First Person Account: Schizophrenia: Some Issues

by Jill Stainsby

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

Schizophrenia is real. Mental illness is a medical event. As David Ransom (1990) wrote:

. . . in the 1960s and 1970s many people like me who thought of themselves as "progressive" came to believe that mental illness did not exist. There was a strange comfort in the idea that a society of everyone except ourselves was "manufacturing" mental illness. But when we faced its devastating impact on the lives of people we knew, we had no idea what to do. Too often we chose to forget they existed rather than acknowledge they were mentally ill. We blamed "psychiatry" and ran away. [p. 5] This avoidance of the issue of mental illness can, unfortunately, often be found among people who have not had much experience with mental distress. For many of us, however, being involved when someone among our family or friends has experienced mental trauma, occasionally to the point where they have needed medical treatment or hospitalization, has been very challenging. Several of us have tried to keep people out of the medical system when they were not coping because of mental or emotional dysfunctions. We have also tried to stay out of hospitals or off drugs ourselves when we were in such a state. Several of us have come home from our experience of medical intervention and denied we needed it or described the experience as unnecessary torture. I do not intend to negate anybody else's experience. At the same time, I do not expect others to refuse me the right to my beliefs regarding mind-suffering. Saying that mental illness is a result of social pressures and is therefore somehow not real is like saying a broken leg does not need fixing because it's the scaffolding that you fell off that was unsafe. The fact is, the unsafe scaffolding created a situation in which your leg broke, and you need a cast. To assert anything else is to risk having the leg mend crookedly or not at all. Our society does tend to provide the precondition of stress that may be required before a person develops schizophrenia. Once that has happened, that person needs help in dealing with the illness. People who are experiencing hallucinations, delusions, or thought dis-
orders of any disorienting kind need care; and if their condition is deteriorating rather than improving, they need increasing levels of care. I think this is straightforward. If they can maintain themselves as they are, then they need only whatever help they ask for.

Schizophrenia is a chronic or episodic family of illnesses that responds to various treatments. Approximately one-third of the people who are diagnosed as experiencing it recover and do not experience another episode of disjunction from reality, according to mental health workers; one-third respond positively to drugs; and one-third continue to have symptoms, whether drugged or not. It's that middle third of those of us who are diagnosed with schizophrenia who are served badly by political or personal arguments against intervention by the medical establishment. To be told "your friends will help you get over this" is to deny that perhaps the leg I described above is really broken. This denial also puts a severe strain on those friends.

I do not disagree with the "anti-psychiatry" movement completely. I agree that many therapies are at best useless and at worst dangerous and destructive. I believe that psychoanalysis and Freudian theory are both more damaging and dishonest than helpful for people who are questioning their own world view. What serves as therapy can be hurtful rather than positive. The image of psychiatry as a mechanism for social control, especially of women, has been altogether too accurate at times. I realize that there is good therapy, though it is rare, and certainly people should not take drugs in isolation, without care and monitoring.

Whether or not a person should be hospitalized depends on his or her ability to cope in the outside world. Only a small percentage of people living with mental stress deteriorate to the point of "genuine madness." and it is only those who suffer from genuine madness that I am concerned with here.

I do not believe that a schizophrenic episode will necessarily and naturally end in due time (though for some people it apparently does), and I do not believe that there are insights gained through experiencing that kind of dysfunction. That idea is perhaps a fantasy born of the experience, rather than a reflection of reality.

The medical model of schizophrenia (Dewitte and Ralph 1989) is that nerve endings in the brain emit too much of the substance called dopamine and other neurotransmitters, so that the brain nerve cells "fire" too often, sending too many impulses. "Antipsychotic drugs appear to block the action of neurotransmitters, particularly dopamine, at receptor sites, thereby limiting impulse transmission" (p. 8). Antipsychotic drugs have an effect only on people who experience delusions, hallucinations, or thought disorders (i.e., random thoughts occurring in quick succession). They tend to make people feel "dopey," dry-mouthed, shaky, and stiff-jointed. There are further medications to stop the side effects, which have no other apparent effects. The potential long-term effects include involuntary muscle tics.

While overmedication of women with minor tranquilizers is justifiably famous in feminist discourse, current medical opinions regarding the use of these drugs has swung the other way.

Antianxiety agents and sedative-hypnotics: Drugs from this group, given in moderate to low doses, help to alleviate anxiety and tension. In higher doses they will help to induce sleep. Usually these drugs are indicated for short-term treatment of anxiety and/or insomnia. Their long-term use is not recommended. [Dewitte and Ralph 1989, p. 2]

I would like to put the emphasis here on the statement that long-term use is not recommended and that it is a mental health workers' manual that says this. Medical opinions have changed, though I hate to be an apologist for the system in any sense. I believe it is public concerns, including feminist beliefs, that have caused this change in doctors' prescribing habits.

