The Family of the Patient with Schizophrenia

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INTRODUCTION

Families play an essential role in supporting people with long-term mental illness in the community and are focal in the social networks of people with schizophrenia [1]. Over 60% of those with a first episode of a major mental illness return to live with relatives [2], and this would seem to reduce only by 10–20% when those with subsequent admissions are included [3]. The carer role is often not without difficulties, and may be associated with considerable personal costs. In schizophrenia, many family members experience significant stress and subjective burden as a consequence of their caregiver role. Not only is such stress likely to affect the well-being of the relatives and compromise their long-term ability to support the patient, but it may also have an impact on the course of the illness itself and on outcomes for the client. This chapter describes research which has examined the impact of schizophrenia on families and the impact of family stress on patient outcomes. It then outlines the background to the development of family interventions in schizophrenia, summarizes the research findings including the evidence base for such interventions, and concludes by drawing attention to important areas for future development.

THE IMPACT OF SCHIZOPHRENIA ON FAMILIES

Approximately 1% of the population worldwide will suffer from schizophrenia in their lifetime, with the onset of the illness occurring usually in late adolescence or early adulthood. Schizophrenia is characterized by a range of symptoms. Although there are large variations in presentation, it is usually associated with severe disruptions to a sufferer’s functioning. First,
disturbed behaviour may be associated with delusional thinking, thought disorder and hallucinations. Although these symptoms may be controlled by medication, the course of the illness is often marked by relapses or exacerbations of these psychotic phenomena and approximately one third of sufferers continue to have persistent positive symptoms despite optimum medication [4]. There are also long-term impairments in functioning known as negative symptoms. These include underactivity, lethargy, poor motivation, general mental slowing, restricted emotions and marked interpersonal difficulties. Due to the wide ranging problems, the illness makes considerable emotional, practical and financial demands on those close to the sufferer—typically the parents or the spouse or partner. These demands are likely to persist over a prolonged period, and advice, help and support may not be readily available.

Under these circumstances, the coping resources of family members may be severely challenged and hence it is unsurprising that the impact of the illness results in negative outcomes in terms of personal distress and burden for many carers. Studies examining the impact of the illness on family members are described below.

**DISTRESS AND BURDEN IN FAMILIES OF SCHIZOPHRENIC PATIENTS**

One of the ways in which the impact of psychiatric illness on families has been investigated is in terms of “burden”. This concept is described as having two dimensions: objective and subjective [5]. Objective burden can be observed by others and consists of measurable effects on the household, whereas subjective burden is the relative’s own perception of the impact of caring. Schene and colleagues [6] refined the concept and suggested that objective burden is the additional caregiving demands imposed on relatives (such as helping, supervising, financial aid) and the loss of their own activities (such as work and social or leisure roles), whereas subjective burden refers to the experiences and emotional responses of a caregiver.

Many surveys have demonstrated that distress and burden associated with caring for a mentally ill family member are very high [6]. However, Chakrabarti and Kulhara [7] report that, in comparative studies across a range of disorders (schizophrenia, affective disorders, anxiety disorders), mean scores of objective burden were greatest among families of schizophrenia patients. A number of studies have assessed the negative impact of schizophrenia on families. Findings indicate that 30–60% of carers suffer significant distress as measured by self-report scales such as the
General Health Questionnaire (e.g. [8–12]). These levels are above what one would expect in the general population and it is assumed that these elevated levels of distress are associated with the demands of the caring role.

Studies have investigated what patient symptom factors predict high levels of burden in relatives, but there are inconsistencies in findings. Some studies report that positive symptoms are problematic [13,14], while others have found that both positive and negative symptoms are related to burden [15]. Clearly, differences in findings are likely to result from sample and measurement differences [16]. A further complication is that the distinction between subjective and objective burden becomes blurred when relatives’ reports are used to assess objective burden [17]. However, there is considerable support for burden and distress being associated with non-psychotic symptoms such as underactivity [18] and negative symptoms [19–21], inappropriate and antisocial behaviour [21,22] and mood disturbance [22,23]. Fadden et al. [20] suggest that, although the positive, florid symptoms such as delusions and hallucinations can also cause problems, they do not tend to be present most of the time, unlike the negative symptoms. Hence, the major proportion of burdensome behaviours seems to come from the negative symptoms, while Provencher and Mueser [22,24] suggest that positive symptoms “interfere only minimally with role functioning in the family”.

