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13.1 Introduction

Cognitive models of caregiving (e.g. Kuipers et al. 2010) and neurobiological models of psychosis (e.g. Garety et al. 2007) both highlight the impact of familial relationships and environment independently, and in combination, on patient outcomes. Understanding the interplay between family relationships and patient and carer functioning remains of significant importance in research and treatment initiatives in psychosis. This chapter seeks to provide an overview of the clinical needs of patients who have regular contact with families and the role of cognitive behavioural family-based interventions in addressing patient and family needs and facilitating optimal outcomes.

13.1.1 Caregiving as a Resource

Schizophrenia has a lifetime prevalence of 0.87 % (Perälä et al. 2007) with the first onset typically falling during adolescence and young adulthood (Harwood et al. 2004). For many, the condition will prove to be long term and disabling, exerting a profound and negative impact on their functioning and their family. The

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global burden linked to schizophrenia spectrum conditions is well documented (Rossler et al. 2005; The Schizophrenia Commission 2012).

In recent decades, several countries have implemented a programme of mental health de-institutionalisation that has, in turn, placed a much greater emphasis on service provision within the community. Clinical and research evidence confirms that a significant proportion of people with psychosis continue to maintain close contact with informal carers (Foldemo et al. 2005). This contact is particularly evident during the first few years following the initial onset of difficulties (Addington et al. 2003; Parabiaghi et al. 2007) and amongst some black and minority ethnic groups (Guada et al. 2009). Informal carers are mainly first-degree relatives such as parents and are predominately female. Thus, a common clinical picture is of a middle-aged mother providing care for an adult male son. However, we also know that many carers are the spouses, siblings, or adult offspring of the service user (Grandon et al. 2008; Kuipers et al. 2006; Onwumere et al. 2013; Bowman et al. 2013).

There is a large body of evidence linking feelings of loneliness to mental health problems (Meltzer et al. 2013). People with psychosis tend to have very small social networks (Gayer-Anderson and Morgan., 2013; Sündermann et al. 2013; Berry et al. 2007; Harley et al. 2011) and few become parents or have adult romantic relationships (Fleury et al. 2008). Carers can therefore provide a vital source of social contact and support to patients (Lester et al. 2011; Parabiaghi et al. 2007) and find themselves in a key role to facilitate their recovery and re-integration within their local community. Carers will often respond to different areas of unmet need for patients including providing financial assistance, advocacy, and accommodation (Lester et al. 2011). They can take an active role in encouraging patient engagement with treatment plans, including pharmacological treatments, identifying and responding to early signs of relapse (Herz et al. 2000), and ensuring patients are able to access appropriate clinical services once the first signs of psychosis emerge (Fridgen et al. 2012; Bergner et al. 2008; Morgan et al. 2006). Recent evidence suggests that patients with carers, when compared to those without, obtained better outcomes from psychological therapies (Garety et al. 2008) and received less intensive interventions from mental health services (Catty et al. 2011; Wilks et al. 2008). We also know that patients with carer support can experience fewer inpatient admissions, shorter inpatient stays, and an improved quality of life (Schofield et al. 2001; Fleury et al. 2008; Norman et al. 2005; Tempier et al. 2013). Further, contrary to some misconceptions, patients themselves often welcome greater opportunities for their carers to be involved in their care (Walsh and Boyle 2009; Askey et al. 2009).

13.1.2 Understanding Caregiving: Impact of Role on Well-being

Carers of those with psychosis provide significant levels of unpaid care. The aggregate unpaid cost to society of the care provided by informal caregivers of individuals with schizophrenia in the UK alone falls in excess of one billion per

annum (The Schizophrenia Commission 2012). Approximately 15 % of carers have taken an average of 12.5 days off from employment and nearly 5 % of carers have terminated their employment due to the ongoing demands of their caregiving role (Mangalore and Knapp 2007).

The carer role is often taken on with little time to decide or prepare, and without a manual of what one should do (Kuipers 1992; Sawatzky and Fowler-Kerry 2003). It relies heavily on on-the-job training, and due to the characteristic relapsing–remitting nature of schizophrenia spectrum disorders (Harrow et al. 2005; Emsley et al. 2013), the role can be a long-term commitment. For many carers, their role will be incorporated into existing duties, which for some can include additional caregiving duties for other family members (Raune et al. 2004).

Supporting a relative with psychosis can have a negative impact on carer well-being (Kuipers et al. 2010; Kuipers and Bebbington 2005). The negative impact has been traditionally described as ‘carer burden’ or in recent years, the ‘impact of care’. Several studies attest to high levels of burden in carer populations across the globe including those from Asia, Europe, and Africa (Awad and Voruganti 2008; Ukpong 2006; Igberase et al. 2010; Tang et al. 2008; Karanci and Inandilar 2002; Ostman and Hansson 2004) and in different carer subgroups such as siblings (Friedrich et al. 2008; Bowman et al. 2013), spouses (Jungbauer and Angermeyer 2002), and carers who are young children under 18 years old (Cooklin 2010). As part of their role, carers can report significantly smaller social networks and derive less satisfaction from their contact (Gouva et al. 2012). They can also experience a broad range of negative emotional reactions including loss, stigma, worry, guilt, and fear (Lauber et al. 2003; McCann et al. 2011; Kuipers et al. 2010). Many carers can express concerns about different aspects of their relative’s functioning and well-being such as poor self-esteem, a lack of social relationships, financial and budgeting concerns, limited access to leisure and structured activities, and the impact of prescribed medications (Iyer et al. 2011).

