

## A Practical Model for Treating Schizophrenia in the Real World

by

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I would like to describe a particular method of the psychoeducational approach to treating schizophrenia. This method is attractive because it has demonstrated an over-all effectiveness in lowering the rate of relapse and it has been used in a variety of administrative and social environments: urban, suburban and rural settings throughout one public hospital system in the United States. In addition, permanent staff were trained so that the treatment would continue as a regular part of State clinic services after its efficacy had been established.

This method was developed as part of a research project, the Family Support Demonstration Project (FSDP), conducted by Dr William R. McFarlane at the New York State Psychiatric Institute in New York City and funded by the State of New York. The Clinical Supervisory team included, in addition to Dr McFarlane, Dr Susan Deakins, Dr Edward Dunne, Ms Bonnie Horen, and myself. Using single family and multiple family group treatment designs, 183 families were enrolled for a two-year period. Five State hospitals and one city hospital

participated. Relapse rates at the end of two years replicated those for previous studies: 21% for participating patients, as compared with 40% to 60% reported in older studies for patients receiving traditional services (Anderson, Reiss & Hogarty 1986). Because it is a highly technical method that allows clinicians to master the form and become teachers of the method in two years, this paper can only serve to pique your curiosity.

Let me begin by making some general remarks about psychoeducation and family therapy in order to address some frequent misunderstandings. First of all, some people think that psychoeducation as a method of treatment means presenting families with information about schizophrenia and giving them suggestions for different ways of coping. For example, a number of in-patient services and out-patient clinics hold family nights once a month, with this idea in mind. These meetings are useful as far as they go, but I want to emphasize that I will be talking about a model devised to lower relapse rates, of which didactic education is only a small part.

Secondly, psychoeducation is often thought of as a sub-set of family therapy, yet it differs from family therapy in a number of ways. It assumes that there is a chronic medical condition and that the patient and family are doing their best given the limitations of the illness and its social consequences. From this follows the idea that support may be needed for a long time just as in chronic medical conditions such as diabetes. And likewise, the amount and nature of the support varies with the phases and course of the illness.

Psychoeducation, then, as originally developed in the United States and England by Anderson et al (1986), Goldstein et al (1976), Falloon, Boyd & McGill (1984), and Leff et al (1982), is a management rather than a cure model of treatment for chronic schizophrenia, which includes the family as an integral part of the treatment team. The approach grew out of the observation that patients relapsed after being discharged from the hospital to their families and that medication and psychotherapy, including family therapy, were of

little help in preventing relapse from occurring (Anderson et al 1986). Furthermore, day programmes and rehabilitation programmes failed to provide patients with an avenue to a better life. These clinical experiences were accumulating during a period when we were also getting a better understanding of schizophrenia as a brain disease.

The assumptions that underlie psychoeducation follow from this experience. There is a brain disease which interferes with a person's ability to maintain focus and attention. This makes decision-making, planning, and responding to and taking social initiative difficult. If you arrange the social environment so that social cues are expectable and stimuli are low-key and simple, the person will have the time and security to learn new ways to respond to novel situations. The implications of these assumptions are that there is a medical condition to be managed, that the family does not cause this condition, and that behaviours which other systems of explanation label pathological, are here labelled as the social effects of coping with the peculiar features of this chronic illness. There is the further implication that each illness has particular characteristics which should influence the treatment design for that condition.

The conclusion that follows from these assumptions and their implications is that everyone, clinicians, family members and patients, are all members of the same management team, a partnership of experts. Any social system that impinges on the patient is a candidate for intervention by the team on the patient's behalf. Building

on this basic idea, there are four elements that appear, with differing emphasis, in all psychoeducational models to date:

1. Joining or establishing an alliance as peer or colleague with patient and family members.
2. Providing the most sophisticated information about the illness, in order to demystify the illness, to serve as the basis for a common language, and to rationalise the guidelines for lowering stimulation.
3. Collaborating over an extended period of time to modify and contain social stimulation by putting the guidelines into action, and clarifying and simplifying social roles.
4. Organizing gatherings where a number of families can meet.

The New York State model (McFarlane 1990; McFarlane, Deakins, Gingerich, Dunne, Horen & Newmark 1991), an adaptation of the work of Anderson, et al (1986), incorporates these elements into four stages of treatment, extending over two years, corresponding to four phases of the illness. These stages take account of the deficits of schizophrenia and their social consequences.

