Schizophrenia
Through the Eyes of Families

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The authors contend that families of schizophrenics have received too little help from mental health professionals, even though in many cases families are the real primary care agents for long-term patients released from mental hospitals. They discuss some of the problems that occur in living with a long-term patient and describe mutual-support and advocacy groups that relatives have formed. They emphasize that mental health professionals can help families of schizophrenics by providing practical, realistic advice on how to deal with the illness, by offering empathy and support rather than placing blame, and by working to ensure that there are adequate treatment and rehabilitation services available.

In this era of deinstitutionalization, families have become the real primary care agents for a large proportion of schizophrenics released from mental hospitals. For example, a recent study found that more than 50 percent of the long-term severely disabled patients in San Mateo County, California, were living with their relatives. Yet until recently this seemingly obvious development went almost unnoticed by mental health professionals. Only now is attention beginning to be turned to the problems of dealing with chronic schizophrenics at home.

Relatives must learn to live with unpredictable, socially embarrassing behavior and even occasional violence. They must come to terms with the patient's social withdrawal, inactivity, and excessive sleeping. The patient's lack of conversation can be a particular hardship for a relative such as a spouse who depends on him for companionship.

If the patient and the relative stay together, they may in time reach an equilibrium that enables the patient to live outside a hospital. But inevitably the situation will severely restrict the family. Often the relative of a schizophrenic cannot even leave the house to go shopping without getting someone to watch him. The relatives may begin to feel not only as if they are jailors but also as if they themselves are in jail.

Far from recognizing such difficulties, many professionals lay all the blame for the patient's problems at the family's doorstep. Many schools of psychiatric thought hold the patient's family responsible for aggravating and even generating his illness. The professionals do not seem to realize that being the relative of a mentally ill person is traumatic and overwhelming enough. Even before their initial contact with the mental health establishment, the family members are usually guilt-ridden and feel a keen sense of failure for having "produced" a schizophrenic.

Professionals are often not sufficiently aware of such feelings and of the additional impact of a parent's receiving a label such as "schizophrenogenic mother." The concept of the "identified patient," which holds that the entire family is ill and the patient is simply the person who has been labeled the sick one, adds further trauma. To the parents, it means not only that they have driven their child crazy but also that the whole family is crazy.

Moreover, long-term schizophrenics are given low priority in community mental health programs, despite the fact that a number of state hospitals have been closed, many thousands of long-term patients have been released into the community, and considerable

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sums of money have been made available for community mental health. Community programs often use these funds for everything but long-term schizophrenic patients. Such patients are left to find their way into community residential settings of varying types and quality where they are forgotten as completely as they were when they were left on the back wards of state hospitals.

Families have often been appalled at the reluctance of local programs to fund aftercare projects that meet the needs of long-term patients and sheltered vocational workshops that offer them an opportunity to be productive and increase their self-esteem. Families have found that even when their schizophrenic relative is initially accepted for treatment in a community program, he is subsequently rejected by staff who explain, "Our job is not to baby-sit for long-term patients." The problem often has to do with the patient's lack of verbal skills to participate in what is considered a satisfactory way in group and individual therapy. What is often lacking is sufficient flexibility in the program and tolerance and patience on the part of staff so that the schizophrenic can remain in the program without being expected to do more than he realistically can.

RELATIVES' GROUPS

Because it has been so difficult for relatives of schizophrenics to deal with these problems and attitudes alone, they began to join together into advocacy and mutual-support groups. Such groups are fast becoming a significant political force. Yet many mental health professionals have not recognized their influence and have failed to realize that they will increasingly be affected and held accountable by these groups. As the members become more powerful and politically sophisticated, professionals will be reminded more and more forcefully when they have been insensitive to the needs of the severely mentally ill and their families.

One of the earliest such organizations, the National Schizophrenia Fellowship, was formed in England in 1972. The fellowship now has 1300 members all over the United Kingdom and Ireland and has been instrumental in the formation of similar organizations in New Zealand, Australia, and West Germany. The group sponsors research on the causes of schizophrenia and works to create a greater understanding of the special problems arising from the illness, to secure the improvement of community care facilities of all kinds, and to encourage patients and their families to help each other and themselves.