Caregiving, in general, is frequently linked to a higher rate of common mental disorders, and significantly higher rates are associated with higher amounts of caregiving duties (Smith et al. in press). In carers of people with psychosis, high rates of emotional disturbance are found (Harvey et al. 2001) which can peak in carers of recent onset or recently admitted groups (Boydell et al. 2013; Martens and Addington 2001; Boye and Malt 2002). At least one-third of carers report clinical levels of depression (Kuipers and Raune 2000; Lowenstein et al. 2010) and trauma type symptoms (Hanzawa et al. 2013; Loughland et al. 2009; Barton and Jackson 2008), and many have found themselves the victims of physical and verbal aggression from their relative (Loughland et al. 2009; Belli et al. 2010). Indeed, family members and carers are more likely than non-family members and general public to be the targets of patient violence (Ural et al. 2012). Further, mental exhaustion and burnout, which are commonly found in paid mental health staff such as psychiatric nurses, have equally been observed in carers (Angermeyer et al. 2006).

Carers who are more socially isolated record greater levels of distress and burden (Magliano et al. 2002). Patient symptoms have been directly linked to reports of carer burden (Roick et al. 2006), although research findings are divided

over which type of symptoms prove most burdensome. In some studies, positive symptoms are associated with higher levels of carer burden (Wolthaus et al. 2002) whilst in others negative symptoms, particularly those characterised by inactivity and poor self-care, have been linked to greater reports of carer burden and distress (Ukpong 2006; Dyck et al. 1999). However, there have also been studies that have observed links between carer burden and both positive and negative symptoms (e.g. Addington et al. 2003).

The negative impact of psychosis on a carer's own physical health is also increasingly recognised within the literature. Results from a large sample of carers of schizophrenia spectrum and bipolar conditions ($N = 264$) found that two-thirds reported having one medical condition such as arthritis and hypertension, with one-third also reporting experiencing at least two conditions (Perlick et al. 2005). In addition, sleep difficulties in carers are not uncommon (Phillips et al. 2009).

13.1.3 Understanding Family Relationships: The Role of Expressed Emotion

The family environment and relationships can play an important role in the illness course for patients with psychosis (Bebbington and Kuipers 1994). The expressed emotion (EE) framework has been used over the last 60 years to assess and quantify the family environment. EE is said to reflect a carer's appraisal of the patient and the quality of their relationship; it provides a snapshot of the family's usual pattern of communication and behaviour (Miklowitz et al. 1984; Scazufca and Kuipers 1996). The gold standard measure of EE is the Camberwell Family Interview, a semi-structured interview completed with a carer that was initially developed in the mid-1960s and later revised (CFI: Brown and Rutter 1966, Vaughn and Leff 1976). EE is measured across five subscales with ratings derived from both the content and prosodic aspects of speech (e.g. tone, emphasis): (1) *Criticism*, which refers to unfavourable remarks about a patient's behaviour and/or personality. (2) *Hostility*, an extreme form of criticism that can manifest as a rejecting remark or global negative expression about the patient. (3) *Emotional over involvement (EOI)* comprises a range of different carer behaviours including self-sacrifice, overprotection, and over-identification with the patient. (4) *Positive comments* which reflect unambiguous positive statements about the patient's personality, skills, and attributes. (5) *Warmth* comprising carer reports of empathy, sympathy, and concern expressed towards the patient. Carers defined as being high EE report above threshold levels of critical, hostile, and/or emotionally over involved behaviours (King and Dixon 1999). Conversely, low EE carers have failed to reach that threshold. Although warmth and positive remarks form part of the EE framework and play a key role in clinical interventions with families, they are not included in the computation of high or low EE classification.

13.1.4 Expressed Emotion and Patient Outcomes

The relevance and importance of EE have continued since its original conception by George Brown and colleagues (Brown 1959; Brown et al. 1958, 1962, 1972) due to its ability to predict patient outcomes across different conditions including psychosis (Wearden et al. 2000; Hooley 2007).

In a meta-analytic review of 25 EE prospective studies from across the globe, Bebbington and Kuipers (1994) examined data from 1,346 cases and recorded a 50.1 % relapse rate for people with psychosis living in high EE households. The relapse rate in high EE households was more than twice the rate for patients in low EE homes. Similar findings were reported by Butzlaff and Hooley (1998) as part of their meta-analysis of 27 EE patient outcome studies. High EE, particularly criticism, has been linked to poorer patient outcomes in psychosis including a greater number of relapses and admissions over a 20-year follow-up period (Cechnicki et al. 2013).

The predictive links between high EE and poorer patient outcomes have also been found in diverse cultural groups in psychosis (Kopelowicz et al. 2006; Marom et al. 2002) but with some contrary findings (e.g. Singh et al. 2013; Kopelowicz et al. 2002; Lopez et al. 2004; Rosenfarb et al. 2006).

13.1.5 Expressed Emotion and Carer Functioning

As reported earlier, EE ratings are said to reflect the usual carer–patient communication and engagement patterns (Miklowitz et al. 1984). Available evidence suggests that carers rated as high EE have a tendency to exhibit poorer communication patterns with patients. Overall, they are likely to talk more and present as less effective listeners (Kuipers et al. 1983; Wuerker et al. 2001). Such carers can also have difficulty in expressing their thoughts in a coherent and supportive manner (Kymalainen et al. 2006). This compares to low EE carers who appear more able to take a step back and remain silent, a style that can often lend itself to being perceived as a good listener (Berkowitz et al. 1981). The research findings suggest that high EE caregivers can frequently find themselves entangled in a sequence of negative interactions with their relative with psychosis, unlike low EE carers, who are more likely to withdraw from challenging situations with patients before they escalate or have greater skills at being able to defuse them (Rosenfarb et al. 1995; Simoneau et al. 1998).

