

important subgroup who present particular management difficulties (Compton & Brugha, 1988). Indeed, working with the relatives of such patients may be the only feasible option open to care staff. However, such relatives will face particular problems and burdens not necessarily shared by the group we worked with. The intervention reported here aimed to supplement the efforts of the day-care staff in providing a coherent and integrated service to the family as a unit. Part of what was being 'treated' therefore, was the relationship between the day-care team and the family unit.

We would argue that this sort of specific, time-limited group needs to become a routine part of the clinical service offered by community care facilities, even if relatives and patients have achieved an

equilibrium in the context of persistent chronic and severe difficulties. Ideally, this should be initiated earlier in a patient's career, to avoid the development of persistent failures of communication between the clinical team and carers. Guidance about attitudes and coping styles is also indicated before these settle into maladaptive but entrenched patterns. However, detailed information and explicit behavioural guidance may not be as crucial a requirement for relatives coping with really long-standing problems. The opportunity to acknowledge and share some pent-up feelings with others in similar circumstances seemed particularly welcome to this group, and may be the best focus for intervention with relatives of the long-term group, who cope with a diverse range of disabilities and deficits.

Acknowledgements, references, and authors' details are given at the end of the following paper, on page 782.

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Counselling the Relatives of the Long-Term Adult Mentally Ill II. A Low-Cost Supportive Model

LIZ KUIPERS, BRIGID MACCARTHY, JANE HURRY and ROD HARPER

A psychosocial intervention is described geared to the needs of carers of the long-term mentally ill, which is feasible for a busy clinical team to implement: relatives were not selected for the group by patient diagnosis or motivation and little extra staff input was required. An interactive education session at home was followed by a monthly relatives group which aimed to reduce components of expressed emotion (EE) and to alleviate burden. The group facilitators adopted a directive but non-judgemental style, and constructive coping efforts were encouraged. The intervention was effective at reducing EE and improving family relationships. The study offers a realistic model of how to offer support to people providing long-term care for the severely mentally ill.

The emotional demands on relatives who provide support for those in continuous and intensive contact with psychiatric services may continue for years. Relatives of the mentally ill have voiced much dissatisfaction with services, and with clinicians who have traditionally blamed or exploited them without recognising that they are an important community resource with needs of their own (Kuipers & Bebbington, 1985). Carers need to have ready access

to sympathetic staff who are familiar with their situation and who can help them to ensure that patients maintain and develop skills and independence despite their residual disabilities. Such help needs to be long-term, supportive and geared to maintaining gains rather than to treating symptoms.

In the project reported here, we were interested in developing a psychosocial approach which suited the specific needs of supporters of the long-term

group. We also wanted to find a model which could be used by a multidisciplinary team (Watts & Bennett, 1983). It had to be feasible, acceptable to all grades and disciplines of staff, and integrated into the general clinical work of the team. While there has been considerable interest in the methods and results of intervention trials which have been published (Leff *et al*, 1985; Falloon *et al*, 1985; Hogarty *et al*, 1986; Tarrrier *et al*, 1988), we have observed a general attitude of reluctance in clinical teams to take on what is seen as specialised and time-consuming work. While in our own clinical team this was not a problem, professionals in many settings say they lack both the time and expertise to work in depth with relatives. A case load usually includes a large number and wide variety of patients with neurotic as well as psychotic disorders, and relatives' needs may not be given priority. Even if relatives' needs are recognised, staff may not be clear about how best to offer them support, and resources may also be limited.

We wanted to test whether a minimal intervention, geared to the specific needs of long-term patients and their relatives, could be shown to be feasible as well as effective. In order to take account of the constraints imposed by a typical clinical situation, the programme made realistically limited demands on staff time, and used care staff currently working in one clinical team. This team employed a case-management approach to patients and aimed to be responsive to relatives' needs as part of its routine clinical practice. The intervention was not therefore a first step in initiating contact with a neglected group of relatives, but rather extended an already existing pattern of clinical practice. All relatives of current attenders were invited to participate, irrespective of their motivation or likely ability to function effectively in a group. As patients' diagnoses were not a criterion for selection, the group included relatives of patients with schizophrenia, major affective disorders and neurotic disorders. All patients also had long-standing and severe disabilities in the area of social performance.

