

# Victims of Schizophrenia: Patients and Families

Margaret G. Kint, M.A.<sup>1</sup>

*John P. Spiegel, M.D., President of the American Psychiatric Association and Keynote Speaker at the 1975 Annual Meeting of the NCC/MHC, used the analogy of a three-legged stool for the mental health care system which has three supports. The first basis is biological, the second psychological, the third sociological. All three are needed and all interact. Dr. Spiegel said that the accent was upon the biological focus from 1900 to 1945; after World War II, the accent was on the psychological; in the 1960's, the sociological basis became the primary focus.*

*It may well be that while attention has been focused elsewhere, the first of these supports—the biological—has stopped functioning as it should and is not bearing its share of the weight in the delivery of mental health care to the public.*

*There are two kinds of false labeling of schizophrenia and other mental illnesses. The first kind, which appears to be foremost in mental health thinking currently, is that of well people being falsely labeled as schizophrenic (or whatever) and thus becoming a self-fulfilling prophecy. The second example of false or misapplied labels is very sick people being considered to have an illness which is only in their "minds or to have only*

*what E. Fuller Torrey calls "problems in living." The results of this kind of labeling can be just as psychologically damaging to all concerned as the first. The second type of false labeling is considered in this paper.*

The American Psychiatric Association Task Force 7 Report of July 1973 states that there is "the nagging question of how many people have been diagnosed as schizophrenic and treated successfully by Orthomolecular means when they may not have been schizophrenic at all" (Lipton, 1973, p. 3).

Emergent data from an 18-month anthropological study of a local affiliate of the American Schizophrenia Association reveal that some individuals related to organization members had indeed been diagnosed as schizophrenic but were not. The study also reveals a pattern of family social problems peripheral to the disease itself and not necessarily connected to child rearing. These problems undermined families as decision-making and supportive units.

## BACKGROUND OF THE STUDY

The "Metropolitan" Schizophrenia Association (MSA) is a voluntary self-help health organization; that is, an organization (1) devoted to a particular illness or disease condition, physical and/or men-

<sup>1</sup> 2403 Carey Lane, Vienna, Va. 22180.

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tal disability, (2) initiated and conducted by patients, ex-patients, or relatives to provide needed support and benefits to the afflicted, and (3) developed outside the aegis of both the medical and health organization establishments (Gussow and Tracy, 1972, p.1). The MSA serves a metropolitan area which includes a major city and outlying suburbs in two states. The area has a population of over a million people.

The Association was founded in 1968 by former patients and relatives of patients who had been diagnosed as schizophrenic. Although it was an affiliate of the American Schizophrenia Association, the major division of the Huxley Institute for Biosocial Research with headquarters in New York City, it was always semi-autonomous and became more so. It had 260 dues-paying members during the time of the study in 1973-74 and a mailing list of 2,000 individuals who had contacted the Association.

The major goal of the Metropolitan Schizophrenia Association was to find successful treatment for schizophrenia. Its major functions were education and service.

The Association held about eight public meetings with speakers each year and one or two "members only" meetings. It made available a wide variety of literature on schizophrenia both to members and non-members and made doctor referrals to both members and non-members.

Individuals requesting doctor referrals were given the names of at least three doctors. These had never included more than one "Orthomolecular psychiatrist" at any one time and had included general medical practitioners, psychiatrists, and neurologists, and an osteopath who specialized in treating hypoglycemia. An office staffed by volunteer members of the Association was opened early in 1973 to facilitate both education and service. The Association worked with the Mental Health Associations in the area and with crisis intervention centers as well as other community agencies. There was no

attempt to duplicate current facilities in the health or mental health fields, but rather, the intent was to make alternative medical treatment more readily available than it had been.

The dues-paying members of the Metropolitan Schizophrenia Association and those who contacted the office for help were primarily of the managerial-professional class. Over 75 percent of the members and those on the mailing list had had schizophrenia diagnosed for a family member or for themselves. About 10 percent of the membership was made up of professionals or paraprofessionals in the health or mental health fields. These included general medical-practitioners, psychiatrists, psychologists, nurses, social workers, nutritionists, teachers, and students. Although some of the referral doctors used by the Association had been dues-paying members from time to time and were on the mailing list, none had ever been on the board of directors or had been involved in the organizational or policy-making processes of the Association.