Although some symptoms may be more likely to cause difficulties for family members, the inconsistencies in findings between studies may also reflect the idiosyncratic nature of difficulties in the context of complex coping situations. Certainly, the lack of a straightforward relationship between symptom severity and relatives’ distress [25–27] suggests that distress may be influenced by the family members’ response, and a number of studies have looked at coping responses in relation to relatives’ outcomes. For example, a study by Birchwood and Cochrane [8] described different coping styles in relatives of schizophrenic patients and found that broad styles of coping were applied with consistency across different patient behaviours. An “ignore/accept style” was associated with lower burden and a “disorganized” (many strategies without consistency or clear style) with higher distress, although the authors note that to some extent the coping style was related to the level of functioning of the patient. A number of studies have found that emotion-focused coping, particularly avoidance, is associated with more distress in relatives (e.g. [25,28,29]).

APPRAISAL PROCESSES AND COPING IN FAMILIES

One of the dominant coping theories is Lazarus and Folkman’s [30] transactional model. This theory has gained support by researchers
studying dementia caregiving (e.g. [31]). The model emphasizes the individual’s appraisals of demanding situations as mediators of affective and behavioural responses. Appraisals here refer to people’s evaluative judgements about the stressor and may be understood as primary (how threatening the person perceives the situation to be, how much concern the situation elicits for him) and secondary (a person’s assessment of his coping resources). Hence, according to Lazarus and Folkman’s theory, where a relative appraises situations associated with the mental illness to be problematic or threatening and feels he does not have the resources to cope, then he is more likely to be distressed. Recent research employing the transactional model framework to relatives of schizophrenic patients does suggest that appraisal processes mediate the relationship between illness factors and carer responses [11,21,25]. These studies have employed independent measures of patient symptoms and have demonstrated that the burden and distress experienced by relatives are more dependent on their appraisal of the patient’s problems than the problems themselves. However, it may well be that some types of problems associated with schizophrenia—for example, the negative symptoms referred to earlier—may elicit particularly challenging appraisals, or that the measurement of clinical symptoms may not correspond to the patient’s behaviour in non-clinical settings [32].

Several studies have focused on one particular type of appraisal—the kind of explanations or causal attributions that relatives make about problematic behaviours associated with schizophrenia—in understanding relatives’ responses to schizophrenia (see [33] for a review of studies). Although these appraisals seem to be important mainly in terms of how the relative responds to the patient (see later sections on expressed emotion for a fuller description), one study found that self-blaming attributions were predictive of distress in relatives [34]. There may be some merit in increasing the scope of the study of relatives’ cognitions about mental illness as a means of understanding variability in how people respond to close relatives with a severe mental illness. In the area of physical health, it is widely accepted that cognitive processes mediate people’s adaptation to their own health problems, and the most notable theoretical framework adopted in this work is the self-regulation model of Leventhal and colleagues [35,36]. It has been demonstrated that patients’ illness representations or models of illness are based around distinct components—identity, cause, time line and illness consequences, as well as controllability (see [37] for review). These representations have been shown to carry emotional, behavioural and coping implications and are related to health outcomes. It has been suggested [37–39] that illness representations may also have important implications for people’s responses to individuals who are ill, particularly in mental illness [40]. A preliminary study by
Barrowclough et al. [26] supported the utility of this model in the context of relatives of schizophrenia patients using the Illness Perception Questionnaire (IPQ) [41]. As with previous studies, there was little association between the measures of carer functioning (using measures of distress and burden) and patient functioning. However, where relatives perceived there to be greater negative consequences for the patient from the illness, they showed greater distress and subjective burden.

The transactional model predicts that appraisals of problems will also be influenced by perceptions of the number and efficacy of one’s resources to manage the problems. In a longitudinal European study of family burden and coping over time [29], a reduction in family burden was found in relatives who adopted less emotion-focused strategies and received more practical support from their social network. Theory and evidence would suggest then that there are multiple routes to helping relatives to reduce distress and burden. These include modifying threatening appraisals of the illness experience (which may include helping to improve the patient’s condition) and increasing relatives’ confidence in managing its troublesome aspects, either through their own strategies or with support from others. However, later sections of the chapter show that there have been few attempts to date to develop family interventions directed at improving carer outcomes, and that the little research which is available has given disappointing results. Despite a good deal of research, it would seem that we are in the early stages of understanding how best to help relatives to safeguard their own well-being.

