

## The Management of Difficult to Treat Patients with Schizophrenia, Using Non-drug Therapies

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When we consider what defines a person with schizophrenia as 'difficult to treat', a number of questions are raised. These concern some fundamental assumptions about patients, therapy and the sick role in society (Parsons, 1951).

For example, 'difficult to treat' suggests that an individual might be non-compliant, and this may refer to medication, to any therapy, or to services; also described as non-engagement. Alternatively, 'difficult to treat' might refer to failure to respond to particular therapies even when adequate 'doses' are taken. Finally 'difficult to treat' might refer to a range of 'personality' factors that make a patient less attractive to staff and so more difficult to offer treatment to.

All of these aspects can be inverted; a patient might see treatment as inappropriate or inaccessible and so refuse to engage or comply. Rates of non-compliance to prescribed medication in schizophrenia are similar to those for physical disorder (Young *et al*, 1986) at around 40% (Curzon *et al*, 1985). Therapies might be ineffective so that a good response is not possible; up to 40% of those with schizophrenia may have medication resistant positive symptoms (Curzon *et al*, 1985). Staff might be unrealistic in their requirements of patients and blame or stigmatise them instead of offering help.

The main starting point for the management of 'difficult to treat' psychotic patients is a critical examination of which factors are patient related and which are due to staff attitudes, ineffective treatment or rigid service provision. The latter are often more immediately amenable to change. An ability to show flexibility and to look at problems from a 'patient centred' viewpoint and not a 'professional' one is likely in itself to reduce difficulties in treatment. Thus the first requirement is to consider the patient as an ally in the process of treatment rather than as a passive or antagonistic recipient. This idea of a partnership or treatment alliance underpins successful intervention, and it is probably even more important in severe mental health problems where stigma, poverty, social

disablement (Wing *et al*, 1992) and poor or fluctuating insight into difficulties (Kapur *et al*, 1991) are almost inevitable.

### Non-drug therapies

The advantages of non-drug therapies in schizophrenia are that they are likely to be low risk, do not have physical side effects, are not physically intrusive and may be more immediately acceptable to patients (have high face validity). Disadvantages include ineffectiveness, making the patient worse, particularly if therapy is too demanding or pressurised (Wing & Brown, 1970) being time consuming, the need for specialist input from an individual therapist (requiring training) and the difficulty of separating therapist effects (charisma, interpersonal skill) from effects of a particular technique (quality control).

Nevertheless there is now a literature on the effectiveness of a range of non-drug therapy in schizophrenia supported by the introduction of training to produce the therapeutic skills required (e.g. Thorn initiative; Gamble *et al*, 1994). The various psychosocial and psychological therapies can be divided into three main areas and these will be the focus of this article. They are family work, individual psychological therapies, and therapeutic staff relationships.

### Family work for schizophrenia

There is now a well established literature on the effectiveness of psycho-educational intervention with the families of those with schizophrenia. This work was developed with a particular group of families; those where patients on medication still had a 50% chance of relapse in the nine months after discharge from hospital if they returned to live with them. Thus these patients were a group who continued to be at a high risk of relapse and were 'difficult to treat' in the sense of being relatively unresponsive to solely physical treatments.

These interventions have been fuelled by the success of the measure of Expressed Emotion (EE) in being able to predict consistently those family settings associated with poorer outcome for patients with schizophrenia (Kavanagh, 1992; Bebbington & Kuipers, 1994a). EE has also enabled changes in family environment to be measured and so allowed these social treatments to be evaluated (Leff & Vaughn, 1985; Kuipers, 1994). While most intervention studies have been successful in improving outcome, some have not (Kottgen *et al*, 1984; McCreddie *et al*, 1991; Vaughn *et al*, 1992). The latter help to elucidate how specific such intervention needs to be.

What has been interesting, however, is that by tackling 'high risk' families, social and psychological treatments have emerged that are not only effective in reducing relapse rates (Leff *et al*, 1982, 1985, 1989, 1990; Hogarty *et al*, 1986, 1987) but also in reducing the burden of family care (Falloon *et al*, 1982, 1985) improving patients' social functioning (Tarrier *et al*, 1988, 1989), and at less cost than conventional treatment (Tarrier *et al*, 1991). These studies have been reviewed in detail elsewhere (Kuipers & Bebbington, 1988; Tarrier & Barrowclough, 1990; Lam, 1991; De Jesus Mari & Streiner, 1994).

The most recent review (Penn & Mueser, 1996) evaluated 12 family intervention studies in schizophrenia and reiterated that if at least 9 months of treatment were offered only two out of ten "failed to show a beneficial effect on relapse" (p. 609). Anderson & Adams (1996) concur with this and described such interventions as "an effective but underused treatment" (p. 505).

Thus, implementation of these methods remains problematic, mainly because they require staff to be both well trained and supported. However, we do know what can help. The psychoeducational techniques that are effective have now been detailed in manuals published by the main research groups (Falloon, 1985; Anderson *et al*, 1986; Barrowclough & Tarrier, 1992; Kuipers *et al*, 1992). These can be broadly categorised as a positive attitude by staff towards carers; education; problem solving and emotional processing; combined with medication.

### Positive staff attitudes to family carers

The burden of care that is taken on by families who live with psychotic patients, particularly those who are high users of services, is now well documented (Gibbons *et al*, 1984; Fadden *et al*, 1987a; McCarthy, 1988; Kuipers, 1992). The emotional demands of the support they provide may continue

for many years with little respite (Noh & Turner, 1987) and often at considerable cost to their own mental health (Fadden *et al*, 1987b). Even in very long-term care, up to half of patients will have contact with families and a proportion of carers will have been patients themselves at some stage (Creer *et al*, 1982; Brugha *et al*, 1988). In the past relatives have often been exploited (Hatfield *et al*, 1987), blamed or seen as overly demanding (Birley & Hudson, 1983) and not as an important community resource with needs of their own (Kuipers & Bebbington, 1985).

In order to counteract this, professionals have to look beyond the initial presentation of some families which may seem overwhelming to a busy clinical team (e.g. frequent phone calls, emotional upset, high levels of frustration and complaints about staff or services). Behind this there is, of course, the certainty of many years of care, frequent patient relapses, poor professional responses in the past, high levels of worry and anxiety and probably other factors such as guilt, fear of the future and exhaustion.

