

**LIVING WITH PSYCHOSIS:
FAMILY PERSPECTIVES ON
GIVING AND RECEIVING SUPPORT**

Lisa Green

**D.Clin.Psy. 2003
University College London**

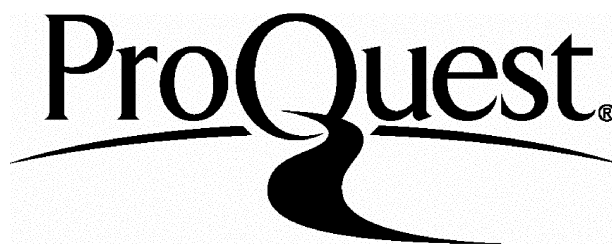
ProQuest Number: U643305

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest U643305

Published by ProQuest LLC(2015). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code.
Microform Edition © ProQuest LLC.

ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

TABLE OF CONTENTS

Abstract	1
Acknowledgements	2
Chapter 1: Introduction	3
Psychosis	4
Families and psychosis	12
Social support	28
The current study	48
Chapter 2: Method	52
Recruitment	52
Participants	55
Procedure	59
Analysis	63
Researcher's perspective	66
Chapter 3: Results	69
Background context	71
Domain one: Normal life	74
Domain two: Issues in help and support	101
Chapter 4: Discussion	127
Findings and literature	128
Methodological issues	145
Further research	155
Clinical implications	157
Conclusion	160
References	162
Appendices	183
Tables	
Table 1: Participant characteristics	58
Table 2: Domains, themes and sub-themes	70

ABSTRACT

The advent of community care has led to the increasing involvement of family members as informal sources of support for people with severe mental illness. This qualitative study explores informal helping in families living with psychosis. Nine people who experienced repeated episodes of psychosis and a member of their family were interviewed. The interview enquired about the types of help and support provided, what was helpful or unhelpful from each person's perspective and the participants' respective experiences in the process of offering and receiving support. The resultant transcripts were analysed according to the principles of interpretative phenomenological analysis.

Several themes captured the key elements of the participants' experiences; these were organised into two higher order domains. The first domain, 'Normal life', encompassed what was offered by family members and what the people who experienced psychosis found helpful. Particularly important were constancy of family interactions and a sense of asylum. 'Issues in help and support' was the second domain. This covered some of the difficulties, tensions and dilemmas which affected the families' support efforts. Despite the disruption caused by psychosis, families were not just passive in the face of psychosis and most also identified positive aspects to living with psychosis. Together, people who experienced psychosis and their family members described an active approach to managing and accommodating the difficulties imposed by the illness. The implications of these findings for researchers, mental health professionals and services are discussed.

ACKNOWLEDGEMENTS

for:

Greens, Kiflawis and Greenbergs

J and K

I would like to thank the families who participated for speaking so openly and thoughtfully about such personal and, at times, painful experiences.

Many thanks go to the people at Mind, the Manic Depression Fellowship and the Mental Health Carers' Association (particularly Sarah Nyandoro, Amanda Harris and Nick Bishop) for their assistance in recruitment. Thanks also to Nina Keay for her calm and timely typing skills.

Huge thanks to John Rhodes for his thesis-saving help with recruitment, as well as his interest and enthusiasm which revived my own.

I cannot thank Nancy Pistrang enough for her superb supervision, advice, ideas, encouragement, containment, time and concern. Many thanks also to Chris Barker for his many helpful suggestions.

And more than thanks to my 'international' proof reading and support team.

CHAPTER 1: INTRODUCTION

OVERVIEW

Psychosis is often a devastating experience for individuals and those who are close to them. In the past, many people who experienced psychosis frequently spent years or even decades in long stay hospitals or asylums (Fuller Torrey & Miller, 2001). Over the latter half of the twentieth century community care became the dominant paradigm, in part due to improved medication. This has led to the increasing involvement of informal care givers with people with severe mental illness (e.g., Dixon, 1999; Dixon, Adams, & Lucksted, 2000; Tennakoon et al., 2000). Family support has recently been described as “an ‘invisible healthcare system’, which constitutes the core long-term care provider in the community” (Ohaeri, 2003, p. 457). The difficulties faced by these families have been well documented. A large body of research has also clearly indicated certain family atmospheres which are unhelpful to the person experiencing psychosis. However, in the context of severe mental health problems, little is known about the actual help and support which goes on within these families: what it is that families are trying to do and what the person with psychosis would like from their family

In this chapter, the current understanding and models of psychosis will first be briefly reviewed together with research on the subjective experience of psychosis. This will be followed by a review of the two main strands of research into families where someone is affected by psychosis: expressed emotion and family burden. Qualitative studies into the experiences of these families will also be discussed. The second half of this chapter will provide an overview of the most relevant aspects of the social support and informal helping literature, in particular, interpersonal approaches to social support and a review of the social support literature as it has been applied to people affected by major mental health problems. Finally, the

literature on family studies and social support will be considered together in order to establish the rationale for the current study.

PSYCHOSIS

At some point during their lifetime, approximately 1% of people will receive a diagnosis of schizophrenia (for example, Stevens & Price, 2000). Figures for bipolar disorder are very similar (Kinderman & Cooke, 2000). The one year prevalence for psychosis has been estimated at 4 to 5 per 1000 people (Jenkins et al., 1997; Singleton, Robert, O'Brien, Lee, & Meltzer, 2000). Despite advancements in neuroleptic medication since the 1950s, psychosis remains a devastating and costly illness for individuals and their families (Stein & Wemmerus, 2001). For example, the annual cost of informal care for people with all mental health problems is approximately £13.9 billion (The Sainsbury Centre for Mental Health, 2003). Psychosis is also costly at a societal level: in-patient care alone for schizophrenia has been estimated at over 5% of total NHS expenditure (National Health Service Executive, 1996). Gupta and Guest (2002) calculate a total annual cost to society of £2 billion for bipolar disorder and, adapting figures from Knapp (1997), £3.9 billion for schizophrenia. Relapse rates remain high and many people with psychotic disorders continue to experience ongoing symptoms which cause distress, disturbance and incomprehension in their everyday lives (Fadden, 1998), as well as in the lives of those who are close to them (Johnson, 2000; Solomon & Draine, 1995)

Definition and concept

The term psychosis describes a cluster of symptoms in which there is generally thought to be a 'loss of contact with reality', although this statement has been charged with privileging one reality over an 'alternative reality' (e.g. Chung & Jenner,

1995; Davidson, 2003). Psychosis may involve delusions (including persecutory or paranoid ones), hallucinations and/or disorganisation of thought or behaviour. The Diagnostic and Statistical Manual-IV (American Psychiatric Association, 1994) describes a range of Axis I disorders in which psychosis may be a feature and it may also be a feature of some of the Axis II personality disorders. This chapter will mainly focus on the literature relating to schizophrenia, bipolar disorder and psychosis in general.

There is much controversy within the literature on psychotic illnesses, particularly over the status of schizophrenia. Clinical and research opinion range from people who view it as a "good working hypothesis" (McKenna, 2003, p. 26) to those who view it as a 'heterogeneous construct' representing a cluster of aetiologies and illnesses (Bentall, 1990, 2003) and others who question the value of such a concept at all (Boyle, 1990, 1996). It is important to note that neither Bentall nor Boyle deny the existence of certain behaviours and experiences. Instead they argue that, as yet, we have little understanding of how these symptoms are linked, what causes them and which are most relevant. Bipolar disorder is less contentious, although it is a broad term incorporating: bipolar I disorder (recurrent manic and depressive episodes; mania may be with or without psychosis); bipolar II disorder (recurrent major depression with hypomanic episodes); and cyclothymic disorder (recurrent depression with hypomanic episodes).

There has been protracted debate over the relationship between schizophrenia, bipolar disorder and schizoaffective disorder (Scully, Owens, Kinsella, & Waddington, 2002). For schizophrenia, three independent clusters of symptoms have been identified: reality distortion (delusions and hallucinations), disorganisation (thought disorder and inappropriate affect) and psychomotor poverty (Liddle, 1987).

In a study comparing the factor structure of schizophrenia, schizoaffective disorder and bipolar disorder, the same three clusters were present for both schizophrenia and bipolar disorder – both disorders also showed other factors, such as grandiosity in the case of bipolar disorder. Schizoaffective disorder did not show the disorganisation cluster. The authors conclude that this provides evidence for an overlap in their dimensions of psychopathology which supports the concept of a unitary psychosis (Scully et al., 2002). Mounting evidence suggests that the psychotic features of many disorders share common aetiological and physiological elements (Tsuang, Stone, & Faraone, 2000). For example, several genetic studies have found linkage to certain gene locations for psychotic disorders in general, but not for schizophrenia alone (e.g. Maziade et al, 1997, cited in Tsuang et al., 2000). In addition, impaired premorbid social functioning is not restricted to schizophrenia, but is also seen in bipolar disorder – although to a lesser extent (Cannon et al., 1997). Another similarity between schizophrenia and bipolar disorder (with psychotic features) are levels of insight during remission (Yen et al., 2002). None of this implies that the disorders are identical, but it does suggest that the nature of psychosis may be very similar across these disorders.

Models of psychosis

A vast body of literature has attempted to delineate a model of psychosis, of which this section will provide only a very brief overview. Implicit in much of the research is the conceptual framework of vulnerability-stress proposed by Zubin & Spring (1977): individuals are thought to lie somewhere along a vulnerability continuum where they have a greater or lesser risk of developing psychosis when exposed to stressors. Thus individuals with a high vulnerability will need a lower level of stress to precipitate psychosis. The vulnerability-stress model integrates biological, environmental and psychological factors into a single framework. Although the

model was developed for schizophrenia, it has been found to be applicable to a wide range of mental health problems, including bipolar disorder (Johnson & Roberts, 1995; Post, 1992).

A dimensional model of psychosis is closely allied with the concept of vulnerability-stress. Substantial evidence suggests that psychotic experiences lie on a continuum: "so-called 'psychotic' traits form part of normal individuality...although the expression of such traits can vary enormously" (Claridge, 1997, p. 301). This continuum has been termed schizotypy or psychosis-proneness. High schizotypy experiences such as magical ideation and perceptual aberration are common amongst people without psychosis (Claridge, 1997). In addition, a sizeable minority of individuals hear voices in the absence of any other indicators of psychosis (Romme & Escher, 1998). Despite the commonness of these experiences, few people later develop psychosis (Chapman, Chapman, Kwapil, Eckblad, & Zinser, 1994). This has led to exploration of both protective factors and those mediating the transition into full psychosis.

Research into psychosis has taken place in parallel across a wide range of disciplines. Although commonly divided into biological, psychological and social factors, there are no clear demarcations between, for example, biological and psychological factors or psychological and social factors. In addition, the experience of psychosis may be caused or maintained by different factors for different people (Kinderman & Cooke, 2000). There is evidence for a wide range of mechanisms, for example: cognitive, attachment, social, environmental, neurological, neurodevelopmental, neuropsychological, biochemical and genetic. To some degree both schizophrenia and bipolar disorder involve hereditary factors, although to what degree and whether this applies to all individuals with these disorders is still contentious (e.g. Bentall, 2003; Jamison, 1994). The 1980s saw the advent of

neurobiological models which viewed psychosis as a 'brain disease'. This shift, from a more parent- or individual-blaming conceptualisation, was mostly welcomed by people with psychosis and their family members since it reduced the judgement, stigma and self-blame for both groups of people: a brain disease is no more their fault than asthma or arthritis (Davidson, 2003).

There has been a common misconception that the more biological factors represent vulnerability to psychosis whilst social, psychological or environmental factors represent the stressors. In fact, each of these could be both a vulnerability factor and a stress factor (Bentall, 2003; Hooley & Hiller, 2001) or indeed a protective factor. The different processes suggested by these theories probably work simultaneously at different levels. They may also interact; for example, abuse and trauma can both influence brain structures which in turn may increase an individual's vulnerability (Bentall, 2003). A review of the theories lies outside the scope of this literature review. However, aspects of social and environmental factors, relevant to the present study, will be explored later in the chapter.

Impact of psychosis

Psychosis commonly disrupts the life course of both individuals experiencing it and their families (Stein & Wemmerus, 2001). Depending on their age and life stage when they first experience psychosis, people may be less likely to develop or maintain a career or long term relationship with a partner (Cook, Cohler, Pickett, & Beeler, 1997; Stromwell & Robinson, 1998); they thus may lose valued social roles (Stein & Wemmerus, 2001). A national survey of psychiatric morbidity found that people who experienced psychosis, in comparison with those who did not, were more likely to be separated or divorced, unemployed, live in public housing, have

lower socioeconomic status and more physical health problems (Singleton et al., 2000). These indicators point to a lower standard of living and quality of life.

A number of reactions have been documented as a response to the difficulties and losses outlined above, as well as to the experience of psychosis itself. These include "pain, the loss of hope and self-esteem, withdrawal, problems in finding a new identity, guilt, fears...depression, social withdrawal, anxiety, worrying, muscular tension, and irritability" (Appelo, Slooff, Woonings, Carson, & Louwerens, 1993, p. 55). These responses may exacerbate negative symptoms (Strauss, Rakfeldt, Harding, & Liberman, 1989) or appear as post-psychotic depression (McGlashan & Carpenter, 1976). Appelo and colleagues (1993) have suggested that these secondary reactions could be termed 'grief' and may be as disabling as the initial psychosis itself (Appelo et al, 1993). This is perhaps most clearly reflected by the words of a guest on a radio broadcast on the experience of bipolar disorder: "The worst thing about manic depression is the humiliation about having to come to terms with it" (Jason Pegler in Gregor, 2003).

As well as having to cope with their own self-judgement, people who experience psychosis frequently need to contend with societal stigma. Corrigan and Penn (1997) have contrasted two common paradigms which describe the impact of severe mental illness. Under a 'disease paradigm' the impact described above is viewed as directly attributable to the illness. The 'discrimination paradigm' maintains that "stigma and social prejudice exacerbate the impact of psychiatric symptoms exponentially. The discrimination that results is as disabling as the illness itself" (Corrigan & Penn, 1997, p. 356). Stigma can be a major problem for people who experience psychosis; society may blame them for their problems or view them as 'mad' or 'violent' (Davidson, 2003; Hayward & Bright, 1997).

Subjective experiences

There has been a relative neglect of people's subjective experience of psychosis in the research literature. This neglect risks overlooking the person and seeing only symptoms and deficits. It may also marginalise their own efforts to manage their illness (Davidson, 2003). As Strauss (1989) noted:

The role of the person in mental disorder is not peripheral, merely as a passive victim of a disease to be fixed by medicine...[they are] a person who is goal-directed, a person whose feelings and interpretations influence actions that in turn affect phases of disorder or recover, and a person who uses regulatory mechanisms (1989, p. 182).

The paucity of research on subjective experiences is particularly remarkable in view of the rich tradition, and large volume, of first person accounts of psychosis published as autobiographies; for example, Millett (1991), Schiller and Bennett (1994), and White (1979). There have also been various autobiographies written by psychologists about their own experiences with psychosis, for example, Jamison (1995), Perkins (1999), and Sutherland (1995). Peter Chadwick has written several articles (e.g. Chadwick, 1993, 1997; 2001) in which he has managed to integrate his two 'psychiatric careers' (after Perkins, 1999): as someone who has experienced psychosis and as an academic psychologist. In these, Chadwick has created a fascinating account merging prevailing psychological theories of psychosis with an 'insider' perspective.

There have been three main approaches to research on subjective experiences in mental health: intensive case studies, interviews and written autobiographical narratives. The majority of studies have adopted the latter approach and analysed

pre-published first person accounts (e.g. Acuff, 2000; Crossley & Crossley, 2001; Ridgway, 2001; Stanton & David, 2000). Acuff (2000), for example, summarised the recurring themes in a special issue of the *Journal of Clinical Psychology* which focused on the 'consumer / psychiatric survivor / ex-mental patient' movement (c/s/x). She identified seven key themes: (1) labels are stigmatising; (2) pathology-based nosologies are destructive; (3) focus should be on the individual not the label; (4) recognise the value of alternative treatments: "sometimes the most healing treatment is one that occurs without us" (p. 1463); (5) the importance of peer support and self help; (6) involve the service user voice in training therapists; and (7) services should be recovery oriented.

It should be noted, however, that the authors of first person accounts are likely to be atypical of those who experience psychosis. First, not everyone can write a book, however healthy. Second, most of the books, ultimately, have a recovery narrative which culminates in near symptom-free status. Sadly this is not a pathway which everyone who experiences psychosis will take. Even the invitation to submit articles to the 'First Person Account' section, regularly published in the National Institute for Mental Health (NIMH) journal *Schizophrenia Bulletin*, states: "articulate patients, with experiences they believe should be shared, might encourage these patients to submit their articles" (emphasis added).

Although an advocate of any form of research which increases our understanding of subjective experiences of psychosis, Davidson (2003) particularly recommends open-ended interviews as a way around this articulacy-bias.

For qualitative research to be most useful in informing the development of interventions to assist such people in reclaiming their lives, studies need to be based on the actual experiences of the people living with the

conditions of interest, and as much from their own perspective and in their own terms as possible. (Davidson, 2003, p. 29)

The personal perspective of people who have experienced psychosis is potentially of great value to service provision. It can provide feedback and recommendations as in the Acuff review described above. Additionally, it helps service providers to understand seemingly 'un-understandable', experience: although a characteristic feature of psychosis is often a lack of insight and awareness, the first person account literature is replete with explanations and interpretations provided by people after they have regained some stability.

FAMILIES AND PSYCHOSIS

Context

The trend towards deinstitutionalisation and consequent care in the community began in the 1950's and culminated in the NHS and Community Care Act (1990). More recently, a number of government White Papers and Acts have formally acknowledged the central role of 'carers' in the lives of vulnerable people. These include Carers (Recognition and Services) Act (1995); Carers and Disabled Children's Act (2000) and Standard Six: Caring About Carers in the National Service Framework for Mental Health (1999). As the latter estimates, "about half of those with severe mental illness live with family or friends, and many others receive considerable support from them" (p. 69). The increasing involvement of informal care givers with people with psychosis can be, primarily, attributed to three historical factors: the advent of new models of psychosis which are not predicated upon families as an aetiological factor; improvements in medication, making it more likely that people with psychosis can mainly reside outside hospital; and, as already mentioned, community care (e.g. Dixon, 1999; Dixon et al., 2000; Tennakoon et al.,

2000). Much of the responsibility for everyday care and support now resides with these informal care givers who are, predominantly, family members (e.g. Tennakoon, et al., 2000). The majority are parents, although spouses, children and siblings may also be involved (Jones, 1997; Stromwell & Robinson, 1998). Although they may rarely be provided with a choice, there is little evidence that families are unwilling to accept this responsibility or to begrudge their role (Johnson, 2000).