**IMPACT OF FAMILY ENVIRONMENT ON SCHIZOPHRENIA**

It is clear that many families of patients with schizophrenia are likely to experience significant stress associated with the caring role. Although writers have acknowledged that such stress affects the well-being of relatives as well as compromising their ability to care for the patient, most family research in schizophrenia has focused on the latter aspect—that is, the impact of the family on the psychosis.

There is a long history of theories that hypothesize an association between the family environment and the development of schizophrenia. In the 1950s and 1960s, writers such as Bateson, Lidz and Laing described various patterns of family structure, interactions and communications which they proposed were responsible for causing schizophrenia [42]. These theories of family pathology failed to withstand empirical investigation and have now been largely discredited. However, some of the ramifications are
still felt today, and Hatfield et al. [43] discuss the distress to families that these messages of family blame can cause.

**EXPRESSED EMOTION RESEARCH**

In the past thirty years or so, research on the effects of the family environment on the course of schizophrenia has become almost synonymous with the work on expressed emotion (EE). EE refers to a construct encompassing several key aspects of close interpersonal relationships. It reflects critical, hostile or emotionally overinvolved attitudes on the part of a family member toward a relative with a disorder or impairment. Originally developed to assess the emotional climate of households containing a person diagnosed with schizophrenia [44], EE is now a well-validated predictor of poor clinical outcome for this disorder as well as for other psychiatric conditions [45]. Although its name might suggest otherwise, EE is not a measure of emotional expressiveness. Rather, it is a measure of the extent to which an individual family member talks about another family member in a critical or hostile manner or in a way that indicates marked emotional overinvolvement (EOI). These attitudes are assessed using a semi-structured interview called the Camberwell Family Interview (CFI) [46]. The CFI generally takes between one and two hours to complete. The interview is audiotaped and later rated on a number of dimensions using operationalized guidelines.

Criticisms are defined as comments about the behaviour or characteristics of the person (patient) that the respondent clearly resents or finds annoying. Hostility is rated categorically on the basis of whether or not the respondent makes generalized criticisms or expresses attitudes that are rejecting of the patient. The EOI score is a composite measure of factors such as an exaggerated emotional response, over-intrusive or self-sacrificing behaviour, and over-identification with the patient. Positive aspects of the relationship may also be measured in the form of positive comments (a frequency count) and warmth (a scaled score taking into account attitudes and comments evidenced throughout the interview). However, it is the dimensions of criticism, hostility and EOI that are used to determine high and low levels of EE. Relatives scoring above threshold on one or more of these dimensions are assigned “high EE” status. The importance of the EE concept to schizophrenia lies in the predictive validity of the dichotomized EE measure. In a meta-analysis of 26 studies, Butzlaff and Hooley [45] demonstrated that living in a high EE home environment more than doubled the baseline relapse rate for schizophrenia patients 9 to 12 months after hospitalization. Over the years, EE methodology has been applied to other conditions, both psychiatric and medical. EE has been found to be
predictive of illness course in other psychiatric conditions, most notably in depression (see [45]). There are associations between high EE and childhood psychological disorders, and there are also indications that it may have predictive utility for some chronic medical conditions, including asthma and epilepsy (see [47] for a comprehensive review of EE research in health care).

Although the initial studies by Brown and colleagues [48] suggested that behavioural disturbance and work history were related to EE and relapse, multiple studies have demonstrated that the association of EE with relapse is independent of patient factors such as severity of illness. Even when potentially important patient variables are controlled statistically, EE still makes a significant and independent contribution to relapse [49]. The general findings contained in the literature also provide no strong support for the assumption that the link between EE and relapse results from their shared association with an unmeasured third variable (see [50]).