High EE components are linked to particular beliefs that carers report about the illness. For example, reports of carer criticism and hostility towards patients are more likely to be made by carers who attribute the patient's symptoms to the individual and their personality, instead of an illness. These carers will tend to express beliefs that their relative is able to control their symptoms and behaviour if they wanted to (Hooley and Campbell 2002; Barrowclough and Hooley 2003) and are more likely to engage in behaviours designed to directly change the patient's behaviour (Vasconelos et al. 2013). These carer attributions are more commonly

observed for negative symptoms rather than positive symptoms (Harrison and Dadds 1992; Weisman and Lopez 1997), although carer criticism has been linked to positive symptoms of psychosis (Shimodera et al. 1998). A lack of knowledge about the illness and greater pessimism about its course and impact have also been associated with carer criticism (Bentsen et al. 1998; Lobban et al. 2005).

In contrast, carers with high levels of emotional over involvement (EOI) tend to report more self-blaming (rather than patient blaming) attributions and perceive the patient as having very little control over their illness and experiences (Peterson and Docherty 2004). Carers rated as high EOI have a tendency to engage in more patient controlling behaviours through actively assuming control of events and completing tasks for the patient, in contrast to low EE carers who tend to attribute more positive events to patients (Grice et al. 2009). Though understandable and normative in many cultures in the short term, in the long term high EOI carer behaviours can invariably lead to a loss of confidence, roles, and independence for the patient and the carer. Evidence suggests that high EE, in general, is likely to be predicted by feelings of shame and the guilt/self-blame of having a relative with psychosis (Wasserman et al. 2012).

In the caregiving literature, coping styles are often categorised in terms of ‘emotion’- and ‘problem’-focused coping (Folkman and Lazarus 1980). Emotion-focused strategies comprise behaviours specifically designed to reduce the negative emotional impact of the stressor and can incorporate strategies based on avoidance and denial. In contrast, problem-focused coping refers to the direct attempts an individual makes to alter the situation such as seeking social support and problem-solving. Carers of people with psychosis employ a broad range of emotion and problem focused coping strategies to cope with the impact of the illness on their lives and relationships (Birchwood and Cochrane 1990). High EE, burden, and distress have all been associated with poorer carer coping styles (Scazufca and Kuipers 1999; Birchwood and Cochrane, 1990), specifically, coping styles based on avoidance (Cotton et al. 2013; Raune et al. 2004; Onwumere et al. 2011; Scazufca and Kuipers 1999).

13.1.6 Caregiving Relationships: Specifying the Mechanisms leading to Poorer Patient Outcomes

With regard to understanding the mechanism by which negative family relationships can lead to patient relapse, the current body of evidence identifies a key role for emotional dysfunction in patient impacting negatively on psychosis symptoms (Kuipers et al. 2006; Docherty et al. 2009). For example, Barrowclough et al. (2003) found that patients reporting negative self-evaluation were more likely to have carers with higher levels of EE. Kuipers et al. (2006) assessed a large sample of patients who had recently experienced a relapse in their positive symptoms; patients with high EE carers were more likely to report having a lower mood. Carer criticism was also predictive of patient anxiety in these settings. In a novel study that exposed patients with positive symptoms of psychosis to high EE and low EE

proxy speech samples, emotional dysfunction in patients, including reports of anger, significantly increased following their exposure to high EE criticism (Finnegan 2011). Recent findings from studies using functional magnetic resonance imaging (fMRI) have identified neural correlates of exposure to criticism and praise in people with mental health problems, including psychosis (e.g. Choi et al. 2013; Hooley et al. 2012; Rylands et al. 2011). Using a sample of patients with a diagnosis of schizophrenia, Rylands et al. (2011) assessed patterns of brain activation after participants had listened to critical comments from a key relative. High EE comments were linked to increased activation in brain regions focused on the processing of aversive social information (e.g. rostral anterior cingulate, left inferior frontal gyrus). It was argued that a neural network of responses may have a role to play in mediating the poor patient outcomes linked to high EE. Similar methods and findings have been observed in non-clinical schizotypal populations (Premkumar et al. 2013).

13.1.7 Positive Family Interactions and Outcomes

In recent years our understanding of the important contribution of positive and warm relationships to patient outcomes in psychosis has slowly increased. Data from long-term adoptee studies attest to the protective roles conferred by positive familial relationships and environment in reducing the risk of developing psychosis in genetically high-risk young people (Schiffman et al. 2002; Ierago et al. 2010; Tienari et al. 2004; Gonzalez-Pinto et al. 2011). Positive family relationships, in terms of caregiver warmth and expression of positive comments, have been linked to improvements in patient symptoms including social functioning (O'Brien et al. 2006). As part of their aggregate analyses of EE outcome studies, Bebbington and Kuipers (1994) reported how carer warmth and positive comments were predictive of improved patient outcomes in psychosis. Bertrando et al. (1992), for example, found that carer warmth was linked to significantly fewer relapses in patients in low and high EE households. There is evidence to suggest that the protective qualities of carer warmth and positivity may impact differently in different cultural groups (Lopez et al. 2004; Breitborde et al. 2007). In a study of EE and relapse in Anglo-American and Mexican-American groups of individuals with psychosis, it was Mexican-American patients returning to live in households characterised by high levels of carer warmth who displayed lower rates of relapse. Warmth, however, did not impact on the relapse rates of Anglo-American groups (Lopez et al. 2004).

13.1.8 Patient Perceptions of Carer EE

Running parallel to the literature on carer EE has been a developing body of literature on a patient's appraisal of the family environment and its link to patient outcomes in psychosis (Renshaw 2008; Tomlinson et al. 2013; Bachmann

et al. 2002). Patient appraisals of carer attitudes are reported to provide key information about the quality of the caregiving relationship and the extent to which carer appraisals about the patient may impact on or 'get through' to the patient (Hooley and Teasdale 1989). In psychosis, there have been a handful of studies confirming that patient appraisals of carer attitudes towards them overlap with a carer's reported attitudes (Cutting et al. 2006). Onwumere et al. (2009) found that patient perceptions of carer criticism towards them correlated positively with carers' reported ratings of patient criticism, hostility, and high EE. The positive links remained independent of the patient's affective and psychosis symptoms. Earlier work from Tompson et al. (1995) reported that it was patient perceptions of carer criticism instead of carer reports of EE that proved to be a significant predictor for patient outcomes over a 12-month follow-up. This finding was specific to black and ethnic minority participants and perhaps highlighted an important role for patient appraisals in this group.

