn. I learned that I needed to be more than a passive, cooperative patient to recover. Now I had to find answers and people who offered more substantial help than before.

There were more hospitalizations and more symptoms. The hallucinations, fears, and suspicions alternated with periods in which I believed that I was dead and with periods of sudden, unpredictable, unpredicated behavior that would surprise me as much as it did others. My doctor began to talk about a more secure environment; he meant the state security hospital for the mentally ill and insane. During the commitment process, I was sent to an interview at a halfway house. Although the halfway house accepted me, the hospital staff members believed that I needed a more structured environment. It was my good fortune that my funding ran out at that point and the staff members, having no alternative easily available, discharged me to the halfway house.
The halfway house changed my life. First of all, I discovered that some of the staff members had once been clients in the program! That one single fact offered me hope. For the first time, I saw proof that a program could help someone, that it was possible to regain control over one’s life and become independent. The house was democratically run; all residents had one vote and the staff members, outnumbered 5 to 22, could not make rules or even discharge a client from the program without majority sentiment. There was a house bill of rights that was strictly observed by all. We helped one another and gave support. When residents were in a crisis, no staff member hustled them off or increased their medication to calm them down. Residents could cry, be comforted and hugged until a solution could be found, or until they accepted that it was okay to feel bad. Even anger was an acceptable feeling that did not have to be feared, but could be expressed and turned into constructive energy. If you disliked some aspect of the program or the behavior of a staff member, you could change things rather than passively accept what was happening. Choices were real, and failure and success were accepted equally. Although I was incredibly suspicious, I could find little about which to be “paranoid.” I could read my file at any time. All problems were discussed at house meetings, so nothing was kept secret. Bit by bit, my distrust faltered and the fears lessened. I slept better and made friends. I was treated with respect and respected others, so gradually I began to respect myself. My life became more manageable as I learned the “tools” I needed. I learned about stress, how to recognize symptoms of stress in my life, and how to control or cope with the stressors. Other residents and staff members who had hallucinated for years and now were able to control their hallucinations shared with me some of the techniques that had worked for them. Things like diet, bioenergetic “grounding,” and interpersonal relationships became a few of my tools.

Since that 18-month experience in the halfway house, I finally have been able to live a full and happy life. After 10 hospitalizations over the course of 12 years of treatment, I have finally learned how to survive, and have not seen the inside of a psychiatric hospital for 4½ years. But although I now feel that my life is under control, I know that thousands of others have not been so lucky and are still facing the same struggles with mental illness that I fought for most of my life. My experiences, as well as the experiences of others from the halfway house, have taught me that regardless of the cause(s) of mental illness, progress toward recovery cannot occur when there is no hope. Negative expectations and stereotyping are among the greatest obstacles to recovery, and keep many mentally ill persons immobilized by defeat and despair. It was to combat this climate of hopelessness that I initiated Project Overcome in 1977. Believing that the lack of visible, successful former patients contributes to the negative expectations held by professionals, community members, and patients themselves, I formed a speakers’ bureau of men and women willing to speak publicly about their successful battles to control their own mental illness. Originally supported by a grant from the Minnesota Department of Public Welfare (the first client-run program ever to receive such a grant), Project Overcome now receives private foundation support to send its speakers to speak to parents, mental health professionals, and communities statewide. The intent and message of Project Overcome is one of hope: hope for others who may never have seen someone who has “been there and back.” Project Overcome speakers share their experiences and what they have learned about recovery with patients in hospitals and community programs. They reinforce the idea that having problems is nothing of which to be ashamed—it is something to be overcome. We promote openness, risk taking, consumerism, and the assumption of responsibility for acquiring needed tools. We are living proof that it is possible to make dramatic changes in one’s life, despite the worst expectations of mental health professionals, families, and the community.

Project speakers also offer hope and a challenge to mental health professionals, who rarely hear from their successful clients. These doctors, social workers, nurses, and others can play an invaluable role in helping people regain control of their lives, but only if they are willing to listen to their clients, their problems, and to help them to acquire the individual survival skills necessary to cope with life and its many stresses. In particular, professionals need to guard against limiting their patients’ hope and participation. It is essential to see each person as a unique individual rather than a diagnostic category. Hiring former patients
and using their advice to develop and plan treatment programs and to teach survival skills is one way that professionals could enrich current programs. The value of former patients as treatment program staff members has long been recognized in areas such as the treatment of alcoholism. It is time for the mental health field to acknowledge its participants.

Last of all, Project Overcome speaks to churches, schools, and community groups, dispelling the media stereotypes of the mentally ill as dangerous and incurable. Audiences typically ask, for the first time, all those questions they had always wondered in secret. What is it like to hallucinate? What is it like to receive shock treatment? The facts are always surprising. We are not only like you, we are you—your sons, daughters, husbands, sisters, and fathers. We need jobs, housing, a chance to become independent, and accepted. We need to learn from and support each other. We need the same respect and freedom that you value and we have much to contribute to our communities and to the mental health field.

The time has come to go beyond the categorizations, the old images, and the destructive expectations. Our hope lies in hope: creating a climate of support, learning, and encouragement for those who seem to have no reasons left for hope.

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