Men and women were almost equally represented in the leadership group, but office volunteers were primarily women, and more women than men contacted the Association. Although about an equal number of men and women called for information or help for themselves, more women than men called about family members. All membership roles in the nuclear family were represented among both those who had been diagnosed as schizophrenic and those calling for help for family members. Roles in the extended family (grandparents, uncles, and aunts) were also represented.

Ages of patients ranged from young children to family members over 70 years of age. Ages of those active in the Association or calling for help for family members ranged from the early twenties to individuals over 60. Most of the active members, non-members who attended meetings, and individuals seeking help for family members, were middle-aged. Most of those for whom help was being

sought were in their twenties or early thirties. Of the patients, more young men than young women had been diagnosed as schizophrenic, but more young women had been diagnosed as manic-depressive.

It was primarily with parents of schizophrenics, leaders of the Association, volunteer workers, and those calling the office for information and help that I worked as an office volunteer for the Metropolitan Schizophrenia Association from the spring of 1973 to the summer of 1974. In addition to participant-observation, research included literature and record review, focused interviews, and questionnaires. The data used in this paper came from office records, "case histories" written by some former patients or their families, interviews, questionnaires, and conversations. My original research was on organizational aspects of the Association but questionnaires contained questions relevant to this paper. Answers and extended answers to questions verified patterns apparent from the other sources. As was stated initially, the findings of this paper are emergent, not the focus of the original study. The paper can be considered as a preliminary study leading to further investigation.

### **SCHIZOPHRENIA IS A FAMILY AFFAIR**

On the level of theory, whether one begins with genetic theory (Kallmann to Cottesman) or family as pathogenic milieu (Henry, Laing, Bowen), schizophrenia is obviously a family affair. Both genetic and kinship charts look mendelian. However, I would have needed to know nothing of etiological theories or controversies about schizophrenia to realize early in my research that schizophrenia is a family affair. The schizophrenia of one member of the family affects the others. This was of concern not only to other family members, but often to the direct victims of schizophrenia.

Although my coworkers as volunteers in the Metropolitan Schizophrenia Association as well as

those calling for help included individuals in most kinship roles, I worked mostly with parents of schizophrenics. They, and other family members, must deal on a daily basis not only with the problems resulting directly from the disease, but also with problems arising from beliefs in the culture at large and beliefs and controversies within the medical and psychiatric professions as these affect treatment.

While families frequently have been studied in relationship to schizophrenia, I have seen no studies of the effects of the cultural beliefs and professional controversies concerning schizophrenia on American middle-class families in the social science literature. It became apparent from records of the Association and from observation that major problems for families, in addition to those inherent in the disease(s), were: confusion as to what was wrong with the victim; getting a diagnosis and treatment; confusion and fear both as to the course of the disease itself and the associated stigma when the diagnosis of "schizophrenia" was received; feelings of guilt, particularly in mothers; confusion engendered by various methods of treatment by various professionals and various institutions; and financial difficulties.

These problems will be discussed under the major headings of "Diagnosis," "Treatment," and "Financial Problems."

### **DIFFERENTIAL DIAGNOSES AND EFFECTS UPON THE FAMILY**

#### **The lay referral system and early symptoms**

Contrary to the popular "Catch 22" folk myth ("If you think you are crazy, you aren't") the schizophrenia victim, like the victim of any other illness, may be the first to be aware that he is ill. He may wait for it to go away, or he may consult other members of his family. (See Freidson's "lay referral system," 1960; also Polgar, 1962, p. 168; Coffman, 1973,

p.399. This "lay referral" system has been found by social scientists in all cultures.) Steps in the lay referral system, regardless of culture, are:

(1) Self-diagnosis, which may lead to negative action; the ill person may decide there is nothing really wrong and that he will wait and see.

(2) Self-medication (which may follow); this is widely available whether it is in the form of the charm box, patent medicine, prayers, or incantations.

(3) Members of the household are consulted, then relatives, neighbors, godparents, and the like.