13.2 Family Interventions in Psychosis

We know that individuals with a diagnosis of psychosis can be sensitive to stress (Myin-Germeys and van Os 2007) and that their recovery is vulnerable to the type of care they receive (Bebbington and Kuipers 1994). It therefore seems reasonable to assume that carers who may find themselves struggling with their own physical and mental health concerns will be less likely to provide optimal support and care for patients, which has negative implications for both patient and carer outcomes (Perlick et al. 2001).

Family interventions (FI) for psychosis were developed as a result of a body of evidence detailing the relationship between patient outcomes and family relationships, the impact of psychosis on carer functioning and well-being, and the unique care needs faced by patients with psychosis who maintain regular contact with carers. The provision of evidence-based family interventions has been included in schizophrenia treatment guidelines in the UK and USA (i.e. National Institute of Clinical Excellence updated guidelines 2009; PORT, Kreyenbuhl et al. 2010). For example, the UK NICE 2009 guidelines recommend that FI should be on offer to families of service users with psychosis who are in close contact and should include a minimum of ten sessions delivered over a three- to 12-month period. Similar recommendations exist in USA, although the intervention length is recommended at 6–9 months. The interventions are recommended as an adjunct to routine treatment packages including medication.

13.2.1 FI Evidence Base

There is a long and strong evidence base with more than 50 controlled trials reporting on outcomes from family interventions in psychosis with mainly longer term psychosis populations. Family interventions have proven efficacy (Pilling

et al. 2002; NICE 2009; Pharoah et al. 2010; Marshall and Rathbone 2011; Pfammatter et al. 2006) and are cost effective (Mihalopoulos et al. 2004; NICE Schizophrenia, Update, 2009; Xiong 1994). The main findings drawn from a recent Cochrane review of 53 randomised controlled trials undertaken within community settings across Europe, North America, and Asia show that FIs are efficacious in significantly reducing rates of patient relapse and readmission in psychosis (Pharoah et al. 2010). Family interventions can significantly improve levels of social functioning and medication compliance in patients (NICE 2009, Update; Pharoah et al. 2010) and reduce EE levels in high EE families (Pfammatter et al. 2006; Pharoah et al. 2010). The evidence on efficacy is stronger for longer term compared to brief interventions (Pfammatter et al. 2006; Mari and Streiner 1994; Pitschel et al. 2001).

In terms of effect size, Pharoah et al. (2010) reported fixed-effect OR of 0.55 for FI reducing relapse at 12 months compared to standard treatment. In an earlier meta-analysis, Pfammatter et al. (2006) observed effect sizes at 6–12 months of 0.42 for relapse reduction; 0.22 for reduction of readmission, and 0.51 for a reduction in readmission at 18–24 months in favour of FI when compared to standard care. Similar findings from Pilling et al. (2002) yielded a fixed-effect OR of 0.37 for FI compared to standard care at 12 months.

13.2.2 Early Psychosis Outcomes in FI

The early illness phase is generally considered to lend itself much better to undertaking family work since service users are more likely to be resident in families and/or be in regular contact with their families and caregivers. However, despite this picture, the number of published studies evaluating the efficacy of FI within early illness groups remains significantly fewer compared to the longer term groups, though the evidence base is increasing. Moreover, where studies have been completed these have tended to evaluate the impact of FI when delivered as part of an overall service approach to working with early intervention, which has complicated attempts to isolate the specific contribution of family interventions to patient and carer outcomes (Grawe et al. 2006).

Some of the earliest FI studies in early psychosis tended to yield equivocal findings about its impact (e.g. Leavey et al. 2004). Linszen et al. (1996) assessed 76 early phase (first episode) families following their receipt of individual psychosocial interventions. The authors failed to observe any significant benefit on outcomes (relapse) when families received a further 18 sessions of a 12-month behavioural family intervention. Moreover, families initially recorded as low EE showed poorer outcomes at the end of the intervention. Five-year follow-up data suggested that family interventions reduced inpatient admission times, although participants did not have an overall better illness course (Lenior et al. 2001). Zhang et al. (1994) examined the efficacy of family interventions using a male-only sample and where, for most of the intervention, the service user was not included within the session. The intervention offered a positive impact on relapse rates and

social functioning at 18-month follow-up. Using a sample of 106 first episode carers randomised to a brief (seven session) family intervention compared to standard care, no significant differences in levels of carer satisfaction or inpatient days were observed between carers in both arms of the study (Leavey et al. 2004). Gleeson et al. (2009) have argued that optimal interventions for early psychosis service users, following a period of symptom remission, should include a combination of individual cognitive behavioural therapy (see previous chapter from Elaine Hunter and colleagues) and family work that particularly targets relapse prevention. Bird et al. (2010) published data from their systematic review and meta-analyses examining the effectiveness of family interventions in early psychosis and offered similar positive findings to those extensively reported in longer term psychosis populations (e.g. Pharoah et al. 2010). Drawing on patient data from three published trials of family interventions ($N = 288$), Bird and colleagues concluded that when used alone, family intervention significantly reduced relapse and hospital admission rates compared to standard care in early psychosis populations (Bird et al. 2010).

13.2.3 Carer Outcomes in FI

Interestingly, despite the extensive evidence base documenting the negative impact of caregiving on carer functioning and well-being, there is a paucity of data recording the impact of family interventions on carer-specific outcomes (Lobban et al. 2013). However, we do know that family interventions can have a positive impact on caregiver outcomes (Lobban et al. 2013; Pharoah et al. 2010) including reducing carer burden (Cuijpers 1999; Tomas et al. 2011; Giron et al. 2010), improving positive caregiving appraisals including those made about the patient (Gleeson et al. 2010), and increasing readiness of carers to continue providing care (Berglund et al. 2003; Giron et al. 2010).