Details of the sample, the assessment procedure and evaluation of the results of the intervention are reported in the preceding paper. The methods we employed, the model used and typical problems which were raised will be described here.

Relatives were offered an interactive education session completed in their home with a research worker (BM or JH), and then invited to participate in a monthly group meeting. A group approach is cost-effective, since it allows several families to be seen together and participants can learn and share from each other as well as from professionals.

The group

Aims

The group meetings had several overall aims:

- (a) to facilitate social interaction among the relatives in order to counteract feelings of isolation and stigma commonly reported of supporters of psychiatric patients (MacCarthy, 1988)
- (b) to repeat and reinforce the acquisition of information about diagnoses and expectations given in the education session
- (c) to offer specific help with problem-solving
- (d) to increase tolerance of negative symptoms and accompanying behaviour problems such as inactivity or poor role performance, which are commonly misinterpreted by long-term carers and are associated with high levels of criticism
- (e) to help relatives hold more realistic expectations about the future
- (f) to help both relatives and patients achieve a level of adult independence despite the patients' disabilities; this is particularly a problem for emotionally over-involved relatives.

The aims were specifically geared to reducing the key expressed emotion (EE) components of critical comments and over-involvement by increasing relatives' understanding and tolerance of symptoms and helping them to achieve as much autonomy as possible. Efforts were also made to reduce burden and decrease isolation by the sharing of problems.

Structure

The setting was a quiet room in the district services centre, a day and residential facility which is designed to serve the needs of the long-term mentally ill from its local catchment area. Two of the authors (LK, RH) were present to act as facilitators. An informal social atmosphere was encouraged, and tea and biscuits were served halfway through sessions. The meetings were tape-recorded with the consent of participants. They lasted an hour and a half and were held monthly in mid-afternoon. As most relatives were retired or near retirement age and the meetings were infrequent, this timing was acceptable. Monthly intervals were chosen since this had been the actual attendance rate of relatives in a previous study (Leff *et al*, 1982) and because relatives of such long-term patients rarely encounter new problems. Relatives attended the group for a year. Two members joined the group after six sessions, so it met regularly for

a total of 18 months to accommodate these later arrivals.

Attendance

Relatives came to ten meetings on average (range 5–14) and each meeting was attended by an average of six relatives (range 4–11). A facilitator was always present.

Strategies

The model used for the intervention was based on elements of three different approaches:

- (a) ideas developed during previous work with a high-EE group (Leff *et al*, 1982)
- (b) group counselling techniques
- (c) behavioural skills training.

All three elements were necessary to deal with the range of difficulties that relatives presented, and are described below.

Leadership style

Throughout the sessions the facilitators adopted a non-confrontational but directive style. They encouraged the group to focus on one topic at a time and to follow a theme through to a constructive conclusion. Unless they were channelled in this way, sessions easily disintegrated into several concurrent conversations. Psychodynamic interpretations of either group or individual processes were avoided. A positive, non-judgemental atmosphere was fostered within which relatives could be frank in discussing difficult issues, while also being able to laugh at absurdities when they arose.

Engaging relatives

Attending a group requires considerable motivation. High drop-out rates have been a feature of early intervention studies with relatives of long-term patients (e.g. Hudson, 1975). We therefore used the home interviews which were undertaken for the evaluation study reported in the preceding paper as an opportunity to establish contact and build up rapport. The use of the Camberwell Family Interview as our major assessment instrument allowed us to demonstrate that we were interested in the relatives' own viewpoints and their particular problems. After the initial evaluation, relatives filled in the information/education questionnaire, and one of the authors then made a further home visit to discuss the issues that emerged. At this point, the possibility of attending

the group was suggested as a way of expanding on this information, and as a setting where problems and support could be shared. Despite the length of time that these patients had been in contact with local services, the relatives had not previously met each other. Lifts were offered to encourage attendance, but because of the central position of the day facility, transport was not a problem. All the relatives knew at least one of the facilitators before joining the group, and this seemed to reduce early anxieties considerably.