UNDERSTANDING THE EE CONCEPT

Although the predictive validity of EE is no longer in question, research studies continue to attempt to better understand the EE concept and its mechanism in relapse. It is generally understood to have its action within a vulnerability–stress model of schizophrenia (see [51] for a review of the models). In essence, such models conceptualize the psychosis as the result of environmental stress reacting with an underlying predisposition or biological vulnerability to develop the disorder. The models can be applied either to the genesis of the psychosis or to subsequent episodes and postulate a powerful role for environmental stress. Within this framework, EE is seen as one possible source of such stress, capable of triggering or exacerbating symptoms once vulnerability is established through the onset of the illness.

The measure of EE has also been applied to professional carers. Although this line of research is much less well developed than with families, there is accumulating evidence that high EE responses in professionals are associated with negative outcomes [52]. In a prospective study of case managers, Tattan and Tarrier [53] found that the absence of a positive relationship between case manager and patient measured 3 months after engagement was associated with poorer clinical outcome 9 months later independently of initial severity of illness. A positive relationship was also significantly associated with a greater improvement in the patient’s quality of life and a negative relationship with the least. Barrowclough et al. [26] investigated staff–patient relationships on a low security inpatient facility. They found that staff viewed the behaviour of patients they felt less positively disposed toward as more the product of the patients’ own
volition, which is consistent with the associations found in the family caregiver research of less benign interpretation of behaviour and critical attitudes [33]. Patients were sensitive to staff feelings towards them; patients’ ratings of perceived thoughts and feelings from staff about them were significantly correlated with those expressed by staff members about the patient. The more negatively perceived patients were significantly more likely to have behavioural disturbances in the 7 months subsequent to the ratings being made.

The extension of EE research to professional carers suggests that people with schizophrenia are sensitive to the effects of interpersonal relationships in general. However, their restricted social networks and lower levels of social functioning may increase the impact of stressful interactions with key formal and informal carers. The studies which have demonstrated that EE is not just of relevance to families provide support for Hatfield’s contention that: “patients . . . are also influenced by other powerful environments, such as hospital wards, treating physicians, rehabilitation centres, and the like . . . . Whatever is useful in expressed emotion theory needs to be applied to community workers” [54].

MECHANISMS OF EE IN RELAPSE

There are a number of lines of evidence indicating that high EE in families represents a significant stressor for patients with schizophrenia, and as such may precipitate relapse. First, a series of physiological studies (see [55] for a review) demonstrated that patients’ arousal levels differ in response to high and low EE relatives. The presence of a high EE relative is associated with arousal maintenance or increase, and that of a low EE relative with arousal decrease. Second, studies of relative–patient interactions in laboratory settings have supported the view that differences in high and low EE relatives assessed in the CFI translate to differences in real-life situations, with high EE relatives demonstrating more critical and/or more intrusive behaviours. As would be expected, the interactions are dynamic, with patient behaviours contributing to negative interactions, but high EE relatives seem less able to change tack, with their responses more likely to contribute to the escalation of negative exchanges [56]. Further support for high EE as a stressor comes from studies demonstrating that high EE relatives themselves report greater levels of persistent personal distress [11]. Third, a particularly fruitful recent avenue of understanding the variability in how people respond to close relatives with a severe mental illness is represented by studies focusing on the role of attributions. Evidence has accumulated that high and low EE relatives may differ in the beliefs they hold about patients and the problematic behaviours associated with the
patient’s illness. In particular, there is consistent evidence from several studies that critical relatives are more likely than non-critical ones to hold patients responsible for their difficulties [33]. In reviewing the relationship of EE and attributions to patient relapse, these authors conclude that carers’ beliefs may play a role in the relapse process in a variety of ways, e.g. by mediating controlling behaviour which increases patient stress or by decreasing the patient’s sense of self-worth, which may serve to reinforce negative self-focused delusions and hallucinations.

Finally, the strongest evidence that EE may act as a causal stressor in relapse comes from family intervention research in schizophrenia, which is reviewed below.

**FAMILY INTERVENTIONS AND SCHIZOPHRENIA**

The development of multifactorial models of the processes determining risk and relapse in schizophrenia briefly described in previous sections provided the general rationale for the development of family interventions. Their emphasis on the contribution of psychological and socio-environmental stressors to the illness course opened up the way to psychological interventions. Within the context of stress-vulnerability models, an individual’s home might be viewed as an environment capable of influencing the illness for better or worse. The reasoning was that if attributes of certain households are responsible for precipitating relapse, then these attributes might be identified and modified, with a resulting reduction in relapse rates. Throughout the past two decades, a series of studies testing this theory have been reported.