There has long been recognition that what happens within families influences the course of schizophrenia. Although there has been less research into families and bipolar disorder, there is a similar conclusion on the influential role of families (e.g. Miklowitz, Goldstein, Nuechterlein, Snyder, & Mintz, 1988). While families of people with schizophrenia were initially viewed as causative agents in the aetiology of the illness (e.g. Bateson, Jackson, Haley & Weakland 1968, cited in Stein & Wemmerus 2001), this does not seem to have been the case with bipolar disorder (Jamison, 1994).

There have been two dominant strands of research informing the understanding of, and interventions with, families with a member with schizophrenia: expressed emotion (EE) and family burden. Before I consider these, however, a brief note on terminology is necessary. Although common in the literature and government documents, the term 'carer' can be viewed negatively by those to whom it is applied – they may not define themselves as such. In addition, as Perkins (2001) states, "If you are sane, you have mothers, fathers, siblings, partners, children. But if you have mental health problems, then these people become 'carers'" (p. 6). Thus I have tried to avoid use of the term carer and instead used family member or care giver as suggested by Ohaeri (2003).

Expressed emotion

Concept and studies

The term expressed emotion (EE) describes negative or intrusive attitudes articulated by relatives about the person who is ill. It is viewed as a measure of the family atmosphere (Hooley & Hiller, 2001). EE is operationally defined by an audio-taped interview assessing the number of hostile or critical comments and the degree of emotional overinvolvement. Initially there were two further scales measuring warmth and positive remarks, however these were not found to be predictive and are rarely used (Kuipers, 1995). Judgements are based on tone of voice as well as verbal content. Families are viewed as either high or low in expressed emotion. Although family members are interviewed separately, if a single member is rated as high the whole family is given a high classification.

Expressed emotion grew out of the work of George Brown and colleagues who were investigating the influence of family life on the course of schizophrenia. They found a marked association between the family's EE status and relapse rates of their relative with schizophrenia in the nine months subsequent to discharge (Brown, Birley, & Wing, 1972). Relapse rates were nearly four times higher for individuals returning to high EE homes in comparison to low EE homes. This striking finding has been replicated many times (e.g. Vaughn & Leff, 1976). Medication adherence appears to have a protective role; individuals who were discharged to live in a high EE environment were significantly less likely to relapse if they were taking medication, although relapse rates still remained higher than those of people living in a low EE environment (Vaughn & Leff, 1976). In a meta-analysis of studies on the link between EE and relapse in schizophrenia, Kavanagh (1992) confirmed the predictive power of EE: the median relapse rates for high and low EE families were 48% and 21% respectively. Similar findings have been found whether EE status is

assessed at discharge from hospital or during remission (King & Dixon, 1999). In addition, associations between high EE and relapse have also been found with other disorders such as bipolar disorder (see, for example, Miklowitz et al., 1988) and major depression (Vaughn & Leff, 1976). Not all studies, however, have provided supportive evidence and several have reported negative findings (e.g. McCreadie & Phillips, 1988). This has led to a refinement in the way EE is measured and conceptualised (Atkinson & Coia, 1995); for example, relapse is now defined as exacerbation of symptoms rather than readmission to hospital (McCreadie & Phillips, 1988). Overall, EE is widely considered to be a robust predictor of relapse (Kuipers, 1995).

Affective style and communication deviance

Whilst this section focuses on EE, brief mention must also be made of two other measures of family relationships. Affective style (Doane, Falloon, Goldstein, & Mintz, 1985) is very similar to EE and measures three emotional verbal behaviours: criticism, guilt induction and intrusiveness. Studies employing affective style have similar findings to those of EE (for a review, see, Hooley & Hiller, 2001). Communication deviance measures the structure, clarity and logical coherence of speech by family members (Singer & Wynne, 1965, cited in Hooley & Hiller, 2001). It appears to distinguish families in which one person experiences psychosis from other families (Miklowitz et al., 1991) and it is suggested to be an indicator of vulnerability to psychosis (Subotnik, Goldstein, Nuechterlein, Woo, & Mintz, 2002). In comparison with the work on EE, little attention has been paid to either communication deviance or affective style.

Issues of causality

The findings from EE studies have been interpreted as families with high EE status somehow *causing* relapse (King, 2000; Lefley, 1992). Implicit within this interpretation are the assumptions that the EE measured during an interview does indeed reflect family interactional style, that this influences the stress level of their relative with severe mental illness, which in turn influences symptoms and relapse rates (King, 2000). However, since its origin, there has been uncertainty regarding the actual direction of causality between EE and symptom level (e.g. Birchwood & Cochrane, 1990; Brown et al., 1972; Fadden, Bebbington, & Kuipers, 1987b). Causality has been difficult to untangle since most of the studies are correlational (Hooley & Hiller, 2001; King, 2000).

In order to assess the direction of causality, King (2000) carefully designed a study involving three waves of assessment of EE components and symptom severity at nine-month intervals. This study examined the relationship between EE in mothers of young adults with schizophrenia. The author notes that "although the current study cannot *prove* causal associations, the results can be used to support hypotheses about causal effects" (King, 2000, p. 74). The major findings of this study were: (1) high EE in mothers is not associated with either concurrent or future symptom exacerbation in their child; (2) there is no association between positive symptoms and high EE; (3) negative symptoms are associated with both critical comments and emotional overinvolvement; and (4) it is likely that highly critical mothers are responding to symptom severity rather than a cause of symptom severity. In conjunction with earlier studies (King & Dixon, 1996, 1999), King notes that emotional overinvolvement has been found to predict both relapse as well as positive outcomes such as social adjustment. Emotional overinvolvement has two main components, overprotectiveness and self-sacrifice. King suggests that these

should be viewed separately, with the former tending to be more negative, whilst the latter may be positive. She also noted that different components of EE predicted relapse in mothers and fathers - with critical comments the key factor from fathers. Whilst not rejecting the concept of EE entirely, King concluded that the association between EE and relapse is significantly more complex than simple EE status suggests (King, 2000).

Limitations of expressed emotion

In spite of its empirical robustness, many aspects of EE remain unclear. There is a "lack of understanding of EE's interactional underpinnings" (Birchwood & Cochrane, 1990, p. 857). It also still remains to be fully resolved which underlying factors of family's interactions are detected by the measure of EE, although some clues are emerging in the literature (Kuipers, 1995). For example, high EE status is associated with an unpredictable home environment (MacCarthy, Hemsley, Shrank-Fernandez, Kuipers, & Katz, 1986) and poor listening skills (Kuipers, 1995). Conversely, low EE status families are not just neutral, but make more supportive statements and can defuse arguments (Kuipers, 1995). Possible negative aspects to low EE status have been overlooked, such as indirect expression of irritation or neglect (Lefley, 1992). It is also unclear whether EE status represents an enduring trait in family interactions or an intermittent state (e.g. Ohaeri, 2003). Finally, some researchers consider EE to not be cross-culturally relevant (Lefley, 1992), although others argue that it has a robust and predictive efficacy both within and between cultures (e.g. Birchwood & Cochrane, 1990).

Another problem with the EE concept is that families resent the implied blame for the relapse of their family member (e.g. Kuipers, 1992; Lefley, 1997a). Although those who developed and continue to research the EE concept have emphasised

that it should not be used to imply blame, the term 'high EE family' has become a pejorative label (Kuipers, 1992). It has been suggested that EE should instead be viewed as an understandable response to the difficulties these families encounter (Hatfield, Spaniol, & Zippel, 1987). In addition, framing the family's input only in terms of relapse precipitation, obscures one alternative interpretation: some families may be acting as a buffer to stressors experienced by the person with psychosis and hence may be protecting their wellbeing. (Johnson, 2000). The EE approach has also been criticised for its focus on family only as ancillary - in the context of their impact on the course of their relative's illness - whilst ignoring the family's overall experiences (Lefley, 1997a).

A third issue relates to the factors influencing the responses by family members to their relative. A recent study adapted a cognitive model of illness representation, derived from the health psychology literature, to exploring family members' perceptions of schizophrenia. (Barrowclough, Lobban, Hatton, & Quinn, 2001). They found an association between these perceptions and both the family members' wellbeing and aspects of their relationship with the person with schizophrenia. Although this is a preliminary study, it has important implications since it suggests that both EE and family burden may be moderated by the family members' understanding of the illness (Barrowclough et al., 2001).

Family burden

The recognition that an illness in one member also has an impact on the family, and that families may need help or support in their own right, led to a parallel proliferation of studies focusing on the burden that these families experience (Baronet, 1999; Solomon & Draine, 1995). Family burden is thought to consist of two broad components: objective burden and subjective burden (Hoenig & Hamilton,

1966 cited in Baronet, 1999). Objective burden involves practical disruptions to the family as a consequence of the symptoms and behaviour of the person with psychosis; for example: managing symptoms, need for supervision, financial costs, providing transportation and household tasks. Subjective burden represents the psychological consequences for the family, including the extent to which they perceive themselves as burdened; for example, fears, worry and stigma (e.g. Baronet, 1999; Cuijpers, 1999; Maurin & Boyd, 1990; Phelan, Bromet, & Link, 1998).

It is now widely accepted that mental illness in a relative may impose substantial demands on family members in various domains; these include: constricted social and leisure activities, financial difficulties, dealing with mental health services and their own physical and psychological wellbeing (e.g. Baronet, 1999; Fadden, Bebbington, & Kuipers, 1987a; Szmukler, Herrman, Colusa, Benson, & Bloch, 1996a). Assessments of the extent of this burden have ranged from substantial (Maurin & Boyd, 1990) to mild to moderate. Solomon and Draine (1995) suggested this range may reflect assessments at different periods of the illness such as during remission and acute phases. Few studies have assessed changes in burden through time, but these indicate that family burden remains stable in the absence of formal intervention (Joyce et al., 2003; Magliano et al., 2000). Interestingly, one study has reported the burden experienced by families appears to be the same whether treatment of their relative is hospital or community based (Szmukler, Wykes, & Parkman, 1998; Thornicroft & Goldberg, 1998).

Factors associated with family burden

A number of studies have explored the factors associated with family burden, although it is, as yet, unclear whether these factors also influence families' overall sense of wellbeing (Webb et al., 1998). The studies have sometimes yielded

contradictory findings which may be attributable to their non-distinction of illness phase (Baronet, 1999; Solomon & Draine, 1995) or the nature of the relationship such as parent, spouse, child or sibling (Harvey & Burns, 2003; Jones, 1997). With regard to mental health problems, three broad factors account for the majority of the variation in family burden: family members' sociodemographic factors; severity of stressors related to the illness; and, family members' personal and external factors (Baronet, 1999; Solomon & Draine, 1995).

In terms of sociodemographic factors, burden has mixed associations with care givers' age, ethnicity and living with the person who is ill (Baronet, 1999). Age seems to influence the content of burden rather than its magnitude (Cook, Lefley, Pickett, & Cohler, 1994; Lefley, 1997b; Reinhart & Horwitz, 1995), although the findings are inconsistent (Baronet, 1999). There is some suggestion that being from an ethnic minority may reduce burden (Reinhart & Horwitz, 1995), although this, too, is equivocal (Cook et al., 1994; Solomon & Draine, 1995). Sharing a house with the person who is ill, is associated with increased burden in some studies but not in others (Reinhart & Horwitz, 1995; Solomon & Draine, 1995). Finally, the nature of the relationship was found to be salient in some studies (Jones, 1997; Reinhart & Horwitz, 1995) but not in others (Baronet, 1999). No relationships were found between burden and gender, education or socioeconomic status (Baronet, 1999).

Family burden has been found to be strongly related to the presence of symptomatic behaviours (Pickett, Cook, Cohler, & Solomon, 1995). This is one of the few consistent findings across these studies and there is robust evidence that severity of symptoms is the most important predictor of burden (Baronet, 1999; Ohaeri, 2003). Interestingly, there is no association between burden and diagnosis, such as bipolar disorder or schizophrenia (e.g. Reinhart & Horwitz, 1995; Solomon & Draine, 1995).

In terms of the personal coping resources of the family member, personality and situational variables, such as sense of mastery, self-efficacy and satisfaction, have been found to be negatively related to subjective burden (Solomon & Draine, 1995). There are no consistent relationships between objective burden and external resources such as social support, membership of self-help group or professional support (Magliano et al., 2002). Social support is related to lower subjective and overall family burden (Magliano et al., 2002), whereas perceived sufficiency of professional support and self-help support is associated with reduced objective burden (Baronet, 1999).

Coping

Framing the difficulties these families encounter solely as burden may be an oversimplification of the processes involved (Joyce et al., 2003; Szmukler et al., 1996b). A number of studies have suggested the adoption of a model of coping to provide a more comprehensive picture (e.g. Scazufca & Kuipers, 1996; Szmukler et al., 1996b). These have mostly been based upon the stress-coping model (Lazarus & Folkman, 1984). Under this model, burden is conceptualised as the stress resulting from an interaction between the family member's appraisal of their relative's problems and their appraisal of their coping abilities and resources. Appraisals may be influenced by external factors such as social support.

Studies using this model have delineated those strategies most associated with specific stages of illness and more successful outcome. One study found that more coping strategies are adopted during crisis in comparison to stable periods; these tend to be problem-solving strategies when the situation is viewed as amenable to change and avoidance if the situation is appraised as immutable (Scazufca & Kuipers, 1996). There also seems to be variation in the type of coping adopted

according to different family characteristics. Younger care givers, people with more social or professional support and those with younger relatives with mental illness are more likely to adopt a problem-focused coping style, such as information seeking. Conversely, care givers with less social support or those who have lived for longer with people with mental illness, frequently adopt emotion-focused strategies, such as avoidance or resignation (Magliano et al., 2000). The overall pattern of coping appears to be similar whether their relative experiences bipolar disorder or schizophrenia, although there is a tendency for family members of people with bipolar disorder to use more problem-focused strategies (Chakrabarti & Gill, 2002).

Limitations of family burden

Researchers have found consistent and strong evidence for the presence of burden in families where someone experiences psychosis. However the finding is so robust that it has virtually occluded other explorations of the family's experience, for example their resilience (Marsh et al 1996) or the positive aspects of caring to the care giver (Johnson, 2000). It has also been criticised for portraying the person with psychosis solely as a source of disruption and burden (Stein & Wemmerus, 2001), and for failing to acknowledge the contributions they make within the family (Johnson, 2000; Perkins, 2001). In itself the term 'burden' carries connotations of negative emotions. It has been suggested that this term should be replaced by 'caregiving' to allow acknowledgement of the positive aspects of caring (Ohaeri, 2003).

The focus on burden has also tended to cast all family members as carers: "To be a relative or a friend is to enjoy a reciprocity – a kind of equality...In the move from relative or friend to 'carer' this reciprocity is lost" (Perkins, 2001, p. 6). The family burden literature considers the impact of the illness on the family, and their attitudes

towards the illness and person with psychosis, but rarely captures the extent of the family's affective experience (Lefley, 1997a). As Tuck and colleagues noted, "exploration of caregiving burden cannot give us the whole, multidimensional aspect of the caregiving experience" (Tuck, du Mont, Evans, & Shupe, 1997, p. 119). This has been echoed by Fadden (1998, p. 119): "any linear, unidirectional models of family functioning would never be sufficient to explain the complex interactions among family members". The focus in family burden studies has been on what families are dealing with; what families are trying to do has received far less attention.

Family experience: qualitative studies

It seems as if neither EE nor family burden approaches explore the detailed dynamics of what is actually happening within families. In light of these criticisms, a number of researchers in the area have called for an exploration of families' experiences which go beyond studies of EE and family burden (Johnson, 2000; Saunders & Byrne, 2002; Tuck et al., 1997). Greater understanding of the experience of family care givers would facilitate services to support, educate and counsel these families (Tuck et al., 1997). There has also been a growing interest in qualitative methodologies in this area since they allow descriptions of experiences which quantitative studies of family factors cannot capture (Johnson, 2000).

As yet, only a few qualitative studies have examined the family experience of caring for a person with severe mental illness (Ohaeri, 2003). These have focused on different aspects of the family experience: general experiences of caring (Tuck et al., 1997); how family members make sense of their experience and how this changes through time (Rose, 1998; Stern, Doolan, Staples, Szmukler, & Eisler, 1999; Veltman, Cameron, & Stewart, 2002); positive aspects of caring (Veltman et al.,

2002); resilience in family members (Mannion, 1996; Marsh et al., 1996); chronic sorrow (Eakes, 1995); and a life course perspective (Stein & Wemmerus, 2001). Despite their differing focus, a number of common themes emerged from these qualitative studies, including: loss, grief or chronic sorrow, positive aspects of caring, concern for the future, and relationship with formal services. Many of these mirror some of the key themes in the literature on caring in other circumstances, such as with people with dementia or children with disabilities. Together these studies demonstrate that, like the experience of mental illness itself, caregiving is not a passive acceptance of role, but an active engagement with the issues faced, involving adaptability as well as cognitive and emotional transformations (Ohaeri, 2003; Stein & Wemmerus, 2001). The common themes are briefly expanded below.

Participants in these studies described a sense of loss, especially in the early stages of their relative's illness (Tuck et al., 1997). This involved both a perceived loss of their relative's social roles (Marsh et al., 1996; Stein & Wemmerus, 2001) – such as independent living, employment or personal relationships – and loss of the person they had known as their relative (Rose, 1998; Tuck et al., 1997). Due to the uncertainty associated with severe mental illness there is no predictable end for this sense of loss (Eakes, 1995). This can lead to grief or chronic sorrow. 'Chronic sorrow', a term first introduced by Olshansky (1962, cited in Eakes, 1995), describes a "pervasive sadness that is permanent, periodic, and potentially progressive in nature" (Eakes, 1995, p. 78). Conversely, a few studies have also identified positive aspects associated with family experiences of caring, such as, family adaptability, resilience, personal growth, or development and family cohesion (Mannion, 1996; Marsh et al., 1996; Stein & Wemmerus, 2001; Veltman et al., 2002). It has been suggested that a greater emphasis should be placed on positive aspects to counteract the prevailing negative view of providing care (Veltman et al., 2002). This

would enable family interventions to incorporate focus on the positive qualities of families, thereby deemphasising pathology and powerlessness (Marsh et al., 1996).

Family members also expressed concern for the future (Stein & Wemmerus, 2001; Stern et al., 1999; Tuck et al., 1997). This was either in terms of trying to maintain hope for a better future for their relative (Marsh et al., 1996; Rose, 1998; Tuck et al., 1997) or, particularly in the case of parents, concern about what would happen to their relative if or when they were no longer able to care for them (Stein & Wemmerus, 2001; Tuck et al., 1997). One study noted a difference between the degree of long term commitment expressed by different family members. For example, parents stated that their child would always have a place with them if needed, whilst partners reported that they would stay as long as their relative made an effort to help themselves (Rose, 1998).