Such families may also be difficult to engage initially in constructive help. They may fear that things will get worse and that any change will be too demanding and are likely to be angry, resigned and entirely pessimistic about the future. Engagement in intervention is likely to require patience, tolerance, persistence and a willingness to be flexible about appointments and about who is seen (the whole family may never arrive together). It is often helpful to offer home visits rather than clinic-based ones, so that carers are on their own territory and staff are seen to have 'made an effort' to come and talk to them. When family carers have become particularly demoralised or frustrated, help may be refused and resisted. This may have to be accepted, but it is always worth leaving communication open and continuing at least to phone about progress or to let carers know that any phone enquiry or visit will be welcome on their part. However, the majority of carers will respond to approaches such as these, particularly if they perceive that offers of help are sincere, that professionals wish to work in partnership and are not going to impute blame (Kuipers & Bebbington, 1990; Birchwood & Smith, 1990; Kuipers *et al*, 1992).

### Education

Relatives frequently ask for information about schizophrenia, and are likely to misunderstand medication, the experiences of patients and the point of social treatment such as day care (Gantt *et*

*al.*, 1989). There is also evidence from EE research that highly critical relatives are particularly likely to misattribute problem behaviour and negative symptoms (Leff & Vaughn, 1985; Brewin *et al.*, 1991). Such relatives tend to blame the patient for problems leading directly to feelings of anger and frustration when things do not improve. Low EE relatives are much more likely to see such behaviour as outside the patient's own control and thus to be sympathetic and supportive. Successful intervention studies have focused on the illness model of schizophrenia as a way of helping carers begin to understand and correctly attribute some of the causes of patients' behaviour, while removing blame and personal responsibility. This can help carers move from "he's just being difficult" to "I could see there was a problem and that he needed help".

Intervention studies have offered information in various formats ranging from leaflets, booklets, videos, relative group workshops and interactive sessions in the home (Leff *et al.*, 1982, 1989; Falloon *et al.*, 1982; Hogarty *et al.*, 1986; Smith & Birchwood, 1987; Tarrier *et al.*, 1988; MacCarthy *et al.*, 1989). However, it is not easy information to transmit, and certainly more than one session is needed. With long-term carers information may already have been given several times (e.g. about diagnosis) and it is not so important to offer facts about schizophrenia as to be able to discuss what the family understands by these terms and their implications. The patient's own views are particularly important in such sessions as they may reject a diagnostic term and disagree with a medical model. However, again, discussion of a person's experiences and how difficult they can be to tolerate, and helping carers to understand the rationale for various treatment approaches are crucial. The effects of giving information are mainly indirect, in that carers do not learn facts about the illness. However, if clinicians are able to share their information, answer questions and continue to offer information when requested, they encourage optimism and are more likely to engage relatives in future intervention (Berkowitz *et al.*, 1984; Smith & Birchwood, 1987). A more recent study aimed at Caribbean patients and their carers (Fowler, 1992a) confirmed that, in a population who often reject services based on an illness model, a relatives' group which clarified, informed and supported families, was successful. While family dynamics did not change, engagement, knowledge, understanding and responses to services were improved, once it became clear that medication compliance did not intrude on culture and belief systems.

### **Problem solving**

This is the most variable component in intervention studies but an extremely central one; families are helped to sort out 'here and now' problems and difficulties regardless of their genesis or prosaic detail. Some studies have used formalised behavioural techniques (Falloon, 1985), most have used what are now called cognitive-behavioural techniques (Barrowclough & Tarrier, 1992). It seems likely that high risk families have poor coping strategies which are linked to a worse outcome for patients with schizophrenia (Birchwood & Smith, 1987). From clinical experience, problem solving is about restructuring a family's ability to communicate, to listen to each other, to pool resources and begin to try out solutions to problems, rather than avoiding them or breaking down into anger and despair. It is often clear that families have tried all the obvious ways to cope, but in schizophrenia problems are unusual and solutions untested. Many families do find out how to manage and adapt their coping strategies rapidly: "I realised that he couldn't manage so I took it bit by bit and gradually she started to do more". Others only learn by trial and error and after many years of relapses and problems. Families who are in the latter situation may be particularly difficult to help; lack of success in the past may make them frightened of any changes and pessimistic of any good outcome (Kuipers, 1991). Further, some seemingly maladaptive coping strategies may in fact have a positive function within the family (Tarrier *et al.*, 1988) and not be amenable to change.

Thus for 'difficult to treat' families, a therapist may have to accept that not all problems are soluble and that not all coping needs to be changed. However, within this there are likely to be problems that can be tackled and, once identified, broken down into small steps and new solutions tried. This can allow a family to experience change, while hope and optimism can begin to reverse the previous, more dysfunctional cycle. All the treatment manuals deal with these issues in some detail (Falloon, 1985; Anderson *et al.*, 1986; Barrowclough & Tarrier, 1992; Kuipers *et al.*, 1992).

### **Emotional processing**

Not all manuals are explicit about this, but all families, particularly if care has continued for many years, will experience a daunting range of emotional responses, akin to the bereavement process (Parkes, 1972). These will vary from shock, denial, guilt, rejection, grief, to fear, worry, anger and lost

confidence. Parents are particularly likely to fear the future and suffer guilt and anger; partners are more likely to mourn the loss of a confidante, most will have considered leaving the relationship, and there may be many unresolved practical issues relating to finances or children which raise anxiety levels.

The negative emotions in particular need to be aired, acknowledged, normalised and then dealt with constructively, usually by problem solving techniques. This can be done effectively in a group setting which has the advantage of increasing social networks, in itself an important treatment goal (Keith *et al.*, 1991), and allowing social comparison so that people feel less isolated and more supported (Kuipers *et al.*, 1989).

### Medication

Medication is the bedrock on which all social interventions have been built. It is important that education sessions are able to focus on this, as many families are not given appropriate information about long-term medication use, prophylaxis and side effects. Most successful interventions have improved medication compliance, but without increasing medication levels in the intervention group (Falloon *et al.*, 1985).