The refusers

Although the majority of relatives were successfully engaged, the four refusers form an interesting subgroup. For two, both relatives of people with schizophrenia, the timing of the offer was inopportune. One wife had felt dissatisfied with services offered in the past and had often refused help before. She had, however, just completed a relatively intensive series of family sessions, which she and her husband had attended with great reluctance. At the time of our intervention, some problems had been resolved and she felt that she did not wish to risk this equilibrium. The second relative, a mother, was interested in attending the group, but as she had recently resolved to become more independent of her son and consequently had begun a new job, she could not get to the group.

A third relative, cohabiting with a patient suffering from manic depression, had severe problems of alcohol abuse and associated memory loss. Although he did attend two group meetings, he clearly found it difficult to cope with the level of discussion. Participation in such groups requires basic levels of cognitive and social skills, which a proportion of relatives, some of whom have been patients themselves, will lack.

Finally, one father expressed interest in the group, but never actually attended. This seemed to be connected with his wife's view of the services: she suffered from agoraphobia, never left the house, and refused all personal contact with the clinical team. The father managed to visit the centre occasionally, at times of crisis, but could not come more regularly. It seems that a regular group cannot meet the needs of all relatives, and a more flexible intervention may be needed for some.

Facilitating communication

Improving relatives' communication skills may not only enhance the effective functioning of the group but also improve interaction with the patient at home.

At their first session, all relatives were asked to give a little information about themselves and their situation. This quickly helped families to recognise areas of common ground, but also allowed participants to control their level of intimacy with the group, and reduced anxiety. By structuring 'turn-taking' in this way, equal participation and alternating listening and contributing in sessions were modelled. Experimental work and previous experience (Kuipers *et al*, 1983; Berkowitz *et al*, 1984) has shown that high-EE relatives are particularly poor listeners and may not readily absorb constructive advice. Listening skills had to be fostered for some high-EE relatives, who tended to dominate meetings. Relatives were discouraged from talking at the same time as other participants, or were asked specifically to listen to someone else, and incipient monologues were interrupted. Some relatives, however, needed to be canvassed directly before they could contribute their views.

The facilitators tried to create an open atmosphere, where disagreements could be aired, and resolved. Setting limits can be particularly difficult for relatives who may resent something but avoid discussing it with the patient for fear of provoking arguments or clinical deterioration. A more direct and constructive style of communicating dissatisfaction was encouraged in the group.

Problem-solving

Elements of a behavioural skills training approach were used. Firstly, once a problem had been identified a detailed description was obtained, and the circumstances of its occurrence were specified. A range of possible solutions was elicited from the group. The facilitators then encouraged the group to focus on one solution, which was broken down into a series of small, potentially manageable steps which the relative could attempt before the next session. In subsequent meetings relatives were invited to report what had happened. Attempts to use new strategies were reinforced by the approval of the facilitators and other relatives in the group. Since relatives often dismissed new behaviour patterns as trivial because of the magnitude of the overall problem, they were encouraged, by noting progress and identifying their own contribution, to recognise the value of achieving small changes. In the long term, the intervention aimed to foster a flexible but consistent approach, which was capable of responding to changing circumstances but also created a predictable home environment for the patient.

Emotional containment

The emotional burden of providing long-term care for the mentally ill was a recurring theme in the sessions. As trust and cohesion developed in the group, the negative emotions that relatives felt, such as guilt, anger, frustration, bitterness and grief, were more freely shared. It was emphasised that the experience and expression of these feelings was both understandable and acceptable. Facilitators pointed out that staff members could also feel helpless and frustrated in the face of some patients' seemingly overwhelming problems. Relatives were able to be supportive of each other since it was acknowledged that many of the group had faced the same difficult feelings. Another important process was the adjustment of expectations. Reframing a behaviour, previously seen as a failure, as a small success helped to encourage optimism in place of resignation: relatives are frequently dissatisfied with the patient and services but feel helpless to effect any change. It was stressed that time itself could be therapeutic for this long-term group, and that gradual improvements could be identified which had taken several years to evolve.