(4) The "lay referral system" becomes more select and distant until the professional (the shaman, the curer, the physician, the psychiatrist, whoever is considered appropriate) is reached. Polgar sees an intermediate type of consultation in literate societies prior to reaching the professional: reference to manuals on health care, religious texts, cookbooks, the "Dear Doctor" column, and articles in popular magazines (Polgar, 1962, p. 168). It is at this point that the Metropolitan Schizophrenia Association enters the "lay referral system," although usually after professionals already have been consulted.

If a young child is ill, he usually turns to his mother for help. One woman told of her young daughter asking her to "make it go away." This was not in the nature of some hallucinatory illusion, but an overall feeling of misery which the child expected the mother to do something about just as she did a stomachache or a sore throat. Other symptoms that children had mentioned to parents were: "I feel like I am running inside myself." "I don't know why, but if someone laughs at my daydreams, I take it very personally." "Words wiggle on the blackboard." "I feel like I am floating away." "I feel screamy inside" (from a three-year-old).

Such comments were heard from children both with and without overt behavioral problems such as withdrawal, or sudden ceaseless activity, or violent mood swings, and in the absence of problems at school, with authorities or with the

peer group. Although there were cases of destructiveness, running away, and the like, these were not always the first signs, when they were signs at all, and families had not always waited until there were social problems to seek help for their children.

It has been the role of the middle-class mother to watch over the health—physical, mental, and emotional—of her children. (See Leslie, 1967, and elsewhere.) Mothers seeking treatment had usually started with a doctor, a teacher, the school psychologist, a minister, or a combination of these, before consulting with, or being directed to, a psychiatrist.

Young children go where they are directed—they have no choice—and, in the class under consideration, can expect to be taken to experts when things go wrong. However, experiences of parent members of the Association with young adults were often more difficult. Drug use and alternative life styles had sometimes been introduced, and individuality, independence, and new experience were presented as values in the culture at large. Although "tender loving care" had been promoted by experts as the norm for parents when the current generation of young adults was growing up, in the late 1960's and early 1970's the explanation for many of the ills of our society was that young people had been "coddled."

Some young adults, as well as older individuals who knew that they were ill, actively sought help by calling the Association. (Out of 410 calls for help in a 10-month period, 135 were for self and 197 for sons or daughters.) Both young adults and older people talked about early and current symptoms, usually in terms of "this awful feeling," "this terrible disease," or, simply, "hell." Many spoke of a great deal of pain, fatigue, and insomnia. I have sometimes read that schizophrenia is enjoyed by those who have it, that it is an escape from a reality which cannot be faced. Those for whom this was true did not call the office.

**Prior diagnoses**

"Schizophrenia" was not usually the first diagnosis given. It was not always the last in a series of diagnoses. One volunteer later learned that she had been diagnosed as "schizophrenic" by one psychiatrist who told her that "anxiety neurosis" would cover her problems, then later was diagnosed as "depressed," while receiving no diagnosis at all from two psychiatrists in between. An officer of another local affiliate of the American Schizophrenia Association said: "We got a different diagnosis from each doctor." Prior diagnoses for young children included: retarded, slow learner, then hyperactive; psychosis of childhood; borderline retarded, later borderline retarded with emotional problems, then schizophrenia; feeble-minded, later schizophrenia; retarded, later schizophrenia; retarded, then simple schizophrenia; autism or childhood schizophrenia, then schizophrenia; minimal brain damage, then hypochondria (this boy was never diagnosed as schizophrenic, but others in his family had been). Most of these "children" were young adults at the time of this study.

The most popular diagnosis for children currently appears to be "hyperkinetic." Starting shortly after World War II, the diagnoses of choice appear to have been (in chronological order): emotional problems, mentally retarded, minimal brain damage, and hyperactivity.

In adults, prior diagnoses had been: neurotic; psychotic; emotional problems, anorexia nervosa; alcoholic, later schizophrenic; nervous breakdown; emotionally disturbed; anxiety neurosis, depression; hypochondriasis; manic depressive. In women only: postpartum depression; menopause.