### Outcome

Despite being focused on a high risk group in which frequent relapses are expected (rather than the 20% relapse rates of low EE families), the successful interventions have consistently improved outcome; relapse rates in patients fall to around 10% in the next 9 months, compared to around 50% for the control high EE families where patients are also on medication. Social functioning may also improve in patients (e.g. Tarrier *et al.*, 1988) and problem solving and levels of burden in carers can improve (Falloon & Pederson, 1985). Over two years the reductions are less impressive as the experimental groups 'catch up'; relapse is delayed but not entirely prevented. However, increasing the time between relapses is itself an improved outcome, particularly for those whose mental health problems are long term and who have not previously experienced long periods without hospital admissions.

These results have been replicated by different groups in different countries (Anderson & Adams, 1996), and there is now an impressive body of evidence and expertise for the success of psychoeducational therapy for 'difficult to treat' patients living in a family setting.

### Individual psychological therapies for psychosis

There have been case studies of attempts to modify persistent and drug resistant positive symptoms in schizophrenia since the 1970s (Watts *et al.*, 1973). However, more recently the volume and sophistication of research has been increased, by several research groups focusing directly on the kinds of psychological approaches that are possible and show some success (Sellwood *et al.*, 1994). This research is, by definition, aimed at 'difficult to treat' patients whose symptoms fail to respond either to medication or to optimal social management (Bebbington & Kuipers, 1994b).

Many of the techniques derive from cognitive-behavioural ideas (Hawton *et al.*, 1989), but are adapted specifically for psychotic symptoms. They include improved coping responses, psychoeducation and belief modification. Some studies have shown improvements using these ideas. Chadwick & Lowe (1990) focused on belief modification, Kingdon & Turkington (1991) on normalisation and psycho-education, and Tarrier *et al.* (1993) on making coping responses more adaptive. Our model differs from these to the extent that it attempts to offer a range of techniques depending on individual need and symptom profiles and also in using strategies derived from cognitive therapy in depression (Beck *et al.*, 1979) as we have found that up to 40% of those with psychosis show evidence of affective symptoms (Johnstone *et al.*, 1991). In a small pilot study of 11 treated patients and seven controls, we were able to show significant improvements in symptomatology, depression and in the conviction with which people viewed their delusional ideas, after six months of treatment (Garety *et al.*, 1994).

### A model of cognitive-behaviour therapy (CBT) for psychosis

Our treatment approach has been developed since the early 1980s. The recent outcome study is one of a series of pilots (Fowler & Morley, 1989; Fowler, 1992b; Garety *et al.*, 1994). The intervention has been derived from general principles of cognitive-behaviour therapy but in an individualised case formulation approach, to try to understand and address the heterogeneity of problems presented by these clients. Over the years, therapy procedures have been tested on a single case basis. For instance, the initial study focused specifically on the management of residual psychotic symptoms, based on Meichenbaum's (1977) ideas of stress inoculation training and on other work developed

to help clients cope with particular symptoms of psychosis (Slade & Bentall, 1988). At that stage the aim of therapy was to help clients incorporate such procedures into their own coping repertoire. While this single case study approach was able to show some success in reducing the clinical impact of specific symptoms, and of increasing clients' ability to tolerate the problems, it was also clear that other problems such as adverse affective reactions, loss of hope and poor understanding of difficulties were equally important (Fowler & Morley, 1989).

This led to the development of a more comprehensive therapy to encompass the associated difficulties of coping with long-term psychosis. Thus a supportive therapy was attempted which aimed to maximise engagement, a particular problem with the 'difficult to treat' client. This included not only a warm, empathic and essentially collaborative therapeutic style, but also an ability to be flexible within sessions and about their timing and location. Particular emphasis was put on reducing 'pressure' or distress within sessions, for instance by changing topic, reducing eye contact, or if necessary by stopping a session early.

A more general strategy for managing disability included giving people information, discussing their understanding of the condition, providing a rationale for medication use and realistic goal setting in both the short and the long term. Strategies for recognising and avoiding future relapses were also discussed. At this stage, the emotional aspects of disability were examined if these were a feature for the individual.

This more comprehensive approach was piloted on 19 clients (Fowler, 1992b). While there were clear improvements among those with residual positive symptoms and for those with accompanying affective problems, very little change was observed in those with only negative symptoms and non-specific difficulties.

The results of these studies provide a rationale for our current therapy. Our aim at this stage is to offer integrated techniques to encompass the wide variety of problems that individuals present with. For instance, for those with both psychosis and affective symptoms, the latter would be seen as equally important and the appropriate help both would be offered. For those with one particularly distressing symptom, poor insight and limited coping skills, the intervention might involve sharing information, extending coping skills, and trying reality testing. For those where depression was a primary feature and residual symptoms were more incidental, or fed into depressive thinking, cognitive restructuring of negative self appraisals might be offered as a primary focus.

Our ideas on treatment have been described in a manual (Fowler *et al*, 1995) but an outline of some of the main strategies can be given here (Kuipers *et al*, 1996). For this client group, techniques developed for those with severe depression need to be adapted and applied flexibly. Both persistence and an ability to be optimistic over a long time scale – a general feature of work with long-term and 'difficult to treat' clients – are necessary therapist attributes.

Within these caveats, therapy is directed at all or any of three main goals.

- (1) To reduce the distress and interference that arises from the experience of persistent psychotic symptoms such as delusions and hallucinations.
- (2) To increase the individual's understanding of psychotic disorders and to foster motivation to engage in self-regulation behaviour.
- (3) To reduce the occurrence of dysfunctional emotions and self-defeating behaviour arising from feelings of hopelessness, negative self image or perceived psychological threat.

We aim for a lengthy assessment of 4–6 sessions. One of the main reasons for this is not only to foster engagement and a trusting relationship within which change can occur, but also to model the collaborative therapeutic style which involves clients in their own formulation of problems. Therapy is very much geared to the difficulties that clients want to change, and areas that are not identified as causing problems or are already coped with, may well be left alone.

Some of the most useful procedures that we have used are described here.