Using assets

Despite the relatives' very real problems and burdens, it is important to remain aware of their assets and adopt a non-blaming stance (Ferris & Marshall, 1987): they themselves are not disabled by mental illness, but are nevertheless reacting to an abnormal and stressful situation. Thus it is possible to tap ordinary resources of humour, sociability and tolerance. Relatives took this beyond the group, offered lifts, inquired after each other's well-being, asked about absent group members. As the rewards of long-term caring include isolation and stigma, the group was a welcome social occasion for some members.

Themes

Initially, much of the discussion focused on relatively external issues such as the need for information, the burden of caring and the continuing stigma of mental illness. As trust developed, more internal, emotional issues such as grief and the need to change expectations came to dominate the content of the sessions. The vulnerability of patients whose serious social disabilities often left them unable to care for themselves reliably and open to exploitation by more competent acquaintances was a particular issue for this group. Some of the relatives recognised that the

special needs this created had to be balanced against providing a deliberately restrained level of care and protection which would not interfere with the patient's ability to develop independence and autonomy. The grief relatives experienced as they adjusted first to the diagnosis and then to the implications of long-term illness in its effects on the patient and their own lifestyle was also apparent. All relatives worried about what the future held and who would continue to care for the patient when they no longer could. Few were confident that hostels, flats or day facilities could provide the levels of care that they achieved.

Ending the group

After one year most families stopped attending regularly, but kept some intermittent contact. The group was finally closed after 18 months. Only one of the relatives wanted it to continue. Most felt that after a year it had achieved most of its aims for them, and had become repetitive. Interestingly, they were united in preferring regular contact with staff, which aided access to team decision-making, rather than interventions solely at times of crisis. Following the experience of sharing problems and support in the group, they asked for regular family meetings with staff which included the patients. This had not been an option which any of the families had favoured before joining the group.

Discussion

A low-cost, relatively infrequent intervention with clear aims proved to be beneficial in certain respects for both relatives and patients. The details of these benefits are discussed in the preceding evaluation paper. We took on all 13 relatives who were willing and able to attend and who were involved with patients currently being cared for by the staff team; this was, in any case, about the maximum number that could be comfortably accommodated in the group if it was to function effectively. Those who support the long-term mentally ill often have entrenched views and coping patterns, and we were interested to see if any changes could be effected. Not everybody could be helped in this way, however. One relative experienced a deterioration in the situation at home during the period that the group met. For other relatives, the process of changing expectations and understanding difficult behaviour had only just begun by the end of the group. Relatives of the two patients suffering from bipolar depression benefited least, and these patients also relapsed during the trial.

This raises the question of whether it is feasible or effective for a single group to include relatives supporting patients with different diagnoses. In our setting, since only a minority of patients had a diagnosis other than schizophrenia, numbers would have been too small to create viable separate groups. However, our experience indicates that as relatives of non-schizophrenic patients found the group less helpful, single-diagnosis groups may be preferable. Such groups would probably be less confusing for supporters, and seem more likely to aid the valuable process of social comparison which was cited as a very positive aspect of the group by most of the participants. At this stage it would be premature to reject mixed-diagnosis groups as possible interventions, particularly since clear-cut diagnoses are often difficult to establish in the long-term population. Further, we would want to discourage an attitude which might exclude families designated 'unsuitable' from receiving help. However, it does appear that professionals should be cautious to maintain an individual approach to the needs of both long-term carers and patients. Some families, particularly in the non-schizophrenic group, may require a more intensive approach that can cope better with an illness which is likely to have a fluctuating course. Carers found it particularly difficult to cope with the contrast between the optimism which both they and the patients felt during manic or recovery phases and the loss of hope which accompanied the return of severe depression.

