

The Development of My Illness

An Anonymous Psychologist

Introduction

There are innumerable moments of decision in the lifespan of any one human being. Some are big; some are small; all have consequence.

The single decision of supreme consequence is the decision to live or to die. It is a decision which can be made—consciously or unconsciously—only by the individual himself. The responsibility for the cessation or continuance of life remains solely within himself.

This does not mean that a decision to continue will be successful. There are situations in which the individual loses this control—accident, disease, war, etc.—over his physical existence. However, his attitude and his response to encounter with the life-death experiences always lie within the realm of his own maneuvers. The determination of the manner in which life will be faced can never be taken away by an external force. It is this factor which gives the human condition its dignity, no matter the environment.

It is this factor which also makes the basic difference in one's opinion of a schizophrenic. If schizophrenics are viewed as handicapped individuals attempting to make the best of their resources, then their dignity as human beings is retained. If they are conceived to be inferior persons, they can only be thought of as weak, ineffective, afraid of facing life—labels which only serve to undermine their already wounded

self-concept and add to the burden of their illnesses.

One's frame of reference relating to people suffering from a psychosis is of critical importance in their handling and in prognosis. It is not how they must live, but the fact they struggle to survive under extreme conditions which should continuously amaze us. It would be far easier to give up—there is no joy in this disease. Its victims suffer a living death—almost noncommunicable except between those with mutual experiences—too often lost themselves.

I cannot remember exactly when I discovered that the world was colorless-gray—without dimension.

This perception startled me, but it also reflected my very mood—a mood which was to last many months. Looking back, I would say that it crept over me slowly, insidiously, probably requiring at least several months before I became aware of its presence.

At first I made an attempt to cope with it. I told myself that I had always been erratic with an unstable personality, given to lows and highs. It would pass. But it didn't pass. In fact, it intensified.

I had in my repertoire of experience innumerable neurotic mechanisms to combine randomly with my basically unstable patterns.

Psychotherapy and my trend of education had illuminated these mechanisms, making me painfully aware of their existence and my inability to reduce them.

I was equally aware that I was unable to trace down the antecedents of many of them—particularly the somatic complaints.

True, they seemed in the past to be more predominant on holidays and weekends; days when the structure was lessened.

True, as young people my husband and I had adjustment problems. I attributed much to this latter factor. Yet, as time had gone on and we were working together on these adaptations the symptomatology seemed to increase and intensify instead of lessen.

But, then, there were always the immediate stresses. Some were brought about by the children. The oldest, a girl, so aggressive, dynamic and bright; so capable of bringing me to the point of total loss of emotional restraint. In many ways so much a reminder of my mother. And the boys—the oldest being lovable, affectionate and able to maneuver me; the youngest, again, like his sister, aggressive, bold, unafraid—a challenge every minute of his life and requiring that challenge be met if his potential was ever to come to fruition.

As if that were not enough there were the pressures of school. As anyone who has been in a doctoral program can well attest, the duality of response necessary to be successful is overwhelming. One must conform and reflect what the faculty wants while simultaneously attempting to hold together one's unique beliefs and rationalize the entire process as means to a necessary end. Certainly, there was fuel aplenty for stoking the fires which powered my personality reactions. Who in such a position might not have reacted the same way? I seemed continuously to be hearing myself make that statement.

I tried, but I could not seem to accept my

shortcomings. So many times the physical complaints were without traceable experiential origin. So many times they defeated a much sought after experience. When all other explanations failed I would fall back on Freud, with his theory of life-death balance of power. I struggled to accept the conclusion that I was an individual who, for some unknown reason, was equipped with an overwhelming tendency to be self destructive.

This was the framework within which I attempted to adapt until the "great depression" began.

I was to receive my doctorate in October.

Naturally, being very tense about the oral examinations my physical complaints worsened. I did not sleep for three days before my examination. My mouth was dry, my mind racing away, my thoughts blocking, my eyes wouldn't stay in focus and the fatigue and depression were constantly dragging me down.

A Neurological Examination

I had been taking an anticonvulsant for a few months. It had been prescribed by a neurologist to whom I had gone regarding the "attacks" I had begun to have during the past summer. I had chosen to see a neurologist because the "attacks" resembled a seizure pattern. I had seizures during childbirth as well as extensive experience dealing with brain injured children.

Although the neurological examination had revealed nothing which could be precisely diagnosed, when I had discussed with him a recent article I had read concerning the use of Dilantin with unstable persons he felt it was worth a try. I had been taking 200 mg. a day. It had helped, but, as the examination came closer I required more to maintain control of my body functions. By the day of the-examination I was taking them every three hours. I was carrying them with me, afraid to be

without them lest I pass out—or worse.

Strangely enough, during the oral examination I was (overtly) cool and self assured. I passed them. My husband was with me. He was ecstatic. I wanted only to crawl in my bed and sleep—alone—forever. I shared none of his emotions. No one could understand my attitude. Depression and fatigue at a time for revelry? I had totally exhausted myself, I said. There was nothing left. It certainly sounded plausible. Others were willing to accept it as the reason and excuse me for my withdrawal. I accepted it myself.