13.2.4 Areas of Development in FI Evidence Base

There are some notable gaps in the FI literature base, for example, identifying the key mediators and mechanisms of positive change. Thus, there are limited data on what specific component(s) within the family-based intervention gives rise to the positive outcomes observed in reduced relapse and readmission rates. Further, given their numbers and unique needs, there is a paucity of data on FI with different carer subgroups for example, younger carers, siblings (Sin et al. 2013), and black and minority ethnic groups (NICE 2009). In the UK, for example, there are significantly higher incidence rates of schizophrenia and psychoses in Black African and Black Caribbean groups (Fearon et al. 2006; Cantor-Graae and Selten 2005). Both groups also tend to experience more negative forms of care including greater user of legal statutes to enforce care and treatment (Cochrane and Sashidharan 1996). In recent years there has been increasing attention on the impact of ethnic membership and culture on family functioning and outcomes, with some

findings indicating that impact of care (burden) and links between high EE and poor patient outcomes may not be uniform across all ethnic groups (Rosenfarb et al. 2006; Singh et al. 2013; Lopez et al. 2004). Research recommendations from the NICE schizophrenia treatment recommendations included a call for further studies to assess the impact of FI on minority ethnic groups. To date, worldwide, there have been a small number of studies that have examined applications of FI models with samples based in the Far East (e.g. Chien and Chan 2004), Latin American populations living in the USA (e.g. Weisman et al. 2006; Telles et al. 1995), and some European and Middle East countries (e.g. Tomas et al. 2011). Although far more investigations are required, data from some of the earlier studies suggest that FI can be successfully delivered but may require some revision for particular groups (Onwumere et al. 2009; Telles et al. 1995).

13.2.5 Models of Family Interventions

There are only a small handful of FI treatment manuals that are evidence based rather than commentary (Addington and Burnett 2004; Kuipers et al. 2002; Barrowclough and Tarrrier 1992; Falloon et al. 1984). The treatment manuals vary in the emphasis given to the exact session format and location, how and whether the patient is included in the sessions, and if families are seen individually or as part of a large group of other families. However, the evidence-based manuals also share some key areas including explicit recognition of schizophrenia spectrum diagnoses as an illness and a stress-vulnerability model of its development and practitioners adopting a non-blaming and positive attitude towards families, a focus on current 'here and now' problems, and an overarching aim of reducing a patient's risk of relapse and the negative impact on family functioning.

In the Kuipers et al. (2002) treatment manual, family interventions are designed to promote cognitive and behavioural change via facilitating positive family communication; information sharing (psychoeducation); and negotiated problem-solving skills. They also include emotional processing of common affective responses linked to caregiving such as grief, loss, and anger. The interventions are provided by two therapists and will usually be offered in the family home.

13.2.5.1 Facilitating Communication

Communication styles that are constructive, in terms of achieving a good balance of talking and listening skills and being able to elicit the perspective of the other, have been linked to improved social functioning in patients (O'Brien et al. 2009). Facilitating optimal communication styles between family members will often provide the foundation for all the other FI therapeutic activities (e.g. problem-solving, psychoeducation) and can minimise the difficulties linked to their implementation (Kuipers et al. 2002; Onwumere and Kuipers 2009). In FI sessions, there are three main communication strategies highlighted. First, all family members are asked to talk directly to each other instead of about one another. This method can

help to reduce the negative exchanges between family members and will often encourage the speaker to apply greater thought and sensitivity to what they say and how they say it and, thus, immediately promote behavioural change within the session. We know that far less effort is required when you make a negative statement about a person: compared to when you have to speak directly to them. Greater thought and sensitivity are also given to the content and the tone in which the statement is delivered when you are encouraged to talk directly. Auditory hallucinations are common symptoms in psychosis and thus likely to be experienced by many patients attending family sessions. Encouraging the use of direct speech can also be helpful for patients, since referring to a patient in the second or third person, particularly when making negative comments, can run the risk of mirroring their own negative experience of auditory verbal hallucinations, particularly where they may have felt isolated, victimised, or humiliated (e.g. Birchwood et al. 2000). Second, family members are asked to talk one person at a time. This simply ensures that the therapists and family members are able to hear what is being said. It also minimises the risk of important information, including expressions of warmth and positivity between family members, being lost, and models good listening skills. Third, as part of a strategy to ensure that all family members are involved with the intervention and have a key role to play in the outcome, therapists ensure that equal talking time is given to all family members. This rather simple yet effective technique serves to reduce the risk of an individual's mental disengagement from the session, which may be a particular concern for some service users especially those with more negative symptoms. Here, the therapists take an active and lead role in facilitating positive communication styles, but always with a view to family members, themselves, monitoring and revising their own behaviour independent of therapists' prompts (Kuipers et al. 2002). In line with the Kuipers et al. (2002) treatment manual, the overview of the communication styles, which can sometimes be described as 'ground rules' in the literature (e.g. Gamble et al. 2012), are always discussed in the initial session to make the process of the sessions transparent. Our clinical experience confirms that promoting and prompting optimal communication styles will often extend over the course of the intervention.

13.2.5.2 Information Sharing (Psychoeducation)

Carers with more optimistic beliefs about how much control patients and themselves have over the illness have tended to report more positive caregiving experiences (Onwumere et al. 2008). Moreover, carer and patient functioning are linked to the appraisals they report about the illness (Watson et al. 2006; Barrowclough et al. 2001) and discrepant illness beliefs (Lobban et al. 2006; Kuipers et al. 2007). Lobban et al. (2006) found that high EE relationships were more common where carers and patients report dissimilar illness beliefs about areas such as the illness impact and consequences. Kuipers et al. (2007) reported that discrepant illness beliefs between patients and carers had a mutual impact on mood.