Adequate preparation for the group was very important because it greatly assisted the engagement of the relatives. Visiting each family at home to provide information and give them an opportunity to explain their own viewpoint in detail before the group began, the relatives' familiarity with the facilitators, and an informal social atmosphere during sessions were essential parts of this process. At one point the relatives asked to visit local hostels as a group. We were able to organise this, and it clearly contributed to establishing the sense of partnership we aimed to foster.

The group also highlighted how far apart the perspectives of the clinical team and carers can become during persistent illness. Staff members would often criticise relatives and assume that they were exacerbating patients' difficult behaviour, while relatives did not always appreciate the inevitable limitations of clinical care, and assumed on their part that the team should do more to contain or prevent behaviour such as suicide attempts. The experience of the group emphasised how easily professionals can take on an antagonistic rather than a collaborative stance in these circumstances.

In conclusion, despite the pressures of working in a busy clinical team, it proved possible to offer a specific, time-limited intervention to the relatives of the long-term mentally ill. This effectively enhanced their coping skills, reduced isolation and negative affect towards patients, and improved relationships between relatives and patients. The patients' social performance improved and their behaviour became less problematic at home (preceding paper).

The model used in the intervention was developed from previous work which relied on insights gained from EE research, but was adapted to the needs of the long-term population and the clinical team. There is recent evidence that discussion-based group work is an effective intervention for high-EE families (Tarrier *et al*, 1988). In the form described here, it is both an inexpensive and feasible approach which requires little extra staff input and is acceptable to staff and relatives. It could be offered routinely to families as part of a tertiary prevention strategy, both to limit the damaging and disabling effects of long-term illness and to support carers in the community.

Appendix

Three families

In order to illustrate the range of problems which families presented, three cases, none of which were unreservedly successful, are described in more detail.

The sceptic

This relative was a 73-year-old mother, a single parent whose husband had died many years ago. Her son, John, had first been in contact with services nine years previously, with bouts of depression. More recently, this had developed into schizophrenia, with reports of hearing voices and thought block. He had also become aggressive and broken furniture at home. Before the intervention his mother had a very rigid view of her son's problems: she had never really believed that he was ill; she described him as lazy and unwilling to do things, and was very critical of him for not helping with household tasks. "He sleeps and eats and puts on weight, does not do any gardening, nothing, doesn't do

anything." In order to help this mother understand and tolerate John's negative symptoms, the similarities with other patients' problems were repeatedly underlined, and it was pointed out that he had to cope with the frightening and disturbing aspects of being ill, as well as with the visible signs of neglect and apathy which she saw. John attended the day facility regularly and kept appointments reliably, although this was a great effort for him, and he had not been violent recently. Although he did little housework, he functioned better than most others in the group. The mother began to appreciate that John was managing some things well, but still tended to take these things for granted and her expectations for his progress remained unrealistic.

The changes in her EE ratings (Table I) support a clinical impression that some circumscribed development had occurred. Her tally of critical comments did not nearly approach the low-EE range by the end of the group, but she became appreciably less critical. Her level of warmth remained minimal. John described her as nagging, and she was often exasperated with his lack of achievement. Over the months, she was able to control this somewhat, and this was reflected in changes in her coping strategies. She also learnt to laugh about their mutual problems. She abandoned some maladaptive coping strategies such as daydreaming and showed signs of adopting some constructive ones such as trying to step back from the situation. When relatives are so critical they are also likely to be resistant to change, particularly if they have held such attitudes for many years. Although this mother attended every meeting faithfully and made some limited progress, she remained sceptical that the group could be useful. She felt that she had opportunities to talk about her problems elsewhere, and therefore did not need the group for this purpose. However, she did discover that others had worse problems than her, and welcomed the increased contact with staff, whom she now felt she could call on in an emergency.

