

## Relatives as a Resource in the Management of Functional Illness

LIZ KUIPERS and PAUL BEBBINGTON

Though there is evidence that the burdens which people face when they live with someone suffering from a functional psychiatric illness have a considerable effect on both relatives and patients, very little is done in routine clinical practice to help in dealing with them. However, intervention with relatives is both practicable and effective, and sufficient is now known to indicate tentative guidelines for involving relatives in the management of patients by the psychiatric services. Strategies are suggested for dealing with problems of this sort which are faced by relatives.

The greatest personal influence which most people exert is likely to be upon those with whom they live, and there is now a sizeable literature on the reciprocal effects that psychiatric patients and their close relatives have upon each other. However, whilst this literature has received attention at a theoretical level, it does not appear to have affected clinical practice to any great extent. The time has now come when this work should influence the services we provide for our patients and their relatives.

Not everyone copes adequately with the problems and burdens which can arise in living with a mentally ill relative. There is probably an intimate relationship between the burdens of relatives, the way they cope with them, and the course of the patient's disorder, so that the problems of the relative represent a point where clinical effort could be applied for the benefit of both patient and relative. To do this, the clinician must be aware of the sorts of burden relatives bear and of the approaches which are useful in dealing with them.

### The influence of relatives on patients

The effect of relatives' behaviour on schizophrenia is now well established through the work on Expressed Emotion (EE). Patients whose relatives are rated high on EE are much more likely to relapse within some months of discharge (Brown *et al*, 1962; 1972; Vaughn & Leff, 1976; Leff *et al*, 1982, 1983). The rating of EE is made on the basis of tapes of the relative talking to an interviewer; the rater assesses what the relative says about the patient and how it is said. Criticism, hostility and over-involvement are rated, and from this the EE status of the relative is recognised (Brown *et al*, 1972). The measure is presumably an effective predictor through reflecting some enduring aspect of the relative's behaviour

towards the patient. Attempts at validation are at an early stage, but it appears likely that criticism does transfer to the interaction between relative and patient (Miklowitz *et al*, 1984) and that the attitude of relative to patient is reflected both in other interpersonal behaviours (Kuipers *et al*, 1983) and in the styles of coping characteristically adopted (Kuipers, 1983). The latter links EE with aspects of burden.

The EE measure has also been used to study the relatives of those with neurotic depression (Vaughn & Leff, 1976). Although it has some predictive value there too, the depressed patients studied seemed to be sensitive to much lower levels of criticism than those with schizophrenia. This sensitivity of depressive patients has recently been corroborated by Hooley *et al* (1985).

### Burden

The concept of burden shares characteristics with that of social performance, since one person's poor social performance is another person's burden; both concepts are relative to social expectations, which are likely to be very variable. Thus, as Platt (1981) has emphasised with regard to social performance, measurement can never be entirely satisfactory. The concept of burden is of great significance in psychiatry, not least because the burdens of those with mentally ill relatives make a considerable contribution to its public image, and this is likely to increase with current policies towards community care.

The existence of a burden indicates the breakdown of the reciprocal arrangements which people arrive at in their relationships, such that one person is doing 'more than their fair share'. This may merely result in them taking on an over-large pro-

portion or number of shared tasks, but it may also restrict their activities outside the relationship. Such a change in pattern can be assessed against approximate norms, but is often accompanied by subjective dissatisfaction. The latter occasionally arises from judgements of the situation which may not be entirely justified, but it is an integral part of burden, in that it requires to be dealt with. In general, however, relatives tend to minimise their hardships (Brown & Rutter, 1966; Creer & Wing, 1974; Creer *et al*, 1982).

Though clinicians are not directly concerned with the prevalence of burden among relatives, they do require to know what sorts of problems may be faced by those who live with people suffering from particular conditions, so that they can question them in a knowledgeable way. Creer & Wing (1974) have provided this sort of typology of burden for the relatives of schizophrenic patients, and Fadden (1984) has done the same for the relatives of those with various depressive conditions.

Any attempt to intervene in the family system for the benefit of the patient requires a consideration of the burdens which relatives face and of the strategies that they use or might use to cope with them. Although a number of studies have examined the burden on relatives of those with functional disorders, it is an area that continues to be rediscovered, since findings have not so far been incorporated into clinical practice. Sociological interest in the family of the psychiatric patient as a social system dates back to the work by Clausen *et al* (1955) in the US. There was an early British study by Mills (1962), and the move towards community care in the 1960s led to the work of Grad & Sainsbury (1963a,b), which recorded some of the additional burdens on families occasioned by this policy.