Psychoeducation can play a significant role in dispelling some of the myths and factual errors that often surround psychosis and impact negatively on family

functioning. In family sessions, psychoeducation will seek to facilitate the families' cognitive reappraisal of patient symptoms and difficulties with the goal of promoting less person blaming appraisals and encourage more adaptive coping behaviours and affective responses from family members. For example, if we look at the appraisal of: *'my son is lazy since he does not like to get up in the morning, and I know he is taking advantage of my good will and generosity'*, psychoeducation will be used to help the parents conceptualise their son's behaviour and difficulties getting up in the morning as part of his negative symptoms. Using feedback from the son, directly within a family session, the carer will be supported in improving their understanding of negative symptoms and the unique way in which it affects their son, including difficulties with motivation and initiation plans.

In the Kuipers et al. (2002) model, a comprehensive information leaflet purposively designed for use with carers and service users together is utilised as part of the psychoeducation. The leaflet covers several key areas on understanding psychosis including diagnosis, incidence/prevalence, symptoms, causes, treatments, and impact on families. In sessions, the patient is always recognised as the expert in their experiences and supported in using their unique lived experience and knowledge to shape conversations with family members. In psychoeducation sessions, the family will be supported to systematically work through different areas of the information leaflet and have guided and facilitated discussions around relevant areas. All family members are encouraged to offer their own perspective and to both listen to and comment on the material offered by fellow family members and the therapists. The psychoeducation sessions are not designed to be didactic or inflexible teaching sessions. On the contrary, the process is interactive and is at its best and most effective when the views of all family members are sought; when patients can be supported to discuss distressing experiences directly with their family, often for the first time, and then discuss how the whole family can begin to cope with this.

13.2.5.3 Problem-Solving

Evidence suggests a positive relationship between carer and patient problem-solving skills; good problem-solving in patients is linked to improved social functioning in patients and carer expressions of warmth towards patients (O'Brien et al. 2009). Kuipers et al. (2002) identifies an important role for structured and focused problem-solving within FI sessions. Given the negative impact that psychosis can exert on service users and their families, it is often important to help families to focus on one problem at any one time; to specify in exact terms the nature of the problem to be solved, and to help the family to negotiate solutions. Families are encouraged to implement (practise) cognitive and behavioural changes as part of their between session homework. This is in order to facilitate emotional processing and to promote more successful coping. In turn, the between session work can provide more immediate feedback of positive experiences, which can encourage feelings of optimism amongst all family members. At all stages, the therapists remain focused on reinforcing any attempts to implement change, however small.

13.2.5.4 Emotional Processing

As reported earlier, carers can experience and report experiencing a broad range of emotional responses as part of their role including high levels of grief and loss over ‘what could have been’ and equivalent to levels observed in a bereavement (Patterson et al. 2005). These emotions can often arise at different times within a session. As part of the tested approach to supporting carers to process these emotions and their impact, therapists will spend time normalising carer feelings in the context of what is readily known about the impact of psychosis on families. Carers are also actively encouraged to attend carer-only support groups that are designed to offer support and to help carers cope with the negative emotional sequelae.

13.3 Case Illustration

The following case of Janet and Lily¹ briefly illustrates some of the aforementioned FI in psychosis therapeutic activities. In FI, different aspects of the work can often overlap within session. For example, facilitating communication and emotional processing can also occur in the context of working on psychoeducation.

13.3.1 Janet and Lily

Janet is 25-year-old woman with a 6-year history of psychosis and is currently seen by her local community mental health team. The onset of her mental health difficulties occurred not long after she started her first job in a publishing office, after leaving college at 18 years. During the last four years, Janet has had three inpatient admissions, two of which involved her being detained under a section of the Mental Health Act (1983, 2007). The admissions were prompted by increasing concerns raised by her family, of Janet’s suspicious and paranoid behaviour, poor levels of self-care and social isolation, and increased levels of voice-related distress.

Janet experiences auditory hallucinations and often hears several voices at once. The content of the voices is predominately negative and tends to oscillate between making derogatory comments about her physical appearance, commenting on her behaviour, and issuing threats. She has poor levels of social functioning and participates in few activities during the day apart from visiting the post office once a week. Janet can generally be found in her bedroom sometimes sleeping and at other times she can be found simply lying down on her bed staring up at her ceiling listening to her voices. Janet lives with her mother, Lily (aged 54 years), and younger half brother, Adam (aged 13 years). Janet’s biological father lives abroad and they have limited telephone contact. Lily works in a part-time domestic role in

¹ This is a composite case using pseudonyms and where all identifiable details have been disguised.

the local primary school and has a childminding job for a couple of hours each week. Lily spends a lot of time driving her son to his various after-school clubs and sporting activities. In recent months, her relationship with her daughter has become strained; Lily has found her daughter's lack of motivation and inactivity (which she perceives as her 'laziness') an increasing source of annoyance and a focus of ill-tempered exchanges between both of them. In addition, she has found it difficult to cope with her daughter's minimal contribution to keeping the house going.

Following a pre-engagement session with Janet and Lily on their own, where both women were encouraged by Janet's mental health team key worker to consider family intervention sessions and given some written information about the intervention, they agreed to meet for family intervention sessions to discuss the recent difficulties in their relationship and ideas for making things a little easier for them both. The sessions were scheduled for midday when Adam was at school, which was a timing that Janet had requested. There was a discussion with the therapists about reviewing the options, at a later date, of perhaps making time to schedule a meeting where her brother might be able to attend. Overall, the family were seen for 11 sessions over a 7-month period. Each session lasted for approximately 60 min.