A strong theme emerging from many of the studies was the families' relationship with formal services. The majority of participants expressed dissatisfaction and frustration with the mental health and, since these were North American studies, legal systems (Johnson, 2000; Saunders & Byrne, 2002; Tuck et al., 1997; Veltman et al., 2002). Family members felt excluded from, and ignored by, formal services. They wanted a partnership or collaborative relationship: to be listened to and to be actively involved in the treatment and treatment planning, of their relative. They also wanted more information on the illness their relative experienced together with ways of caring and coping.

All but one of the studies described in this section have focused exclusively on the relatives of people who experience severe mental illness. The exception adopted a life course perspective to examine the reciprocal impact of schizophrenia on the whole family, including siblings, parents and the person with schizophrenia (Stein &

Wemmerus, 2001). The experiences of people with psychosis and their families have rarely been explored within the same study (Hatfield, 1987, cited in Stein & Wemmerus, 2001). Instead the two strands of research have remained separate. This has prevented an understanding of the ways in which the *entire* family makes sense of, and adapts to, the situation and the ways in which they try to help one another. It has also resulted in most studies portraying the person with psychosis as a source of burden or disruption, unable to contribute to family life. Finally, including the people with psychosis also legitimates their role as part of the family (Stein & Wemmerus, 2002).

Within the consumer movements, there are frequently opposing views among user and carer groups...For disorders such as psychosis which are complex in nature, we need interactive, multi-dimensional models which take account of all of the relevant variables. The first challenge into the next century therefore is integration of models so that the needs of all those involved are taken into account. (Fadden, 1998, p. 120)

Family interventions

Recognition of the association between EE and relapse rates led to the development of a range of psychosocial family interventions. (Dixon et al., 2001; Fadden, 1998; Pitschel-Walz, Leucht, Baeuml, Kissling, & Engel, 2001). At least initially, the primary aim of these was to reduce relapse rates for the person experiencing psychosis, with the goal of reducing family burden as important but subsidiary (Fadden, 1998; Dixon, 2001). Although almost all involve psychoeducation as a core component, a variety of programmes have been

developed, ranging from single family therapy to group educational courses (for a review, see, Dixon et al., 2001; Pitschel-Walz et al., 2001).

A recent meta-analysis found that involving families of people with schizophrenia in family interventions can reduce relapse rates by an average of 20% and that rates remained lower for at least the next few months or years (Pitschel-Walz et al., 2001). Another, smaller, meta-analysis concluded that these interventions can have a considerable impact on family burden (Cuijpers, 1999). Both analyses noted that the best outcomes are for programmes of more than three months' duration, (Cuijpers, 1999; Pitschel-Walz et al., 2001). Family interventions which combine education about the illness, support, problem-solving and crisis intervention are most effective (Lehman & Steinwachs, 1998). Despite these findings, in many countries (including the UK), family psychoeducation programmes have yet to become an integral part of treatment for people experiencing psychosis and their families (Perkins, 2001).

Summary: families and psychosis

Due to a number of converging factors, family members are increasingly involved as primary care givers for people who experience psychosis. In recognition of this, a large body of literature has focused attention on families and psychosis. There have been two main strands: expressed emotion and family burden. The former focuses on the wellbeing of the person who experiences psychosis, the latter on family members' wellbeing. To a far lesser extent, family experiences have also been explored in qualitative studies. However, the perspective, voice and experiences of the person with psychosis has, almost entirely, been absent from this literature – leading to a call for their inclusion. Although much has been elucidated about families where one person experiences psychosis, there are still many areas which

are unknown. In particular, it remains unclear what factors motivate families to respond as they do: the 'interactional underpinnings' of family support.

The next section turns to the literature on social support which helps to shed some light on the factors influencing support within families and how support may be delivered within ongoing relationships.

SOCIAL SUPPORT

The literature on social support, particularly its interactional aspects, provides an alternative perspective on what might be happening within these families. It is an extensive literature and only the most salient aspects to this study will be reviewed. In order to understand the importance of friends and family in providing support, this section will begin with an overview of people's help-seeking behaviour – where people turn when they need support. Following this is a brief examination of the key findings, dimensions and mechanisms of social support. Having provided a context, interpersonal aspects of social support will be reviewed. Finally the section concludes with a detailed overview of the literature on psychosis and social support.

Help seeking and informal helping

Sociological and psychological studies have consistently shown that when people need help, they tend to seek it from people with whom they have close relationships (Clark, 1983; Cowen, 1982). People also look first to their everyday relationships for support in the context of psychological problems (e.g. Barker & Pistrang, 2002; Cowen, 1982). When asked who they would talk to about personal or emotional problems, British adults endorsed partners, close relatives, friends and neighbours above the family doctor, who in turn was two and a half times more frequently endorsed than a mental health worker (Barker et al., 1990). Despite this, most

literature about helping processes and effectiveness had focused on that offered by formally trained mental health professionals (Cowen, 1982; Barker & Pistrang, 2002).

In the discussion below, informal helping refers to “helping between ordinary people in everyday settings” (Barker & Pistrang, 2002). The prefix ‘formal’ implies trained mental health professionals such as counsellors or psychologists. The distinction lies in training, form of support offered and the setting in which it is offered (Cowen, 1982). There is a continuum between formal and informal support which includes, for example, family doctors, clergy, support workers and community workers (Cowen, 1982). There is, of course, no clear demarcation and there are many commonalities in the processes involved in formal and informal helping.

It is not just that people look first to informal sources of support; they may never seek formal support for their difficulties. The recent UK Survey of Psychiatric Morbidity, found that less than 14% of people with a neurotic disorder were currently in receipt of treatment (Bebbington et al., 2000). Certain groups of people are even less likely to seek help. Cultural factors influence help-seeking behaviour; they shape both the recognition of potential problems as well as ways of dealing with these problems (Kirmayer & Corin, 1998; Rogler & Cortes, 1993; Sheikh & Furnham, 2000). Cultural norms may not define some symptoms as undesirable, for example, in the Xhosa culture voice hearers are regarded as gifted and trained as healers (Jones, Guy, & Ormrod, 2003). In other cultures, particularly South-East Asian, seeking formal help is stigmatised since it represents a tacit public admission that such help is needed and results in a ‘loss of face’ for the whole family (Sue, 2002). In terms of where help is sought, some people may make more use of religious or culturally based institutions, others may be more likely to turn to family or close community ties (Cinnirella & Loewenthal, 1999; Summerfield, 1999).

Other factors also influence people's help seeking behaviour. For example, logistic or geographic constraints on service provision may impede help-seeking (Cowen, 1982). In US studies, people with low socioeconomic status tend to experience a greater frequency of mental health difficulties, but make less use of formal services (Link & Dohrenwend, 1980, cited in Rogler & Cortes, 1993, Nadler, 1991). This finding may be less relevant within a free public health system such as the NHS. Socioeconomic status did not affect the proportion of people seeking formal treatment in either the hypothetical or actual help-seeking UK surveys mentioned above (Barker et al., 1990; Bebbington et al., 2000).

The more psychological problems people are experiencing, the more likely they are to seek help – from all sources (Barker et al, 1990). People's help seeking behaviour may thus be conceptualised as a pathway with help being sought first from informal sources before, if still necessary, turning to formal sources (Rogler & Cortes, 1993). This has been likened to people managing their own form of 'stepped care' (Barker & Pistrang, 2002; Haaga, 2000). Even when people are in receipt of formal treatment, they may simultaneously use informal sources of support (Barker & Pistrang, 2002).

This pattern of help seeking behaviour suggests that we should consider people's natural bias towards informal help in designing interventions (Barker & Pistrang, 2002). However, prior to doing so, it is necessary to understand the elements of informal help. What is it that people are offering or seeking? Under what circumstances? What is helpful or unhelpful? The field of informal helping forms part of the wider literature on social support, within which tentative answers to some of these questions may be found. Since this is an enormous field, a very brief overview will first be provided setting out the relationship between social support and

wellbeing. This will be followed by a more detailed review of the most relevant theoretical aspects and empirical findings.

Social support and wellbeing

Definitions and concepts

The notion that social support is important for wellbeing is intuitively apparent and has been recognised for centuries (Barker, Pistrang, Shapiro, & Shaw, 1990; Brugha, 1995; Cobb, 1976; Monroe & Johnson, 1992). In the academic literature the field has grown exponentially since the earliest articles appeared three decades ago (for early reviews, see, Cassel, 1976; Cobb, 1976). From its origins in epidemiological studies, the concept has been developed by a wide range of disciplines, such as psychiatry, psychology, biology, sociology and public health (Brugha, 1995; Coyne & Bolger, 1986). Across these fields the notion that social support is a good thing has been, more or less, upheld.

However, the breadth of exploration has come at the cost of unity and utility; as Monroe and Johnson (1992) have commented, "the gangly literature lacks an overriding sense of coordination and coherence" (1992, p. 93). In the main, the field has been empirically led rather than theory driven (Coyne, Ellard, & Smith, 1990). Despite many attempts to define the concept, none have been sufficient to encompass all, or even the majority, of uses of the term (Veiel & Baumann, 1992). Social support has become such a heterogeneous concept that it is unlikely that a single theoretical formulation could be adequate (Veiel & Baumann, 1992). This has been described as "a persistent vagueness in the concept of social support" (Coyne & Bolger, 1990, p. 149).

Social support has been conceptualised in multiple ways and different fields have tended to focus on different aspects of social support. For example, in the sociological literature, support is conceptualised as a social network. In psychology, studies have focused on such factors as: functional category of support (e.g. emotional, informational or instrumental); the quality of available support; and individuals' perceptions of, or satisfaction with, the support they receive. There is a growing consensus that social support is best viewed as a multidimensional concept (e.g. Barrera, 1986; Uchino, Cacioppo, & Kiecolt-Glaser, 1996; Veiel, 1985).

The association with wellbeing

Overview of studies

There is a robust association between social support and both physical and psychological wellbeing (e.g. Cohen & Wills, 1985; Coyne & Bolger, 1990; Hogan, Linden, & Najarian, 2002; Johnson, Meyer, Winett, & Small, 2000). Social support has a beneficial role in a range of physical health problems, from susceptibility to the common cold (Cohen, Doyle, Skoner, Rabin, & Gwaltney, 1997) to reduced mortality in cancer (Ell, Nishimoto, Mediansky, Mantell, & Hamovitch, 1992). In terms of psychological wellbeing, social support has also been implicated in adaptation to a range of adverse life events, such as bereavement (Lehman, Ellard, & Wortman, 1986) and unemployment (Gore, 1978). Positive associations have also been demonstrated between social support and the course of many mental health problems, particularly chronic depression (e.g. Brown & Harris, 1978).

The association between social support and wellbeing has, therefore, been well established. However, the measures used have tended to be non-specific, merging different psychological states, phases and disorders into a single index of functioning such as 'distress' (Munroe & Johnson, 1992). The majority of studies on

social support and mental health have focused on the more common mental health problems such as depression and other non-specific, non-psychotic disorders (Brugha, 1995). It is likely that different aspects of support are relevant both between disorders as well as within disorders at different stages (Munroe & Johnson, 1992).

Social strain

Social relationships, however, are not always beneficial. Nearly three decades ago, Cobb pointed out that “social support is not a panacea” (Cobb, 1976, p. 310). Despite this, a Panglossian perspective has dominated the social support literature which has mostly overlooked the fact that social relationships can be a source of stress or strain as well as support (Rook, 1990). Unhelpful support can include discouraging or withdrawing from open communication, over or under-emphasising the impact of illness and premature encouragement of recovery (Pagel, Erdly, & Becker, 1987; Pistrang & Barker, 1995; Rook, 1990). What is helpful from one person may not be from another – or may even be distinctly unhelpful (Dakof & Taylor, 1990; Rook, 1984). Likewise, the degree of unhelpfulness may differ for different sources of support; there is evidence to suggest that conflict with intimates is likely to cause the most distress (Coyne, et al., 1990; Rook, 1990).

It is important to consider quality as well as quantity in social relationships. Although social relationships are most often beneficial, when negative interactions do occur they may have a powerful impact (Coyne & Bolger, 1990; Rook, 1990). These negative elements have a stronger and more consistent influence on wellbeing than the positive elements of social relationships (Rook, 1984). Most global measures of satisfaction with support, however, do not disentangle negative from positive perceptions but instead aggregate the two into a summary evaluation. People who apparently lack support may be retreating from adverse relationships and what is

measured by 'low support' may be either the absence of supportive relationships or the presence of adverse support (Coyne & DeLongis, 1986). There is growing evidence for a threshold effect above which 'better' social support adds little, that is "the critical distinction is between having no support relationships and having at least one" (Coyne & DeLongis, 1986, p. 454). Thus it may be that most of the apparent benefits of a good relationship could be better construed as the absence of the detrimental impact of a poor relationship (Coyne & Bolger, 1990; Coyne et al., 1990).

Mechanisms

Despite the general acceptance of a robust association between social support and health, what is less clear is *how* social support contributes to wellbeing. Researchers have focused at a number of different levels of explanation. In the psychosocial literature, social support is viewed as influencing cognitions, emotions and behaviours (Cohen, Underwood, & Gottlieb, 2000). It is thought to do so by such mechanisms as: providing norms for appropriate behaviour (e.g. Cohen et al., 2000); bolstering self cognitions such as self esteem (Brown & Harris, 1978; Wills, 1991); problem solving through provision of an alternate perspective (Barker & Pistrang, 2002); coping assistance (Thoits, 1986); and, acting as an impetus for self care through a sense of shared fate (Coyne & Bolger, 1990). There has been particular debate over whether support has a role only when people are experiencing stress (stress-buffering model) or whether it has a beneficial effect irrespective of stress (main or direct effect model) – Cohen and Wills (1985) have suggested there is evidence to support both models. Other researchers have focused at a psychophysiological level of explanation; social support has been found to influence cardiovascular, immunological and neuroendocrine functioning (Uchino, et al., 1996). None of these mechanisms are exclusive and it is likely that the way in

which support is helpful will differ depending on phase, disorder, individual and their relationship to the person offering support (Dakof & Taylor, 1990; Munroe & Johnson, 1992).

Whilst the explanations provided above are proximate mechanisms for the beneficial impact of social support, the ultimate level of explanation is likely to reside in humankind's evolutionary origins as a social mammal: we need social relationships, namely bonds and attachments, in order to survive and successfully reproduce. We are thus adapted to seek and respond positively to close social ties (Barrett, Dunbar, & Lycett, 2001; Gilbert, 1995; but cf Stevens & Price, 2000).

Limitations

There have been a number of criticisms levelled at much of the social support research, some of which, such as the persistent vagueness in concept, have already been alluded to in the foregoing discussion. Within psychology, the majority of empirical studies on social support have used a standard methodology characterised by a correlational design, support conceptualised by category, and the use of retrospective self report measures (Barker & Pistrang, 2002). These have provided good evidence of an association between the support people receive, or say they receive, and their wellbeing. However, they are unable to go beyond this association with outcome and, for example, illuminate the process by which social support has this effect (Barker & Pistrang, 2002). As Coyne and DeLongis (1986) have stated, "There are undoubtedly profound connections between having good relationships and wellbeing, but they are likely to be complex reciprocal and contingent" (p. 454). The limitations of this standard research design and methodology are outlined below.

Much of the early data linking social support and wellbeing came from correlational, retrospective studies measuring the association between stress, support and outcome. Amongst other limitations, these studies could not determine causality; that is, whether people have more psychological distress because they lack support or if having greater psychological distress has an inhibiting effect by reducing people's ability to develop or use social support (e.g. Brugha, 1995; Lloyd, 1995). It has been suggested that this polarised debate on causality is an oversimplification and that environmental and dispositional factors have a dynamic, interactive relationship (Brugha, 1995). However, there are other limitations with a correlational evidence base. It may mask spurious relationships, for example: personality variables may mediate the support-distress relationship; or, a third variable may account for both social support deficits and psychological distress (Lloyd, 1995). Education, unemployment, occupation and age all correlate with social support (Fischer & Phillips, 1982, cited in Lloyd, 1995) and adversely influence wellbeing (Brown & Harris, 1978). In addition, these studies say little about the context in which the associations occur, nor what is needed by the people with low support (Coyne et al., 1990)

Frequently support has been conceptualised in terms of a few broad functional categories such as emotional, instrumental and informational. Such categorisation has been criticised for its over-generality: the categories are broad and each subsumes a number of different approaches to helping (Barker & Pistrang, 2002). In addition, the breadth and non-specificity of these categories makes it difficult to make links with psychological theory (Barker & Pistrang, 2002). The focus on functional content obscures the influence of process factors such as empathy (Pistrang, Barker, & Rutter, 1997; Pistrang, Clare, & Baker, 1999). Finally, as discussed earlier, these discrete categories neglect potentially unhelpful aspects of social relationships (Rook, 1990).

Support has been predominantly explored using retrospective self-report measures assessing individuals' perceptions of, or satisfaction with, the support they receive. In the main, this has not included the perspective of the person offering the support as well as that of the person receiving the support. The social support literature based on these measures, therefore, cannot say what support consists of when it occurs between two people (Pistrang et al., 1997). Nor can it say which aspects of support bring about change in the person being supported (Barker & Pistrang, 2002). In addition, there has been the assumption that perception of support is the crucial factor which somehow influences a person's appraisal of the stressor and coping resources. However, unnoticed support appears to be more efficacious (Coyne & Bolger, 1990) – this will be explored in more detail in the following section.

Together, these criticisms suggest a need for methods which incorporate the interactive nature of social support, such as the support person's perspective, the context in which support occurs and the detailed process of supportive transactions (e.g. Coyne & Bolger, 1990; Barker & Pistrang, 2002). The next section further explores this interpersonal perspective.

An interpersonal perspective

Many researchers have argued that it is crucial to consider the interpersonal context within which social support occurs: the people involved are interdependent and have a sense of 'shared fate' (e.g. Barker & Pistrang, 2002; Coyne & Bolger, 1990; Coyne et al., 1990; Pistrang, Barker & Rutter, 1997). An illness in one acts as a stressor to both (Coyne et al., 1990; Lehman et al. 1986). Families have a stake in their relative's recovery: they care about the individual and so experience distress themselves when their relative is unwell. Attempts to be helpful may therefore be motivated to alleviate their own distress as much by altruism or obligation, (Cialdini

et al., 1987; Lehman et al., 1986; Pistrang & Barker, 1998). Their distress may be exacerbated by such factors as: needing to adjust to changes in family routine or dynamics, uncertainty about how to help, uncertainty about the future and, feeling responsible for outcome or even onset (Coyne et al., 1990). These factors overlap with the construct of family burden discussed earlier and it is likely that they are particularly pertinent in the case of severe mental illness since uncertainty is a dominant theme in the lives of family members (Baier, 1995; Vatri-Boydell, 1997). Four elements of an interpersonal perspective are discussed below.