There have been several descriptive reviews of the schizophrenia family intervention studies (e.g. [57–61]). Typically, the controlled trials recruited families at the point of a patient’s hospitalization for an acute episode of schizophrenia and commenced the family intervention when the patient was discharged back to the home. The intervention period lasted from 6 to 12 months, at the end of which relapse rates were compared between patients who received the family intervention as an adjunct to routine care and those who received routine care only. Routine care included the use of prophylactic medication. Table 1.1 presents a summary of studies that have compared family intervention with routine or standard care for patients with schizophrenia.

Although the table selects only studies where the intervention lasted at least for 10 sessions, the variety of programmes delivered is apparent. Interventions developed by the various research groups differed on some important dimensions, including the location of the family sessions (home versus hospital base), the number of sessions offered, the extent of the
<table>
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</table>
| Kottgen et al.   | Family intervention, high EE  
Customary care, high EE  
Customary care, low EE | 49 | Psychodynamic: separate groups for patients and relatives        | Weekly or monthly up to 2 years     | 2 years: family intervention equal to customary care for families with either high or low EE |
| Falloon et al.   | Behavioural family therapy  
Individual management | 36 | Home-based behavioural family therapy                            | Weekly for 3 months  
Biweekly for 6 months  
Monthly for 15 months   | 2 years: behavioural family therapy better than individual management |
| Leff et al.      | Family intervention  
Customary care          | 24 | Psychoeducation to help relatives with high EE  
Model coping in low EE relatives | Biweekly for relatives' groups for 9 months | 2 years: family intervention better than customary care            |
| Tarrier et al.   | Behavioural family therapy enactive  
Behavioural family therapy symbolic  
Education only  
Customary care | 77 | Behavioural family therapy comprising stress management and training in goal setting | 3 stress management and 8 goal-setting sessions over 9 months | 2 years: behavioural family therapy better than education or customary care; education and customary care equal |
| Vaughan et al.   | Single-family psychoeducation and support  
Customary care         | 36 | Psychoeducation                                                   | 10 weekly sessions                 | 9 months: single-family education and support equal to customary care |
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<tr>
<td>Mingyuan et al. [71]</td>
<td>Multiple-family psycho-education and support</td>
<td>2076</td>
<td>1 year</td>
<td>Multiple family education and support better than customary care</td>
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<td></td>
<td>Customary care</td>
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<tr>
<td>Randolph et al. [72]</td>
<td>Behavioural family therapy</td>
<td>39</td>
<td>Weekly for 3 months</td>
<td>Behavioural family therapy better than customary care</td>
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<tr>
<td></td>
<td>Customary care</td>
<td></td>
<td>Biweekly for 3 months</td>
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<td>Biweekly for 6 months</td>
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<td>Xiong et al. [73]</td>
<td>Behavioural family therapy</td>
<td>63</td>
<td>Bimonthly for 3 months</td>
<td>Behavioural family therapy better than customary care</td>
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<td></td>
<td>Customary care</td>
<td></td>
<td>Family sessions for 2 years (plus individual sessions with family members and patients): maintenance sessions every 2–3 months</td>
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<tr>
<td>Zhang et al. [74]</td>
<td>Multiple and single family psychoeducation and</td>
<td>78</td>
<td>Individual and group counselling sessions every 1–3 months for 18 months</td>
<td>Behavioural family therapy better than customary care</td>
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<td>support</td>
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<td>Customary care</td>
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<td>18 months: family education and support better than customary care</td>
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<tr>
<td>Buchkremer et al. [75]</td>
<td>Relatives’ group</td>
<td>68</td>
<td>Fortnightly for 2 years</td>
<td>No differences between groups at 1 year or 2 years</td>
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<td></td>
<td>Customary care</td>
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<tr>
<td>Telles et al. [76]</td>
<td>Behavioural family management</td>
<td>–</td>
<td>Weekly for 6 months</td>
<td>12 months: for total group conditions equal; for “poorly acculturated” patients, individual management better; for “highly acculturated” patients, conditions equal</td>
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<tr>
<td></td>
<td>Individual case management</td>
<td></td>
<td>every 2 weeks for 3 months, monthly for 3 months</td>
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Table 1.1 (Continued)