But I didn't rebound. My body seemed to have lost its ability to rejuvenate itself. My husband worked every moment to keep me going. I set up a schedule for work which I followed exactly. I dragged myself from moment to moment, the only relief from fatigue an overpowering anger. At what? At whom? I could not track it down.

By Thanksgiving the situation was intolerable. I sought another consultation with the neurologist. I couldn't even read a newspaper now and understand it. I felt like the dyslexic children I worked with. I could say the words but they had no meaning.

Headaches had begun and they were continuous and severe. My neck was so tense I could not bear to hold my head up or put on my wig. The left side of my body developed a paresthesia which immobilized me temporarily several times. Speech was hesitant and stuttering had begun. I often lost control over the content of what I was saying. My thoughts ran together without structure or form. There was no joy at all—only depression, anger and anxiety.

An EEG Under Drugs

For the first time I requested that my husband accompany me to see the doctor. It was a move I

was never to regret. They took an EEG and then another was ordered under the influence of a dose of an amphetamine. How large a dose I did not know until my husband retrieved the vials which had been disposed of in the trash can under my bed. We were told the EEG would not be taken for half an hour. My husband went out for coffee. I laid there, alone, feeling quite comfortable. I trusted these people. They told me there was nothing to fear.

Suddenly, I began to feel the aura of an "attack." It was similar to the aura of a convulsion beginning with anxiety, dizziness, nausea, an inability to "focus" the sensory mechanisms. I could not gauge the time which passed, but I know I felt fear and I called out to the technician what was happening so that he could be ready.

Although I thought I spoke aloud, he did not respond. I realized only when my husband returned later and talked with him that no one could hear me. My speech was entirely internal.

I began to hallucinate—bells ringing, a radio playing, voices whose words could not be distinguished, laughter. The cracks in the ceiling tile began to move and form images. Forms which altered as quickly as in a kaleidoscope, seeming to slither from one design to another. And the color of it all was a variety of shades of red—always changing in hue.

My body trembled uncontrollably, yet my left side felt completely paralyzed. I was freezing internally with a cold that could not be detected by touching me. Nausea overcame me. It seemed to be related to an odor which filled my very body—as if it were seeping in like a gas through the skin and orifices. My mouth was parched, my tongue felt swollen. All the sensory reactions seemed to blend together and yet to be isolated, too. An overwhelming feeling of panic set in and I began to scream—or thought I did. As control of bowel and bladder began to require

conscious thought I knew I was close to a seizure.

At that point my husband returned. He was concerned, but did not know what to do. He held my hand and talked to me and eventually the panic eased. The apex of the seizure was never reached.

Gradually, the symptoms subsided. Within a half an hour, he could hear me talk to him, but my speech was peculiar and very much out of control. My thoughts were confused and I cried and could not stop. I wanted to get out. I wanted to go home. I insisted we leave although I could barely stand. Through all of this the technician sat coolly aside, doing nothing but watching the tracings being recorded. He phoned the doctor requesting permission for me to leave. The doctor wanted to see me first.

Half carrying, half-dragging me, they got me into his office. This man talked with me as though I were exactly as I was when I had entered his office the first time that morning. My husband asked many questions. I tried to, but my thought connections were rigid and jerky and I could not concentrate. I could barely keep myself upright. My insides were shaking so badly that it seemed incredible to me that there were no observable external signs of it.

EEG-Negative Results

Only one statement this man made during this meeting has stuck with me. When asked what the EEG had shown, he responded negatively. When asked what he thought had happened and what was wrong with me, he said only that I was an "unstable" person and it would be best if I would go home and try hard to forget about myself.

I was numb. Stumbling, shaking and incoherent, somehow I got to the car. That evening I had still not recovered. In a sense, I do not feel

I ever really did, for from that time on the symptoms accumulated more rapidly than ever. Not only had I been given a dose of a drug which would have caused even a "normal" brain to malfunction, but a professional in whom I had a great deal of faith had dismissed me, in a sense, as an unworkable patient—one who was overreacting to a set of minor symptoms. A person who could not learn to accept herself.

Determined to make myself fit into the advice we were given, we set about holding me together. My nights were sleepless nightmares. My days divided between chaotic periods of anxiety and bottomless depressions. By Christmas I was losing at least one working day per week. Saturday and Sunday we jokingly referred to as "lost weekends."

Another Fruitless Consultation

I sought a consultation with another well known neurologist. He was very kind and very indignant at what had been done to me before, but he had nothing to offer unless I would submit to hospitalization for further testing. I was not up to it at all. I could not face the ordeal of hospitalization, let alone the unpleasantness of the testing itself. The thought of even minor pain terrified me. It was odd for me to be this way, for I had always thought of myself as having a high tolerance for pain. But at this time I did not know how I could ever have thought that, for the slightest bump would bring me to tears. In other ways, too, I seemed to have become a paradox to myself.

In contrast to my affection for my children my response to their very appearance at breakfast time was uncalled for irritability and continuous expressions of hostility. They began to show the effects of my acting out. The youngest, regressed into childish behavior. The oldest boy withdrew into himself, saying little and making every effort to be as independent as possible. The

girl's preadolescent rebellious qualities became more exaggerated until she was almost unbearable to live with. She was continuously arguing, fighting, challenging—everyone and everything. I saw what was happening, yet I could give them nothing, for I required all my energies for myself.