Communal interdependent relationships

As noted earlier, people tend to first seek support from those closest to them. Frequently these are 'communal relationships': intimate relationships with family, friends and partners characterised by a sense of special obligation and wish to be responsive to one another's needs (Clark & Mills, 1979, cited in Clark, 1983). The most fundamental support comes from these communal relationships (Coyne et al., 1990). There is some evidence to suggest that, if such support is inadequate, other relationships cannot act as a substitute (e.g. Brown & Harris 1978, Coyne et al., 1990). One caveat is that most research on this point has been conducted on partner relationships.

Support in communal relationships takes place within an ongoing caring relationship; it is generally mutual and is motivated by a sense of obligation or commitment. Much of the support is subtle and unnoticed, occurring within the context of shared understandings and routines (Coyne & Bolger, 1990; Coyne et al., 1990). In fact, explicitly supportive transactions may only be necessary if this automatic undercurrent proves inadequate in the face of exceptional stress (Coyne & Bolger, 1990; Coyne et al., 1990). Measures of observed support and support

seeking may, therefore, be detecting the times when routine support is insufficient and thus may confound stress with support (Coyne & Bolger, 1990; Coyne et al., 1990).

Intention versus impact

There is a distinction between the intention underlying supportive efforts, the action taken and the impact of the action – this has often been obscured in the social support literature (Barker & Pistrang, 2002). As has already been discussed, social relationships are not always helpful. In part this may reflect uncertainty by the people offering support as to what would be helpful (Lehman et al. 1986). However, even when people do know what could be of help, they may have difficulty translating this into action and words. In a study examining social support with people who had been bereaved the researchers found that, although potential supporters may accurately identify what hypothetically would be helpful to a person who had been bereaved, this was not what they actually said or did (Lehman et al. 1986).

Thus, the intention to be helpful is not always successful. In part, the explanation for this may lie in the interpersonal context within which support occurs. Providing support can be an anxiety provoking experience. If people have no previous experience of the situation they may be uncertain what to say or do. Awareness of the other person's vulnerability may exacerbate their anxiety because they fear saying or doing the wrong thing and intensifying the other's distress. This anxiety may impede people's support efforts (Lehman et al. 1986). Although these ideas were developed from a study on bereaved parents, it seems likely that they may also be relevant to families where one person experiences psychosis, since there

may also be an awareness of the other's vulnerability and, as already noted, uncertainty is one of the issues faced by family members (Vatri-Boydell, 1997).

Dilemmas of helping

Social support cannot be viewed solely as one person, 'a carer', offering support and the other receiving or perceiving the support (Coyne & Bolger, 1990). Support is potentially reciprocal with each person trying to balance their own needs with those of the other person (Coyne et al., 1990). Inevitably what benefits one may not help the other, or may even be detrimental to the relationship. For example, in a study on couples where one person had experienced a myocardial infarction, Coyne and colleagues (1990) found a trade off between buffering and self-efficacy such that care givers who adopted a buffering style (hiding concerns and avoiding disagreements) promoted their partner's self efficacy but at the expense of their own wellbeing (Coyne et al, 1990). Trying to coordinate these competing goals and demands will necessarily entail some conflict. This has been termed 'dilemmas of helping': "predictable conflicts between each person's needs" (Coyne et al., 1990 p. 139). These dilemmas may become particularly apparent where it is unclear what is the best course of action (Coyne et al., 1990).

One common dilemma of helping is overprotectiveness. This is an interactional pattern commonly seen in families where one person experiences chronic illness (Dakof & Taylor, 1990) and may be associated with the care giver feeling burdened (Coyne et al., 1990). Such overprotectiveness may stem from genuine concern and "an intention to be helpful and not harmful" (Coyne et al., 1990, p. 135). However, whilst it may reduce their own distress, it can also have the counterproductive effect of reducing the recipient's self efficacy, autonomy and/or personal responsibility (Coyne & DeLongis, 1986). If the chronic illness is psychosis, it may be unclear what

would be helpful or harmful (e.g. Vatri-Boydell, 1997) and this uncertainty could exacerbate the sense of burden and therefore, overprotectiveness. During acute phases, people who experience psychosis may be considerably less able to help themselves, further exacerbating the overprotectiveness.

The concept of overprotectiveness has obvious overlaps with that of emotional overinvolvement, a factor in expressed emotion which is known to exacerbate or perpetuate problems (e.g. Vaughn & Leff, 1976). For example, in an early study exploring social support in schizophrenia, an inability to meet the role expectations of those around them, led to people feeling more stress and anxiety (Tolsdorf, 1976). Rather than assuming a unidimensional view of support where individuals with social support deficits are presumed solely to need more support, it has been suggested that what they may actually need is those around them to disengage from ineffective efforts (Coyne et al., 1990). As an interesting comparison, 87% of family therapists reported their primary goal as increasing both autonomy and individuation within families (Group for Advancement of Psychiatry, 1970, cited in Coyne & DeLongis, 1986).

Commonalities across helping relationships

As has already been stated, one of the limitations of the standard approach to social support is its focus on outcome, which has made it difficult to elucidate the factors responsible for these outcomes. Whilst there has been limited research on these process factors within informal helping relationships, a number of factors have been identified in the psychotherapy literature (Barker & Pistrang, 2002; Rogers, 1957; Stiles, Shapiro, & Elliott, 1986; Winefield, 1987). In his seminal paper, Rogers (1957) suggested that the key components of successful therapy included: empathy, unconditional positive regard and congruence (genuineness). He noted that these

characteristics could also be found in good friendships. This stimulated a large body of research to assess these and other processes within psychotherapy relationships such as intimacy, disclosure and the therapeutic alliance (e.g. Stiles et al., 1986; Winefield, 1997).

It seems likely that these factors are common across different helping relationships including informal helping, although they may be manifested in different ways (Barker & Pistrang, 2002; Pistrang, Picciotto, & Barker, 2001). Barker and Pistrang (2002) have suggested a framework for examining the fundamental processes in both psychotherapy and informal helping: (1) 'establishing a relationship' by creating a mutually satisfactory working alliance; (2) 'making meaning' through helping people to consider their difficulties from a new perspective; and (3) 'promoting change' which encompasses active attempts to bring about change (see also, Stiles et al., 1986). Whilst these have been adapted from the psychotherapy literature, each of these processes can be considered with respect to informal helping relationships (Barker & Pistrang, 2002). For example, 'establishing a relationship' entails building a therapeutic alliance: establishing mutual bonds, tasks and goals (Bordin, 1979). Whilst social support generally takes place within existing relationships, it has been suggested that "processes similar to the therapeutic alliance must be present if the relationship is to provide effective help" (Barker & Pistrang, 2002, p. 369). The authors add that informal helping mainly works at the 'bond' level, namely: empathy and mutual respect.

Social support and psychosis

Issues

One difficulty in examining the relationship between social support and mental health is the potential overlap between symptoms of disorders and measures of

social support. For example, both depression and psychosis tend to cause individuals to withdraw from social relationships (Brugha, Wing, Brewin, Maccarthy, & Lesage, 1993; Monroe & Steiner, 1986). The behaviour of a person experiencing psychosis may affect their ability to enlist support (Rudnick & Kravetz, 2001). In addition, many disorders can affect an individual's perception of their social network (Monroe & Steiner, 1986). It has also been suggested that other factors, such as neuroticism or social competence, could influence both psychological distress and deficits in support (Cohen & Wills, 1985; Lara, Leader, & Klein, 1997; Monroe & Steiner, 1986).

In comparison to other mental health problems, relatively few studies have investigated the relationship between social support and psychotic disorders (Cresswell, Kuipers, & Power, 1992; Erickson, Beiser, & Iacono, 1998). One factor distinguishing psychosis from other mental health problems is 'understandability' (Jaspers, cited in Bentall, 2003): it is easier to understand and empathise with the more common 'minor' difficulties, such as mild depression, than with psychotic disorders. There appear to have been no studies explicitly addressing whether the 'understandability' of difficulties influences support, although a few studies have compared the quality and quantity of social relationships of people with either mild or psychotic depression. For example, Billings and Moos (1984) found no difference in the quantity or quality of social relationships between people diagnosed with mild depression and those diagnosed with "severe or endogenous-psychotic types of depression" (see also, Brugha et al., 1987). In reviewing this literature, Brugha (1995) has suggested that chronicity rather than understandability may be the distinguishing factor in social support.

As noted earlier, a vulnerability-stress model posits that, in individuals who are phenotypically vulnerable, biological or psychosocial stressors may precipitate

illness or relapse. One factor which is somewhat confusing in the literature is the role ascribed to social support. Within this model, absence of support has been construed as a stress factor in its own right and as contributing to an individual's vulnerability to illness. In a converse construction, the presence of support is generally thought to reduce the impact of stressful events (that is, to act as a buffer; Cohen & Wills, 1985) as well as preventing their occurrence (Vilhjalmsson, 1993). In addition, it is likely that different facets of social support have differing roles in onset, relapse and general course.

Most of the studies examining the relationship between social support and severe mental illness have used a social network conceptualisation of support - examining the structure and quality of social relationships. Some have also examined the factors associated with outcome. Each of these will be reviewed in turn.

Social network size and psychosis

People who experience psychosis have consistently been found to have smaller social networks (Cohen & Sokolovsky, 1978; Macdonald, Hayes, & Baglioni, 2000; Meeks & Murrell, 1994; Romans & McPherson, 1992; Tolsdorf, 1976), fewer intimate relationships or friends (Cohen 1978; Erickson, Beiser, Iacono, Fleming, & Lin, 1989; Macdonald et al., 2000; Meeks & Murrell, 1994; Strauss, 1989; Tolsdorf, 1976), and a higher proportion of service providers within their network (Meeks & Murrell, 1994). These findings may not be directly attributable to the psychosis but could be confounded by the potential sequelae of a prolonged psychiatric illness, such as depression, unemployment, low socioeconomic status and being without a partner (Macdonald et al., 2000). However, the findings were supported by a recent study examining the social network of people with early psychosis which matched participants with controls on these factors as well as age and gender (Macdonald et

al., 2000). The network deficits seem to be a consequence of psychosis rather than an aetiological factor (Andreasson, Allebeck, Engstrom, & Rydberg, 1987). Together these studies suggest that it is something about psychotic illness itself which constricts social networks.

Of relevance here were the diverse findings on the role of family reported in these studies on social network. These ranged from significantly more family within people's social network (Tolsdorf, 1976) to significantly fewer (Meeks & Murrell, 1994). It is possible that the contradictory findings represent a disparity in participant's age or duration of their illness since the Tolsdorf study focused on first episode psychosis. One study, which matched participants on age, found no difference in family network size between individuals with first episode psychosis and people without mental health problems (Macdonald, Hayes & Baglioni, 2000). It has been suggested that relationships may be 'damaged' by the first several episodes (Johnson, Winett, Meyer, Greenhouse, & Miller, 1999), but little is known about the changes in family relationships across the duration of psychotic illnesses (Cook et al., 1997).

Outcome, social support and psychosis

In psychotic disorders, the relationship between social support and outcome has rarely been explored (Erikson, et al., 1998; Johnson et al., 1999). In a retrospective study, Christensen and colleagues reported that people with schizophrenia who had more frequent social interactions showed lower mortality rates over the following 60 years, whereas quality of interactions was not predictive (Christensen, Dornink, Ehlers, & Schultz, 1999). However, as the authors concede, the severity of the individual's schizophrenia may underlie both the increased mortality rate and reduced social interactions found in this study.

In general, outpatients with schizophrenia who have larger social networks show lower relapse rates over the subsequent year (Cohen & Sokolovsky, 1978). The same has been found for people with bipolar disorder (Johnson, Lundström, Åberg-Wistedt & Mathé, 2003). Individuals with bipolar disorder who have high social support recover more quickly from mood episodes (Johnson et al., 1999; O'Connell, Mayo, Eng, Jones, & Gabel, 1985; O'Connell, Mayo, Flatow, Cuthbertson, & O'Brien, 1991; but cf Staner et al., 1997). It appears that the beneficial effect of larger networks may be particularly associated with the number of non-kin in these social networks, especially supportive acquaintances or 'distal social relationships'. Erikson and colleagues found that individuals who reported more non-kin in their social network in the period leading up to their first psychotic episode showed better adaptive functioning at both 18-month and 5-year follow-ups, while kin did not predict 5-year outcome (Erikson, Beiser, Iacono, Fleming & Lin, 1989; Erikson, Beiser & Iacono, 1998). This was true for people with both affective and non-affective psychoses and despite controlling for baseline adaptive functioning. They concluded that the differential impact of kin and non-kin may reflect the closeness of families increasing the likelihood of adverse expressed emotion, whereas there is more flexibility in the way friendships and acquaintances evolve.

The evidence base specifically for bipolar disorder is more contradictory. As noted above, most studies report a positive association between support and outcome. In addition, Johnson and colleagues report that social support may have a differential impact on the different phases of bipolar disorder: social support predicts changes in depressive but not manic symptoms (Johnson et al., 2000; Johnson et al., 1999). It is important to note that mania in these studies included both people who experienced psychotic symptoms and those with non-psychotic mania. However these findings were not supported by a larger study (Johnson et al., 2003). It has also been suggested that manic behaviour has a more deleterious influence on

relationships than depressive behaviour (Romans & McPherson, 1992), although some studies have not supported this suggestion (Johnson, et al., 2003).

In a study on men with schizophrenia, Corin (1990) noted that many perceived societal exclusion, rejection and marginality. What seemed to distinguish the men who were more frequently re-hospitalised was their conflicting desire for more social relationships. In contrast, those who were not re-hospitalised had adopted an attitude of detachment which Corin termed 'positive withdrawal' (Corin & Lauzon, 1994; Corin, 1990). This finding may explain why, despite smaller social networks, people who experience psychosis do not necessarily report low perceived social support (Macdonald et al., 2000). This has generally been ascribed to people receiving more support from the fewer members within their network (Macdonald, Hayes & Baglioni, 2000). However, it could also reflect 'positive withdrawal': people perceive themselves as having sufficient support because they do not want more. In addition this phenomenon may contribute to the social withdrawal commonly noted in both psychosis (Cresswell et al., 1992) and its prodromal phase (e.g. Chapman, 1966).

Summary: social support

When people need support they tend to turn first to those closest to them and most never seek more formal support. Consistent positive associations have been found between this social support and both physical and psychological wellbeing. A number of mechanisms at a number of levels have been suggested to account for this association, for example a stress-buffering effect. The strong beneficial effect associated with social support has, however, tended to occlude consideration of less helpful support efforts; the presence or absence of adverse aspects of support may have a potent impact – as exemplified in the expressed emotion literature. These

adverse aspects are often not deliberate but reflect a distinction between what people intend to do, in offering support, and the actual impact of their behaviour.

It is important to consider that social support generally takes place within existing relationships in which there is mutual concern for one another's wellbeing. Much of this support may be subtle and occurs within the context of shared understandings and routines. Sometimes there can be a conflict, or 'dilemma of helping', such that actions which benefit the person receiving the support can be detrimental to the person offering the support or even the relationship as a whole. It appears that both positive and negative aspects of social relationships are important determinants of the course of psychosis. However, the literature exploring social support in the context of psychosis has predominantly focused on the size of individual's social networks. Few, if any, studies examine the mechanisms by which social support has this association with the course of psychosis; nor have studies examined whether there are differences in the support process in psychosis compared to other, more understandable, difficulties.

THE CURRENT STUDY

Summary and rationale

Informal care givers, particularly family members, are increasingly involved in the day-to-day care of people with severe mental illness. It has been recognised that what happens within families can influence the wellbeing of the person with psychosis, both in terms of relapse and as a buffer to external stressors, and that families themselves experience 'burden' due to their care responsibilities. To a lesser extent, it has also been recognised that the family's caring role can be rewarding and that the person with mental illness may make valuable contributions

within the family. The experiences of family members and the person experiencing psychosis have rarely been explored within a single study.

The research on families and psychosis has tended to focus on predominantly negative aspects of their interactions: how much burden these families experience and how detrimental their expressed emotion can be to the person with psychosis. What remains unclear is what family members actually try to offer, how such informal help is perceived by the person receiving it, and what the person with psychosis would find most helpful from their family members.

Some of these areas may be clarified by the application of an informal helping framework. Despite the vast literature documenting the association between wellbeing and social support, informal helping relationships have rarely been examined within the context of severe mental illness. In considering using such a framework, a number of considerations arise. By its very nature, psychosis is an illness which is often incomprehensible and which distorts interactions within, and perceptions of, relationships. Thus, it may be that, in this context, the helping relationship is perceived and experienced somewhat differently by both sides. It may also be more difficult to offer support when the subjective experience of the person with psychosis is viewed as incomprehensible.

For formal services to best provide support to families living with psychosis, it is crucial to continue to further our understanding of what happens within these families (e.g. Tuck et al., 1997). In a critique of the literature, Dixon (1999) has argued that:

The gap between what we know and what we do for families of people with schizophrenia [or psychosis] appears to be large. Our

research agenda must increase what we know by a greater understanding and closing of this gap. (Dixon, 1999, p. 7)

Aims

This qualitative study explores the types of help and support offered within families where one person has experienced repeated episodes of psychosis. It examines the 'informal helping' relationship from the perspective of both the family member offering help and support and the person who has experienced psychosis.

Given the impact of psychosis on individuals and their families, there seems to be a good case for exploring the processes of support which occur within these families. Such research is needed in order to identify the issues and experiences which may be unique to offering support in the context of psychosis – or indeed to identify the commonalities with informal helping relationships in other contexts. By increasing our understanding of the interactional factors associated with help and support from the family, this research may suggest ways to improve the match between what people who experience psychosis are offered and what they would actually find helpful. Moreover, as improved helping is likely to lead to general improvements in their relationship, it may in turn have a positive impact on the wellbeing of all members of the family.

Methodological approach

Both quantitative and qualitative methodologies have their strengths; however in the context of this study, qualitative approaches have a number of distinct advantages. As this chapter has amply documented, while much research has already been conducted into family factors and psychosis, relatively little attention was directed at exploring what happens within families. Qualitative approaches have been

recommended for exploratory research in areas where little is known (Barker, Pistrang, & Elliott, 2002). They are particularly relevant where “knowledge is sought concerning complex, little-understood personal, interpersonal and social processes” (Ridgeway, 2001, p. 226; see also Barker et al., 2002); as is the case in this study. A qualitative approach also carries the advantage of retaining the “meaning, subtlety or ambiguity of the actual phenomena being studied” (Barker, Pistrang, & Elliott, 1994, p. 81), aspects which are likely to be relevant in the experience of offering and receiving support within families. Moreover, they allow greater freedom to participants to express the issues as they see them (Barker et al, 2002) – a facet which may help to counteract their generally disempowered state, not just in previous research but also in the context of formal services and in the face of such an overwhelming experience as psychosis.

Research questions

This study sets out to explore the support process in families where one person has experienced psychosis – both from the perspective of the family member and that of the person who has experienced psychosis. Specifically it will address the following research questions:

- What types of help and support do family members offer to people with psychosis?
- What do family members do or say that is perceived as helpful or unhelpful?
- How do family members and people who experience psychosis experience the process of offering and receiving support?