I do contend, however, that there are a substantial number of individuals whose symptoms are relieved by drugs rather than therapy. I think people who show symptoms of dramatic brain disorientation should try them. They should also be given all the care and monitoring that they require. It is difficult to imagine recovering from severe hallucinations or thought disorders without a structured lifestyle and therapy, if required, to help sort out the confusion these individuals have been suffering. It is also crucial that their perceptions of their health and their wishes be central in any treatment program.

While there is no cure for schizophrenia at present, antipsychotic drugs do their job well. I'm here to tell you that I have been prescribed one of these drugs for most of the past 13 years, and I'm doing just fine. It is difficult to make a statement that indicates I have schizophrenia because of the social stigma attached to the label. Besides that, I do not necessarily identify myself.
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throughout metropolitan Van-
couver. They cannot require that
individuals take drugs and can only
hospitalize them if two psychiatrists
agree that that is an appropriate
course of action. The Mental Health
Teams are a service dedicated to
maintaining individuals' quality of
life. As Linda Bouma, a Broadway
Team nurse, reported:

We're a voluntary service, we can't
force anybody to take anything or
do anything that they don't want
to do, and we will still monitor
them if they go off their drugs.
[We can't hospitalize anybody]
unless they're certifiable.

"Certifiable" means that an individ-
ual is determined, by two psychia-
trists, to be a danger to themselves
or to others. This is a tenet of the
provincial Mental Health Act, which
is currently undergoing revision. It
will be tightened up, according to
Linda, "which will make our jobs
more difficult." Her understanding of
the new regulations is that it will
become more complicated to medi-
cate or hospitalize someone against
their will in the future, and that it
will be very difficult for her, as a
mental health worker, to watch peo-
ple who could benefit from drugs
deteriorate instead. Her analysis is
that those who refuse all drugs even
though they have repeated episodes
of dysfunction are those with "little
insight." Given the intensity of the
psychotic experience, it is quite likely
that some people have little energy
for "insight," which may in fact
work against them. It is a matter of
a person perceiving the symptoms
and diagnosing themselves accurately
as having the illness, while suffering
from hallucinations, fantasies, or
frantic brain activity. This is a diffi-
cult task, but I would not want the
medical system to force drugs or
hospitalization on anyone who was
not endangering themselves or oth-
ers. At the same time, there can be a
great deal of pain and distress associ-
ated with the mental trauma of
schizophrenia, and anything that can
be done to alleviate this suffering
should be actively promoted by a
person's caregivers. But decision-
making power must be left in the
hands of the individual.

On June 28, 1991, the Ontario
Court of Appeal ruled that even in-
voluntary (i.e., incarcerated) incom-
petent psychiatric patients, who had
previously, when mentally compet-
ent, asserted their desire not to be
treated with antipsychotic drugs,
must have that right respected. The
issue was whether the patients' "best
interests" overrode their "prior com-
petent wishes," and the court ruled
that they did not. The ruling further
stated that

In my view, although the right to
be free from nonconsensual psychi-
atriatic treatment is not an absolute
one, the state has not demon-
strated any compelling reason for
entirely eliminating this right,
without any hearing or
review... To completely strip
these patients of the freedom to
determine for themselves what
shall be done with their bodies
cannot be considered a minimal
impairment of their Charter right.

In other words, the Ontario Court of
Appeal found that the point at which
a psychotic patient can be forced to
receive medical treatment, if they
themselves have previously stated,
while competent, that they do not
wish to be so treated, has to do with
whether they are a threat to them-
selves or others. Nobody can legally
be given drugs they consistently
refuse, except in emergency situa-
tions or when they are a danger.

Whether an individual's refusal of
drugs is a good or bad idea depends
completely on their physical reaction to the drugs. My considered opinion is that the drugs are worth trying as they can have a profoundly calming and normalizing effect on the workings of a mind. As I say, I prove that assertion every week, as I take my medication and continue my life without mental distress.

Schizophrenia, or madness, is a topic that is guaranteed to bring complete silence to most groups of people. I would ask these people to consider whether they honestly believe that the illness does not exist and/or does not incapacitate people. Or are they afraid of the illness, of the pain and dysfunction that has happened to their friend or colleague? Are they afraid it will happen to them?

Schizophrenics need empathy, support (both in terms of emotions and finances as well as, often, structured living arrangements), acceptance, and as much autonomy as we are capable of managing. We are victims, not typically threats. Refusal to accept the illness, either on the part of the individual or on the part of her or his family and community, often causes unnecessary stress and suffering. The illness is grievous enough, without denial. It is not good enough to "let them be," to turn away from schizophrenics and justify this by saying, "I don't want to be the one who locks them up." We have a social responsibility to take care of each other. And a person suffering from schizophrenia certainly needs our care.

References


The Author

Jill Stainsby was first diagnosed as having schizophrenia in 1977. In 1991 she earned a Master's degree from Simon Fraser University, Burnaby, British Columbia, Canada. She is currently employed as a union coordinator.