Records of the Association reflect that few young children had been or are diagnosed as "schizophrenic." Adults, including young adults, are diagnosed as having "simple schizophrenia" or "paranoid schizophrenia." When a diagnosis of a neurosis is given, "anxiety neurosis" appears to be giving way to "depression" as the most common

diagnosis.

The confusion of both families and direct victims caused by puzzling symptoms was augmented by the confusion over multiple diagnoses or lack of any diagnosis. The safeguard of consensus of psychiatric opinion insisted upon by the profession for genetic, population, and other studies of schizophrenia had not been available to these families. Possibly some of this confusion could have been avoided had the family consulted just one psychiatrist. However, some of the managerial-professional class families moved frequently; some of the young adults were in college or graduate school at the time the problem manifested itself and later returned home for further treatment; doctors or psychiatric institutions were changed as the family's ability to pay decreased.

Although parents have complained that "They will do anything to avoid giving you a diagnosis" and psychiatrists have stated that they do not give the diagnosis of schizophrenia because of the stigma attached, the diagnosis of "schizophrenia" is still given.

**Diagnosis: "schizophrenia"**

Some individuals who called the Metropolitan Schizophrenia Association office had just received the diagnosis of "schizophrenia." A few were terrified and asked that their names not be written down anywhere. If they wrote, such individuals asked that their letters be destroyed. (These wishes were always honored.) Others were relieved to have the illness given a name so that they could find out more about it. Terrified or not, most individuals were looking for more information and alternative medical treatment approaches, and most were still confused as to the meaning of the term.

**Folk beliefs about "split personality"**

"What *is* schizophrenia?" was a question frequently asked by those calling the Association office. Some might add, "I know it means 'split personality,' but what does that mean?" Others mentioned "split personality" rather tentatively, as

though they were aware that there is more to it than **The Three Faces of Eve** or **Sybil**, with one or more fully developed alter egos unknown to the usually normal appearing primary personality.

Although only designated experts can diagnose the disease, the term "schizophrenia" has entered the language with "dual personality" or "divided beliefs" connotations.

The idea of several personalities within a single body, however rarely seen in practice, lends itself well to novels and science fiction. Advertisers have picked up the concept: clothes which can express several "you's"; couches that turn into beds.

In other literature, the term is sometimes applied to groups within a culture or subculture holding opposing beliefs to others within the larger group. Although anthropologists have been cautioned (since the early days of Benedict and Mead) against using psychological terms to apply to whole cultures, as late as 1972 Kaplan and Manners used the terms "methodological schizophrenia" and "split personality" to apply to anthropology in this way (1972, p.5).

It was difficult for many patients to relate to the concept of split personality when they had never thought themselves to be anyone else. (Most people hold some beliefs not rationally consistent with others.)

### **The folk fantasy of "total maximal illness"**

Social scientists Cussow and Tracy first presented their concept of the folk fantasy of "total maximal illness" in a paper given at the Second Annual Research Foundation of the National Association for Mental Health in 1966. In this fantasy, the two darkest fates are to "lose one's mind" as in schizophrenia or to "lose one's body" as in leprosy. Both represent a sort of living death. While in neither case is the total maximal illness the majority case, the fantasy is nurtured by the extreme deterioration that these real diseases may, and sometimes do, exhibit (Cussow and Tracy,

1966, 1968).

In addition, the possibility of violence has been dramatized in fiction and in the press. In science fiction, a man who wants to buy a "home therapy machine" for his "homicidal mania" is asked by a clerk if the problem is of "schizophrenic" or "manic-depressive" origin (Scheckley, 1957, pp. 77-93). News stories during the period of study reported violence done in the area both by "paranoid schizophrenics" and "former psychiatric patients." (Suicides, however, were infrequently reported.)

### **The stigma**

"Madness" (equated with schizophrenia by Snyder, 1974), "insanity" (equated with schizophrenia by Osmond et al., 1974), or "lunacy" (used to replace "schizophrenia" by Cussow and Tracy, 1968), by whatever name it is called — and it is called by several names in most languages—is stigmatizing to the victim because of the folk fantasy of "total maximal illness."