The dissection of burden through the effects on the performance of various roles by the patient's relatives was an approach first used by Mills. It was applied by Creer & Wing (1974) in their study, which documented the financial and social cost of caring for a schizophrenic relative. Relatives bear their considerable burdens in the main uncomplainingly and with very little help from those involved professionally in caring for the sick family member. They are used primarily as sources of information, but are themselves deprived of information and advice which might make it easier to cope with patients and the difficulties they suffer and impose. They know nothing of the nature of psychiatric illness, and so find the less florid symptoms particularly difficult to tolerate (Creer & Wing, 1974; Vaughn, 1977); socially embarrassing behaviour and

depressed mood (Fadden, 1984) also cause relatives great concern.

In addition to the disruption and rescheduling of relatives' roles, there is evidence that living and coping with someone who is mentally disordered may have a direct effect on the physical and psychiatric health of the relative (Brown & Rutter, 1966; Kreitman, 1964; Kreitman *et al*, 1970; Fadden, 1984). Despite all this, and despite their general dissatisfaction with their experience of psychiatric facilities, remarkably few relatives withdraw from the task, and many would welcome any help which could permit them to deal with problems in a manner beneficial to the patient.

### Intervention studies

The intervention studies recently reported (Falloon *et al*, 1982; Leff *et al*, 1982) derived strategies from a straightforward consideration of the problems which relatives face. Leff *et al* based their approach on information provided by Creer & Wing (1974). Falloon *et al* gave structure to their intervention through an essentially behavioural framework, but again the style of interventions was based on a knowledge of the problems and burdens to be expected. Both studies were innovative and had to rely on educated guesses of the sorts of strategy which might be useful.

Leff *et al* provided a package of interventions for their experimental group: these included sessions with relatives devoted to a structured transmission of information about schizophrenia, as well as the setting up of directive groups, orientated towards the practical solution of problems. This approach was pursued further in conjoint sessions with the patient and relative. Content analysis of the reports of relatives concerning the ways they have of dealing with specific difficulties suggest those characteristic of low-EE relatives are centred on the patient, whilst those seen in high-EE relatives are concerned more with the relative's own responses to the situation (Kuipers, 1983). Falloon *et al* also placed weight on the value of education: their intervention comprised family therapy, which took place in the patient's home and was mainly composed of a structured approach to the problems of living together.

### Intervening with relatives

From the literature on burden, it appears that the policies of psychiatrists and their teams towards relatives are often a cause of complaint. Moreover, both EE and intervention studies suggest that different policies would not only help the relatives, but

also the patients, though the optimal approach to the involvement of relatives in the management of functional illness has yet to be worked out. However, we need to know whether the work which has been carried out so far and the extensive clinical experience which has been acquired in the process can be used to produce guidelines now, which psychiatrists and their teams may usefully bring into their routine clinical practice.

We have therefore made an attempt to derive guidelines and practical advice from this literature and from the first author's experience of intervention.

#### Is training necessary for intervening with relatives?

EE is a research measure in the use of which raters require considerable training, but this probably does not matter from a clinical point of view. The spoken attitudes to the patient which go to make up the measure can be recognised by the alert clinician, who should use it not in a rather pointless and potentially pejorative attempt to allocate the relative to a correct EE category, but to identify those who may be in need of help in coping with the problems of living with the patient.

Falloon *et al* (1982) used the closely formulated behavioural procedure of functional analysis in their approach to helping relatives and patients solve problems. Obviously, the more experience a professional has in dealing with people, the greater the likelihood of effective intervention with relatives, but this experience may be augmented through specific training in techniques such as family therapy.

Which member of a multi-disciplinary team should see relatives to inform them, help them, and involve them in management? If information about the illness is to be imparted, this may best be done by a psychiatrist. Apart from this, the member of staff to be involved should be determined by who has an interest in and aptitude for this type of work. The person directly working with the family should, of course, operate within a policy agreed by the multi-disciplinary team, and should report back to it. In the future, it may be possible for clinical workers to receive specific training in the sorts of intervention which have been carried out so far (Leff *et al*, 1982). However, such training is never likely to be of more than limited availability, and the topic is sufficiently important for professionals to be prepared to use the expertise afforded by their general training towards these ends.

