

Schizophrenia: the problems for the family

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Background

The relatives of people with schizophrenia are a group who have much to offer professional carers and other relatives. They have a huge store of knowledge, often gained painfully by trial and error, about the problems involved in caring for sufferers from schizophrenia.

The National Schizophrenia Fellowship is a registered charity and the largest support group in this country for schizophrenia. It began in 1970 when a correspondent wrote a letter to *The Times*. He described two difficulties experienced when his son developed schizophrenia: "The first is how to cope with this strange, new member of the household . . . the second is how to penetrate the obfuscating fog of hospital vagueness and evasiveness and to obtain intelligible guidance on the first set of problems".

Creer & Wing (1974) identified the main problems relatives had to cope with to be social withdrawal, excessive sleeping, lack of conversation and socially embarrassing behaviour. The relatives suffered feelings of depression, grief and a sense of failure and guilt which was sometimes made worse by professionals. The authors felt that some of the distress of the relatives could be avoided by applying existing knowledge.

Hatfield (1979) had similar findings and also noted that marital relations of the relatives were severely taxed. She found, however, that despite the near intolerable burden borne by these families, they were electing to stick with the patient.

More recently services have become community based and people suffering from schizophrenia are treated at home, where possible. The formation of a local branch of the National Schizophrenia Fellowship provided an opportunity to research into the problems families were experiencing in the light of the development of community care.

The study

The aims were to describe the problems experienced by relatives of people with schizophrenia since the introduction of community care; and to investigate ways in which relatives could be helped.

Subjects were people from the local National Schizophrenia Fellowship branch or relatives of

out-patients, who volunteered to be interviewed. They all had a family member with schizophrenia.

A semi-structured interviewing technique was used and each relative(s) was seen for an average of two hours. Interviews were taped where relatives permitted.

A total of 17 interviews were held from 20 families contacted. Fifteen were conducted in the relatives' home and two were held in the psychiatric department of The Royal Hallamshire Hospital, Sheffield, at the request of the subjects.

Findings

Seventeen interviews were held, eight were with both parents, seven with the mother only, one was with a sister and one, a husband; a total of 25 people.

There were ten male and seven female patients. The mean age of onset of schizophrenia was 19 years and the mean age of the patient at the time of interview was 34 years. Eight sufferers were living with their parents, seven lived alone, two were in hostels, and one lived with her husband and family.

Discovery of diagnosis

Questions were asked about the initial information given to relatives. Four relatives had discovered the diagnosis from the psychiatrist and this was thought to be good. Three had been told by the general practitioner and felt that this was good, but wanted more information. Three relatives had read the diagnosis on a sick-note or prescription and felt deceived. One parent found out that their son had schizophrenia when the patient's court case came up. The relative was appalled. Two relatives did not know the diagnosis and were therefore not asked. One relative had been invited to join the National Schizophrenia Fellowship by her GP and was told about it there. She was content with this. Finally one patient had been told prior to the relatives, who were annoyed at this.

The meaning of schizophrenia

People were asked what the word "schizophrenia" meant to them at first. Nineteen knew it was a mental illness, of these eight thought it meant "split personality" and two thought it involved delusions and

hallucinations. These two had found this out from the media. Five people had never heard of it and one was not asked as she was unaware this was the diagnosis.

Information supplied

In 16 out of 17 interviews relatives said that either little or no information had been provided initially. Eleven of these would have liked to know more, but two were content and the rest were happy to find things out gradually. In one case a private psychiatrist explained "everything". This family were pleased.

Thirteen families said they now had enough information, but had found this out themselves. The others still wanted to know more. One lady said, "I've never had any information from the medical side, even the social welfare; I don't think they've got time to sit and talk, have they?"

Problems

Main problems were identified. These varied, but many had problems with minor religious sects influencing the sufferers. Delusions were acted on. Sometimes violence was directed at family members and their social life was adversely effected. Most experienced a sense of loss because the person they once knew had changed. There were financial problems caused by patient's spending sprees and breakages, but also because many found the benefits system baffling. Relatives, especially parents, were worried about the future and who would look after the patient once they were dead. Concerns that siblings would have children with schizophrenia were voiced.

Some relatives experienced feelings of blame for the patient's illness. Two said they were blamed by the patient, two felt blamed by other relatives or neighbours, two by social workers and one by a GP. Ten relatives did not have this problem.

Services

People were asked how good the services were. In 11 of the interviews relatives said there was poor communication with professional carers. All the subjects preferred community management, but said that hospitals were needed for acute episodes. Three families had difficulties getting admission arranged when things were desperate. A need for the education

of everyone was advocated. Several thought respite care would help. Community psychiatric nurses were appreciated.

Comment

A small, selected group of relatives was used, with obvious limitations.

Many findings are similar to the earlier studies. It would seem that little has changed in nearly 20 years. Fewer relatives felt blamed by others than previously, perhaps due to a change in ideas about aetiology held by professionals.

Three main conclusions may be reached. Communication between health professionals and relatives is poor, relatives would prefer to be treated as part of the multidisciplinary team, and there is a need for general education about schizophrenia.

This study therefore agrees with the comments of Atkinson (1991), suggesting that we need now to consider the practicalities of making relatives, who are carers, part of the team. This would aid both communication and education. For "community care" to truly involve the whole community, education of the general public would help. Mental illness is no longer cocooned within the asylums and people need to be aware of what it is.

Relatives who care for people with schizophrenia have a huge burden and need support. In this study they ask for respite care, more community psychiatric nurses, hostels and back-up services. An understanding of their problems should help professionals provide this care.

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References

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