CHAPTER 2: METHOD

OVERVIEW

This was a descriptive, qualitative study. In all, 21 participants were interviewed about their respective experiences of offering and receiving support with psychosis. Nine were people who had experienced psychosis and 12 were their relatives (in three cases, both parents were interviewed together). A specially designed semi-structured interview schedule was used. The interviews were tape recorded, transcribed and analysed using interpretative phenomenological analysis (IPA, Smith & Osborn, 2003). This chapter describes the recruitment, participant characteristics, interview process and method of analysis, it ends with a statement about the researcher's own position.

ETHICAL APPROVAL

Initially, ethical approval was sought and received from the Joint UCL/UCLH Committees on the Ethics of Human Research. When the study was later expanded, ethical approval was also sought and received from Barnet, Enfield and Haringey Local Research Ethics Committee (Appendix 1).

RECRUITMENT

Rationale for criteria

Although the initial aim was to interview people who had experienced repeated episodes of psychosis as part of schizophrenia, it became clear during recruitment that a number of the people who were interested in the study had experienced psychotic episodes as part of bipolar disorder. Consequently, following reference to the literature on psychosis as well as to previous studies in similar areas, it was

decided to widen the inclusion criteria to include people with affective as well as non-affective psychosis.

The choice of psychosis over a particular diagnostic entity was because it is likely that families living with psychosis will have some experiences in common, whether the psychosis is attributable to schizophrenia, bipolar disorder or schizoaffective disorder. By its very nature, psychosis entails unusual perceptions or beliefs which are not shared by those around them. These may be both disruptive within relationships and seem incomprehensible to family members trying to offer support. Psychotic depression was excluded from this study because of a potential overlap with a previous study (Harris, 2002).

Inclusion and exclusion criteria

Inclusion criteria for the people who experienced psychosis were: (1) self-definition as having experienced repeated episodes of psychosis; (2) psychosis was not related to substance misuse, post-natal or major depression; (3) not currently experiencing a major relapse or an in-patient; (4) first episode of psychotic experiences more than three years ago; (5) age 21-50 years old; and, (6) a member of their family who was involved in giving help and support also agreed to participate in the study. The only inclusion criterion for the family member was that they had regular contact with the person experiencing repeated psychotic episodes.

Exclusion criteria for both the people who experienced psychosis and their family members were: (1) reception of substantial family intervention, such as a family psychoeducation programme; (2) currently experiencing a major life event which was perceived as stressful; and (3) insufficient English to partake in an interview since there was no funding for an interpreter.

Procedure

Over the course of the study, the researcher employed several recruitment strategies encompassing both voluntary agencies and the NHS. It was initially (mistakenly) thought that people approached through a voluntary agency would be more likely to be in a stable phase than those in contact with the NHS. The mental health organisation Mind was selected due to the structure of the organisation – it offers many service user groups. Initially 15 branches of Mind were approached of which two invited the researcher to talk at one or more of their service user groups and three placed an advertisement in their newsletter (Appendix 2). At the service user meetings the researcher explained the rationale for the study and what participation would involve. People who were interested in taking part were given an information sheet (Appendix 3) and asked to take it home to discuss with a member of their family.

After several months of sustained effort at recruitment through Mind, resulting in very few participants, it was decided to broaden the recruitment strategy to incorporate people with bipolar disorder. An advertisement was placed in the London newsletter of the Manic Depression Fellowship, followed by an advertisement in their support group newsletter and, finally, by another in their national newsletter. The advertisements outlined the questions the study intended to address and provided the researcher's contact details for those people who were interested in hearing more about the study. People who contacted the researcher were told more about the study and what taking part would involve. Those who were interested were sent an information sheet and asked to discuss the study with a member of their family.

After 10 months of recruitment through voluntary agencies, recruitment was expanded to include clinical psychologists working in an NHS psychology department and their colleagues in a Community Mental Health Team and a voluntary carers' support organisation. These people were asked to review their caseloads, describe the study to individuals who appeared to match the research criteria and, for people who seemed interested, seek consent for the researcher to telephone them. In this initial contact, the researcher described the study in more detail and emphasised that their decision whether or not to take part would not affect their contact with formal services. Where appropriate, the researcher offered to send an information sheet for them to consider and discuss with a relative (Appendix 3).

Once people had received an information sheet – whether through voluntary agencies or the NHS – the procedure was identical. The researcher waited at least a week before telephoning potential participants to answer any questions they may have had. For those who had decided to participate, the researcher sought permission to contact their relative who had also expressed interest in participating. An information sheet was sent to the family member which was followed with a telephone call after a week. This conversation addressed any additional questions or concerns the relative may have had and clarified their consent to participate. Interviews were then arranged with both members of the family.

PARTICIPANTS

In total 27 pairs of people expressed an interest in the study. Of which, five people experienced bipolar disorder but without psychotic episodes, five people were too unwell to participate, two people did not have a family member who was also willing to participate, two people refused once they were sure that non-participation would not impact upon their contact with formal services, two people had co-morbid

borderline personality disorder and two people felt that they were too busy to participate. It is important to note that, although one of the exclusion criteria for this study was that participants should not have received substantial family intervention, no potential participants had received such support. Likewise no potential participants were excluded because of insufficient English.

In total, nine sets of participants were interviewed: one pair of participants were recruited through Mind, three pairs through the Manic Depression Fellowship, three pairs through the NHS and two pairs through a carers' association. Of these nine sets of participants, interest in the study was initiated by the person who experienced psychosis in five cases, and by their family members for the remainder.

Characteristics

People who experience psychosis

Of the nine people who experienced psychosis who participated in this study, four (44%) were female and five (55%) were male. Their mean age was 32 (range: 22-47). Eight (89%) people described themselves as white British and one (11%) described himself as black British. In terms of religious beliefs, three (33%) people described themselves as Christian and the remainder (67%) had no particular religious affiliation. At the time of the interview, five (55%) people were living independently, two (22%) people were living with their family of origin and two (22%) people were living with their partner. In terms of educational attainment: four (44%) people had left school at 16, one (11%) person had left school at 18 and four (44%) people had a university or postgraduate degree. Three (33%) people were working and six (67%) people were not working.

Four (44%) of the participants stated that they had a diagnosis of schizophrenia, four (44%) had received a diagnosis of bipolar disorder and one (12%) currently had a diagnosis of schizoaffective disorder with co-morbid temporal lobe epilepsy – this participant's diagnosis had changed several times over the course of his illness. It was difficult for participants to pinpoint exactly when their difficulties began, but the mean age for their first major episode of psychosis was 20 (range: 15-29). The mean duration of their illness was 12 years (range: 4-19). All participants had experienced at least two major episodes requiring admission to hospital.

Family members

In terms of their relationship to the person who experienced psychosis: six (50%) were parents; two (22%) were partners; and one (11%) was a sibling. In three cases, both parents were jointly interviewed; altogether therefore 12 family members participated in this study, of which eight (67%) were female and four (33%) were male. Their mean age was 56 (range: 31-77). Eleven (92%) people described themselves as white British and one (8%) person described herself as black British. In terms of religious beliefs, two (17%) people described themselves as Christian and the remainder (83%) had no particular religious affiliation. Six family members were married or cohabiting and the remainder were single or divorced. In terms of educational attainment: five (42%) people had left school at or before 16, two (16%) people had left school at 18 and five (42%) people had a university or postgraduate degree. Five (42%) people were working and the remainder (58%) were either retired or not working. Within four of the families there was another close relative who also experienced psychosis. Participant characteristics are set out in Table 1.

Table 1: Participant characteristics

	Family relationship	Age	Education	Age at first episode	Years since first episode	Living Situation	Marital Status	Work Status	Diagnosis	Other relative with psychosis
P1	Son	37	University	20	17	Independent	Single	Not working	Bipolar disorder	-
	Mother	69	University							
	Father	77	University							
P2	Daughter ^a	22	School: 16	16	6	Independent	Single	Working	Bipolar disorder	Brother
	Mother	43	School: 16							
P3	Son	33	Postgraduate	29	4	Independent	Single	Working	Bipolar disorder	Sister
	Mother	60	University							
	Father	61	School: 18							
P4	Male partner	31	University	15	16	With partner	Cohabiting	Working	Bipolar disorder	Mother
	Female partner	31	Postgraduate							
P5	Daughter ^a	35	School: 16	22	13	Independent	Single	Not working	Schizophrenia ^b	-
	Mother	65	School: 15							
P6	Wife ^a	47	School: 16	28	19	With partner	Married	Not working	Schizophrenia	Son Daughter
	Husband	52	School: 16							
P7	Daughter ^a	23	School: 16	17	6	With family	Single	Not working	Schizophrenia	-
	Mother	46	School: 16							
P8	Son ^a	29	School: 18	17	12	With family	Divorced	Not working	Schizoaffective disorder ^c	-
	Mother	64	School: 16							
	Father	66	School: 18							
P9	Brother	34	Postgraduate	20	14	Independent	Single	Not working	Schizophrenia	-
	Sister	33	University							

^a These families elected to have joint interviews.

^b This diagnosis had recently been placed in doubt by a new psychiatrist

^c This person reported receiving six different diagnoses over the duration of his difficulties. He currently has a diagnosis of co-morbid temporal lobe epilepsy.

PROCEDURE

Participants were offered a choice of locations for the interview: at their home, at the Sub-Department of Clinical Health Psychology at University College London or in an office at the voluntary or NHS service through which they had been recruited. All of the participants preferred to be interviewed in their home. It was initially intended to interview all participants separately since it was felt that this would enable the participants more freedom to discuss the difficulties they encountered or unhelpful aspects of support. However, five families expressed a preference for a joint interview. In three cases, they stated that they were open in their families about such discussions and would feel able to talk freely. The remaining two families cited time constraints. Thus, of the nine sets of participants, four chose to be interviewed separately and five chose to be interviewed together, giving a total of 13 interviews.

Opening the interview

At the start of the interview, the key aims of the study were reiterated. It was emphasised to the participants that there were no right or wrong answers and the researcher was hoping to understand their personal experiences in, what can be, difficult and stressful circumstances. It was also emphasised that, for most people, there were both good and bad aspects to support within families and that, however well intentioned, attempts to be helpful did not always work. The confidential and anonymous nature of the research was reiterated and, for those who chose to be interviewed separately, that information arising in the interview would not be shared with their relative(s). Participants were encouraged to ask questions and to let the researcher know if she was asking them to discuss an area which was too difficult, painful or personal.

Participants were given two consent forms: one related to general participation in the study and the other concerned audio-taping of the interview (Appendix 4). Most participants chose to complete these at the end of the interview, once they knew what had been said.

Interview Schedule

The interviews were based around a purposely designed interview schedule. This sought to explore people's personal experiences of giving and receiving help in families where one person has had repeated episodes of psychosis – both from the perspective of the person who experienced psychosis and from that of a family member. The general structure for the interview schedule was derived from previous related research which explored informal helping in couples where one partner experiences depression (Harris, 2002). This was adapted to incorporate issues which the literature suggests may specifically relate to psychosis. The interview schedules of both the family members and the people who experienced psychosis were identical, except for pronoun changes (Appendix 5).

The schedule was used as a flexible guide and not all questions or prompts were asked of each participant. The aim was to follow what participants themselves brought to the interview and only use questions to guide participants back to the help and support focus should this be necessary. In this way it was hoped to balance an exploration of help and support with “allowing the interviewee the space to re-define the topic under investigation and thus to generate novel insights for the researcher” (Willig, 2001, p. 22). To encourage a flowing discussion, context and background questions were only asked at the end if they had not already been mentioned by the participant. Interviews were conducted in an empathic and non-judgemental manner

with an attitude of curiosity (Barker et al., 2002; Burman, 1994). They were audio-taped and lasted between 45 and 90 minutes.

The schedule was organised as a series of open questions arranged around five main areas, each followed by potential prompts; these are outlined below:

Recent episode

Participants were asked to briefly describe a recent or memorable episode of psychosis. This enabled participants to have a clear episode in mind when later talking about help and support. It also gave the researcher some idea of context including the nature of the difficulties people experienced and a brief history of their difficulties.

Family support and help during recent episode

For relatives of people with psychosis this section explored the types of help and support they offered, whether any of these seemed more or less helpful and what it felt like to be offering this support. It also examined the rationale behind the types of support offered and whether the person with psychosis gave any indication about what they would like. For people who had experienced psychosis, the questions were reversed. Thus they explored the types of help and support they were offered, whether any of these seemed more or less helpful and what it felt like to receive this support. They were also asked what they wanted their families to be offering them. Both groups of participants were asked about the ways in which the people with psychosis supported their family.

Differences with stage, time and nature of difficulties

Participants were asked to reflect upon any differences in offering or receiving help and support through the different phases of psychosis: becoming unwell, being unwell, gradually recovering and the stable periods in between. They were also asked to talk about any changes in their understanding of help and support since the initial episode.

Ideas about support and helping

This section explored participants' views on the factors underlying remission and relapse. It also asked what advice they would now give to a friend in similar circumstances. These questions aimed to understand how families made sense of helping a person with psychosis and what they felt that they had learned or gained from their experience.

Background and context

If participants had not already covered these areas during the interview, this section asked about demographics (age, ethnicity, religious affiliation, years in education, number of hospitalisations and family structure). As already noted, participants were self-defined as having experienced psychosis. As such, no systematic information regarding diagnosis was collected; however, the interview schedule did include a checklist of typical symptoms of psychosis to ensure that what people were describing was indeed psychosis. Participants were also asked for a brief snapshot of these difficulties since their onset.

At the end of the interview, participants were asked if there were any areas which had not been addressed during the interview and that they felt to be relevant.

After the interview

In concluding the interview, participants were thanked for taking part in the study and for discussing their personal experiences with the researcher. They were asked if they had any questions for the researcher or about the research. Any issues which had arisen from the interview were addressed and, where appropriate, participants were offered a sheet listing some national sources of support. If people no longer had the original information sheet, they were given the researcher's telephone number should they wish to contact her later - no participants subsequently did so. The participants who had been recruited through the NHS were asked for the contact details of their key worker or psychiatrist. This was written straight onto a prepared letter stating that they had taken part in the study (Appendix 6). A copy of the letter was left with the participants and the original, together with copies of the consent forms, was sent to the psychiatrist or key worker. The participants who had been interviewed separately from their relative were invited to contact the researcher should they want a joint follow-up session; no participants took up this offer. Finally participants were told when they could expect to receive an anonymised summary of the research.

ANALYSIS

Each of the interview tapes was transcribed verbatim. Any identifying features, such as names and locations, were removed. The transcripts were then analysed using IPA (Smith & Osborn, 2003).

Rationale

Interpretative Phenomenological Analysis is a relatively new approach to qualitative analysis and was specifically designed to enable insight into people's psychological worlds (Willig, 2001). It was chosen as the mode of analysis for a number of

reasons. The nature of this study did not lend itself to a discursive analysis since the aim was to explore how participants themselves experience help and support within families rather than to account for the historical, cultural, social and linguistic influences upon their constructions of help and support. It was also felt that the aim of the study was more aligned with that of IPA than Grounded Theory. The goal of the latter is to produce an explanatory theory accounting for the phenomena. In contrast, IPA is concerned with describing the “nature or essence of phenomena” (Willig, 2001, p. 69).

Interpretative Phenomenological Analysis aims to explore “how particular individuals attempt to make sense of, or find meaning in, their [experiences]” (Smith, 1996, p. 266). The term itself signifies the duality of the approach. It is phenomenological in that it is concerned with individuals’ personal perceptions of a phenomenon, such as an event or experience, rather than aiming to produce an objective statement regarding the phenomenon itself. However, in doing so, IPA acknowledges the influence of the researcher’s own conceptions in making sense of the other’s personal world. In this sense it is also interpretative. The outcome of IPA is therefore recognised as “a co-construction between participant and analyst in that it emerges from the analyst’s engagement with the...participant’s account” (Osborn & Smith, 1998, p. 67).

Process

Smith and colleagues have published many clear and systematic guidelines on the process of IPA (e.g. Smith, 1996; Smith, Jarman & Osborn, 1999; Smith & Osborn, 2003). The analysis conducted in this study was loosely based upon the outline described by Smith and colleagues (1999). This emphasises, however, that “there is

no single definitive way to do qualitative analysis” (p. 220) and that most researchers will find themselves adapting the method to their own way of working.

The analysis began by selecting one interview and reading it several times until the researcher was thoroughly familiar with the transcript. In doing so, anything of significance or interest was underlined and noted in the right hand margin (stage 1, Appendix 7). These initial notes were then entered onto a computer table, noting page numbers (stage 2). The next step entailed identifying tentative theme titles which seemed to capture the essence of what was being expressed by the participant – these were added to the computer table (stage 3, Appendix 8). Once all the themes had been noted from this transcript, the complete list was grouped into a tentative framework of themes and superordinate themes (stage 4, Appendix 9). The researcher continually checked back to the original transcript to ensure that the emergent structure actually reflected the participant’s account. At this stage, certain themes seemed peripheral to either the original transcript or to the framework of themes. These were relegated to notes at the bottom of the table of sample themes.

The master list of themes produced for the first transcript was put aside and the process described above was repeated for each transcript in turn. Where two family members were interviewed simultaneously their contributions were analysed together, but note was made of which person said what. For the five joint interviews with both the people who experienced psychosis and their family members, the organisation into a tentative framework (stage 4) was first done separately for each participant. However, in every case, the themes and frameworks which resulted were very similar and were thus merged.

Once a tentative structure had been produced for each transcript, a master list of themes from all participants was constructed (stage 5). In doing so, themes contributed by families living with schizophrenia were noted in a separate font from those from families living with bipolar disorder (the themes for the person who experienced schizoaffective disorder were treated with those who experienced schizophrenia). This was restructured into a single conceptual framework of themes which best captured the participants' experiences (stage 6). At this stage, some themes which seemed less central to the participants' accounts or with little inter-participant support were omitted. All transcripts were recoded according to this final framework (stage 7). Finally, a master table was constructed with the complete list of domains, themes and sub-themes together with the participant quotes representing each instance of its occurrence (stage 7, Appendix 10).

Credibility checks

A credibility check on the emerging themes and framework was provided by a second researcher with extensive experience in research into informal helping and in IPA. She independently analysed three transcripts and read three others. Following this, the two researchers discussed their respective themes and frameworks before arriving at a tentative consensus. After analysing the remaining transcripts, the initial researcher then presented her preliminary master framework to the second researcher. They discussed its reflection of the original material and, together, constructed a final master framework.

RESEARCHER'S PERSPECTIVE

Guidelines to good practice in qualitative research recommend "owning one's perspective" (Elliott, Fischer, & Rennie, 1999) or 'reflexivity' (Henwood & Pidgeon, 1992; Willig, 2001). This involves explicit consideration of the researcher's values,

assumptions and interests in order to make apparent how these may have influenced the study direction and findings.