#### Initial barriers

The mental health professional faces a considerable barrier, partly self-imposed, in using the resources which are provided by relatives and in offering them an adequate service. A number of professionals unfortunately still fail to conceal a central attitude that relatives are in some way responsible for the psychiatric condition of the patients with whom they live. Though those seen are very often exactly those who cope badly with their situation, uncomplaining relatives are also likely to have problems with which they can be helped. Furthermore, relatives are most likely to be seen at a time of admission or crisis, and will then be particularly anxious and guarded. They very often feel they are going to be blamed for what has happened, and will readily read this into the behaviour of the psychiatrist whether it is there or not. Those who are most upset and most in need of help are unlikely to be cooperative, and may make inappropriate demands. Although they may say they want to be told what to do, they will typically reject advice, as this implies a failure on their part. Indeed, one of the specific benefits of setting up a relatives' group is that it may circumvent this problem.

These initial difficulties, although considerable and a test of perseverance for the professional, are dispelled once relatives can be convinced that a real and understanding attempt is being made to help them. The first requisite is a positive attitude towards them, and those working in this field of intervention have the firm clinical experience that this is the major and necessary precondition for improving the family situation.

#### Imparting information

The first contact between psychiatrist and relatives will probably be a formally arranged interview. It is essential that this should be a two-way process, which requires sympathetic probing into the problems which families have been facing and into their fears and fantasies about mental illness and its effects on the patient. In the course of a single interview, people do not take in information or advice, so that a number of sessions needs to be offered.

A willingness to be open with relatives itself creates problems, since decisions have to be taken over how much to say and how to say it: it is almost always appropriate to give the relatives a diagnosis early in the development of the illness, but this must be followed by a prognosis. One of the worries that professionals have in giving a diagnosis of schizophrenia is in handling its pessimistic connotations.

This is probably best done by getting across an idea of the range of the condition, viz—a quarter of those so diagnosed recover without further attacks or continuing disability and only 10% are completely disabled. At the same time, relatives must be given some warning that they may have to face difficulties of various sorts in the future, and if this is not done, they are likely to complain later on that they were never told what to expect. Beyond a general and gentle probing, it is probably better to be responsive than to initiate detailed enquiry about specific problems at this point. One of the difficulties in attempting to impart information about the functional illnesses is that questions are sometimes asked to which no clear answer can be given. A frank admission of the limits of knowledge, far from discouraging relatives, will help to create an atmosphere in which they feel able to voice their disquiet and to seek advice in the assurance of a honest response.

Relatives need to know about aspects of psychiatric illness and its treatment that the professional may think are obvious. Many patients with functional illness are on maintenance medication, but both they and their relatives may find it very difficult to understand the purpose of this. They require to be told that such medication works, not by making the patient feel better, but by reducing symptoms, not all of which may be perceived as unpleasant, and that it must be taken for a long time. It should be made explicit that neither neuroleptics nor lithium work in the manner of an aspirin, but take time to produce an effect and operate by preventing the return of symptoms.

Another source of confusion for relatives is the 'negative' symptoms which are characteristic of schizophrenia, but many aspects of severe depressive disorder are negative in the same sense. Relatives need to be told that such symptoms as reduced motivation or social withdrawal are not due to a character defect, e.g. laziness, and are not due to medication (and therefore caused by the doctors). It is often hard for relatives to comprehend what is going on when the patient appears to be totally inactive: "he can't be happy like that". They should be encouraged to be more accepting of under-activity, whilst enlisting the patient in simple activities such as going to fetch a newspaper.

### Coping

Some of the positive symptoms of schizophrenia are socially embarrassing or disruptive, and so cause problems for relatives. Low-EE relatives character-

istically cope with such behaviour by ignoring it or playing it down and responding to the more normal actions of the patient; within limits, they will often give the patient time to himself.

High-EE relatives have often reached a position where only two responses remain available to them—becoming angry or becoming upset. Their attempts to cope are thus inevitably centred on their own feelings and not on what is best for the patient. Many of them are over-protective or otherwise intrusive in their attempts to control the patient's behaviour, and are often retaliatory in manner. Others have a restricted style; they cannot express anger or are frightened to let their feelings out because of the effect they know it will have on the patient, but they still end up by making demands the patient cannot meet. Such relatives feel they cannot complain about things to the patient and do not know what else to do. They very frequently become restricted in their activity as well as their emotional responses, and find themselves totally but resentfully tied to the patient.