The fellowship has also established a liaison with an American counterpart, Parents of Adult Schizophrenics, as part of attempts to form an international organization. Parents of Adult Schizophrenics, based in San Mateo County, California, has a membership there of more than 200 families. In addition, it has spawned eight similar organizations in other California counties, one in Oregon, one in Ohio, and four in the Chicago area. The Chicago groups were formed largely as a result of a radio program and subsequent newspaper article in which one of the authors (EO) was interviewed. Further, other parents' groups have been formed in ten additional California counties as well as in Missouri, Wisconsin, Florida, Georgia, Texas, Louisiana, Washington, and the District of Columbia. Moreover, relatives of patients currently in state hospitals are forming alliances with these groups in the community.

Parents of Adult Schizophrenics began in 1973 when a group of 15 parents who had schizophrenic children over the age of 18 got together to compare notes. They felt they were getting far more than their share of the blame for what happened to their children and that no one in the professional ranks seemed to understand the problems inherent in being the parent of a schizophrenic. They wondered why the parents of a child with leukemia were treated with sympathy and understanding while the parents of a schizophrenic child were treated with scorn and condemnation. They began to wonder if there was not more wrong with the system than with them.

The parents began their advocacy efforts by sending a delegation to community mental health administrators to tell them what they saw as the needs of their sons and daughters. They were not exactly welcomed with open arms. They were informed that if the mental health staff were instructed to run such programs, they would say they were not therapeutic, merely baby-sitting. The parents' suggestions were ignored. They were furious because they believed that gearing a program to the level at which patients can function and grow is not baby-sitting. Besides, they wondered, weren't community mental health programs supposed to be run for the patients rather than for the staff? They did not give up. They realized that if their views and demands were to be taken seriously, they would have to be credible, knowledgeable, vocal, and highly visible. Therefore, they began to use every channel open to them to learn about mental health programs and administration. Many members of the organization now have a better over-all understanding of the mental health system than do some of the professionals who work in it.

They lobbied to have all mental health programs studied and evaluated. They visited local politicians. They went to the newspapers. They had eight to ten people at every meeting of the local mental health advisory board. They discovered the importance of being political.

Having begun with considerable naivete, they have come to recognize how crucial it is to know where the power is, not only in the mental health system but also in the community, and to know what motivates and influences those in power. They have come to realize that having a role in fiscal deliberations and some control over the budget is the key to successful citizen participation.

So far, Parents of Adult Schizophrenics has had considerable success. The members have been influential in getting professionals to change their attitudes toward parents. They have applied pressure and have been successful in getting programs for long-term patients funded and expanded; some of those programs were about to be cut back or dismantled. They have also obtained public money and grants from private foundations to establish a therapeutic housing program for schizophrenics who have not been able to meet the expectations of other community therapeutic housing programs.

The organization also takes into account the needs of its own members. There is a monthly "woe night" to which any parent is welcome to come and talk about his problems and feelings. The discussions are led by an experienced member of the organization. In some instances, parents have been helped through crises, and emotional breakdowns have been averted.

The organization has helped many of its members feel less isolated. Changes occur in friendships when one family has a schizophrenic child. Friends hesitate to talk about the accomplishments of their own children and do not know whether or not to discuss the illness. The friendship often becomes strained, and the friends begin to see less and less of each other. Within the group, parents find others who have similar problems and with whom they can talk openly. They also begin to re-establish a social life.

Parents' organizations often begin with a concern about the members' own children. Then members gradually begin to want to do something about the overall problem of community treatment and rehabilitation for the chronic schizophrenic. As a result, there now exist an increasing number of effective citizens' groups devoted to advocacy for the needs and rights of long-term schizophrenics.

It is essential, however, that such organizations maintain their separate identities and not become a part of the mental health establishment. In some instances, when their leaders have been appointed to mental health advisory boards or positions in mental health associations, most of their energy has been directed to that job, leaving the relatives' organizations to falter and collapse. While getting involved in such positions is in one sense a positive development, it nevertheless can deprive the community of an independent, effective advocacy and support group for patients and their relatives.

THE FAMILIES' NEEDS

One of the most important functions relatives' support groups can serve is to pass along to less experienced members the practical tips that can make living with a schizophrenic easier. Relatives do acquire considerable expertise in coping with difficult behaviors, usually through trial and error, since such helpful advice is difficult to obtain from professionals. Frequently mental health professionals totally avoid the issue when asked for advice on the practical management of schizophrenics.