#### Stage 1: *Joining*

As an acute episode begins to build, the patient usually comes to the attention of the mental health delivery system and is often hospitalised. This is the ideal time to meet with the family for the first time. Family members are anxious and more open to new ways of handling the situation. Paradoxically, this is the time when families are

usually ignored. In the psychoeducational approach, clinicians get in touch with the family as soon as possible to offer an alliance or partnership of experts in confronting the illness.

Clinicians demonstrate that they are interested in the family's experience, expertise and burden, by providing information about the illness, acting as advocates wherever necessary, reviewing the present crisis, identifying early warning signs of relapse, and providing opportunities for family members to grieve the loss of their expectations for the patient. Since family members live with the problem of the illness twenty-four hours a day, clinicians share the burden by making help available twenty-four hours a day.

At the same time clinicians are meeting with families, they begin to meet with the patient. These meetings are usually brief because symptoms interfere with the patient's ability to attend. Their purpose in meeting remains, however, to establish themselves as colleagues and advocates.

The goals for these meetings with the patient and family are: to agree to work for at least two years (the period of recuperation [9-18 months] plus six months of the rehabilitation phase), to fend off relapse and then focus on social and vocational improvement for the patient; and to help the family to regain some semblance of normal life. It will require at least three meetings to establish a peer relationship, contract for the goals of treatment, and to gather essential information about the strengths, resources, and early warning signs.

### Stage 2: Education Workshop

When the joining stage is completed, a didactic workshop is held, based on the one described in Anderson et al (1986). If two clinicians are going to lead a multiple-family group, this workshop will be the first meeting of the families with which each will have joined. Patients, who are usually still beleaguered by symptoms, do not attend.

The most up-to-date information about schizophrenia is presented, followed by descriptions of how patients and families experience the illness. Then family members are encouraged to talk about how they have coped with this experience, and the clinicians present a list of guidelines for management based on what has worked for other families, the deficits of the illness and their social effects.

The purposes of the workshop are:

- to establish a common body of knowledge to which to refer in the future;
- to demonstrate that the focus of the work will be on managing the illness and not on any supposed psychopathology of family or patient;
- to break into the isolation and stigma that feeds despair and worry;
- to introduce the notion of new ways of coping.

These new ways are opposite to the usual response of most American families, patients and clinicians faced with illness of a family member. People typically assume that any deviation from what we consider to be normal physical and mental functioning will be brief, responsive to our efforts to help, and that the

patient will be his or her own self again shortly after the episode is declared to be over. During the episode, we take the patient's daily responsibilities on our own shoulders, tolerate difficult or unpleasant behaviour, and coax the patient to try various remedies. When the episode is over, we urge the patient to resume habitual activities as quickly as possible while considering any delay in recovery a reflection on the patient's character and possibly our own. The psychoeducational guidelines, on the contrary, advise that in the face of this chronic mental illness, everyone should back off from expectations and social stimulation (including urging efforts toward improvement), while holding firm on placing limits on disruptive, bizarre and upsetting behaviour.

### Stage 3: Stabilization

This stage begins shortly after the workshop and addresses the phase of the illness in which the patient leaves the hospital and begins to deal simultaneously with the flux of the day-to-day world and the problems resulting from negative symptoms. I will describe this stage and stage 4 in terms of multiple-family group meetings since this is the form of treatment which clinicians, families and patients seem to enjoy most. The group, by its mere existence, has the added advantage of directly attacking some of the social consequences of schizophrenia.

The group meets every other week for an hour and a half, and consists of the six to eight families who attended the workshop and the two clinicians who joined with them.

All patients are invited to attend who are minimally able to tolerate social interaction. Clinicians are available between meetings for consultation. The goals of this stage are to help everyone put the guidelines into action; to model low-key, calm, consistent demeanor; to develop a tolerance for the slow pace of recovery by lowering expectations for the time being; and to promote the cohesion of the group. It is very important for clinicians to have supervisors available to them in their efforts to restrain their natural impulse to push patients and families towards change, and it is equally important that this supervision be offered in the same collegial, low-key manner that clinicians adopt with their clients.

In both the stabilization and rehabilitation phases of treatment, the method used for implementing the guidelines (as well as lowering stimulation in the meetings and creating an expectable environment that promotes attention), is formal "problem-solving", an adaptation of the work of Falloon et al (1984). This method ensures the testing of workable solutions to common, vexing problems. Problems are defined in terms of the nature of the illness and the guidelines for management, never as attributes of persons. Each session, starting with the third group meeting, follows the same form:

1. There is a period of social chatting, at least 15 minutes, which is orchestrated by the group leaders so that only one person speaks at a time. Any topic is acceptable except illness-related subjects.
2. When people are more relaxed, each family reports in turn on the

illness and its effects during the previous two weeks. One problem is chosen for study by the group, based on a priority list where safety or substance abuse takes precedence over everything else. The remaining problems are dealt with outside the group, put off to the next meeting, or restated in terms of a guideline and some biological information accompanied by a suggestion for experimentation.