My interest in this area of study has many origins – professional, therapeutic and personal. My earliest interest was personal. Several years ago two close friends were, almost simultaneously, affected by psychosis. At the time I had not studied psychology and did not know the word. Despite obtaining a dictionary definition, I still felt I did not fully understand the experience of 'psychosis'. This led to an ongoing process of discovery and an interest in psychosis which has shifted in focus over the years: from neurobiological and psychological, to personal accounts and, most recently, the recovery movement.

Many years later, before training as a clinical psychologist, I worked on a mental health telephone helpline which offered support, advice and information to people affected by mental illness. Calls came from people who themselves experienced mental health difficulties as well as from relatives of these people. Those from relatives of people who experienced psychosis frequently expressed a strong desire to help but uncertainty whether what they were doing was helping or harming. This resonated with my own earlier uncertainty and search for information. The relatives' calls were mirrored by those from people who experience psychosis: many recognised their relatives' good intentions but added that what their relatives actually did was not always helpful.

As I began working with clients as a trainee clinical psychologist, I became aware that, although they may be involved with formal services from one to several hours each week, most of their time was often spent within an informal network of family or friends. I wondered about the relative impact of the formal and informal contacts

and how the two could better coordinate care and information without breaching confidentiality.

Before converting to psychology, I spent five years studying biology. I thus came to this field with a positivist, 'scientific' background and experience of quantitative research. Since the move, my beliefs have gradually shifted in recognition of the limitations of such an approach when trying to understand people's experiences and beliefs. In my clinical practice, due to a longstanding interest in human rights, I am influenced by notions of empowerment and collaboration.

These experiences and interests led me to hold certain expectations whilst I was developing the ideas and protocol for this study. I anticipated that relatives would be uncertain what to do and unsure if what they were doing was helping or hindering the person they cared for. I also expected relatives to have difficulty empathising with psychosis. Finally I wondered if the people who experienced psychosis would articulate different needs at different phases of their illness. Further reflection on how my personal interests, expectations and biases may have influenced the course of the study will be presented in Chapter Four.

CHAPTER 3: RESULTS

The analysis yielded a number of themes and sub-themes, organised into two broad, higher-order domains: 'normal life' and 'issues in help and support' (Table 2). 'Normal life' represents what families as a whole are doing or trying to achieve. The second domain encompasses the issues which influence family help and support in the context of psychosis: what helps or hinders the offer of support and the dilemmas involved. The themes within each domain are not mutually exclusive; the concepts expressed in one often relate to those discussed in others. This chapter begins with a brief overview of some of the issues concerning families where one person experiences psychosis; this sets a context for the rest of the chapter, which describes the two domains and their respective themes and sub-themes in detail.

Note on terminology and notation

Within the interviews participants discussed a number of people: themselves as the person who experienced psychosis or the family member of the person who experienced psychosis; the relative who was also taking part in the study; and wider family members. To minimise confusion, I have used specific terms to refer to each of these people. The term 'person who had experienced psychosis' becomes unwieldy when repeatedly used and has therefore been abbreviated to PEP (similarly, PEPs indicates 'people who had experienced psychosis'). In using this abbreviation, it was not my intention to identify these participants wholly as a function of their psychotic experiences but merely to enhance the readability of the text. Throughout the chapter, the terms 'family member' and 'relative' will be used interchangeably to refer to the relatives who participated in the interview. 'Family' refers to the whole family including other relatives such as siblings or children, as well as both the interviewed participants. Throughout this chapter I have made reference to psychosis as an 'illness' because this was the term used by participants themselves to describe their experiences.

Table 2: Domains, themes and sub-themes

DOMAINS	THEMES	SUB-THEMES
Normal life	1 Continuity	Continuing as normal More than an illness Remembering and Forgetting
	2 Sanctuary	"Knowing there's a base" "A stable environment" "Free agent in a secure environment"
	3 Being there	"Need to know they're there" "A secure and safe feeling"
	4 Protection and Rescue	"Watching like hawks" Concealing impact Disclosure Rescue from aftermath
Issues in help and support	5 Independence, autonomy and beneficence	Being proactive Being reactive Transferring control
	6 Trying to make sense	Not knowing Normalising Uncertainty Powerlessness
	7 Psychosis disrupts relationships	Psychosis disrupts helping Awareness Positive aspects to support

Quotations from the participants who have experienced psychosis are indicated by 'P' followed by the family's research identification number (for example, 'P1' refers to the person who experienced psychosis in family 1). Quotations from family members have been indicated by 'F' and their research identification number, followed by the relationship between this person and the person who experienced psychosis (thus 'F1, mother' refers to the mother of P1). Where dialogue has been included, 'I' refers to the interviewer. The extracts from transcripts have been edited for brevity and readability. An edited omission in the text is indicated by three dots (...). Omissions where there have been intervening comments by the interviewer or other participants have been indicated by '...//...'. All identifiable information has been removed and replaced by a descriptor in square brackets, for example [wife].

BACKGROUND CONTEXT

A number of factors discussed by participants were not directly related to help and support within families; these include: relationships with formal services, the phase dependent nature of support, social and societal factors and reciprocity. These factors provide a context in which to understand the major themes identified by this study and have, where possible, been integrated into the exploration of the relevant themes. A brief overview of the most pertinent ones will first be provided.

Relationship with formal services

Despite a deliberate omission of formal services in the interview schedule, almost all participants spontaneously discussed their relationship with formal services. Participants described their experiences with formal services as 'a lottery'. Most had encountered both good and bad practice. Some of the difficulties they discussed involved aspects of the system such as high staff turnover rates. This was frustrating and destabilising for participants. They did not feel that staff knew them

and it was hard to build trust. As staff moved on participants felt that personal knowledge of the PEP or family was lost and they had to start again. Family members were extremely frustrated by issues relating to confidentiality – as will be discussed later in this chapter. Although in general the PEPs had fewer complaints about formal services, most described in-patient wards as threatening places. Other difficulties were more closely related to poor local practice. Family members felt that they had to struggle with formal services as well as struggling to manage the PEP's illness, for example: not being supported; not being able to access or engage services to help the PEP – especially in the early stages; not being heard or listened to within the formal system; services taking inadequate care of the PEP; being excluded from decisions which affected them as well as the PEP – particularly around discharge; no sense of partnership or collaboration; and, feeling blamed by professionals. Interestingly, the PEPs themselves expressed a cautious wish for a closer partnership between their family members and formal services – although this could also feel disempowering at times. On a more positive note, some family members did describe a very satisfactory relationship with formal services, although this had taken time to establish.

Phase dependence

The importance and nature of family help and support varied over time. It was particularly important when the PEP was in the process of relapse and recovery. During the most acute phase of their psychotic episodes, PEPs were in hospital and not with their family (although all participants described their continuing involvement in the sense of daily visits). In addition, once the PEP had become stable – for those who were able to achieve this phase – they regained their independence from their families. It is also important to note that what was helpful to the PEP at one stage may not have been at other stages, as will be discussed below. Participant accounts also had a time dimension in which there was a general trend towards greater

awareness of what had worked, or not worked, in the past, and thus how they might handle future episodes.

Social and societal factors

There was a general consensus that it was fortunate that prevailing social attitudes viewed mental health problems as an illness, analogous to a physical illness. Participants felt this reduced their self-blame and helped them to accept mental illness in themselves or in their family. However, some participants also mentioned negative societal attitudes that they had encountered. Family members described people blaming them for the PEP's illness or responding with fear to the word schizophrenia. The PEPs felt that their inability to meet societal expectations – social off-timeness – exacerbated their sense of shame and made it harder to accept the illness. The PEPs also described social isolation. They themselves had, at times, withdrawn from social contact because they felt ashamed or because social situations became too stressful whilst they were unwell. In addition, they noted that others had withdrawn from them.

Reciprocity

Participants emphasised that support within their families was 'not all one-way'. Although there were times when the PEPs were largely unable to reciprocate, at other times they were very much part of the ordinary family life. Family members described how the PEPs, for example, offered them reassurance and were there in return for their relative. The PEPs added that they felt a sense of needing to pay the family back for the support they had received. Thus, although the themes below emphasise the support offered by family members to the PEP, it is important to remember that the relationships they describe involved a sense of reciprocity.

DOMAIN ONE: NORMAL LIFE

For the majority of participants – both PEPs and family members – the aim of family help and support was to continue as near normal a life as possible. This was a response to the total disruption caused by psychosis; as one family member put it, “...the main thing is you’ve just got to leave him there and lead, as near as possible, a normal life...we just sort of allow him to be able to have as normal a life as possible” (F8, father). As part of this, there was no sudden break in the way family members related to the PEP, instead they tried to see beyond the illness to the person – continuing to view them as their child, partner or sibling. To a large extent, family life did not revolve around psychosis. Three factors were particularly highlighted, by both the PEPs and their family members, as central to the maintenance of normal life. Firstly, the provision of a sanctuary, a safe, containing environment in which the PEP could be protected from the world as they recovered. The next factor was ‘being there’, an immutable passive presence which conveyed to the PEP that they were still loved and part of the family. Finally, family members in particular discussed keeping an eye out for the PEP and trying to protect them from any adverse consequences to their illness.

Theme 1: Continuity

...my sister came to see me [in hospital] and I think it helped me come to terms with being there and come to terms with the fact that I was actually going to be able to move on from that and be well again. It meant that I hadn’t just dropped out, completely out of my previous life, but there was some way back. (P9)

One of the aspects of family help and support which was repeatedly alluded to by PEPs was a sense of continuity. Support within families occurs within the context of

ongoing relationships. Family members were therefore able to view the PEP as a whole person – more than just an illness. As far as possible, most families tried to continue as normal in both their interactions and their activities. This not only provided stability for the whole family but also, for the PEP, a long term perspective and context: a sense of being the same person through time, despite their difficulties. This contrasted with the experience of psychosis which represented a break in the way the PEPs viewed themselves. In turn, this helped them to consider a future self as someone continuous with their past self.

Both family members and PEPs contrasted the sense of continuity achieved through ongoing family involvement with the discontinuity inherent in much of their contact with formal services, in particular: being viewed as primarily an illness or diagnosis and frequent staff changes. As one participant noted: *“Ten different doctors, six different diagnoses, all different types of care” (P8).*

Continuing as normal

For the family members continuing as normal was a way of coping with the disruption caused by psychosis: *“...it just blurred into a kind of coping. So we carried on making the food, washing clothes, and you know” (F3, mother).* Initially, during early episodes, continuing as normal was not a planned strategy. Instead, amidst the uncertainties of the situation, it was viewed as the only thing family members knew to do: *“...it’s just the way our household operates. We just kind of muddled along” (F3, mother).* Family members acknowledged the need to make some adaptations such as cutting down on work or spending more time with the PEP: *“So, you carry on with your own life, but you can’t necessarily quite do all the things you would normally have done” (F1, mother).*

Continuing as normal entailed two main aspects. The first involved doing whatever necessary to maintain a normal life, such as keeping things on an even keel or overlooking the PEP's more extreme ideas and behaviours:

That's something we've had to be careful of over the years. Those times of year...like Christmases. They are the times when someone with [daughter]'s illness can get very affected. So I always try and keep a very low key on everything these days. (F7, mother)

For the PEPs, this felt as if their families were able to cope with their difficulties and gave them a sense of containment:

...life would go on as normal. They carry on doing all their normal things. Carry on their hobbies and the things they like doing...And although they'd try and discuss things with me they wouldn't, they didn't try and make it a huge issue in itself, they just tried to carry on. And take it in their stride. (P1)

Seeing their family continuing as normal also helped the PEP's to cope themselves:

...if we were in a café or something, it would help me to relax a little bit...because I could see that she was normal and relaxed and so there was no real reason for me to feel threatened. (P9)

In continuing as normal, families hoped to provide some kind of stability to the PEP.

There was no sudden break in the way that families related to one another:

...the way you respond, if it's in your own family, is the way that you've always responded to your children...//...I suppose you've got to try and go on behaving in the same way so that the patient doesn't feel you've kicked them out from your affections or family life. (F1, mother)

This contrasted with the break in the sense of self which participants experienced as a result of their psychosis:

...because there was continuity and structure. There wasn't a breakdown in the things I grew up with, the normal things. It's like, if there's a problem in life, you don't want everything else to fall to pieces as well. (P1)

The second main aspect of continuing as normal was family members providing just enough support, or 'scaffolding', for the PEP to lead a normal life despite their difficulties. Such 'scaffolding' included practical support, such as accompanying the PEP should they feel uncomfortable going out alone, or helping them with their social life, housework or finances. This was in recognition of the major disruption caused by psychosis:

I suppose organising some sort of normal life...//...It sounds silly but organising nice things to do so that you can have, sort of, a decent life. Because it spoils so much. It affects so much. (F4, partner)

Within this lay the acknowledgement that, at times, the PEP may need more support in order to do 'normal things':

...if he has to have extra help, that's all there is about it...Because there's no doubt that a lot of things that you and I would take in our stride are quite an operation for him, quite stressful for him. (F1, father)

One of the after effects of psychosis described by the participants was self-doubt and the PEP frequently sought advice and reassurance from their family members.

Several relatives commented on this:

He said he's been really, really hearing a lot of voices and he didn't know what to do: whether to go out or stay in. And I said, 'well make sure you stay in because, you know, anything could happen if you go out'. (F9, sister)

The experience of psychosis and its aftermath acted as a major limitation on people's lives, and being enabled to do ordinary things through the help and support of their family gave PEPs a sense of achievement:

Just to have someone say the way you've dressed is okay, or to laugh about something or to plan to do something and then to do it, is like an achievement. If you're not doing a great deal and you've got worries about going out in the public and so if you plan to meet somebody at a certain time and you go at that time to meet them and so on and then to go back home. I mean that's like an accomplishment. (P9)

More than an illness

Psychosis is a pervasive experience, affecting every aspect of people's lives. It was therefore crucial to the PEPs to be able to identify themselves as a person distinct

from the psychosis, and for those around them to also make this distinction. One aspect of this was viewing themselves as a whole person: more than just an illness. A second aspect was separating their person from their actions when they were in the midst of a psychotic episode.

Due to their ongoing relationships, family members could and did relate to the PEP as a whole person. *"...somebody that already knows that you're ill and knows you as a person that's not ill as well"* (P9). Their relationship was not just because the PEP had an illness but because of who they are as a person: their son, daughter, brother or partner. As one PEP put it:

...it's not simply because I'm ill that I'm in touch with her. It's not really because I'm ill that I'm in touch with her. I'm in touch with her because she's my sister and it just so happened that I've been suffering from this illness. (P9)

In perceiving themselves as more than just an illness, PEPs wanted their interactions to be about more than just psychosis: *"...when you relate to people you want to relate about other things, not just about the fact that, just the fact that you're ill"* (P9). Most family interactions therefore did not revolve around illness, but instead focused on everyday issues. This furthered the PEP's sense of normality and continuity.

I don't constantly remind her that she's schizophrenic and she's mentally ill...//...I mean our day to day life is literally, we don't discuss much about mental illness. You know, I mean, some days yeah...we come here mostly and it's 'what are we having for dinner today?' And then we laugh and joke, you know, and silly things. (F6, husband)

Another aspect of distinguishing themselves from their psychosis was the importance, for the PEP, that people did not continue to hold them responsible for the behaviour they had displayed whilst in the middle of an episode:

...he hates if he feels he's being punished for the behaviour. He feels like it's being held against him. You know if he's said things to people, if he's done things that they remember that and they held that against him he hates that so much. It's just like 'I was ill'. If you don't separate him from his behaviour when he's ill. (F4, partner)

However, as this family member acknowledged, it could be hard to make this distinction since the person who did these actions was, in essence, the same person: "...you think it's him. You know it's him. It's the same body, it's the same voice. It's still elements of him even when he's ill to a certain extent" (F4, partner). Herein lies a contradiction: the PEP wanted to be treated as the same whole person at all times, but did not want to be viewed as the same person who had done certain things when they were unwell. One of the ways in which families managed this contradiction was by forgetting.

Remembering and forgetting

Running throughout participants' accounts was a tension between wanting to remember what had happened during an acute episode and a wish to forget and move on. Forgetting was both an active and a passive process.

Family members had difficulty remembering what happened during the psychosis. In part they attributed this to the shock and strain of what they were dealing with.

"There are bits that I forget, you know, because it was a strain before [daughter]

was sectioned. I remember certain things: I know I was under a lot of strain at the time" (F5, mother). They also deliberately tried not to remember, since it was such a painful and stressful time for them: "I've forgotten a lot of it because you simply don't want to remember it" (F1, mother).

For the PEPs, the very nature of the psychosis made it hard to remember what had happened whilst they were acutely unwell. Some participants had almost no memory of these times. Most could remember isolated incidents, but were unable to connect events. When people had experienced several episodes, these began to blur together: *"...if you've had a lot of psychotic episodes it's quite hard to remember them after a while" (P4).* As well as forgetting due to the illness, there was also an active choice to forget some of what had happened whilst they were unwell.

...we never talk about it, not particularly...it's better really that way. After all, all of this is just something that really you just want to forget isn't it?...There are plenty of things in my life that I've forgotten, maybe because my memory isn't all that good or maybe because I've been ill so much, but I'd like to consign these things into that kind of category really. (P4)

Much of the time, both family members and PEPs worked together in the process of forgetting by avoiding discussion of the more painful events and experiences. As noted above, this was a way of being able to view and treat the PEP as the same through time whilst also overlooking their more extreme behaviours: *"After he's ill you've almost got to forget what's happened and not even talk about it that much" (F4, partner).*

Inherent in being part of a family is a sense of shared narrative - sharing past and present experiences in a common family 'story'. For the families who took part in this study, one of the difficulties with forgetting certain events was that this shared narrative was then lost for these periods. Thus, as well as wanting to forget, PEPs also wanted to know what they had done:

...when he comes out of it he usually says, 'what did I tell you?' And then we'll just tell him what silly things he was saying and he goes, 'oh that's awful'. And then he comes out of it completely and life goes on the same. (F8, mother)

In addition, family members wanted the PEP to know what had happened. In part this was to continue the sense of shared narrative. They also hoped to give the PEP some insight after they had recovered. Some family members had gone against the wishes of the PEP whilst they were having an acute psychotic episode by involving the police or formal services, they felt it was important that the PEP could later understand their actions. Some also documented the psychotic episodes. One father – who had had to involve the police for an incident – wrote a report for his son:

I did write a sort of four-page report on it or something, to show [son] when he was better so he knew what had happened...//...I was trying to give him insight. Because at the time he didn't think anything was wrong with him...I did this really because I thought, when he did get started again, it might help him understand what he'd been doing, because...half the time, I don't think he realised what he had been doing actually. (F3, father)

This father could not remember whether he had later given the report to his son. This reflected a general concern expressed by family members who were anxious not to hurt the PEP by reminding them what they had done:

Well to be honest I'm wondering whether he did [read the report]... Whether I then thought it was a bit painful for him and didn't give it him, to be honest I can't remember. (F3, father)

One of the ways families managed the tension between wanting to forget and wanting to remember was to take a light-hearted view of the events:

"It's all stuff that we can chat about and I mean we all now have a laugh, you know, say 'you were twirling sticks on the lawn with a hat' and this sort of thing. I think he genuinely laughs as well. No-one's mocking. (F3, mother)

This attitude was appreciated by the PEPs:

It's better than saying, being condemning and saying 'you shouldn't have done that'...//...And to me that's quite good because it's very light-hearted and humorous and it's better than saying, 'oh he said this and he said that, and this is terrible and that's terrible'. (P8)

Theme 2: Sanctuary

A pervasive theme in participants' accounts was the notion of home as a sanctuary, somewhere to seek refuge from the world: "...somewhere where I could duck into and hide from the rest of the world... acting as a shield from the outside world...as a

buffer" (P3). Participants used various terms to describe this, such as: 'safe haven', 'base', 'retreat' or 'safety net'. It was particularly strong in reference to a parental home, especially for those PEPs who had spent time living independently, but it was also expressed by participants in relation to the home they shared with their long term partner.