In America, more than in any other country, the family is stigmatized as well. Parents, particularly mothers, are held responsible for most kinds of mental illness and emotional or behavioral problems. The family as "pathogenic milieu" and the "schizophrenogenic mother" are concepts widely known and held in the country, although laymen may put them into other language: "There are no problem children, only problem parents," or "Schizophrenics come from such terrible home conditions."

These concepts could not easily remain unknown to the well-educated parents of the Metropolitan Schizophrenia Association, or to their often equally well-educated offspring. Intellectual young schizophrenics are as capable of reading the books on the family or mother as causal agent as are their parents and possibly more likely to do so. Parents in the Association have told of being accused of causing the illness by their children, by other young patients, by hospital personnel, and by psychiatrists.

The assumption that the family itself, and particularly the mother, causes schizophrenia has been devastating for some family members. In addition, they often expressed feelings of guilt without knowing what they had been guilty of, other than the fact that the child had been diagnosed as schizophrenic—all the proof needed in the culture at large. (One function of the Metropolitan Schizophrenia Association is to lift the stigma from both patient and family. A latent function of the organization is to reaffirm the family as the basic decision-making and supportive unit of society. It is an inherent assumption of the Association that parents do and should care deeply about their children, want what is best for them, and actively seek effective treatment for them when they are ill.)

### **Subsequent diagnoses**

Although most patients already had been diagnosed as schizophrenic by psychodynamically oriented psychiatrists, some patients were later diagnosed as schizophrenic by Orthomolecular psychiatrists as well on the basis of sensory dysperceptions as primary symptoms. When the changed sense perceptions of schizophrenia were explained to them, parents and other family members said that they could understand, often for the first time, that patients really did experience reality differently.

The Hoffer-Osmond Diagnostic Test (HOD) or the Experiential World Inventory Test (EWI), both of which show abnormal or changed sense perceptions, are widely used by Orthomolecular psychiatrists as preliminary tests. All five of the senses are involved: the senses of taste, smell, and touch, as well as the senses of sight and hearing. Sense of time is also involved, and the sense of gravity often is. (Faulty sense perceptions are considered as primary symptoms of schizophrenia by research psychiatrists outside of the field of Orthomolecular psychiatry. See psychopharmacologist Solomon Snyder of John Hopkins, 1974, pp. 154-169, and E. Fuller Torrey of NIMH who is researching virus as a possible cause of a subgroup of schizophrenias, 1974,

pp.158-160.) Most patients were also extensively tested by biochemical laboratory tests to find underlying physical causes for these dysfunctions as well as for symptoms directly expressed to the doctors.

The physical problems discovered included: homocystinuria, hyperlipoproteinemia, malabsorption, hypoglycemia, heavy metal toxicity, trace mineral deficiencies, severe allergies, diabetes, hyper- and hypothyroidism, epilepsy, and congenital syphilis. In other cases there were combinations of problems, or the diagnosis was not clear, although treatable metabolic or biochemical abnormalities were found.

### **VARIOUS TREATMENT MODALITIES AND EFFECTS ON THE FAMILY**

Confusion as to what was wrong with the patient had been compounded by difficulty in getting a diagnosis in some cases and by a variety of diagnoses in others. Families experienced further confusion and frustration because of differences in treatment and different causal theories. Therapy given by a psychiatrist in his office and that given in a hospital often varied greatly.

"Schizophrenics" do not necessarily limit their search for help to the field of psychiatry within the field of medicine and may avoid the diagnosis of schizophrenia in this way. After the film "The Exorcist" was released, some patients or families consulted spiritualists or exorcists prior to contacting the Association. Records show that this was not usual.

The 47 questionnaires completed by MSA members show that the following methods of treatment had been tried in various combinations for 39 patients: psychotherapy 21; psychoanalysis 5; group therapy 5 or more; chemotherapy (tranquilizers) 22; electroshock 10; insulin shock 1; family milieu therapy 1; drama therapy 1; just medical 1; hospitalization 22. It is also known that lobotomies had been recommended for

some patients not represented by questionnaires. (Questionnaire responses showed that 22 patients had later had Orthomolecular therapy, with another 11 qualified answers such as "just starting," "only briefly after long illness," "half-heartedly, doctor's cohort does not approve," etc.) Other records show the same pattern for member families and those calling for help.