The failure

The relative was a 50-year-old man whose twin sister, Jane, lived with him. She had been diagnosed as depressed and anxious but also displayed a number of severe behavioural problems, such as inactivity, incontinence, neglect, and verbal and physical abuse. She had been in continuous contact with services for 25 years. In the last two years, she had taken to staying in bed all day and did nothing for herself. She attended the day facility irregularly and very reluctantly. Her brother had to struggle to get her up and

TABLE I

	<i>The sceptic</i>		<i>The failure</i>		<i>The copier</i>	
	<i>Before intervention</i>	<i>After intervention</i>	<i>Before intervention</i>	<i>After intervention</i>	<i>Before intervention</i>	<i>After intervention</i>
Critical comments	17	12	21	31	3	0
Hostility	1	1	3	1	0	0
Emotional over-involvement	2	1	2	4	0	0
Warmth	1	0	0	0	4	4
Positive remarks	5	5	0	0	6	3

dressed each day, which made him so late for work that he was about to lose his job. His own life-style was severely restricted by his sister's problems, although these restrictions seemed to fit in with some of his own needs.

Because he had to take more time off work, the brother was reluctant to attend the group. During the year that the group met, his sister's social functioning deteriorated further, which set him apart from the other group members whose relatives made some gains. He felt very strongly that a different drug regime would benefit his sister, and spent much of his time in the group talking about this. He could be prevented from dominating the group, but had difficulty listening to other members' problems. He was able to express some of his anger and frustration, both with his sister and with staff. The major disruption to his life that his sister's problems caused evoked sympathy in other group members.

During the group, the brother's EE ratings deteriorated (Table I). He found it harder than ever to leave for work in the mornings and increased his level of criticism and over-involvement. Despite his exasperation, he became less rejecting, although generally his coping efforts became less effective. For instance, he started daydreaming and stopped trying to discuss things calmly with his sister.

He said that although he had occasionally found the sessions useful, he would have preferred to use the valuable time to do practical things at home. He thought that Jane's problems were rather different from those of others in the group: he had to face a greater range of problems, and only he had to deal with emotional blackmail.

Shortly after the group ended he died, quite unexpectedly. His sister was admitted to the centre and her behaviour deteriorated further. She is now known to suffer from an organic syndrome in conjunction with her emotional problems. Although they are unusual, problems of this sort, with multiple origins, may occur among the families of long-term patients, and some consideration is required of the specialised help that such severely disabled patients need. This relative was probably right in recognising that the group could not address his specific needs.

The copier

This 77-year-old widow lived with her schizophrenic son, who had been in continuous contact with services for the last 16 years. She had a wide range of problems to deal with, usually associated with acute phases of the illness, as her son, Richard, was constantly disturbed by severe psychotic symptoms. He could do very little around the house, and often failed to arrive at the centre if he travelled by himself, as he would get off the bus at the wrong stop and return home. Despite being intellectually very able, he could not concentrate to read, watch TV or complete even simple tasks. The mother managed these problems well and rarely complained, but felt very isolated and distressed at times. She was physically ill so she missed some meetings, but always came if she could. She used the group to reduce her isolation and to discuss her difficulties. She was usually able to make suggestions for others, as she was familiar with most of their problems. When she first came to the group she was low in EE, and so would have been excluded

by most intervention trials, despite her difficulties. At the end of the intervention she was still low-EE, but no longer had any critical comments, which suggests some improvement (Table I).

Despite her low-EE attitudes, she also described adaptive changes in her coping strategies, such as being able to tell Richard more clearly what she disliked about his behaviour. She was encouraged to set clear, consistent limits without anger. She found the group very interesting since it had opened her eyes to other peoples' problems and made her feel less isolated with her situation. She felt that she had always been realistic but that the group had helped her to face things more calmly.

This case suggests that a group of this type can benefit even those who are coping well but still experience stress and social isolation that can result from long-term caring. Usually only relatives rated high in EE have been offered help, a practice that has been criticised (Birchwood & Smith, 1987) as it excludes families with other needs.

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