

World Fellowship for Schizophrenia and Allied Disorders

Speeches during the WFSAD Symposium, 1 October 2003

Article based on audiotape of the Symposium

Co-operation Not Conflict: The Strategy for Solving The Problems of Schizophrenia

By Julian Leff, F.R.C.P.

I suppose Venezuela is a developing country, certainly in comparison to North America or Britain. There has been an interesting convergence with developing and developed countries, regarding families as main carers. Developing countries have never had the massive investment in psychiatric hospitals that we have had in the developed world. As a consequence, in India, South Africa, etc, the majority of patients with Schizophrenia are taken care of by their families. In developed countries the massive development of psychiatric hospitals meant that the majority of patients were behind walls, they were not with their families.

Throughout the western world there have been sweeping changes in the focus of care. In Britain we have closed almost all our psychiatric hospitals. As a result the great majority of people with schizophrenia are living in the community. How do we define community? In a developed society we no longer have the cohesion of social networks that still exist in the developing world, so if the family is to look after the patient they have very little external support. We often see a middle-aged person with schizophrenia being looked after by a single person usually an elderly mother. This is an enormous burden on this single relative to care for someone long term. In Britain we have developed sheltered residences in the community with psychiatrically trained and untrained staff who looks after the patients in ordinary houses. But, there are not enough of these. What has disappeared from the system is long-term rehabilitation. This used to be possible in the psychiatric hospital where there used to be good facilities for rehabilitation. In the move to the community these facilities have disappeared. So, many very disabled patients are still under the care of their families.

Back in the 50s some colleagues and later myself, developed a measure called Expressed Emotion. This was a measure of emotional response of one person to another person with psychiatric illness. Original work was carried out with schizophrenia. An interview was developed together with the carer, which focused on the symptoms and behaviours of the sick person in the previous three months. It is audiotaped. The interviewer listens carefully to it and rates the following characteristics:

1. Critical Comments: Comments about the patient's behaviour made in a critical tone:

"My son never washes his underwear he's always wearing dirty clothes."

This can be said in a critical tone. Those changes in the voice signal criticism, that the relative is angry. We count the number of critical comments in the course of an interview. If criticism is extensive it is called hostility. Hostility can also be based on patient's personality.

"My son...I have never met a lazier boy." In this example the criticism is focused on the patient's personality.

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2. Over involvement: It is measured from a number of different aspects of the relative's observed and reported behaviour during the interview. An example could be the relative being overemotional in the interview: "I don't know how to carry on I feel my life is ended." This is a subjective view but it is important to take into account the cultural background of the person who is saying this to assess it correctly.
3. Overprotective behaviour: Occurs when the carer behaves as if the patient is much younger. An example: a mother who will not allow patient, her daughter of 20, to cross the road on her own.
4. Excessive self-sacrifice: Occurs in families that give up too much of their life; that do not look after their own needs. Studies have shown that one third of people caring would qualify as a case of depression.
5. Over identification: When the carer cannot separate psychologically from the patient, he/she can anticipate the patient's needs, knows what the patient wants before he/she asks.

Over involvement is less common than criticism and occurs equally in husbands and wives, and in parents. Over involvement is much more common in parents and particularly in mothers. If the mother is absent and someone else takes over parenting role, this person is likely to get over involved.

What do these aspects of emotional response have to do with Schizophrenia? The answer is that they are closely related to the outcome. In a patient followed up after discharge, who goes back to an environment with high criticism, the frequency of relapse is higher. If the relative does not show negative criticism but in contrast is high on warmth the patient is likely to do well. We use these measurements to classify households with high or low Expressed Emotion.

Slide: This shows you 13 studies. There have now been over 20. In high EE families about 50% of patients relapse. In low EE families only 20% relapse. This is different in first or recent onset cases. The studies were carried out in Europe, China, India, and America--No study in South America but there was one in Spain.

Work progressed well beyond Schizophrenia. High EE occurs in all other psychiatric conditions and also in diabetes, epilepsy, Parkinson's, and inflammatory bowel disease. High levels of EE have been found in families of these conditions. This is very important because it tells us that it has nothing specifically to do with Schizophrenia. Tells us that if a person looks after another individual with a long standing or current condition they are likely to develop over involved attitudes.

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The work on Schizophrenia has looked at protective factors. We wonder what about the other half who stay well. There are two protective factors.

1: Medication

2: The amount of contact between relative and patient. The more contact the more likely the patient is to relapse. The studies show:

- Patients in high contact environment + without medication = 92% relapse rate.
- Patients in high contact environment + with medication = 50% relapse rate.
- Patients who keep out of their relatives' way + without medication = 40% relapse.
- Low contact + medications can reduce relapse rate to as low as 15%.

When we discovered this we decided to develop a program for High EE families. The program puts all patients on medication. This is essential. We work with the families either to lower EE or to lower contact between patient and family. The program starts with education about schizophrenia. We go into the homes and give two sessions of an hour each in which we tell families about the cause of illness. We emphasize that there is no evidence that it is caused by families. It is a genetic or biological disease. Changes in the brain make the patient very sensitive to their social environment, so that is very important to keep calm atmosphere.

Then we do problem-solving. This includes patient and family. The idea is to improve communication; some families have difficulties in maintaining clear communication. We aim to lower EE, and to reduce criticism, and over involvement.