Relatives who get upset and who cannot see any way of dealing with things are probably better off if they remove themselves from the situation temporarily, which may merely involve going outside for a walk. In other instances, it may be appropriate for the psychiatrist to arrange a short-term admission to relieve the situation. A relative who temporarily opts out in this way is not making an optimal response, but it may be the best that is possible in the circumstances, and probably represents an intermediate step on the way to the coping styles typical of low-EE relatives, who do not become so upset, and therefore do not require to get out of the situation. The more relatives are capable of managing their own feelings, the more they will be able to deal with the patient on a practical and effective level.

### Setting limits

This is one difficult aspect of living with patients which relatives may bring up: limits have to be set both on positive and negative behaviour, and have to be formulated to take into account the context of impaired performance. For instance, one family set limits on the patient talking to himself by asking him to do it only in his bedroom; another relative, faced with a daughter who did nothing, gave her a small, specific amount of housework to do each day, without expecting too high a standard, and being pleased if she could manage it on most days of the week.

It is often necessary to draw the line between coping with a situation calmly and not coping with it



at all. Relatives must make allowances, but not at the expense of over-permissiveness: patients should be gently encouraged to meet realistic expectations, but should not be permitted to become too 'special' at home. They are likely to have lost many of their friends and to be very reliant on their relatives, who often go out of their way to take the patient along to social gatherings outside the house. This can be taken to excess, for it is very important that relatives do not jeopardise their own social outlets. Merely getting the patient to tolerate visitors, without necessarily participating at high levels, may be an adequate and useful goal. Depressed patients very often withdraw from social contacts outside the home, but are very dependent on the company of relatives and may spend all their waking time with them, which can be suffocating for a relative. If a professional gives such relatives 'permission' to spend time apart and to fulfil some of their own needs, this can relieve guilt and also lessen the strain. It may then be possible for them to go out for a walk or for the evening, or even to get a job, which can also provide very necessary social and financial gains for the relative; a part-time job is often seen as most appropriate, since the needs of the patient and relative can then be balanced.

Many underactive patients do not get out of bed readily, and this common problem indicates the sorts of low-key but firm strategies which are necessary and most likely to be effective. There is no point in relatives making unrealistic demands—e.g. that the patient should be out of bed, dressed and groomed by 8 am. The aim should be a reasonable goal and a reasonable time to achieve it by; if the patient has not risen by, say 10 am., the relative should go in and ask him to do so. After a half-hour with no response, it is reasonable to take in a cup of tea (but not breakfast!) and make the request to rise more firmly. After a further half hour, the relative may go in and say something like "come on, you've got to get up now, I'm ready to go out". It may be appropriate occasionally to tip the patient out of bed in a friendly way—one relative would do this saying "come on, head first or feet first?". In dealing with this particular problem, it is helpful to have some definite reason for the patient

to get up, such as attendance at a day centre. This example emphasises the importance of deciding what is realistic in the light of the patient's symptoms.

#### The choice of venue

Relatives may be seen and helped in a variety of settings, which can include a straightforward interview with the professional, family sessions, or relatives' groups. There is no clear evidence as yet about which is most effective. Groups have the advantage that they extend the relatives' social network and reduce families' isolation; they can provide a safe outlet for relatives to discuss problems, which many feel constrained about in the patient's presence. They are also an efficient use of limited staff time, as several relatives are seen together.

In general, family sessions with schizophrenic patients, despite differing theoretical origins, end up looking rather uniform, in providing education, support, and focussed help with solving problems. They can also permit more detailed and individual help than group sessions (McFarlane, 1983).

#### Conclusions

Much remains to be known about the mutual influence exerted by patients with functional disorders and their close relatives. However, the clinical experience of intervention studies permits the suggestion of certain principles which could and should be implemented in routine clinical practice.

Firstly, the family should be seen as a positive and irreplaceable resource; no-one else will provide such continued interest in and care for patients in the community. Secondly, the problems of the family must be treated as real and not trivial: crises should be dealt with by anticipatory action. Thirdly, the professional must be seen to be offering something of value to the relatives (information, advice, a chance to talk). Finally, some member of the clinical team should be prepared to be readily available to the family over a period which is likely to be several years. The time has come when such intervention should be considered part of the standard management of functional psychiatric illness.