According to the expectations of the "sick" and "patient" roles and the traditional supportive role of the mother in American society, mothers of patients, especially young patients, expected to be taken into the confidence of the doctor and told what they should do for the patient—as they had when a child was to be given an antibiotic every four hours. To their reported surprise and dismay, some mothers did not even see the psychiatrist after the initial visit until they were told that the psychiatrist had done all that he could and/or the patient was dismissed. Some mothers expressed great frustration over this, saying that they had thought they would be told what to do right if doing something wrong had caused the problem.

Not seeing the doctor in charge of the case, either in an office or in a hospital (state or private), was a common experience and complaint. Mostly parents had dealt with a psychologist, a psychiatric social worker, or the floor nurse on the psychiatric ward whom they could not get past to consult with the doctor.

Croup therapy for parents, with or without the patient, often an obligatory part of treatment, usually was not conducted by the doctor in charge. Most parents and other family members considered that group therapy had merely brought out resentments without improving the health of the patient.

Confusion for some patients and families stemmed from multi-theories and multi-practitioners, and multi-institutional experiences as families moved, changed doctors, or financial resources were depleted.

One patient whose family moved a great deal

told of the confusion of switching from one approach to another. She said she found it very difficult to believe each psychiatrist in turn "...when I was already so sick and so confused." Patients (and their families when allowed access to the psychiatrist) were expected to believe, and apparently tried to believe, what the current psychiatrist taught in trying to restructure attitudes and beliefs. This was confusing, however, when the current thrust was in direct conflict with beliefs learned from earlier psychiatrists as well as beliefs and values previously held.

Although they might have known the widely held belief that families cause schizophrenia, parents were not prepared for some of the consequences of the theory in practice. This was particularly true in connection with hospitalization. (As has been noted, about half of the patients and their families had had experiences with hospitals.)

Simmons et al. (1956) found that when there was conflict between patients and parents over where the patient would go upon release from the hospital, the patient always got his way. They said that under the impact of current thinking about "institutionalization" of patients, hospital personnel believed that almost any community setting was better than the hospital. However, since hospital personnel tended to view the family as "pathogenic milieu," the patient's rebellion against returning to the family was often viewed as therapeutic improvement and the patient's acquiescence to family wishes as unfavorable signs (Simmons, 1956, pp.21-28).

"We couldn't get rid of him if we tried," said one mother well acquainted with the "revolving door" policy of quick release and quick readmittance prevalent at the period of this study. She and her husband had received calls from hospitals in several states to pick up their son (sometimes only to find upon arrival that he had been given a bus ticket to "just over the state line"). Eventually he always returned home. Whatever hospital personnel thought about the family as



pathogenic milieu, there was no one else ready to accept this young man, or others like him, convinced by psychiatrists that there was really nothing wrong with him.

### **Orthomolecular therapy and the medical model**

When the medical model is taken seriously, all physical symptoms are physically analyzed. This is the first step. Parents and other family members are consulted and advised. When serious and very real physical problems were discovered, families who had been told to "throw him out" were glad they had not taken this previous advice.

Since laboratory tests showed diverse physiological conditions previously diagnosed as "schizophrenia," treatment was also diverse. For some conditions massive doses of vitamins were prescribed. Homocystinuria is a genetic disease in which Pyridoxine (B6) is a needed coenzyme (see Rosenberg, 1970, pp. 59-66.) There are a number of the familial hyperlipoproteinemias for which B3 is a treatment of choice (see Lindner, 1974.) Vitamin B3 and other vitamins were used by some doctors to treat hypoglycemia with good results. Obviously where there are problems with mineral toxicities or deficiencies or allergies, treatment depends upon the substance(s) causing the trouble. Diet is considered important in treatment of the above and in treating diabetes. Diabetes, epilepsy, thyroid problems, and congenital syphilis all require different kinds of treatment. In the group of patients and families studied, there was no one entity which could be called "schizophrenia" and no one cure.