Very often the patient is living at home and the carers may be elderly and retired. We encourage family to take up activities outside home, to get away from claustrophobic home environment, where everything is focused on illness. We encourage the patient to do the same: to go out to day centres or other programs.

Families become isolated stop going out or stop inviting people because of shame or embarrassment. We encourage them to go the groups that we have established so that they can meet and share with others in similar circumstances. We help the family to lower their expectations – families expect a cure. We know the drugs will reduce symptoms in the majority of patients, but we also know that 30-40% are left with persistent psychotic symptoms that drugs do not control. It is very difficult for families to cope with these symptoms.

A new and exciting development is the Cognitive Behavioural approach to psychotic symptoms. I will talk more about this in the workshop. In essence that is what we do. There is a book on it in English. In Chile colleagues are preparing a translation that will be available soon.

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Just to show you the evidence that this is worthwhile, there have been 9 published trials that show the value of these programs. Randomized controlled trials show that. You will see that with only medications relapse rates are as in the original studies - 50%. When family is involved relapse is only 10%. In China the slide shows higher relapse rates but the study was over 18 months long.

Over two years the two-year outcome relapse rate is two thirds with only medication and one third if family work is added to medication. Relapse rate can therefore be reduced to a half.

If this was a new ant-psychotic drug you can imagine that the drug companies would be advertising this aggressively! But no one makes money from this research, yet it is a highly effective method of treatment. This is the reason I come whenever I can to talk about it, because this is a very exciting development. Every family who needs it should be given the opportunity to try it.

Notes on Professor Julian Leff's Workshop

Support for Families Caring for a person with schizophrenia

October 3 2003

The different stages the family goes through:

Shock:

This may be different in areas where people search the Internet for information. But it can go on for a long time. People look for other causes of the behaviours and symptoms: drugs and alcohol, problems with life.

Families say things like: "My son has been keeping bad company. If we keep him away from these influences he will be well."

Denial:

The family would often prefer that the person with the symptoms is taking g drugs rather than be diagnosed with mental illness.

Acceptance:

Involves questions as to what the future will be.

Substance Abuse

Professionals need to be trained to deal with both mental illness and drug abuse at the same time. Many professionals are trained in each area but not in both.

Grief Work.

What kind of loss does the family feel? It is often the loss of the person you used to know and the loss of the hopes and aspirations you had for the person. If this grief work is not done the relative is left with unrealistic expectations. You may hear a mother say such things as "He was such a beautiful boy!" Living in the past is not healthy but it is difficult for people to accept their hopes will not be realized.

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Some families say such things as "If only he would meet the right woman." This is very difficult for the patient, trying to meet these unrealistic expectations. Sometimes a patient with delusions of grandeur, which may have come from the need to meet expectations. So both the patient and the family need to mourn these lost hopes.

Helping the patient with his social life

Patient often doesn't know how to approach a woman. He will start telling her about the computer chip in his head. We must help with appropriate behaviour. Skills training is important to help people mix with others and be able to talk about events. There is often nothing in their lives to talk about. By meeting people skills can be developed.

Contraception

We need to talk to patients about contraception. In the old hospitals the wards were segregated, but the grounds were large and there was a lot of sexual activity there. Professionals are often embarrassed to talk about sex. A survey of patients' sexual function finds at least half the patients have sexual dysfunction. They have problems with erection and orgasm. If the professionals don't ask the right questions the problems never get dealt with satisfactorily.

If people who are ill want to have children then they need to know the risks (genetic counseling). But it is his decision. If the person's siblings have children he/she may have a very useful role, contributing to the family. Often they get on very well with the children and really get involved in their niece's or nephew's activities.

Delusions as false beliefs that cannot be shaken

New research in the UK says that this approach is wrong and that the textbooks are wrong. Now new advice is given on hallucinations:

1. Distinguish negative from positive voices. If you feel at the mercy of the voices try to respond only to the positive voices to get back in control.
2. Set limits on your responses. Decide when and where you will listen to the voices. You can negotiate when you will listen. Only going to listen to you between 2 and 4 in the afternoon. Won't answer at other times.
3. Interpret them as a way of coping with painful experiences in the past.
4. Meet others who hear voices. Useful – no longer feel strange; there are groups now of people who hear voices. Talking to each other has given them insight. Strategies for dealing with the voices can be taught.
5. Take responsibility for our decisions. Don't blame the voices.
6. What makes voices louder or softer. Avoid situations that arouse them.
7. Use distractions – listen to music; read; work. etc.
8. Try earplugs!
9. Practice relaxation and try meditation. The level of arousal in the body increases hallucinations.

Note: When **anyone** loses a loved one, 50% see, hear or feel that person close to them.

We need to be sensitive to the first signs of anxiety. That is the time to do something. Tell the person that you can see that he needs to be out of the situation. If that doesn't work, get out of the situation yourself – leave the house – to allow calm to reassert itself.

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Shortness of time prevented Prof. Leff from giving information on a cognitive behavioural approach to delusions. He kindly provided his slide:

1. Consider evidence for and against beliefs
2. Attribute belief to own state of arousal or mood
3. Focus on mood. E.g. feeling of being threatened rather than 'the FBI are after me.'
4. Identify what activates the belief-avoid stressors or become desensitized to them
5. Thought-stopping techniques
6. Time out

Replace belief and its emphasis on patient's importance in the world.