3. The group, including the leaders, contributes suggestions for solution to the problem defined, for example, as "What Jim can do if he feels anxious at his sister's wedding". All suggestions, no matter how tangential or foolish, are written down. All discussion and comment is vigorously discouraged until the list is completed. Then each option is discussed, first the advantages of each option and then the disadvantages. Any attempts to short-circuit this process are dealt with courteously and promptly.

4. When the discussion is finished, the family concerned chooses an option or a cluster of related suggestions to experiment with until the next meeting in two weeks. The experiment is then planned as to who exactly will do what, where and when, with whom and how often.

5. The group meeting ends with at least five minutes of social chat. Emergencies are dealt with outside the meeting so that the process of problem-solving can proceed.

6. At the next meeting, the family with the experiment is the first to report on events. If the experiment went well, they are congratulated. If it went poorly, the leaders take the responsibility. In this way the group builds on successes.

Clinicians are very active in keeping an orderly, low-key atmosphere in the room and in promoting family contributions and interaction among families. The chatting at the beginning and end of each meeting reminds everyone that there is a life apart from schizophrenia, supports the collegial relationship between leaders and group members, and allows everyone to return to a relaxed state after the intensity of the problem-solving effort.

The most common problems encountered in the stabilization phase of the illness are: sleeping a lot, medication compliance, tolerating the slow pace of recuperation, aggressiveness, and avoiding street drugs including alcohol. For example, a mother may remark that the patient has been shoving her. A leader will remind the group of two of the guidelines: "Ignore what you can't change but don't ignore violence"; and, "Set limits because a few good rules keep things calmer". Then one of the clinicians may refer to the workshop where it was pointed out that disturbing behaviour is most often a reaction to some form of stimulation such as lowered levels of medication or some other change or event, even a pleasant one. After a detailed discussion of the circumstances in which shoving seems to occur, the family might agree to a definition of the problem as "What to do when the shoving occurs". Suggestions for solution should include the entire range from ideas about how the patient can stay calm so that shoving never occurs, to calling the police when it does, to pretending it didn't happen.

#### Stage 4: *Social and Vocational Rehabilitation*

In keeping with Anderson et al's (1986) conception, when a patient shows consistent signs of focussed and productive activity, it is time to reverse the effort for that patient and to push gently for the achievement of some modest goal, either social or vocational but never both at the same time. This usually happens somewhere between 9-18 months after the group started to meet. By this time the meetings are more family-led with clinicians acting as consultants most of the time. Crises are at a minimum. Each patient is moving at his or her own pace, seeking an optimal level of activity whether it's day programme or sheltered work, competitive employment or doing fishing once a week with a cousin.

The principal problem encountered at this point is the temptation to give in to rising expectations, to move too swiftly in too many areas of activity. Clinicians are as vulnerable to this temptation as other group members. One way to counterbalance this temptation is to use early warning signs as a litmus test for the consolidation of a step forward before the next step is taken. Here is an illustration of the process. The patient may wish to go to work and discussion in the group might identify travelling alone on the public bus as the next step toward that goal. The problem-solving effort might produce an experiment in which the patient would take one bus trip a week with a retired uncle. Though mildly delusional at first for a few hours following a trip, the patient might be calm before, during and

after the experience by the end of the fifth excursion, and wish to do more. The next experiment might be to take a trip alone one way, once in the following two weeks. During the next week, in addition to the mild delusions which are tolerated for the sake of the gains to be made, the patient may also stop eating breakfast with the family and then start listening to voices on the day of the trip. During the walk to the bus, the patient might feel panicky and turn back home. These early signs of potential relapse warn everybody to return to the original task for a while and then to take a smaller step forward, such as discussing what unusual things might happen on the way to the bus, how these could be dealt with, and then walking alone to and from the bus stop without actually getting on the bus. Families tend to pool their resources in designing these steps and clinicians negotiate with programmes and employers to fashion schedules to suit each individual.

At the end of two years, groups are usually meeting less frequently and many members will have joined one of the mutual aid societies. There is a fair amount of visiting and trading of advice among group members between meetings. Many patients are at a plateau of functioning and family life is as satisfactory as it can be under the circumstances. Families may choose to continue in a clinician-led group, or to keep in touch with the agency only for occasional reassurance that support is available should the need arise. This may be all that is necessary to keep the situation stable.