Engaging with individual family members is a therapist behaviour that runs throughout the duration of the intervention and not just for the first few sessions. To facilitate Lily and Janet's engagement with the sessions, the therapists met the family at home. Further, given Lily and Janet's initial reluctance to attend the sessions, the therapists were mindful of the possibility of either party dropping out and thus agreed to focus on actively trying to engage both family members. For each session, one therapist would work on positively engaging Lily, while the other would engage Janet. To ensure the therapist roles were balanced and to reduce the risk of one family member only engaging with one therapist, the therapists swapped the focus of their engagement at every session. The therapists were able to engage the family through using standard techniques such as empathy and validation alongside active listening, for example, checking with each family member whether they had heard and understood what had been said.

From the very beginning of the intervention, facilitating positive communication styles was an important area for the therapists to focus on. At the start of the intervention, Janet often sat with her head lowered. She tended to speak with a low voice tone and the pace of her speech was slow. This presentation often meant that Lily, as part of a bid to move things along and ensure the therapists time was not 'wasted', would interrupt the therapist's question that was designed for her daughter or attempt to speak on her behalf. Thus, it was important for the therapists to establish a balance between Lily and Janet in the levels of listening and talking and encourage both family members to pay close attention to how they talked and listened to each other.

Lily was able to report that one of the main issues that she wanted to address in the sessions was her concern that Janet did not want to get better. She was upset with her daughter over her lack of progress since her discharge from her most recent admission, 7 months ago. Lily felt that if Janet showed greater motivation and effort, she would 'obviously' make far greater progress and could return to work

since she was always bright. She accepted that her daughter had some difficulties with her mental health, but was aware of other people with similar difficulties who were doing more with their time. Lily often referred to a young man who was a relative of a colleague at work who had similar difficulties to Janet but held down a job in the local supermarket. One of the main issues that Janet wanted to address in the session was feeling that no one cared for her or understood what it was like with her difficulties.

In line with their agreed agenda and forming part of the problem-solving strategies, Lily was encouraged to be specific about what aspect of Janet's behaviour she was referring to and in what way she would like the situation to be different. Although she struggled with this request in the initial session, through careful questioning and the therapists' support and modelling of non-vague (clear) communications, Lily was able to specify that she would like to see her daughter looking after laundry. In behavioural terms, this meant that she wanted her daughter to be able to sort the soiled clothes from the recently laundered clothes. This was helpful for Janet to hear since sorting the laundry into clean and soiled piles was something that she felt able to do. The family were encouraged to think about how Lily could support Janet with this task. Janet was able to communicate clearly that she did not need any help. However, Lily and Janet were both able to agree that Lily acknowledging the positive contribution Janet made to the household chores was important and impacted positively on Janet's beliefs about herself.

It was clear to the therapists that some of Lily's main issues reflected, in parts, her limited understanding of psychosis and its clinical expression. Although she knew of other people with psychosis, this did not necessarily facilitate her understanding or appraisal of her daughter's symptoms. Psychoeducation proved a very helpful way to address issues around her understanding of psychosis and relate this to Janet's lived experience. It also served as a perfect opportunity to begin to address Janet's goal for the therapy and thus for Janet to explain to her mother and help her to understand how things were for her. The sessions given over to psychoeducation extended over the course of the intervention and provided a helpful platform for discussion of areas that were bothersome to Lily and Janet, but hitherto had only been raised as part of a heated argument or indirectly. As part of the discussion on positive symptoms, Janet was able to talk directly to her mother about her voice hearing, which often kept her up at night-time and impacted negatively on being able to get up the following day. In addition, the negative content of the voices tended to heavily influence her ability and motivation to engage in activities and to be with other people.

Lily reported that she had not previously been aware of the extent of Janet's difficulties. She now wondered whether trying to do something together in the evening that was pleasant could benefit Janet in terms of her mood and 'perhaps' distract her. Both women generated a few activities that they added to their 'evening fun list' and set about completing an activity and feeding back at each session on how they found it. Lily and Janet negotiated with each other what item of the list they would follow. The items on the list were varied and included activities such as watching a popular situational comedy together and going for a short walk

in a nearby park, Janet accompanying her mother to watch Adam at one of his sports classes, shopping together in the local mini market, and sitting in their garden. As we approached the end of the intervention, Janet and Lily became more flexible about when they completed items from their list and occasionally swapped an evening activity for a daytime activity at the weekend. Feedback on what the family had been able to achieve outside of the appointments and a recap of what they were planning to do always provided an excellent start and end to the individual sessions.

In parallel to addressing issues of psychoeducation, the sessions were also used to facilitate emotional processing for Lily. The family discussions about causal explanations for psychosis and for Janet's difficulties, which included discussions on the initial onset and the months immediately preceding onset were emotive, particularly for Lily. Through questioning, the therapists learnt that Lily had never really spoken to anyone about how she felt at the time or the years that followed including coping with subsequent admissions. The therapists were able to enlist the help of Janet to make suggestions about what her mother could do to help Janet to feel a little better.

The therapists also encouraged Lily to attend a support group for the family members of people with psychosis. In parallel to the FI sessions, support groups for carers can often provide a valued source of support. They provide a safe setting where an individual can express and normalise their feelings about their role and the person they care for, for example, feelings of anger, guilt, and loss (Kuipers et al. 2002; Lowenstein et al. 2010). Initially Lily was unsure about attending the group because she did not think it would be of any help to her. She was also reluctant to attend due to the timing of the group; for example, she was concerned over whether she would have enough time to prepare an evening meal for Adam and Janet and be on time for the group. Lily and Janet were encouraged to problem-solve the issue and devised a plan where Janet would prepare a pasta-based meal for Adam and herself. The therapists learnt that Janet had always liked pasta, enjoyed cooking, and looked forward to doing something else around the house. Janet reported that it was important to feel that she was doing something useful.