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<thead>
<tr>
<th>Study</th>
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<th>N</th>
<th>Type of family intervention</th>
<th>Frequency and duration of treatment</th>
<th>Results</th>
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<td>Leff et al. [77]</td>
<td>Multiple-family psycho-education and support Single-family psycho-education and support</td>
<td>23</td>
<td>Multiple-family groups in the clinic; single family sessions at home</td>
<td>Biweekly for 9 months, varying amounts afterward</td>
<td>2 years: conditions equal</td>
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<td>Zastowny et al. [78]</td>
<td>Behavioural family therapy Single-family psycho-education and support</td>
<td>30</td>
<td>Hospital-based behavioural family therapy; hospital based single-family psychoeducation and advice on handling common problems</td>
<td>Weekly for 4 months, monthly for 12 months</td>
<td>16 months: conditions equal</td>
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<td>McFarlane et al. [79]</td>
<td>Multiple-family psycho-education and support Single-family psycho-education and support</td>
<td>83</td>
<td>Multiple-family groups or single family sessions in the clinic</td>
<td>Biweekly sessions for 2 years</td>
<td>2 years: multiple family conditions better than single family condition</td>
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<td>Schooler et al. [80]</td>
<td>Applied family management Supportive family management</td>
<td>157</td>
<td>Applied management comprising home-based behavioural family therapy sessions plus supportive family management; supportive family management comprising clinic-based multiple family groups</td>
<td>Applied family management: behavioural family therapy weekly for 3 months, biweekly for 6 months, and monthly for 3–6 months plus concurrent monthly supportive family management for 24–28 months; supportive family management monthly for 24–28 months</td>
<td>2 years: conditions equal</td>
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patient’s involvement, whether families were seen individually or in groups, and the precise content of the sessions and the mode of delivery. Since the researchers did not have a clear understanding of the mechanisms of patient relapse in the home environment, determining the content involved making certain assumptions about the kinds of problems associated with families which might contribute to stress, and hence deciding what issues needed to be targeted. In practice, all the studies assumed families had inadequate knowledge or misunderstandings regarding the illness and placed an emphasis on educating relatives about schizophrenia, to the extent that some reviewers have subsumed all family intervention under the category “psychoeducation”. The other common area targeted was helping the family members in coping with symptom-related difficulties, either by a specific problem-solving approach [81] or through assessment of individual problems and application of appropriate cognitive–behavioural techniques [82]. Despite differences in approaches, Mari and Streiner [83] have provided a useful summary of the common “ingredients” or “overall principles” of the treatments: to build up an alliance with relatives who care for the schizophrenic member; to reduce adverse family atmosphere; to enhance the problem-solving capacity of relatives; to decrease expressions of anger and guilt; to maintain reasonable expectations of patient performance; to set limits safeguarding relatives’ own well-being; and to achieve changes in relatives’ behaviour and beliefs.

A number of meta-analytic reviews ([83], updated by [84] and [85]; [86,87]) of the family intervention studies have been published. These reviews include family intervention studies where the patient has a diagnosis of schizophrenia or schizoaffective disorder; where there is some form of control or comparison group against which to evaluate any benefits from the experimental treatment; and where patient relapse or hospitalization is examined as the main outcome. The Pharoah et al. [85] analysis adopted fairly stringent inclusion criteria (excluding studies with non-random assignment, those restricted to an inpatient intervention; those not restricted to schizophrenia; and when the intervention took place over less than 5 sessions) and included 13 studies. The review confirms the findings of the earlier descriptive accounts of the studies. It concludes that family intervention as an adjunct to routine care decreases the frequency of relapse and hospitalization; and that these findings hold across the wide age ranges, sex differences and variability in the length of illness found in the different studies. Moreover, the analysis suggests that these results generalize across care cultures where health systems are very different—trials from the UK, Australia, Europe, the People’s Republic of China and the USA were included. The more inclusive review [86] examined 25 studies spanning 20 years (1977–1997). Again, it confirmed the lower relapse rate of family-treated patients compared with control groups,
finding an effect size of 0.20, corresponding to a decrease in relapse rate of 20%. Although this treatment effect may seem relatively low, one must bear in mind that this analysis includes studies where the intervention was extremely brief and with little resemblance to the intensive programmes in the original studies. For example, the studies of Falloon et al. [63], Leff et al. [65] and Tarrier et al. [67] (see Table 1.1) demonstrated decreased relapse rates for family-treated patients of approximately 40%.