#### References

- BROWN, G. W., MONCK, E. M., CARSTAIRS, G. M. & WING, J. K. (1962) Influence of family life on the course of schizophrenic illness. *British Journal of Preventive and Social Medicine*, **16**, 55–68.
- & RUTTER, M. L. (1966) The measurement of family activities and relationships. *Human Relations*, **19**, 241–263.
- , BIRLEY, J. L. T. & WING, J. K. (1972) Influence of family life on the course of schizophrenic disorders: A replication. *British Journal of Psychiatry*, **121**, 241–258.
- CLAUSEN, J. A. & YARROW, M. R. (1955) The impact of mental illness on the family. *Journal of Social Issues*, **11**, 3–64.

- CREER, C., STURT, E. & WYKES, T. (1982) The role of relatives. In Long term community care: experience in a London borough (ed. J. K. Wing). *Psychological Medicine*, Monograph, Supplement 2.
- & WING, J. K. (1974) *Schizophrenia at Home*. Surbiton: National Schizophrenia Fellowship.
- FADDEN, G. B. (1984) The relatives of patients with depressive disorders: A typology of burden and strategies for coping. M.Phil thesis, Institute of Psychiatry, London University.
- FALLOON, I. R. H., BOYD, J. L., MCGILL, C. W., RAZANI, J., MOSS, H. B. & GILDERMAN, A. M. (1982) Family management in the prevention of exacerbations of schizophrenia: a controlled study. *New England Journal of Medicine*, **306**, 1437–1440.
- GRAD, J. & SAINSBURY, P. (1963a) Evaluating a community care service. In *Trends in the Mental Health Service* (eds. H. Freeman & J. Farndale). Oxford: Pergamon.
- & — (1963b) Mental illness and the family. *Lancet*, **i**, 544–547.
- HOOLEY, J. M., ORLEY, J. A., TEASDALE, J. (1985) Levels of Expressed Emotion and relapse in depressed patients. *British Journal of Psychiatry* (in press).
- KREITMAN, N. (1964) The patient's spouse. *British Journal of Psychiatry*, **110**, 159–173.
- , COLLINS, J., NELSON, B., & TROOP, J. (1970) Neurosis and marital interaction: I Personality and symptoms. *British Journal of Psychiatry*, **117**, 33–46.
- KUIPERS, L. (1983) Family factors in schizophrenia: an intervention study. PhD thesis. Institute of Psychiatry, London University.
- , STURGEON, D., BERKOWITZ, R. & LEFF, J. P. (1983) Characteristics of Expressed Emotion: its relationship to speech and looking in schizophrenic patients and their relatives. *British Journal of Clinical Psychology*, **22**, 257–264.
- LEFF, J. P., KUIPERS, L., BERKOWITZ, R., EBERLEIN-FRIES, R. & STURGEON, D. (1982) A controlled trial of social intervention in schizophrenic families. *British Journal of Psychiatry*, **141**, 121–134.
- , —, —, VAUGHN, C. E. & STURGEON, D. (1983) Life events, relatives' Expressed Emotion and maintenance neuroleptics in schizophrenic relapse. *Psychological Medicine*, **13**, 799–806.
- MCFARLANE, W. R. (ed.) (1983) *Family Therapy in Schizophrenia*. New York: Guildford Press.
- MIKLOWITZ, D. J. GOLDSTEIN, M. J., FALLOON, I. R. H. & DEANE, J. A. (1984) Interactional correlates of Expressed Emotion in the families of schizophrenics. *British Journal of Psychiatry*, **144**, 482–487.
- MILLS, E. (1962) *Living with Mental Illness: A Study in East London*. London: Routledge & Kegan Paul.
- PLATT, S. (1981) Social adjustment as a criterion of treatment success: just what are we measuring? *Psychiatry*, **44**, 95–112.
- VAUGHN, C. E. (1977) Patterns of interactions in families of schizophrenics. In *Schizophrenia: The Other Side* (ed. H. Katschnig). Vienna: Urban & Schwarzenberg.
- & LEFF, J. P. (1976) The influence of family and social factors on the course of psychiatric illness: a comparison of schizophrenic and depressed neurotic patients. *British Journal of Psychiatry*, **129**, 125–137.

\*Liz Kuipers, MSc, PhD, *Honorary Principal Clinical Psychologist, District Services Centre, The Maudsley Hospital, Denmark Hill, London SE5 8AZ. Lecturer, Institute of Psychiatry.*

Paul Bebbington, MA, MPhil, MRCP, MRCPsych, *Honorary Senior Lecturer, MRC Social Psychiatry Unit, Institute of Psychiatry, De Crespigny Park, London SE5 8AF.*

\*Correspondence

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