Individual treatment for individual physical problems obviously makes it impossible to run accurate blind or double-blind experiments using one substance as a specific for one disease, although niacin appeared to be beneficial for the largest number of individuals for whom there were reports. While the difficulty of controlled experiments may be bewailed in the scientific community, patients and their families expect individual diagnosis and treatment using the

findings of all medical science for the benefit of one patient. That is why they go to doctors and what they expect to pay for.

Only those patients who were not hospitalized or those who were able to leave psychiatric hospitals in the area were able to obtain "Orthomolecular" therapy. There were no hospitals allowing "megavitamin" therapy in the area and no clinics giving the batteries of tests which knowledgeable members of the MSA recognized as being used by qualified doctors. Laboratories giving such tests were known, but laymen do not have access to them.

Because most people who called the Association did so as a last resort and after financial resources were depleted, to have a local diagnostic and treatment clinic within financial reach of those needing help was a long-term goal of the Metropolitan Schizophrenia Association.

### **FINANCIAL DIFFICULTIES FOR FAMILIES**

The current rate for private psychotherapy in the area was \$50 an hour. Not as well known to laymen is the high costs of private mental hospitals. Private hospitals in the area charged some members over \$3,000 per month. That there sometimes had to be a choice made by member families of college for one child or hospitalization for another obviously created tensions within families.

Since it was usually only after family finances had been exhausted that families called the Metropolitan Schizophrenia Association, patients had often been undergoing psychotherapy or hospitalization for some time. Insurance, available for some psychiatric treatment and hospital care, did not pay for long-term care and had frequently run out.

The lessening ability to pay for therapy was responsible for some of the variety of learning experiences patients and their families had had with psychiatry. A patient might start out in private therapy,

go into less expensive group therapy and from a private hospital to a state hospital in the course of treatment. Sometimes patients who appeared to be doing well with one psychiatrist at a community mental health clinic did less well with another as these professionals left to go into private practice.

Some people who called the Association office had heard of "megavitamin therapy" which sounded simple and cheap. Although this often costs no more than \$20 per month after the first year of treatment, it is not cheap initially under the supervision of a doctor, and vitamin-dependency diseases were not always the problem. Physical laboratory tests alone sometimes ran to \$300 or \$500, and some Orthomolecular psychiatrists used for referrals charged the current rate for visits.

Because of the depletion of financial coverage (or the unwillingness of some insurance companies to pay for physical laboratory tests) the ability of the Association to respond to calls for help was complicated and frequently frustrated.

#### WHO IS RESPONSIBLE FOR WHAT?

In both psychiatric and social science literature the patient is often held responsible for his own plight, or the family is considered as cause of schizophrenia. This frequently has to do with wrong learning or wrong teaching, however unintended this may be or how widespread are "wrong" beliefs and practices in the culture. It must be asked, and is asked by some of the families studied, can patients or their families be held responsible in this way for even genetic diseases or congenital syphilis?

Parents who sought and tried various therapies for "mental illness" from various sources only to ultimately discover physical abnormalities which yielded to relatively simple physical treatment ask the medical profession, "who has been responsible here?" They ask this sincerely and increasingly bitterly

as no answer is heard from the medical

"establishment."

There has been a widening gap in American medical theory and treatment between germ-caused "diseases" treated by "drugs" and socially caused "mental illnesses" treated by "talking." While oversimplified, this description accurately reflects the body/mind dichotomy and the common experience of members of the Metropolitan Schizophrenia Association. Meanwhile debate continues in the medical establishment generally as to whether vitamins are medicine or drugs, or even worthwhile, and in the psychiatric profession as to whether or not "megavitamin therapy" is worthless in curing schizophrenia.

Since the early 1960's, "niacin therapy" has expanded to become "megavitamin therapy" as other vitamin-dependency diseases known to cause mental or emotional problems were added to "the schizophrenias." The concept was expanded further when Linus Pauling coined the term "Orthomolecular psychiatry" in 1968. This therapy included trace mineral deficiencies and other nutritional diseases known by biochemists and other scientists to cause symptoms of mental illness and which had been found in patients previously diagnosed as "schizophrenic." At the time of this study, it appeared that "Orthomolecular psychiatry" was expanding to fill the whole physiological-biochemical gap between medicine and psychotherapy as practiced in this country. In practice it frequently covered the entire medical model of treatment for biological problems which can affect the mind (see Sieglar and Osmond, 1974.)