The presence of this sanctuary was especially relevant as people were recovering from psychosis. PEPs described a sense of vulnerability in the period of time following a major episode. Some faced ongoing symptoms such as threatening voices or paranoia. They also struggled with coming to terms with what had happened: the fact they had had another episode, the impact this had had on their life, and the things they may have done during this episode. PEPs described an inability to make decisions or to trust their own judgement. Although participants with affective psychosis frequently experienced a protracted period of depression as part of the cycle, almost all participants described a general loss of confidence and social withdrawal following an episode.

"Knowing there's a base"

For PEPs, the knowledge that there was always somewhere they could go provided a sense of security. Family members were aware of the PEP's vulnerability and tried to make it clear that, however hard, they would continue to offer sanctuary: *"I mean even me and [my partner] started bickering but we wouldn't, but I wouldn't ever turn her away"* (F2, mother).

During acute episodes as well, most PEPs stated that they would rather be at home than in hospital and most either discharged themselves early or ran away home:

She just went in there and she just had enough and said, 'I hate this place, I'm coming home'. She felt as though home had more to offer.
(F6, husband)

What we found very interesting, and I suppose in a way you could say rewarding, was that in the whole of [son]'s things, any time he walked out of somewhere or he left he always came home. Whereas he could've just gone up to London and disappeared into the middle distance. (F3, mother)

This could create conflict when family members felt that the PEP should be in hospital at this time. One father also wondered if the knowledge of this base could also be counterproductive in that it allowed his son to be more extreme:

They know that there's a base. And I feel, in a way, well it cuts both ways because they sort of feel that they can cut loose with whatever extravagances they're up to, knowing that actually there is a sort of safety net. (F1, father)

This father's concerns were echoed by one PEP' who wondered whether having such a 'safety net' actually may have been so comfortable that it removed his motivation to regain independence.

Maybe they should have tried to goad me along a little bit more...It was difficult because they realised I wasn't well, so they didn't want to put pressure on me. My father did try and raise it from time to time but, I don't know, maybe they were a bit too soft...Maybe if I didn't have that

safety net I would have had to have coped a bit quicker, but maybe not...I didn't have the reason to start getting myself motivated. (P3)

"A stable environment"

Several of the PEPs commented specifically on the 'stable environment' provided by family members. It was a predictable environment in which families mostly did not argue with each other or with the PEP. The atmosphere remained constant even when their own behaviour was erratic: "...[my parents] were pretty much the same throughout. It's just me. I might react in certain ways" (P1). This consistency and predictability contributed to the PEPs' own sense of stability and helped them in turn to keep their mood stable.

Because they're always the same. They don't have like erratic moods really and things like that...//...there's nothing they do that sort of makes my mood change or anything like that. It's a stable environment. (P8)

"I suppose it's because they're a stable couple and they don't fight, they get along, dad does his own thing, mum does her own thing, they get together in the evening, they sit down and have a meal. We don't do, it's not as if we sit down and have earnest discussions way into the middle of the night...nothing much happens but it's very comfortable nothing much happens. We don't get at each other's throats. We don't wind each other up unnecessarily. Okay we tease each other a bit, but it's just very easy going...We always eat together and stuff like that so there is a sort of semi-structure...it just feels like that's always been the way it has been...it's just very very fluidly calm. (P3)

One participant contrasted the impact of this stable environment with what he termed a 'hostile environment':

I was in a hostile environment and I started to get vicious and violent and aggressive and do things that weren't really in my nature, but I felt cornered and if I feel cornered I get violent, very very rarely, but it does happen. (P8)

For some family members maintaining a stable environment reflected an attempt to continue as normal, to overlook unusual behaviours or utterances:

...a stable environment...whatever his temper. When you pussy foot round...//...if he's irritable you smile and hug him, you don't snap back. You try and go on as normal all the time (F1, mother)

The major motivation underlying their provision of a stable, non-challenging environment, may have been fear for some family members; as this PEP acknowledged:

...a kind of more passive approach...more patient, non-challenging, is a better way of handling it really. I mean [partner] has said to me since...that she did that for a number of reasons. Mainly because she felt that was the best course of action but also she felt that she was quite terrified and she felt that if she did challenge me, if she did confront anything that I was doing, confront me any way, then she didn't want the consequences of what that might be. (P4)

During psychotic episodes and in the aftermath, the importance of maintaining a stable environment subsumed family members' usual way of relating, even for those who did not usually relate to the PEP in a stable or calm manner.

Like normally, I've got a really bad temper and I'm on quite a short fuse most of the time...in a relationship, I'm not like softly softly. I'm quite straight talking. But, I find that when I have seen [partner] like that, it really brings out the patient side of me and I'm just really nice to him.
(F4, partner)

“Free agent in a secure environment”

PEPs mentioned three specific aspects of their family home which contributed to the sense of sanctuary: no pressure, no judgement and no threats. As far as possible, family members allowed them to get on with their own lives on an everyday basis as well as in the context of longer term decisions. *“They didn't insist, so I was my own free agent but within a secure environment...//...[I was] in a normal environment, but I was not regulated, but secure as well. I couldn't get myself into trouble really”* (P3). They did not put pressure on the PEPs to do anything – except to take their medication, for those PEPs who tended to stop.

It's an accepting attitude I suppose...No criticism. I haven't worked since I was 17 and things like that. None of this, 'well if you'd done this or done that then maybe by now you would have been working or you would have been doing this or you'd have a car or you'd have a house and family'. Because there's none of that attitude, they just accept that this is where I'm at, that's the situation I'm in, and that's where I'm going to be for a little while. (P8)

For this participant, his family's accepting attitude contrasted with the pressure he perceived from the outside world. *"Society's expectations of me and questions why I'm not leading a certain kind of life. Those things are unhelpful and they made me feel cornered. Yeah, I find that very unhelpful"* (P8). As will be discussed later, the lack of pressure was not always a deliberate, planned strategy for most family members. In many families it stemmed from uncertainty about what to do for the best. Whilst in a few other families, fear of the PEP's response was the major motivating factor. Family members did, however, deliberately attempt to create a safe, non-threatening environment:

You're trying to create, if you like, making this a safe environment for that person (F6, husband)

I think he felt safe here, that's the thing. And presumably that was because of the ambience we've created around, you know. There weren't threats and things. (F3, mother)

The lack of threats contrasted with PEPs' experiences with formal services:

...when you're first in hospital, it makes you feel quite vulnerable. When you see other patients - and it was an all male ward - you can feel quite threatened sometimes. You feel like it's not a safe environment. Especially when you've been living on your own and you suddenly get surrounded by people. (P9)

Theme 3: Being there

The importance of family 'being there' was a ubiquitous theme from the perspective of both the PEPs and family members. However, it was difficult for people to articulate what they meant by 'being there': *"I don't know what it means by being there, we just are"* (F2, mother). It was frequently a passive presence, where the knowledge that the other person was there was supportive in itself. For the PEPs there was a strong phase-dependent element to 'being there'. It was particularly central as they were relapsing or moving into the recovery phase of psychosis, whereas when they were acutely unwell, the presence or absence of other people was less important.

"Need to know they're there"

The PEPs described the importance of knowing that the family members were there. This was especially relevant as they began to recover from a psychotic episode, and come back to a bleaker 'reality'. As one participant said:

...at that point where the delusions just start to end and you're still in hospital. And you realise that it really is literally just a hospital and everybody is just a nurse and not some religious person from the bible or something or alien or angel or something. The reality really bites, that's really when you need people around you the most. It's the most painful time. (P4)

The central element of this need to know, for the PEPs, was that their families had not rejected them for being ill or for the things that they had done whilst unwell: *"...they didn't alienate me for being ill"* (P1). They needed to know that their relative still loved them despite what may have occurred: *"...knowing that she still loves me*

and cares for me” (P2). This helped to counter their own sense of shame over what had happened.

Family members explicitly tried to make it clear to the PEPs that they were there for them:

You've got to try and make it obvious that whatever they do you're there, you still love them. (F1, father)

...you're offering the knowledge that, even though this awful thing is happened to him you're still there. (F4, partner)

For many families it felt as if 'being there' and letting the PEP know they loved them was one of the few things they could do to provide support: *“It's just being there – it's all you can do” (F2, mother).*

“A secure and safe feeling”

The knowledge that their family members were there for them gave the PEPs a sense of security and containment. This was particularly pertinent as they were relapsing – even for those participants who were unaware they were relapsing.

I suppose deep down inside you know that you're not right and you know that you probably are on a hyper mission. But you feel safe knowing that you're there [pointing to mother]...it's a secure and safe feeling really. (P2)

In part, the mere presence of some family members, whether in person or on the telephone, was calming. This perhaps stemmed from the ongoing bond between the two people: "...your voice in itself I find soothing mum. That's one of the reasons why I phone you up and talk, because you calm me down just by talking me through" (P5). Frequently, the PEPs were unable to articulate what they needed from their family member and described themselves as unaware of needing anything at the time. Their family members, however, felt they detected an undercurrent, in their interactions with the PEP, which was obliquely asking for help:

It's almost, when they ring me, as if they are crying out for help and they are saying 'help me' but they can't say it...They go around it in other ways but you know they are crying out for help but they can't ask for it. It's weird. But they do things and it's almost a way of asking for help but it doesn't register with them that they are asking for help but it does to the family. (F2, mother)

For most PEPs, 'being there' transcended understanding. It did not matter that their families did not understand what was happening; their presence in itself was containing. As one participant put it:

P3: I think I relaxed quite a bit when [my father] got back actually. He's always been someone to look up to and I think that when he got back I sort of thought, well he's back, things are going to be – well not okay but, you know, things would be under control. And I think that did help me a lot actually.

I: So it was the knowledge that he was here?

P3: Yeah, I mean he couldn't understand.

However, this was not the case for one participant, who hoped that her family could not understand because she did not want them to be hurt: *"They're not 100% here, because they don't understand. They can't imagine what it's like. Well I hope they can't because it was so hurtful and painful"* (P7).

Theme 4: Protection and rescue

Clearly, when people are experiencing psychosis, they may do things they would not do when well. At the extreme, they may even make choices which can put them or other people at risk. Afterwards, they may need to face the consequences of what they have done. One of the roles which family members took was that of protecting the PEP from seeing the impact of their psychosis and rescuing them from any aftermath. They also tried to recognise relapses early and take appropriate action. This protection was not all one-way; the PEPs also described a wish to protect their family which manifested itself in uncertainty about what to disclose.

"Watching like hawks"

Most family members described maintaining a near continual level of vigilance around the PEP. This entailed both keeping an eye out, to ensure they were safe, as well as a sensitivity to possible symptoms. They described this as like living on a 'knife edge'. A very few family members did not mention vigilance or sensitivity; in these instances, the PEP tended to show less distinct phases of psychosis and experienced a high degree of residual symptoms even when stable.

One aspect of the family members' vigilance revolved around ensuring the safety of the PEP by, for example, making sure they remained close or enlisting the PEP's friends or workplace to keep an eye on them. This tended to be done covertly without the PEP's awareness:

...it's always people working in the background. When you've got somebody going hyper or manic you always got people ringing round, making sure they're alright, where they are. 'You know they're ill?' 'Yeah, but we'll keep an eye on them'. It's a terrible situation to have to be in, because it shouldn't be like that. (F2, mother)

Only one participant was aware when he was becoming unwell and was able to contact formal services himself. Most family members therefore felt they needed to respond quickly and be proactive if the PEP was relapsing. This was partly due to a general sense that, if they caught a relapse early enough, it could either be averted or curtailed. It was also about protecting the PEP so that they did not do anything which they could later regret. The family member's response always involved contact with formal services – either increasing the PEP's medication or getting them into hospital.

You see the days getting worse and then you think, well, I've got to do something quick here, you know. There's a relapse on the way. And then obviously, you know, it's the nearest thing. Normally I go straight to [hospital], phone them up, get in touch with her psychiatrist and literally start asking for medication to be upped. (F6, husband)

Family members were continuously alert to possible symptoms, making sure that they did not represent the beginning of a relapse. These signs could be quite subtle such as becoming annoyed if the cat was on the table or talking about religion. One PEP, who tended to relapse very fast, described how his partner was on continuous 'yellow alert':

...she's on like different stages of alert...yellow alert or red alert. I think at the moment she's on yellow alert possibly, she just checks any possible symptom to see whether or not that's a possible symptom, not a definite symptom. And to see whether or not it's something to be actually concerned about. And if it is then she goes into red alert...she starts picking up the phone, speaking to my dad, insisting that I speak to my CPN, or contact the CPN myself. So I think those are her two stages really. She never goes down into, there's no lesser, there's no green alert. Perhaps there may never be, I don't know. (P4)

Over time, most family members became sensitive to subtle changes in the PEP's state of mind: *"I can tell by his voice" (F9, sister)*. Other family members described how difficult it was to detect the early signs of a relapse in their relative. *"It goes from really being quite difficult to being so obvious you can't ignore it, in a matter of 24 hours" (F4, partner)*. These family members in particular were concerned that they had become oversensitive, worrying about too many things which could be potential symptoms: *"I think you become hypersensitive...//...Only the smallest little indication, you think 'oh G-d is this going off again?'" (F1, mother)*. One partner described how formal services had encouraged her not to be so vigilant, but this felt somewhat unrealistic to her:

...the official line [from formal services] is 'you've just got to live your life...we're here...we'll do it as well' But it's not really true is it? I'm here every day. They're not going to get him to A&E, I will. (F4, partner)

Whilst this hypersensitivity potentially could create problems in their relationship with the PEP, it only seemed a source of irritation for the PEP if they were in fact relapsing. At other times, the PEP tended to view their relative's vigilance with

tolerance or even view it as positive. Both family members and PEPs felt it was important that someone was taking notice of their wellbeing. Many felt sad for people who had 'no-one to notice':

...it's good to have someone there who is watching out as much as that. I work in the voluntary sector and I'm aware that a lot of people with mental problems, even living on the street, have no-one to look out for them at all and their mental health symptoms go totally unchecked. And it's reassuring really. I don't particularly have historically very good insight, so to have someone to do half the work for you or even three quarters of the work is really quite a good thing. (P4)

Concealing impact

Whilst helping the PEP, family members experienced a range of reactions, some of which were distinctly negative; for example, feeling physically sick with worry and feeling frightened. Family members tried to protect the PEP from knowing the impact their difficulties were having by concealing their negative responses from the PEPs: *"I would sort of try not to be horrified or showing her that I was horrified"* (F6, husband). Some family members mentioned a difficulty coordinating their own needs with those of the PEP; there were times when they just did not feel like offering support. This was not revealed to the PEP. Instead, the support they offered was not contingent on their own moods, but was available whenever necessary. In part, this was about providing an even, stable presence. Family members felt that, by minimising the overt impact on their own lives and maintaining as near normal life as possible, they might be able to prevent the PEP feeling guilty about the impact of their difficulties on the family.

In addition, family members described how important it was that the PEP did not know or worry about their own feelings of inconvenience or being overwhelmed, since the PEP might otherwise not feel able to seek support:

Because I've never said 'oh [brother] I don't want to hear this'. You know, I'd feel that I wouldn't want to say that to him. Or 'I've had a bad day today'. Or, 'I'm down today'. Or 'things aren't going that well today and I don't really want to hear this. I want someone I can tell'. But I don't. (F9, sister)

Even after the PEP had regained some stability, family members were reluctant to disclose how hard the experience had been for them. Some participants described how isolating it could feel to go through such a major stressful event with someone and yet be unable to fully reveal their perspective with the person with whom they shared the experience:

"...it's difficult though to say to someone 'do you really know how difficult you become?'. When you experience something that is never going to be your fault. So you have this thing, it messes up your life, it's not your fault and also then I'm telling you how [difficult it was]...I do think we both experience it and we experience it in different ways. Because I'm out here carrying on, often working, but he's in there...//...it feels lonely. (F4, partner)

Disclosure

Despite their relatives' attempts to conceal the impact, the PEPs were, to some extent, aware of their family members' difficulties. Thus they also described trying to

protect their relative. For some, this resulted in a dilemma over what to tell family members, particularly at the time when their symptoms were beginning to increase but before they had begun to lose insight. They wanted to enlist their family members' support or advice, however, they were concerned that if they disclosed that they were experiencing more difficulties, their relative might experience 'compassion fatigue' or think that they were overreacting or whingeing:

It reaches a point when your partner or your CPN, kind of gets a little bit tired of...hearing the same thing again and having to give the same advice. They get a little bit weary of it and I thought I'll just ring up and say 'I'm having difficulties' and they'll say 'oh not again, complaining again'. (P4)

This therefore left them trying to cope alone, as this participant continued:

People only have so much to give, I mean. People aren't infinite resources of patience and time and energy. And as hard as that may be when you feel that you're not really getting anywhere, and you're not improving and you're still stumbling across the same obstacles. Sometimes you really have to keep stumbling and keep stumbling and that's just the way it is. (P4)

These PEPs did not want to burden or distress their family member, but the cost of their silence was a sense of isolation in addition to trying to cope alone. Although superficially they might be sharing an experience with their family member, if they could not explain what was really happening, the PEPs felt alone in their own experience. From the PEP's perspective, the family lost their shared narrative. As one participant put it:

I was experiencing delusions. So after telling [my sister] about this thing then she in turn also started to tense up, so it was like I was just feeling stressed that I was making her stressed so there was nothing to be gained in it. But on the other side I felt a little bit desperate because I thought, if I am not able to tell her these things, it means we will be walking along and she will be completely oblivious that I am experiencing all these delusions...But after a while of hearing all these things saying I should have turned back, it got it was so depressing I didn't want to carry on. So I turned to her and explained a little bit about what I was experiencing but I think it just upsets her totally...But that's what I'm going through. But she didn't really want to experience it, she didn't really want to hear it at that time. Which I can understand, but it did make me feel a little bit more alone in a way. (P9)

Just as with family members, even after the psychotic episode had finished, there were things that had happened which the PEP found hard to tell their family about.