When advice is given, it is usually bad. For instance, thinking they are empathizing with the relatives' problems, they advise, "If the patient behaves badly, throw him out and lock the door after him so he cannot get back in." That could be a dangerous course of action for the patient and a difficult one to live with for the relative. Still another common piece of advice is "Forget about him; live your life." That is easy to say but difficult, if not impossible, to do when one feels guilt-ridden about a schizophrenic relative.

There is practical advice that can be extremely helpful. Goals for patients should be realistic; it is important for professionals and relatives to determine together what a patient can achieve. Then, if a relative can maintain objectivity and emotional overinvolvement does not cloud his judgment, he can apply pressure to counteract the patient's social withdrawal. However, the patient must not be pushed to achieve standards beyond his capability, and he must be left with a good deal of control over what he actually does. Many families have learned this lesson through experience over a period of years, but often only at great emotional cost when compared with having help from knowledgeable professionals in setting realistic goals.

Relatives can be helped to see that it is often useless to contradict delusional ideas, but that patients can be told not to talk back to hallucinations in public. They can also be helped to understand that social withdrawal may be a necessary defense for schizophrenics, but that too much withdrawal may lead to a form of institutionalism at home.

A crucial time to deal sensitively with relatives is at the point of the patient's first psychotic break. Professionals need to appreciate the intensity of the guilt and shock relatives feel then. Support and empathy, not condemnation, are essential. Professionals must also be aware of how the patient's illness can strain the marital relationship of the parents.

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Relatives must be told that schizophrenia is not purely the result of environmental factors—that there are hereditary factors and almost certainly a biochemical imbalance. Such information reduces their fears that by their actions they will drive other relatives, especially their children, crazy. It also makes them more willing to cooperate with the patient’s treatment.

In some instances, assertiveness training may help the relative set limits on the schizophrenic’s behavior and deal more effectively with professionals. Of course, some relatives are already too assertive; professionals should tactfully work with them to lessen their assertiveness or to channel it into activities such as advocacy for better services for their schizophrenic relative.

There is a need for adequate treatment and rehabilitative services for the patient so relatives will have help in caring for him. Without these services the family may have all they can do to simply cope with the patient, much less treat and rehabilitate him. A whole range of facilities with all degrees of structure are needed for that large proportion of patients who need out-of-home placement. Otherwise the schizophrenic may be unwilling and the parents too guilt-ridden to effect the separation. One type of schizophrenic patient who probably needs a highly structured program with intense supervision, at times even restriction, is the patient with an alcohol or drug problem or both. Other patients need a less structured, highly nurturing environment. All patients need mental health professionals able to determine who should have what kind of placement.

Many families can manage their schizophrenic relatives well at home if they have access to periodic respite care so that they can take a vacation from the hard work of managing a schizophrenic. Such vacations are also helpful for the siblings, who frequently are neglected in the midst of the family’s preoccupation with taking care of the patient.

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A Social Interaction Program for Chronic Psychiatric Patients Living in a Community Residence

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A psychiatric center in Brooklyn provided a socialization program in a community residence for adults discharged from state hospitals and made a study of the program’s outcome. Residents on two floors of the home, the experimental group, received an enriched treatment program; those on the other four floors, the control group, received a minimum of therapeutic intervention. A comparison of residents’ ratings on assessment scales made early in the program and after seven months of operation showed that residents on all floors improved on measures of socialization, men improved more than women, and residents over 65 years of age improved the least. Residents in the experimental group did not improve much more than those in the control group. Costs for the experimental group, including room and board, were $16.59 a day per resident. Costs for the control group were $15.61 a day per resident.

When the South Beach Psychiatric Center opened a geographic mental health center in Brooklyn in 1972, it assumed responsibility for a catchment area that contained a private residence housing approximately 230 regressed chronic mental patients who had been discharged from state hospitals. While the center had limited resources, it wanted to meet two specific goals: to reverse the negative effects of institutionalization on the residents and to convert the home into a low-cost, long-term therapeutic alternative to inpatient care for chronic patients.

Before a program to meet those two objectives could be established, the parameters that formally and informally govern the home’s institutional functioning had to be considered. In return for a statewide fixed rate for publicly funded residents (few are privately funded),