The Task Force 7 Report previously cited questions how many people had been diagnosed as schizophrenic and treated successfully by Orthomolecular means when they might not have been schizophrenic at all. This could be read as implying that these people were both initially diagnosed and treated by the same professionals. However, that was not the experience of the families studied. The diagnosis of schizophrenia

usually had come first from psychodynamically oriented psychiatrists, whereas successful "Orthomolecular" treatment came from biochemically oriented doctors, psychiatrists, and "Orthomolecular psychiatrists." Orthomolecular psychiatrists and those using the biochemical approach known to the Metropolitan Schizophrenia Association accounted for no more than .4 percent of the psychiatrists in the local area (which had one of the highest concentrations of psychiatrists in the country).

Whether or not the Task Force Report intends to imply that Orthomolecular psychiatrists wrongly diagnose schizophrenia, it does not state that there is to be a general effort made within the field of psychiatry to screen out the individuals "who may not have been schizophrenic at all."

The following unanswered social questions are apparent:

(1) How are the individuals "who may not have been schizophrenic at all" to be identified by the profession before they are diagnosed as "schizophrenic?" Psychiatrists may think that general practitioners do (or ought to) routinely screen out and treat physical problems which give rise to symptoms of mental disorder, while other physicians may think that psychiatrists do this (or ought to). Laymen expect it of both. MSA members said that they had gone to psychiatrists assuming that the M.D. after the name insured that possible physical causes or contributing factors would be ruled out prior to other psychotherapy.

(2) From the point of view of the family, the question of overriding importance is: How, in general, can families identify physicians (including psychiatrists) who give laboratory tests for treatable physiological dysfunctions which can cause symptoms which have been diagnosed as "schizophrenia" or "mental illness" before families and patients undergo the frustrations and anguish of some or all of the common problems outlined in this paper?

People do not call the Metropolitan

Schizophrenia Association until they have already been through the agony.

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The families, many health officials have only recently concluded, are forgotten victims of this baffling disorder that disables one of every hundred Americans at some point in their lives. Parents and siblings of schizophrenics say they are racked by demands that would overtax a Mother Theresa. They describe themselves as bitter, despairing and wrung out. Yet in fact, some 65 percent of patients discharged from mental hospitals return to their families, usually their parents, according to the National Institute of Mental Health. An estimated 800,000 schizophrenics now live with their families and many more live nearby, depending on relatives for crucial support. Two thirds of patients with schizophrenia return to their parents' house after discharge from a hospital for the first psychotic episode. Family members generally receive very little education as to what they can expect. They may not know the importance of medication compliance. Family members are the primary victims of violence from psychotic individuals, usually their own son or daughter, and most families cannot believe their own son or daughter would be capable of such a thing. Although families are usually the main care givers at the beginning of schizophrenia they often find their experience Victims of schizophrenia. sought were in their twenties or early thirties. Of the patients, more young men than young women had been diagnosed as schizophrenic, but more young women had been diagnosed as manic-depressive. It was primarily with parents of schizophrenics, leaders of the Association, volunteer workers, and those calling the office for information and help that I worked as an office volunteer for the Metropolitan Schizophrenia Association from the spring of 1973 to the summer of 1974. 232. Victims of schizophrenia. The assumption that the family itself, and particularly the mother, causes schizophrenia has been devastating for some family members. Schizophrenia, although rare, with a median incidence of just around 15 cases per hundred thousand of the population per year, is as yet incurable and persists in people, resulting in a relatively high prevalence (McGrath et al, 2008). There has been a consensus that violence risk is increased in schizophrenia. Half-siblings were excluded. Where there were families with more than one case eligible for inclusion, one was selected at random. Differences in the prevalence of criminal conviction were assessed between cases and controls. Logistic regression was used to adjust for age, gender, marital status, parity, substance misuse, and suicide attempts. Among patients/cases, violent crime conviction was predicted significantly by: male gender. substance misuse.