The shared family discussions about psychosis alongside the facilitation of communication skills, emotional processing, and problem-solving slowly but gradually led to a much more positive interaction cycle that the family were able to build upon on. This was in contrast to the feelings of hopelessness, anger, and isolation that the family previously exhibited. For the therapists, there was evidence of increased warmth between Janet and Lily. In her reflection on her experience of the sessions, Janet was candid in her reports that she was initially doubtful about attending appointments. She reported that it was helpful to do things with her mother because it provided them with some nice things to talk about. Janet also found it helpful to have the psychoeducation material to discuss since it allowed her to feel less isolated, because she felt her mother understood her a little better. Attending her brother's weekly football practice became a regular fixture for Janet. The lead she took in preparing an evening meal for her brother and herself once every 3 weeks had gradually progressed to a weekend breakfast and a weekday

meal. She frequently expressed enjoying cooking and was in discussion with her key worker about attending a community-based cookery class.

Janet continued to be distressed by some of her voices, but subjectively reported that her distress levels and episodes of feeling overwhelmed by her experiences had reduced. This was evident in her improved social functioning. As part of a plan to address her ongoing difficulties with the voices, Janet was due to be seen by a clinical psychologist for individual cognitive behavioural therapy sessions soon after the FI sessions had ended and expressed an interest in attending a community-based coping with voices group at some point in the future. In her reflection about the FI sessions, Lily said that she liked the sessions because she felt she understood more about her daughter's experiences. She reported that the meetings had increased and improved the level of communication between Janet and herself. She was attending the carers' meetings regularly and had signed up for additional carer well-being days.

13.4 Summary and Future Developments

The negative impact of psychosis on patients and their families is widely recognised in the literature. The family environment, including interpersonal exchanges, has an important role to play in patient and carer outcomes in psychosis. Since the early 2000s, family interventions have been recommended treatments for schizophrenia spectrum disorders in the UK (NICE 2003, 2009) and the USA (PORT 2004, 2010). The interventions are cost-effective, acceptable to patients and carers (Gregory et al. 2009), and underpinned by a strong evidence base particularly for their role in reducing relapse and readmission rates (Pharoah et al. 2010) even at first episode (Bird et al. 2010).

The costs of psychosis to the individual, their family, and the wider society remain high. Each relapse and readmission is associated with increased risks of further disability and social exclusion. The *raison d'être* of evidence-based family interventions in psychosis continues to be the reduction of the patient's vulnerability to and risk of relapse. Through its key therapeutic activities, which include facilitating positive communication, psychoeducation, problem-solving, and emotional processing, family members are encouraged and supported to engage in cognitive and behavioural changes. These are designed to lead to optimal outcomes, including improved family relations, adaptive coping, and more time in recovery.

Despite the strong evidence base underpinning family interventions, their proven application in routine clinical settings, and the publication of treatment guidance advocating their provision, the numbers of families actually receiving the intensive family interventions in clinical services are low (Glynn 2012; The Schizophrenia Commission 2012; Dixon et al. 2001; Berry and Haddock 2008). Anderson and Adams (1996) described FIs as effective but underused treatments. Sadly, it remains common that contact between professionals and carers can remain limited to telephone calls and only during crisis periods (Kim and Salyers 2008). Several factors have been identified as playing a role in the limited access to and provision

of evidence-based family interventions (Kuipers 2010, 2011). To date, these have included a lack of understanding from clinical staff about family interventions and its role in treatment outcomes; organisational barriers which are not conducive to staff offering such interventions to meet the specific needs of families (e.g. high caseloads; financial cutbacks; no out of hours provision; lack of time); workforce issues that include a lack of specialist training and supervision opportunities for practitioners; engagement difficulties from carers and patients; and poor translation from research settings to routine services (Onwumere et al. 2013; Prytys et al. 2011; Fadden, 2006; Kim and Salyers 2008; Berry and Haddock 2008). Thus, patients may decline an offer to engage in the intervention or refuse to have their carers involved despite having high levels of contact with their carer and carers being negatively affected by their role.

In the UK, it is typically not the job of any one professional to provide a service to families of people with psychosis. Consequently, families can often lose out and feel neglected by services that are caring for their relative (Kuipers 2010). However, it is important to note that not all families require or need intensive help (Cohen et al. 2008; Gamble 2004). Some families may not agree that help is required at a particular time point or fail to perceive the relevance for family meetings. However, most families at some point during the illness course are likely to benefit from some additional professional help. Future developments in family interventions in psychosis have begun to focus on offering the least intensive interventions necessary to reduce family distress (Cohen et al. 2008). There is some early work evaluating service models designed to offer triaged interventions that cater for those in need of full family interventions but also for those who require brief, focused interventions. The latter interventions can be delivered to carers alone or carers and patients, together, for a few sessions and are more likely to be delivered by larger sections of front-line mental health staff (Cohen et al. 2008).

Data are also emerging on the impact of utilising more novel methods for supporting families. For example, recent developments in the online provision of family interventions have yielded promising results for service users and carers in their understanding of psychosis (Rotondi et al. 2010). (Dixon et al. 2011) also offered some encouraging findings, in terms of impact on carer coping, from a randomised 12-week intervention that was delivered by family members of service users with mental health problems who had themselves undergone training.

Conclusion

As the UK Schizophrenia Commission ('The Abandoned Illness' 2012) commented, 'Families who are carers save the public purse £1.24 billion per year but are not receiving support and are not treated as partners'. There is a range of targeted psychological interventions that have good evidence for improving outcomes for both carers and patients of those with psychosis, of which FI has the largest evidence base. There is a continuing need to offer this kind of support to those with psychosis and their families. Although such therapy can be difficult to prioritise in our currently stretched mental health services,

where they can be incorporated, such as in early intervention services (Bird et al. 2010), the benefits are clear as reflected by the evidence base.

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