### *Cognitive-behavioural coping strategies*

These procedures aim to equip the client with a set of adaptive ways of managing the occurrence of psychotic experience. For example, psychotic symptoms may be triggered by specific situations, such as being isolated. Symptoms such as voices may interfere with a person's ability to enter social situations or to go shopping, and may result in severe distress. If a pattern can be found it is discussed with the patient as are the implications for new ways in which the patient might act or think to reduce the frequency or distress of symptom onset. The patient is then encouraged '*in vivo*' to experiment with a number of different strategies until a useful coping repertoire is developed. Generally the aim is to encourage the client to use one or two strategies consistently. It is sensible to abandon a strategy if it cannot be readily

used. Examples of specific coping strategies include listing rational alternatives to paranoid ideation or learning to distract attention from hallucinations. Such approaches have been described in more detail by Fowler & Morley (1989) and by Tarrier *et al* (1990, 1993).

#### *Relabelling and psycho-education*

The aim of these strategies is to help the person to relabel psychotic experiences and to suggest that such experiences are not unique, but have been described by others. It is not simply to give information which may or may not be accepted. Johnson *et al* (1977) and Kingdon & Turkington (1991) describe similar approaches. Therapy proceeds by first eliciting specific examples of psychotic experience and then gently suggesting that there may be rational explanations for the occurrence of such experience. Information is provided to begin to correct maladaptive assumptions concerning the nature of psychotic experience, and to add weight to more adaptive appraisals. Initially the implications for an alternative explanation of symptoms within a general illness framework are not forced. The discussion is descriptive rather than explanatory and the client is left to decide what the implications might be. In this way, careful questioning may lead to the development of rationales for taking neuroleptic medication, or adopting behavioural patterns likely to reduce the risk of relapse.

#### *Goal setting and overcoming hopelessness*

A number of patients describe being overwhelmed by their situation and have little understanding of how to help themselves. Here the aim is to generate hope by highlighting worthwhile short-term and long-term goals which may be achieved despite continuing disabilities. This may involve discussion of the person's experience of more enduring problems. It may be important to clarify limitations caused by such disabilities and help a client to reframe expectations so that a small change is perceived as a success rather than a failure. Once the nature of the problem is clarified, proposals for the self-regulation of disabilities may be discussed, and tasks set that may be achievable.

#### *Modification of delusional belief*

There is a growing consensus on psychological approaches to modify strongly held beliefs. The process has been described by Shapiro & Ravenette (1959), Watts *et al* (1973) and Chadwick & Lowe

(1990). The therapist first carefully elicits the person's view of the reasons for the development and maintenance of the delusional beliefs which may involve extensive discussion of the development of beliefs in the past. The therapist then invites the patient to consider alternative interpretations of specific pieces of evidence cited by the patient. Many clients will resist this and the alternatives must be considered in the atmosphere of a trusting and collaborative therapeutic relationship. More peripheral evidence and beliefs are addressed before moving to a re-evaluation of more central beliefs. Any unwillingness by the client to discuss more central beliefs is noted and the therapist must be prepared to backtrack or move material into a future session if the client is not coping. For some clients with really firm convictions it may be better to aim at altering or loosening beliefs rather than accepting alternatives. A client with unshakeable belief about controlling voices may be asked to come to a reasonable compromise with them, rather than to reject his or her views. This might mean answering back to the voices, or accepting their validity but separating this from behavioural consequences so that client distress begins to reduce. For instance, it might be possible to suggest that a voice which says 'Watch the 9 o'clock news' should be ignored and not acted upon, and the client might then find that no dire consequences actually occurred. This can help reduce feelings of powerlessness and control and distress.

#### *Modifying dysfunctional assumptions*

A number of patients with continuing psychotic symptoms may hold dysfunctional assumptions about the self which imply worthlessness, uselessness, unlovability. 'I feel like a piece of meat' or 'I've no self-confidence left'. Such assumptions may be associated with self-defeating patterns of thought and behaviour, and may be an important cause of the failure of earlier coping strategies. To address such assumptions, the therapist starts by attempting to clarify their nature. Sometimes it is necessary to offer some guesses, at other times the client may be able to identify them. Most often this is done by a longitudinal assessment (Williams, 1992) or life review – a process involving questioning about the origins of assumptions and how they have affected the person's life. This may predate the onset of psychosis, or be part of the initial or subsequent episodes. The process of sensitive questioning and discussion may help the client to realise the implications of dysfunctional assumptions, and then

be able to develop a more appropriate and adaptive general view.

### Outcome

Evidence is accumulating that even previously unresponsive and medication resistant psychotic symptoms can be modified. A larger randomised controlled trial is in progress to test the effectiveness of this treatment, its generalisability and maintenance.

Such interventions require that delusional beliefs are conceptualised along a continuum with normal belief formation although particular information processing may be dysfunctional (Garety, 1992). This is in contrast to previous ideas of delusional beliefs being categorically different from those of 'normals' (Jaspers, 1963). As with the family work, specific details on individual therapy may end up being less important than a shift in professional attitudes that this kind of work is possible and can show improvements. Psychological approaches to treatment resistant symptoms of psychosis, all emphasise the importance of listening to patients, giving importance to their view of their predicament, establishing collaborative relationships, empathising about distress and normalising even the most bizarre personal experiences. This very basic way of interacting with a person who is expressing delusional ideas seems to have been lost; either specific and detailed questions are asked for a diagnosis, or delusional ideas are not discussed in case they become more frequent. However, the evidence so far is that being able to discuss, understand and share the distress that may be caused by psychotic symptoms is likely to be helpful in enabling patients to manage, cope and reduce overall symptomatology.

### Therapeutic staff relationships

Many 'difficult to treat' patients fall into the category of being disliked, or in some other way unacceptable to staff (too demanding, not grateful, not responsive). These are often referred to as clients' 'personality problems'. Previously anecdotal, there is now some evidence on the sorts of issues that can cause staff-patient difficulties and impede therapeutic relationships from developing. Such features may exist both in individual, and in family work, and may be separate from problems found in those with schizophrenia. However, for some clients they will interact with psychotic disorder and lead to poor engagement in services,

poor acceptance of treatment, and poor clinical and social outcome.

Frank & Gunderson (1990) looked specifically at the role of therapeutic alliances in the treatment of schizophrenia, in 143 patients and 81 therapists. They found that developing an alliance was a difficult task that took considerable time. Even after six months only a minority (30%) of patients were in good alliances, although if it had been established by then, patients were much less likely to drop out of treatment and made more gains in more areas over two years. Good alliances were associated with greater acceptance of pharmacotherapy (although less medication) and psychotherapy. They comment that while it may take up to six months to form an alliance, persistence up to that point is worthwhile as some patients who had not formed an alliance by one month or three months engaged by six months. However, no further significant gains were to be found after this time. These results argue for the importance of continuity of care (the same key worker), persistence and therapeutic optimism, in that gains can still be made within the first six months of trying to establish a therapeutic relationship with a client with schizophrenia.