Unfortunately, the absence of treatment fidelity measures makes it very difficult to judge quality control within or between studies. Further comparison analyses within the Pitschel-Walz et al. review [86] draw attention to some of the wide variations in the content and duration of programmes in recent years. It would seem that there has been considerable dilution of the potency of the family interventions in the large meta-analyses where there is no quality control. Categorizing studies into those lasting more or less than 10 weeks, they found that longer-term interventions were more successful than short-term interventions; and that more intensive family treatments were superior to a more limited approach (for example, where relatives were offered little more than brief education sessions about schizophrenia). When families were provided with an effective “dose” in terms of duration and intensity of intervention, the Pitschel-Walz et al. review [86] suggests there is some evidence of long-lasting effects from family treatment. Several studies found a significant difference remaining between the intervention and control groups at 2 years. The 5- and 8-year follow-up data of Tarrier et al. [69] demonstrated how durable are these effects. However, it must be emphasized that all the studies show that relapses increase with the number of years from termination of the intervention.

The most recent meta-analysis by Pilling et al. [87] included 18 studies and its conclusions were in line with previous reviews in confirming the efficacy of family intervention for reducing relapse. It included a comparison of single family treatments, and group family treatments, and found group treatments to have poorer outcomes in terms of the re-emergence of psychotic symptoms or readmission to hospital. They agree with previous reviewers [83] that the effects from family interventions have decreased over the years, and they suggest that this might in part be explained by the increased use of family group approaches (e.g. [75,79,80,88al]). However, they add that this may not be due to the group format per se, but rather due to other factors: the variable content of the group treatments; the fact that group treatments may have benefits unmeasured by the studies (e.g. on carer burden); or the fact that group treatments may have particular benefit for sub-populations.

One of the criticisms of the family intervention studies has been their narrow focus on the end results of reductions in patient relapse and hospitalizations [83]. The inclusion of other outcome measures has been
variable, and consequently there is usually inadequate systematic data such that can be subjected to meta-analytic review. The Pitschel-Walz et al. review [86] is more optimistic than the Pilling et al. review [87] in the conclusions that can be drawn about wider patient and family outcomes. As regards patient outcomes, both reviews agree that there is some evidence of better medication compliance. The Pitschel-Walz et al. review [86] also asserts that there are indications of improved quality of life and better patient social adjustment in family-treated patients. Several studies have demonstrated that these improved outcomes are achieved with reduced costs to society (e.g. [63,69,73]).

As noted by Pilling et al. [87], the potential benefit for family members themselves from the interventions has received relatively little attention. It has to be remembered that although the trials sought to reduce intrafamilial stress, improvement in patient outcomes and not family outcomes was the prime target. Where family burden was assessed as a secondary outcome, the results appear to be inconsistent. For example, among studies which have employed a similar intervention format—behavioural family therapy (BFT)—some (e.g. [64,88b]) reported reductions in family burden, while a later much larger one [89] found that BFT did not influence family burden. Szmukler et al. [90] identify three randomized controlled trials aimed specifically at carers [88a,91,92], although with very brief interventions. These studies showed some advantages, although in terms of outcomes that are only indirectly related to distress and burden, such as knowledge and attitudes. The use of different measures makes comparisons between studies assessing carer outcomes problematic. A recent trial with a longer duration of intervention which did focus primarily on improving carer outcomes did not produce encouraging results [90]. A two-phased intervention with 6 family sessions followed by 12 relatives’ groups was compared with standard care. Engagement into the trial was poor, and the authors report that the carers’ programme did not offer any significant advantage on any of the outcome measures: psychological morbidity, negative appraisal, coping or support. Szmukler et al. [90] conclude that there is still uncertainty about the most effective interventions for carers of patients with psychotic disorders.