**I**n the final portion of this paper, I'd like first to describe some ways in which the treatment model has affected the clinicians and the hospital system in which they work and then say a few words about some theoretical matters.

The research design called for a two-year commitment from families and clinicians in keeping with the concept of a two-year recovery period from an acute episode of schizophrenia. Long-term commitment by the staff and the assurance that treatment would continue to be available at the end of the research protocol, are also compatible with the present conviction that continuity of care is an important factor in preventing relapse. However, neither family members nor patients were required to attend meetings. As long as one family member came, the family and patient remained part of the project. The low drop-out rate for families - 26% over two years - may be some measure of their appreciation of these arrangements. Indeed, when at the end of the project, all participants were offered the chance to continue, most accepted.

All the clinicians, and particularly those who worked as co-leaders of multiple family groups, found that the methodology made work with chronic illness easier, the partnership with families and patients made it more fun, and the long-term commitment kept their interest alive as they were able to see the slow evolution of the fruits of their labours.

The advocacy activity of the clinicians put them in touch with many parts of the delivery system as they negotiated for low-stimulation

environments for their clients. This sparked interest in doing things in a different way, even beyond the walls of the hospitals and clinics. The method affected the treatment sites in a variety of ways (McFarlane, Lukens, McLaughlin-Toran, Newmark & Dunne 1991). Most were impressed with the lower relapse rates for patients from the higher risk categories, and some skeptics were converted when they saw the pay-off from working with their colleagues on tailor-made solutions to problems. Within the hospitals, one director was sufficiently impressed to free two clinicians to teach the method full-time and a medical director in another hospital contracted with the Project staff and the clinicians trained in one of the out-patient clinics to design applications of the method for a number of difficult in-patient wards. Clinicians on their own initiative began adapting the model to a variety of settings such as community residences, foster care, day programmes, sheltered work and their own non-psychiatric practices.

The difficulties encountered in setting up psychoeducation treatment were, for the most part, those any new programme runs into. Someone with authority over the clinicians opposes the work either on theoretical or practical grounds. The more highly placed the person, the less trouble for the clinician in the short-run and the more trouble in maintaining the programme in the long-run. These obstacles were dealt with by applying the model to each situation. That is, stay calm, avoid confrontation, and work with the pivotal person in a step-by-step fashion towards a mutually agreeable

goal. As in the clinical model, we expected only a long, slow process of incremental change.

My final point is a theoretical one. There has been some discussion back and forth about the effects on patients of labelling them as having one illness or another. Warner et al (1989) evaluated the two principle schools of thought, one that accepting a diagnosis is necessary for improved functioning, and the other, that accepting a diagnosis undermines self-esteem and institutionalises a patient role. This small study found that accepting a label when the locus of control of the situation was internal correlated with better functioning. Given this finding, psychoeducational treatment is interesting in a number of ways. First of all, neither family nor patient is urged to accept the schizophrenia diagnosis. They are asked to give the approach a try to see if it helps prevent relapse and leads to a more rewarding life for everyone. The method described here focusses on each patient's unique early warning signs so that they may be harnessed to maximise recuperation and rehabilitation. This promotion of mastery, empowering patients and families in their own lives, builds self-esteem and an internal locus of control. It could be argued that insight or acceptance of responsibility for a problem, usually understood to mean making an "I" statement about one's relationship to the problem, is an internalization, whereas the psychoeducational approach as a whole is an externalization process, placing patient and family in the driver's seat (Warner et al 1989).

## Conclusion

Labelling and long-term treatment contracts are seen by some as disempowering and supporting hopelessness. Our experience has been that families and patients feel they are escaping from stigma when there is acknowledgement that something is wrong that is no-one's fault and that the situation is difficult, serious and burdensome to manage alone. The long-term commitment has been seen as a demonstration of trustworthiness, of the intent to follow through, in contrast to previous experiences with offers of help. Since patients relapse less frequently in psychoeducational treatment programmes, it is hard to argue that the approach reinforces chronicity. The Vermont Longitudinal Study, along with several European studies (Warner 1985), suggest that schizophrenia recedes as patients grow older. Perhaps it makes more sense at this time to think of people struggling with schizophrenia as individuals whose course of illness and whose needs will differ depending on any number of different biological, psychological and social factors. For some in our study that meant independent living and competitive employment. For a few that has meant fewer hospitalisations and one day a week attending a programme. We can at least assume that clinicians using a psychoeducational approach can help each person and each family member achieve a better adjustment than they had hoped for, given their particular circumstances.

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