Another strand of evidence has recently been provided by EE research which has been extended to look at optimum therapeutic relationships in staff. It was hypothesised that staff in long-term relationships with clients might share not only the problems faced by relative carers, but also some of their attitudes.

A series of studies have now confirmed this idea. In the first study, over 40% of 35 key workers had a high rating about at least one key patient (Moore *et al*, 1992a). This was also found by Herzog (1988) who showed a majority of staff to have high EE relationships with clients. In Italy, Beltz *et al* (1991) found no consistent relationship between staff and family levels of EE even though high EE responses were common in each. Case managers have also been shown to have a range of high and low EE responses to their clients (Oliver & Kuipers, 1996).

In a content analysis of 61 interviews (Moore *et al*, 1992b), criticism was most frequently focused in both high and low EE interviews on socially embarrassing or difficult behaviour, and on the clinical poverty syndrome, e.g. apathy, slowness and poor self-care (Wykes, 1982). The categories which attracted the most criticism were the repetition of inappropriate behaviour and attention seeking. This mirrors a result found in a study on EE in Alzheimer's disease, that the behaviour most often criticised by carers was repetitious speech and behaviour (Bledin *et al*, 1990). In staff, high levels of criticism were significantly related to attributing

patients' difficulties to them (under their own control), and having negative rather than positive expectations of a patient's ability to manage independently. A prospective naturalistic study of differential outcome in two hostels, one characterised by a majority of high EE staff, the other by low EE staff, suggested that patients in the former hostel had a significantly poorer outcome in the subsequent nine months (Moore, 1992; Ball *et al.*, 1992).

Finally, three extremely difficult patients were looked at in detail and found not to predict reliably a high EE rating in staff members (Moore, 1992). In other words it was possible for some staff to manage and even like these long-term and challenging behaviour patients.

The group of patients who were more likely to elicit critical remarks and were more obviously disliked were those who were not perceived as warm and who were less responsive to therapeutic effort. They were a more withdrawn group who were easy to ignore and might require rather specialised and focused input in order to receive adequate levels of care in the community.

Thus for staff to be able to deal with 'difficult to treat' patients several factors seem to be important. Firstly, persistence, up to six months spent in engaging a client in services. Secondly, a low case load of up to 15 clients to allow for assertive out-reach and complex care packages to be organised. Staff overload and dissatisfaction is likely to be high with higher case loads of the severely mentally ill (Moore *et al.*, 1992a). Thirdly, staff support seems essential. Working in a multi-disciplinary team and allowing time for ventilation of staff anger and frustration, while acknowledging and rewarding staff endeavour are crucial (Watts & Bennett, 1983). For this, training in being able to distinguish negative symptoms and reattributing blame to illness rather than just to personality factors, also seems likely to be helpful. Ideally this should be not only part of formal training but also a feature of multi-disciplinary team reviews and staff supervision.

Finally, an ability to identify at least one aspect of the client which can be viewed positively and focused on, regardless of disturbed or challenging behaviour, is a feature of low EE staff-client relationships. "He can be difficult but I've got a soft spot for him."

Such issues are rarely discussed, but are likely to be increasingly vital if case management in the community is going to be sustainable.

### Conclusion

A range of psychological and psychosocial therapies exist which can lead to a successful outcome,

even for those previously considered 'difficult to treat' in the sense of being unresponsive to more traditional approaches. Treating a family can help to change a difficult environment, even when individual work with a client has not been successful. Now that 'families' encompass a wide variety of relationships, from parents and partners to friends, and can even include settings such as hostels or group homes, the scope of such interventions in the community is increasingly important. Individual psychological treatments of medication resistant symptoms also look promising and for the first time allow for a form of psychotherapeutic intervention in psychosis that is sensitive to the particular problems of this client group, is structured, and can be successful.

The ingredients of optimal therapeutic alliances in schizophrenia are being delineated. These can help those considered more difficult to offer treatment to. However, the findings emphasise the importance of ongoing staff support and training in order to sustain such therapeutic partnerships and avoid staff 'burn out' and low morale. These consequences are just being acknowledged, as the requirements of community care place high levels of responsibility on case managers (Muijen *et al.*, 1994).

Non-compliance or non-engagement in treatment is not directly dealt with by the above approaches, but is implicit in the ranges of strategies described. 'Non-drug' treatments typically stress the importance of noncoercive and partnership relationships both with individuals and family systems. This also affects clients' attitudes towards drug treatments and, as it turns out, most social and psychological therapies improve drug compliance without increasing total amounts of medication. A recent study improved compliance itself, by discussing issues about medication with clients, and this is another new approach to this particular area (Kemp *et al.*, 1996). Adapting services so that they are client centred and acceptable, is now a standard part of care in the community. However, services will need to continue to be flexible and open to user feedback if this aspect of 'difficult to treat' is to improve further.

Non-drug therapies in combination with medication, can be cost effective because they typically reduce symptoms and the expense of time in hospital. The 'difficult to treat' are often high users of hospital services and require high input from staff and relatives in the community. However, these newer and often effective ways of treating and managing such patients have other costs which should not be disregarded (McCrone *et al.*, 1994).



These include the space and time to spend with clients (sensible case loads), training in the specialist skills, and sufficient support to allow staff to work enthusiastically even in this difficult area. Community management systems must be able to encompass these, if successful and high quality care is to be provided for the wide range of people who suffer from schizophrenia.