And so we passed the winter. My morbid mood was perseverated, dominating our household. I clung desperately to the idea that spring would provide a lift—a stimulus—that would make a difference and enable me to pull myself together.

Then, one day I realized it *was* spring—it *had been* spring and that the world was still colorless and dead for me but that everyone else was responding to the natural change. I felt as if I were a hundred years old. I looked in the mirror and my face seemed to change and age as I observed it. Ever present was the feeling that I was experiencing dying.

I worked harder—longer hours—coming home as little as possible. Despite my efforts I made no progress. My interviews with people were less and less satisfactory. My paperwork lay unfinished despite the hours set aside to work on it. Where was the time going? What was I doing with it? The "lost weekends" extended themselves to include Fridays and then Mondays, too.

My time when I was able to force myself was spent at work. The rest of it stretched into interminable periods of exhaustion. I no longer even answered the phone. There were days when overwhelming free floating anxiety pursued me everywhere. The vibrations in my head were constant. I developed facial tics and my speech became more and more staccato and less and less under my control. I gained weight. My eating habits varied from insatiability to complete abstinence. I tried desperately not to allow myself to acknowledge the deterioration.

Then, one night, after my clients had all left I sat in my office and I realized I could not move. I was behind a glass wall—seeing, hearing, perceiving everything but unable to respond.

"This is a catatonic state!" I screamed inwardly—"do something!"

But nothing happened except some silent tears. My husband became worried and came looking for me. He took me home and said we would find a way together, but I knew that we couldn't for I could feel the fatigue beginning in him. He could not go on supporting both of us. I knew that as soon as the state passed I must take all my energy and direct it toward finding help.

The episodes would get longer and each time there would be less strength to fight back. My mind inside this unresponsive body was confused but still active and struggling. I had to admit to myself I was involved in a psychotic process.

I Turned to Research

From this admission I made my decision. I resolved to find help or to kill myself. I could not permit my family to bear the burden of my affliction. I knew the outcome—the destruction of the family unit—too well. To admit psychosis was to sign a death certificate. I did not *want* to die, but I *could not* live and be "mentally ill."

I fell back on what my education had given me—I turned to the research. There I found references to the theories of Dr. Humphry Osmond and Dr. Abram Hoffer. I purchased their books and wrote for information to the American Schizophrenia Foundation. I called Dr. Osmond and obtained from him the name of a psychiatrist who followed his ideas.

All of this was done without ever admitting the information I sought was for my own use. Despite the compassion of these men—which comes through clearly in their writings—I could not trust anyone with my knowledge about myself. I was

still bearing the shock and stigma of being a schizophrenic and could not yet believe that there really were people who would not turn me away.

On my first visit to the psychiatrist I panicked before reaching his office. I was unable to drive that morning and my husband had accompanied me. It was necessary for him to stop the car and deal with my hysteria. At one point I almost asked him to turn back. But we didn't. I knew we wouldn't. I had to admit this to someone who knew more than I did. I had with me all my papers from earlier consultations with other physicians. I gave them to the psychiatrist and asked him to make copies, for if what he had to offer didn't work I would have to search further—if I had the strength.

He stated his feelings about my condition and we agreed on a one year trial period of treatment. I remember adding that if there was no change I would hang on that long, but that was all. Suicide was inevitable unless there was improvement.

Discussion

In reflection, I would say that it was an overestimation of my own strength to set a one year limit. Had the treatment been ineffective for any lengthy period of time I would never have been able to survive that long. I now see the visit with the psychiatrist as taking the last of my energy. Today I can still feel fear as I realize how close I was to the breaking point and to losing all control over my way of life.

The rest of the story would make a book. It has been two and one-half years since the initial contact and today I function (both physically and emotionally) far better than at any other time of

my life. We have turned back the disease process which threatened my life. I would be either stupid or blind if I did not recognize that psychological conflicts existed within myself and were worked through simultaneously with the restoration of the body's chemical balance.

Yet, I believe that without the intervention at a chemical level, the process could not have been reversed to the extent it has been. I might have learned to live with and to control my symptoms by just being exposed to a compassionate and capable therapist (Note: I had had two years of psychotherapy two years earlier). But, to remove the symptoms and permit me to live a normal life again without the use of rigid controls over my bodily functioning was more than I had ever hoped to gain.

A Dual Approach to Schizophrenia

To all of us—those who treat and those who suffer—the origins of the schizophrenic process still lie open to question. Quite possibly they will vary from individual to individual. However, to me, it seems that the approach to dealing with it has clearly been defined as one which *must* encompass *both* physical and mental levels. Without this dual approach we condemn the person with whom we are working to a lifetime spent under the burden of what can be an an overwhelming handicap. One which reaches out beyond the individual and contaminates all those who surround him.

As professionals we cannot fail to realize the inadequacies of our existing knowledge and thus remain open to new ideas and concepts. If we refuse to do so, then we lessen our effectiveness markedly.