**DISSEMINATION OF FAMILY INTERVENTIONS IN ROUTINE CARE**

In the UK and elsewhere, in recent years, there have been attempts to disseminate the benefits of family intervention in schizophrenia into routine service delivery. This has been largely through training programmes designed to provide clinicians, mainly community psychiatric nurses, with the knowledge and skills required to implement the family work (see [93]
for a review of dissemination programmes). Despite the solid evidence base for the efficacy of family-based psychological treatment programmes in schizophrenia, and the efforts of the training programmes, the implementation of family work in routine mental health services has been at best patchy. The consensus view in the literature is that family intervention implementation faces complex organizational and attitudinal difficulties (e.g. [94–96]), and insufficient attention has been paid to these in dissemination programmes. In discussing the factors which might make the transfer from research to practice difficult, Mari and Streiner [83] suggested that the requirements of durable service-oriented interventions may differ from those based on time-limited research models. In an attempt to demonstrate the effectiveness of family interventions in standard psychiatric settings which take account of these differences, a randomized controlled pragmatic trial was carried out [97]. The family intervention was based on the formal assessment of carer needs, and the programme was carried out by a clinical psychologist in conjunction with the patient’s key worker—thus, training was in situ. The fact that the intervention was found to be effective in reducing carer needs and in reducing patient relapse at 12 months post-treatment [98] suggests that there are advantages in developing dissemination models based within services. The need for changing the clinical practice of the whole service rather than training individuals is underlined in the work of Corrigan and colleagues [99–101]. However, difficulties arise not only from staff but also from carer reluctance to engage in family work. Several studies of community samples (e.g. [90,97,102]) have shown that carer participation in family intervention is relatively low, with only 50% or so of carers taking up the offer of either a support service or family intervention [97], with possibly higher rates when help is offered at a time of crisis [103].

CONCLUSIONS

This chapter has attempted to encompass the main themes and findings from research into families of schizophrenic patients that has taken place in the past 20 years or so. While a number of conclusions can be drawn, some areas are clearly in need of further research and development.

It is now acknowledged that having a close relative who has a severe mental illness very often results in high levels of stress and perceived burden. The consequences of the caring role for relatives would seem to be influenced by a number of factors, including available support and the nature of the patient’s problems, but also by the relatives’ appraisals of the experience—the sense they make of the illness and the ways in which they perceive the symptoms and their own coping efforts. Despite the problems
that relatives experience and the volume of research that has documented their difficulties, few studies have had the primary goal of helping these carers to reduce their distress, and those that have been conducted have by and large shown disappointing results. On the other hand, most of the family intervention work has been targeted at improving patient outcomes, and studies have demonstrated clear gains for patients in terms of reductions in relapses and hospitalizations, such that there is now robust evidence for the efficacy of family interventions in schizophrenia. However, the content of family intervention in evaluated studies has varied widely and there have been problems in the dissemination of the work into routine care. It would seem that successful family interventions require considerable investment in time, skill and commitment, and since for many patients the effect is to delay rather than to prevent relapse, many patients and families will need long-term and continuing intervention. There are also strong indications that the adverse effects of stressful interpersonal interactions in schizophrenia are not confined to family relationships. It would seem that much that has been learned from EE research and family interventions might usefully be transferred to work in improving therapeutic relationships with informal carers.

Future work with families and staff might usefully focus on recent-onset patients. Work with relatives of recently diagnosed schizophrenia patients indicates that help needs to begin from the first onset of the psychosis [104]. It has been suggested that the issues facing a first-episode patient and family are different from those facing someone with a long-term illness [105]. For example, there is often more diagnostic uncertainty, which means that education about the condition needs to be more flexible. Family intervention work in early psychosis programmes has been recognized to be important but has received little evaluation.

Dissemination and engagement issues in family work also need to continue to be addressed. Although many patients and families benefit greatly from the intervention programmes, a substantial number of families are hard to engage, and the implementation of family programmes within services presents many challenges. Finally, further work needs to be done to identify optimum techniques for changing family attitudes where problems are particularly complex, for example in schizophrenia and comorbid substance misuse. To date only one recent trial has evaluated a family-based component for this client group [106,107].

REFERENCES