### References

- ANDERSON, C., REISS, D. & HOGARTY, G. E. (1986) *Schizophrenia in the Family: a Practical Guide*. New York: Guilford Press.
- ANDERSON, J. & ADAMS, C. (1996) Family intervention in schizophrenia. *British Medical Journal*, **313**, 232–236.
- BALL, R. A., MOORE, E. & KUIPERS, L. (1992) EE in community care facilities: a comparison of patient outcome in a 9 month follow-up of two residential hostels. *Social Psychiatry and Psychiatric Epidemiology*, **27**, 35–39.
- BARROWCLOUGH, C. & TARRIER, N. (1992) *Families of Schizophrenic Patients: Cognitive Behavioural Interventions*. London: Chapman & Hall.
- BEBBINGTON, P. E. & KUIPERS, L. (1994a) The predictive utility of expressed emotion in schizophrenia: an aggregate analysis. *Psychological Medicine*, **24**, 707–718.
- & ——— (1994b) The social management of long-standing schizophrenia. I. The deployment of service resources. *Clinician*, **12**, 17–29.
- BECK, A. T., RUSH, A. J., SHAW, B. F., *et al* (1979) *Cognitive Therapy of Depression*. Chichester: Wiley.
- BELTZ, J., BERTRANDO, P., CLERICI, M., *et al* (1991) Emotiva Espresso e schizophrenia: dai familiari agli operatori psichiatrici. Symposium on Expressed Emotion in Latin based languages. Barcelona, Spain.
- BERKOWITZ, R., EBERLEIN-FRIESS, R., KUIPERS, L., *et al* (1984) Educating relatives about schizophrenia. *Schizophrenia Bulletin*, **10**, 418–429.
- BIRCHWOOD, M. & SMITH, J. (1987) Schizophrenia and the family. In *Coping with Disorder in the Family* (ed. J. Orford), pp. 7–38. London: Croom Helm.
- & ——— (1990) Relatives and patients as partners in the management of schizophrenia. *Psychosocial Rehabilitation Journal*, **13**, 27–30.
- BIRLEY, J. & HUDSON, B. (1983) The family, the social network and rehabilitation. In *Theory and Practice of Psychiatric Rehabilitation* (eds F. N. Watts & D. H. Bennett), pp. 171–188. New York: Wiley.
- BLEDIN, K., MACCARTHY, B., KUIPERS, L., *et al* (1990) Daughters of people with dementia: EE, strain and coping. *British Journal of Psychiatry*, **157**, 221–227.
- BREWIN, C. R., MACCARTHY, B., DUDA, R., *et al* (1991) Attribution and Expressed Emotion in the relatives of patients with schizophrenia. *Journal of Abnormal Psychology*, **100**, 546–554.
- BRUGHA, T., WING, J., BREWIN, C., *et al* (1988) The problems of people in long-term psychiatric day care. An introduction to the Camberwell High Contact Study. *Psychological Medicine*, **18**, 443–456.
- CHADWICK, P. & LOWE, F. (1990) The measurement and modification of delusional beliefs. *Journal of Consulting Clinical Psychology*, **58**, 225–232.
- 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), pp. 29–39. *Psychological Medicine*, Monograph, Suppl. 2.
- CURZON, D. A., BARNES, T. R. E., BAMBER, R. W., *et al* (1985) Long-term depot maintenance of chronic schizophrenic outpatients. *British Journal of Psychiatry*, **146**, 464–480.
- DE JESUS MARI, J. & STREINER, D. L. (1994) An overview of family interventions and relapse in schizophrenia: meta-analysis of research findings. *Psychological Medicine*, **24**, 565–578.
- FADDEN, G. B., BEBBINGTON, P. E. & KUIPERS, L. (1987a) The burden of care: the impact of functional psychiatric illness on the patient's family. *British Journal of Psychiatry*, **150**, 285–292.
- , KUIPERS, L. & BEBBINGTON, P. E. (1987) Caring and its burdens: a study of the relatives of depressed patients. *British Journal of Psychiatry*, **151**, 660–667.
- FALLOON, I. R. H. (1985) *Family Management of Schizophrenia*. Baltimore: Johns Hopkins University Press.
- & TALBOT, R. E. (1981) Persistent auditory hallucinations: coping mechanisms and implications for management. *Psychological Medicine*, **11**, 329–339.
- , BOYD, J. L., MCGILL, C. W., *et al* (1982) Family management in the prevention of exacerbations of schizophrenia. A controlled study. *New England Journal of Medicine*, **306**, 1437–1440.
- , ———, ———, *et al* (1985) Family management in the prevention of morbidity of schizophrenia. Clinical outcome of a two year longitudinal study. *Archives of General Psychiatry*, **42**, 887–896.
- & PEDERSON, J. (1985) Family management in the prevention of morbidity of schizophrenia. Adjustment of the family unit. *British Journal of Psychiatry*, **147**, 156–163.
- FOWLER, D. (1992b) Cognitive behaviour therapy in the management of patients with schizophrenia: preliminary studies. In *Psychotherapy of Schizophrenia: Facilitating and Obstructive Factors* (eds A. Werbart & J. Cullberg). Oslo: Scandinavian University Press.
- & MORLEY, S. (1989) The cognitive behavioural treatment of hallucinations and delusions: a preliminary study. *Behavioural Psychotherapy*, **17**, 267–282.
- , GARETY, P. A. & KUIPERS, L. (1995) *Cognitive Behaviour Therapy for People with Psychosis: A Clinical Handbook*. Chichester: Wiley.
- FOWLER, L. (1992a) Family psychoeducation: Chronic psychiatrically ill Caribbean patients. *Journal of Psychosocial Nursing and Mental Health Services*, **30**, 27–32.
- FRANK, A. F. & GUNDERSON, J. G. (1990) The role of the therapeutic alliance in the treatment of schizophrenia. Relationship to course and outcome. *Archives of General Psychiatry*, **47**, 228–236.
- GAMBLE, C., MIDENCE, K. & LEFF, J. (1994) The effects of family work training on mental health nurses' attitudes to and knowledge of schizophrenia: a replication. *Journal of Advanced Nursing*, **19**, 893–896.
- GANTT, A. B., GOLDSTEIN, G. & PINKY, S. (1989) Family understanding of psychiatric illness. *Community Mental Health Journal*, **25**, 101–108.
- GARETY, P. A. (1992) Making sense of delusions. *Psychiatry*, **55**, 282–291.
- , KUIPERS, L., FOWLER, D., *et al* (1994) Cognitive behaviour therapy for drug resistant psychosis. *British Journal of Medical Psychology*, **67**, 259–271.
- GIBBONS, J. S., HORN, S. H., POWELL, J. M., *et al* (1984) Schizophrenic patients and their families. A survey in a psychiatric service based on a district general hospital. *British Journal of Psychiatry*, **144**, 70–77.
- HATFIELD, A., SPANIOL, L. & ZIPPLE, A. M. (1987) Expressed Emotion: a family perspective. *Schizophrenia Bulletin*, **13**, 221–226.

- HAWTON, K., SALKOVSKIS, P., KIRK, J., *et al* (1989) *Cognitive Behaviour Therapy for Psychiatric Problems*. Oxford: Oxford University Press.
- HERZOG, T. (1988) Nurses, patients and relatives: a study of family patterns on psychiatric wards. In *Family Intervention in Schizophrenia: Experiences and Orientations in Europe* (eds C. L. Cazzullo & G. Invernizzi). Milan: ARS.
- HOGARTY, G. E., ANDERSON, C. M., REISS, D. J., *et al* (1986) Family psycho-education, social skills training and maintenance chemotherapy in the aftercare treatment of schizophrenia. I. One year effects of a controlled study on relapse and Expressed Emotion. *Archives of General Psychiatry*, **43**, 633–642.
- & ——— (1987) Family psycho-education, social skills training, and medication in schizophrenia: the long and the short of it. *Psychopharmacology Bulletin*, **23**, 12–13.
- , MCEVOY, J. P., MUNETZ, M., *et al* (1988) Dose of fluphenazine, familial expression of emotion, and outcome in schizophrenia: results of a two-year controlled study. *Archives of General Psychiatry*, **45**, 797–805.
- JASPERS, K. (1963) *General Psychopathology* (Trans. J. Hoenig & M. W. Hamilton). Manchester: Manchester University Press.
- JOHNSON, W. G., ROSS, J. M. & MASTRIA, M. A. (1977) Delusional behaviour: an attributional analysis of development and modification. *Journal of Abnormal Psychology*, **86**, 421–426.
- JOHNSTONE, E. C., OWENS, D. G. C., FRITH, C. D., *et al* (1991) Clinical findings: abnormalities of mental state and their correlates. The Northwick Park follow-up study. *British Journal of Psychiatry*, **159** (Suppl. 13), 21–25.
- KAPUR, S., GANGUILI, R., ULRICH, R., *et al* (1991) Use of random-sequence riboflavin as a marker of medication compliance in chronic schizophrenics. *Schizophrenia Research*, **6**, 49–53.
- KAVANAGH, D. H. (1992) Recent developments in Expressed Emotion and schizophrenia. *British Journal of Psychiatry*, **160**, 601–620.
- KEITH, S. J., MATTHEWS, S. M. & SCHOOLER, N. R. (1991) A review of psychoeducational family approaches. In *Schizophrenia Research. Advances in Neuropsychiatry and Psychopharmacology, Vol. 1* (eds C. A. Tamminga & S. C. Schulz), pp. 247–254. New York: Raven Press.
- KEMP, R., HAYWARD, P., APPLEWHITE, G., *et al* (1996) Compliance therapy in psychotic patients: random controlled trial. *British Medical Journal*, **312**, 345–349.
- KINGDON, D. G. & TURKINGTON, D. (1991) Preliminary report: the use of cognitive behaviour therapy with a normalizing rationale in schizophrenia. *Journal of Nervous and Mental Disease*, **179**, 207–211.
- KÖTTGEN, C., SONNICHSEN, I., MOLLENHAUER, K., *et al* (1984) Group therapy with the families of schizophrenic patients: results of the Hamburg Camberwell Family Interview Study: III. *International Journal of Family Psychiatry*, **5**, 84–94.
- KUIPERS, E. & MOORE, E. (1995) Expressed Emotion and staff-client relationships. *International Journal of Mental Health*, **24**, 13–26.
- KUIPERS, L. (1991) Schizophrenia in the family: the needs of long-term psychiatric carers. *International Review of Psychiatry*, **3**, 105–117.
- (1992) Expressed Emotion research in Europe. *British Journal of Clinical Psychology*, **31**, 429–443.
- (1994) The measurement of expressed emotion: its influence on research and clinical practice. *International Review of Psychiatry*, **6**, 187–199.
- & BEBBINGTON, P. E. (1985) Relatives as a resource in the management of functional illness. *British Journal of Psychiatry*, **147**, 465–471.
- & ——— (1988) Expressed Emotion research in schizophrenia: theoretical and clinical implications. *Psychological Medicine*, **18**, 893–910.
- & MOORE, E. (1995) Expressed emotion and staff-client relationships. *International Journal of Mental Health*, **24**, 13–26.
- , MACCARTHY, B., HURRY, J., *et al* (1989) A low cost supportive model for relatives of the long term adult mentally ill. *British Journal of Psychiatry*, **154**, 775–782.
- & BEBBINGTON, P. E. (1990) *Working in Partnership: Clinicians and Carers in the Management of Long-standing Mental Illness*. Oxford: Heinemann Medical.
- , LEFF, J. P. & LAM, D. H. (1992) *Family Work for Schizophrenia: A Practical Guide*. London: Gaskell.
- , GARETY, P. & FOWLER, D. (1996) An outcome study of cognitive behavioural treatment for psychoses. In *Cognitive Behavioural Interventions with Psychotic Disorders* (eds C. Haddock & P. Slade), pp. 116–136. London: Routledge.
- LAM, D. H. (1991) Psychosocial family intervention in schizophrenia: a review of empirical studies. *Psychological Medicine*, **21**, 423–441.
- LEFF, J. P., KUIPERS, L., BERKOWITZ, R., *et al* (1982) A controlled trial of social intervention in schizophrenic families. *British Journal of Psychiatry*, **141**, 121–134.
- , ——— & ——— (1985) A controlled trial of social intervention in the families of schizophrenic patients: two year follow up. *British Journal of Psychiatry*, **146**, 594–600.
- & VAUGHN, C. (1985) *Expressed Emotion in Families*. New York: Guilford Press.
- , BERKOWITZ, R., SHAVIT, N., *et al* (1989) A trial of family therapy v. a relatives' group for schizophrenia. *British Journal of Psychiatry*, **154**, 58–66.
- , ———, ———, *et al* (1990) A trial of family therapy versus a relatives' group for schizophrenia: a two year follow-up. *British Journal of Psychiatry*, **157**, 571–577.
- MACCARTHY, B. (1988) The role of relatives. In *Community Care in Practice* (eds A. Lavender & F. Holloway). Chichester: Wiley.
- , KUIPERS, L., HURRY, J., *et al* (1989a) Evaluation of counselling for relatives of the long term adult mentally ill. *British Journal of Psychiatry*, **154**, 767–775.
- , LESAGE, A., BREWIN, C. R., *et al* (1989b) Needs for care among the relatives of long term users of day care. *Psychological Medicine*, **19**, 725–736.
- MCCREADIE, R. G., PHILLIPS, K., HARVEY, J. A., *et al* (1991) The Nithsdale Schizophrenia Surveys VIII. Do relatives want family intervention and does it help? *British Journal of Psychiatry*, **158**, 110–113.
- MCCRONE, P., BEECHAM, J. & KNAPP, M. (1994) Community psychiatric nurse teams: cost effectiveness of intensive support versus generic care. *British Journal of Psychiatry*, **165**, 218–221.
- MEICHENBAUM, D. (1977) *Cognitive Behaviour Modification*. New York: Plenum.
- MOORE, E. (1992) Care of the long-term adult mentally ill: expressed emotion in staff-patient relationships. PhD Thesis, London University.
- , BALL, R. A., & KUIPERS, L. (1992a) Expressed Emotion in staff working with the long-term adult mentally ill. *British Journal of Psychiatry*, **161**, 802–808.
- , KUIPERS, L. & BALL, R. (1992b) Staff patient relationships in the case of the long-term mentally ill: a content analysis of EE interviews. *Social Psychiatry and Psychiatric Epidemiology*, **27**, 28–34.
- MUIJEN, M., COONEY, M., STRATHDEE, G., *et al* (1994) Community Psychiatric Nurse Teams: intensive support versus generic care. *British Journal of Psychiatry*, **165**, 211–217.
- NOH, S. & TURNER, R. J. (1987) Living with psychiatric patients: implications for the mental health of family members. *Social Science and Medicine*, **25**, 263–272.
- OLIVER, N. & KUIPERS, E. (1996) Stress and its relationship to EE in community mental health workers. *International Journal of Social Psychiatry*, **42**, 150–159.

- PARKES, C. M. (1972) *Bereavement: Studies of Grief in Adult Life*. Harmondsworth: Penguin.
- PARSONS, T. (1951) *The Social System*. Chicago: Free Press.
- PENN, D. & MUESER, K. (1996) Research update on the psychosocial treatment of schizophrenia. *American Journal of Psychiatry*, **153**, 607–617.
- SELLWOOD, W., HADDOCK, G., TARRIER, N., *et al* (1994) Advances in the psychological management of positive symptoms of schizophrenia. *International Review of Psychiatry*, **6**, 201–215.
- SHAPIRO, M. B. & RAVENETTE, A. T. (1959) A preliminary experiment on paranoid delusions. *Journal of Mental Science*, **105**, 295–313.
- SLADE, P. D. & BENTALL, R. P. (1988) Treatment of hallucinations. In *Sensory Deception: Toward a Scientific Analysis of Hallucinations* (eds P. D. Slade & R. P. Bentall). London: Croom Helm.
- SMITH, J. & BIRCHWOOD, M. J. (1987) Specific and nonspecific effects of educational intervention with families living with a schizophrenic relative. *British Journal of Psychiatry*, **150**, 645–652.
- TARRIER, N., BARROWCLOUGH, C., VAUGHN, C., *et al* (1988) The community management of schizophrenia: a controlled trial of a behavioural intervention with families to reduce relapse. *British Journal of Psychiatry*, **153**, 532–542.
- , ———, ———, *et al* (1989) Community management of schizophrenia in a two year follow-up of a behavioural intervention with families. *British Journal of Psychiatry*, **154**, 625–628.
- & ——— (1990) Family interventions for schizophrenia. Special issue: recent developments in the behavioral treatment of chronic psychiatric illness. *Behavior Modification*, **14**, 408–440.
- , HARWOOD, S., YUSOPOFF, L., *et al* (1990) Coping Strategy Enhancement (CSE): a method of treating residual schizophrenic symptoms. *Behavioural Psychotherapy*, **18**, 283–293.
- , LOWSON, K. & BARROWCLOUGH, C. (1991) Some aspects of family interventions in schizophrenia. II: Financial considerations. *British Journal of Psychiatry*, **159**, 481–484.
- , SHARPE, L., BECKETT, R., *et al* (1993) A trial of two cognitive behavioural methods treating drug-resistant residual psychotic symptoms in schizophrenic patients: II treatment specific changes in coping and problem solving skills. *Social Psychiatry and Psychiatric Epidemiology*, **28**, 5–10.
- VAUGHN, K., DOYLE, M., MCCONATHY, N., *et al* (1992) The Sydney intervention trial: a controlled trial of relatives' counselling to reduce schizophrenic relapse. *Social Psychiatry and Psychiatric Epidemiology*, **27**, 16–21.
- WATTS, F. N., POWELL, G. E. & AUSTIN, S. V. (1973) The modification of abnormal beliefs. *British Journal of Medical Psychology*, **46**, 359–363.
- & BENNETT, D. H. (1983) *Theory and Practice of Psychiatric Rehabilitation*. Chichester: Wiley.
- WILLIAMS, J. M. G. (1992) *The Psychological Treatment of Depression: A Guide to the Theory and Practice of Cognitive Behaviour Therapy*. London: Routledge.
- WING, J. K. & BROWN, G. W. (1970) *Institutionalism and Schizophrenia*. Cambridge: Cambridge University Press.
- , BREWIN, C. R. & THORNICROFT, G. (eds) (1992) Defining mental health needs. In *Measuring Mental Health Needs*, pp. 1–17. London: Gaskell.
- WYKES, T. (1982) A hostel ward for new long-stay patients. In *Long-term Community Care* (ed. J. K. Wing). *Psychological Medicine Monograph Supplement* 2, 59–97.
- YOUNG, J. L., ZONANA, H. V. & SHEPLER, L. (1986) Medication noncompliance in schizophrenia: codification and update. *Bulletin of the American Academy of Psychiatry and the Law*, **14**, 105–122.

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