This further increased their sense of isolation:

I struggle with a lot of things. I still struggle with some things now. But there are things that I don't really get an opportunity to discuss. I mean who can you have a conversation with about the fact that you had unprotected sex with someone in a hospital. Not work colleagues, not friends really, certainly not your partner. It's just hard isn't it? So you have to kind of work it through yourself. (P4)

Rescue from aftermath

As the PEPs were relapsing, they often did things which were out of character and that led to financial, legal or interpersonal trouble. This was particularly the case for participants with bipolar disorder. Family members tried to circumvent this trouble by, for example, hiding the PEP's passport or cash point card. This could lead to conflict because, at the time, the PEPs wanted to be allowed to get on with their own lives and just wanted approval for their plans and decisions. Once again, this had a phase-dependent element to it, since after recovery the PEPs regretted their actions. As one participant put it: *"Then it makes the depressions worse as well. Because you think of all the things that you've done when you were hyper"* (P2). Thus they were later thankful for their relative's intervention:

"I didn't want my cash card to be taken away...//...But it's probably for the best because I didn't want to spend all that money, keep on spending and spending money. (P4)

However, it was not always possible for family members to prevent the PEP taking actions which led to trouble. In these instances, their first priority was to try to get the PEP into hospital. Once the PEP was safe, family members then took responsibility for sorting out any aftermath:

"I've been really out of control and done things which I could have been prosecuted for. But fortunately in every instance my father handled it and avoided any further action being taken by the police". (P4)

For family members, this was viewed as a way of protecting the PEP's future. Thus some family members tried to minimise any long-term impact from the psychotic

episode which a criminal record or mental health sectioning would incur on the PEP's career or social role:

"I think at that stage we were also very concerned for his future career, that people shouldn't know...that he had had this blip. And we thought that that would be bad for his career opportunities and all the rest of it. So we were not publicising it and I didn't want anything to go down on...you know, the fact that he'd been sectioned or anything else at that stage. (F3, father)

This was not a concern for all family members, as the mother of this participant noted: *"It never crossed my mind, anything about criminal records or anything. I just wanted to have him back"* (F3, mother). Thus, for some family members, there could be a tension between protecting the PEP in the 'present' and protecting their future: what most helped the PEP at the time of relapse, getting them into hospital, could potentially have adverse consequences for their future. Balancing these conflicting tensions added a further layer of difficulty to any decision by family members to involve formal services.

DOMAIN TWO: ISSUES IN HELP AND SUPPORT

In discussing the types of help and support offered within their families, participants also highlighted a number of issues or dilemmas which affected this support. During certain phases of their illness the PEPs became dependent on their family members or needed them to be proactive. At other times, it was important that the PEPs were autonomous and that their relatives were responsive. Families described a difficulty shifting between these two phases of independence. Another difficulty faced by families was their lack of knowledge about the psychosis and what the PEP was

experiencing. Stemming from this was a strong sense of uncertainty, for family members, over how to best support the PEP. In addition, the nature of psychosis itself made it harder to offer or receive support.

Theme 5: Independence, autonomy and beneficence

One of the major issues faced by the families in this study was that of balancing the PEP's need for care and protection with their need for autonomy and independence. Both the PEPs and their family members acknowledged a tension between acting in the PEP's 'best interest' but going against their current wishes or letting them get on with their own lives. What was wanted or needed by the PEP depended on the phase of their illness: as the PEP relapsed they wanted those around them to be proactive; during recovery they wanted responsiveness to their needs; and once stable they wanted independence. The difficulty, for both PEPs and their family members, came at the transition points: relinquishing or regaining control and knowing when to do what.

Being proactive

As they began to relapse, the PEPs wanted their relatives to notice and then to take immediate action – generally contacting formal services or insisting that the PEP take their medication. However, this was in hindsight. At the time, as noted before, the PEPs may not have recognised anything was wrong and certainly did not want contact with formal services. This difficulty was acknowledged by the PEPs:

...perseverance in the beginning and the fact that they might have to make decisions which are hard and unpleasant – for example like getting the police involved and getting me sectioned...sometimes tough

decisions have to be made on [my] behalf, about [me], which [I'm] not going to agree with (P3)

Thus family members had to organise the necessary help on behalf of the reluctant PEP; as one mother noted: *"It is a reluctance on the part of those who are mentally ill to come forward and seek help so it is up to the carer to get that help"* (F5, mother). Even when family members had persuaded the PEP to access formal services, they faced two further hurdles. First, the PEP tended to underplay their symptoms in front of doctors. Family members used various terms to describe this: 'put on a jolly good show', 'holds it together' and 'a mission to hide it'. As one PEP put it:

I didn't tell them about the voices and the hallucinations so part of it is my own fault for not saying how ill I was or confessing to all the symptoms I was having. (P8)

The second hurdle, stated by several family members, was that formal services frequently would not listen to relatives' views:

...doctors say 'well until they ask for help we can't do anything'. Duh, come on let's get real here. They don't know they need help! This is another thing that really bugs me. (F2, mother)

For family members this whole process of being proactive was frustrating and sad. They felt torn between two options, both of which were distressing. On the one hand they felt bad for going against the wishes of the PEP and taking away their autonomy: *"he very reluctantly went in to see the doctors and was then sectioned. Which was pretty upsetting for us. You know, we felt we'd betrayed him"* (F1,

father). But the alternative, allowing the PEP to remain untreated and vulnerable, seemed even worse:

...people were laughing at him...if anyone had seen him out there 'ooh look at him, he's bloody mad'. Now to me that's degrading. Wouldn't it be kinder to put somebody in hospital? (F2, mother)

Although later, the PEPs were happy their family members had taken control, the words they used to describe their feelings at the time were 'disempowered', 'confused', 'threatened' and 'pressured'. What they wanted was contradictory; their immediate and longer-term wishes were incompatible:

I think it was because I felt I was being put into a box. And I felt, when I was by myself, things were working fine; when I was up here or [my family] were involved, I was being channelled into the social system. Things were pushed in to social workers, psychologists, institutions, and I didn't want to be in an institution, and so I suppose [my family] represented that to me, they represented you know the harsh reality of it: I was ill and I needed to be in care but...it didn't feel like that. (P3)

Being reactive

Once the PEPs were over the acute phase of psychosis, there needed to be a gradual transfer of power and autonomy back to the PEP. This required a switch in the family member's strategy from being proactive, and taking charge, to being reactive, and allowing the PEP to dictate their needs. Initially, the PEPs wanted a safe space in which to recover (as described in the themes of sanctuary and being

there). One father used the analogy of a game of tennis to describe the recovery phase:

...he's done something, we've responded. Rather like a game of tennis, you know. The shot comes and you just have to have a go and decide what will work. And gradually you learn which are your good strokes and your bad strokes. (F1, father)

As they further recovered the PEPs wanted to regain their independence as adults: *"I wanted to be independent because it's no good living in the countryside with your mum and dad. I mean, what are you going to do? It's bound to cause problems"* (P1). This involved the PEPs resuming self-reliance, by for example, taking responsibility for their medication, becoming involved with voluntary organisations or, in the case of those staying with their parents, finding themselves somewhere to live. This could be hard, as several participants expressed:

I did make a conscious effort after that to try not rely on other people so much when I'm going through things, to try to be able to get through them by myself. It's very difficult. (P9)

In addition, for the PEPs to regain their independence family members needed to be responsive and 'let go' so that the PEP could lead their own life: *"...we're making him do it for himself because we shan't be here forever...You can't live somebody else's life can you. We can't live his life"* (F1, mother). There was a sense of respect and admiration conveyed by family members when they discussed the way in which the PEP had moved on: *"he's handled his illness himself in a remarkable way"* (F1, mother).

Transferring control

The transitions between being proactive and being reactive were complex. An issue for both the PEPs and their family members was when this transfer of control should happen. The PEPs expressed uncertainty about when they had sufficiently recovered to resume more independence. As one participant put it:

...if I'm in my mum's company and I'm ill, it can be comforting...And then after a while, the focus is that I want to get on with my life and purpose and do things and so on. So it's difficult to gauge when you should pick up and move on or when you should just recuperate. (P9)

Some PEPs mentioned that having support from both formal services and family helped them to balance their dependence on either source; as this participant continued:

...hospital in itself is not necessarily a curing process. It's quite a negative process and if you rely on the profession and not on your family I don't think you'll get very far...I think if you just have the medical profession and didn't have friends or family helping you then, I don't know how you would cope really, you would become dependent on the medical profession. (P9)

For family members the complexity was, in part, because the PEPs were saying they did not want help – as they were relapsing. This made it unclear, for some family members, about when they should become more proactive and take control:

...when they get like that [start to relapse], it's 'I don't need you. What do I need you for? I'm all right. I can cope on my own. I'm fine.' But they know they're not really and that's when they don't want me - but they do...and then you don't know what to do (F2, mother)

This uncertainty was especially strong in the early stages of living with psychosis. Family members did not necessarily recognise the onset of relapse as quickly and found it hard to make the transition from viewing the PEP as 'rational'. Family members also described uncertainty about when to begin to transfer control as the PEP began to recover.

For family members, it could be hard to relinquish control. For example, one participant worried that she bullied her brother: "So I was trying to go through the papers, find jobs, send them to him and everything...I think I was bullying...And I was trying to do it all. And you can't. I mean he's got to do it himself hasn't he?" (F9, sister). This was not done with any malign intent, but instead reflected a genuine wish for the PEP to recover and move on. Sometimes this wish to be helpful resulted in the family member becoming overprotective and so was counterproductive:

...when [wife] was first ill...I was going, 'be careful, don't do this, don't do that because you're mentally ill. You've got to look after your illness. Don't do too much'. Even things that she wanted to do, I would be taking them out of her hands saying 'no, no, no, you go and sit down and have a rest'. And apparently I didn't realise I was taking her independence away...//...she really wanted so much to take back her role as a mother and as a key player in this family. And I...stole her job, because I was trying to do the lot. (F6, husband)

Another reason why family members had difficulty transferring control was that they had become used to making all the decisions, maintaining the house, managing the finances and so on. This was particularly the case if the PEP's psychotic episode was long, there was post-psychotic depression or the PEP experienced on-going distressing symptoms even when well. This was clearly described by the partner of one participant:

...I think it does have long term effects on you as a couple. I'm quite strong willed anyway but I think we got into a sort of pattern where I almost like lead...but it's only sort of really now we've started to talk about the fact that I need to relinquish a little bit of the control. It needs to become more equal. (F4, partner)

Theme 6: Trying to make sense

Both family members and the PEPs struggled to make sense of psychosis. Initially they felt they knew nothing. Even after they began to learn about and gain more experience with the illness, family members felt they could not understand what the PEP was going through. Nor could the PEPs describe the illness. One of the ways in which family members tried to understand was by normalising the PEP's experiences; although helpful, this only went so far and could not fully account for the PEP's difficulties. The experiences of these families is characterised by uncertainty. In particular, for the family members, a desperate wish to help, but uncertainty about how to go about this. This left them feeling powerless, at times, to help the PEP.

Not knowing

When the PEP first started to become unwell, neither they nor their family members knew what was happening. Family members portrayed themselves as 'clueless' or 'bewildered'. Some attributed the PEP's difficulties to substance abuse, others thought that the PEP was just being a 'real pain' or a 'grumpy teenager'. One partner described believing that their neighbours were plotting against them because this is what his wife was telling him:

And there was a change in her. Not drastically but there was a change over the course of about a year. The psychosis, in the way of her hearing voices, got worse and they were so convincing what she was telling me. I actually believed she was hearing voices and I actually believed – because I didn't know anything about schizophrenia at that time – I actually believed we had dodgy neighbours. And one time she had me out there listening. And I was saying, 'well I can't hear anything'. And she was saying, 'but I can'. (F6, husband)

The PEPs were also unclear about what was happening to them: *"I thought I needed to go and be exorcised or I didn't know what was going on and didn't know what strategy to take to try and sort my problems out" (P9).*

If the PEP had an acute and rapid onset, diagnosis followed fairly swiftly, but for those PEPs with a more insidious onset, it could take several years before they received a diagnosis. To some extent this was a combination of a difficulty engaging formal services together with the PEPs hiding their experiences from formal services. However, in addition, family members described not wanting to know: *"Going back to the very beginning the main feeling I had was, I think, well to start*

with you didn't want to think it was happening" (F1, father). Even once they were told, some family members had difficulty accepting it, partly because the diagnosis held no meaning for them and they did not understand what it entailed:

And then all of a sudden I just burst, I went into one and I said to [the doctor], 'she's not mad, what are you talking about?' And literally I threw him out...I didn't want to believe she was mentally ill...And the same night I come to grips that she perhaps was and that she needed hospital...She went in there with the thought that she was going to die and when she went in there I had the thought that I wasn't ever going to see her again. (F6, husband)

At the other extreme, some families thought the PEP would be well in a couple of weeks: *"We thought he'd be well in a couple of weeks and it's been twenty years. You've absolutely no idea what's ahead of you. At all. Thank G-d, I think, really" (F1, mother).*

Receiving a diagnosis, however, did not necessarily help family members to make sense of what the PEP was experiencing. Psychosis felt like an unimaginable experience: *"...its somewhere where they can go that none of us will probably ever go, I hope...you could never understand it" (F2, mother).* This was mirrored by the PEPs; they felt it was impossible to fully explain what psychosis was like:

...part of the illness is that, you can involve other people, but there is an element of it which is about the individual, you can't relate everything because some of it is just the way you're feeling in a way, it's difficult to describe. It's like a mixture of depression and confusion. (P9).

Even if they could explain the experience, some PEPs felt that their family members would not be able to understand, nor be able to help. As one participant put it: *"If I did explain it, I don't think she would have understood completely but then she wouldn't be able to stop it" (P2).*

The response of most family members to 'not knowing' was to inform themselves. Many felt they had become 'experts' on psychosis: *"You read all you can...//... Every article about it, you look at" (F1, mother).* However, other family members were too bewildered by the experience to consider finding information: *"...if we'd been different we might have known to look it all up on the internet and try and work it all out and things. But we were just – in shock" (F3, mother).*

Normalising

Family members also tried to make sense of the PEP's experiences by extrapolating from their own experiences. To the family member, this helped them view the psychosis as something not so 'alien'. As one father described:

With things like this, when he would be spouting a stream of rubbish and so on, he's not so far from me. And I think most of us who are, as it were, alright, have a stream of rubbish, inconsequential, unsatisfactory, reprehensible, obscene, or whatever, thoughts rumbling on in your mind. But we, the rest of us, have a kind of filter that we filter out all those things. It's not that they don't cross our mind, but we know that they're not presentable or acceptable. But somebody in [son]'s state, I think that mental filter's gone and whatever comes into his head comes, comes pouring out. (F1, father)

For the PEPs, their family members' attempts to normalise their experience could help to give them some perspective on their difficulties:

...one of the symptoms of my illness was that I felt very frightened in public spaces. I felt as though there was a hostility towards me from strangers and it would build up in my mind to be almost real...But talking with my sister...would give me that sort of counterbalance of saying that this isn't real, that everybody is stressed to some extent, going out. Not stressed about the fact that somebody's going to do something to them, but stressed in going in public places and using public transport and so on. [It] is normal to a certain extent, and there is no reason for me to feel particularly threatened. (P9)

Adopting a dimensional perspective made the psychosis seem marginally more intelligible to the family members and helped guide their efforts in support and help:

Because we're all a bit like that. If we all just laid in bed, which I know is a negative symptom to the illness, but if we all just laid in bed our dreams would go into reality and we would all become disturbed by our dreams. So that's one of the reasons why I try so emphatically to get you up, to get you into a different reality. (F2, mother)

However, as one mother pointed out, some of the things which are usually viewed as helpful to someone experiencing difficulties, such as eating well or exercising, seemed to have little impact upon the psychosis itself:

But you see, you think of all those things, sound so good don't they? You know fresh air, good food. But I don't think they actually deal with

what's going on in here [taps her head]. I really don't. I can remember walking along somewhere outside and [son] was picking up little bits of grit, whatever it was, and thinking 'I'll keep that' [gestures putting it in her pocket]. Quite oblivious of what was really going on. (F1, mother)

Uncertainty

A near ubiquitous theme within family members' accounts was that of uncertainty. This was expressed across a wide range of areas, such as: how to help, whether they helped, what precipitates relapse and what was going to happen in the future. Strongest amongst these was uncertainty about how to help:

It's the old thing that, you know, you've got a little boy and he falls over and he hurts his knee and you put a plaster on and you hug him and then he's alright. But you don't do that, you can't do that with this sort of illness and I think that's the most difficult thing. The answers are not easy to find. There aren't answers, that's the trouble. You've just got to hack your way through it in the only way that you can. (F1, mother)

They desperately wanted to help the PEP to recover, but were unsure what to do; whether, for example, to let them be, put pressure on them, challenge them, go along with their ideas or encourage emotional off-loading:

And I mean I really didn't know how to handle it...I really didn't know, should I be growling at him telling him to get out of bed, should I just let it go with a glare. So I suppose I did a mixture of both actually. One was trying to get him back up but you didn't quite know what you were supposed to do to help him get back up. (F1, father)

As a result of this uncertainty, family members either tried to do a mixture of all these things, as the above participant described, or just 'going with the flow' and doing nothing; as this participant noted:

...but we didn't know whether we should be saying, 'come on get up', or 'darling what is it you're feeling?' Or what have you. So I think we probably said nothing and just left him to cope. (F3, mother)

Exacerbating the difficulty of not knowing the 'right' way to help, was the family members' concern that there could be a 'wrong' way – one that would be detrimental to the PEP. That they also were uncertain about what this might be, led to increased pressure on family members: *"Extremely careful without any real knowledge of what was going to be good and what wasn't" (F1, father)*. Sometimes, therefore, their best intentions went amiss: *"We thought we were doing the right thing but as far as he was concerned, it was very much the wrong thing" (F3, mother)*. Almost all family members were uncertain whether or not they actually did help.

Linked to this ambiguity over how best to help, was a general uncertainty over what precipitated relapses. Family members collectively suggested a number of potential triggers, such as fever, acts of G-d, not taking medication or stress. However, most relatives did not feel confident that they knew enough to help the PEP to circumvent a relapse, as this participant described: *"My biggest fear is that there's no pattern and that it's random and then that really is frightening" (F4, partner)*. This was particularly difficult for the those family members who described their own wellbeing as bound up with the PEP's current state, as these parents commented:

It colours your whole attitude to life. (F1, mother)

...because it is so uncertain, you never know where you are. (F1, father)

Both family members and the PEPs repeatedly expressed uncertainty over the future. This related to two main aspects: firstly, the PEP's future wellbeing:

...it's also scary because I think I've got my life to live and what is going to happen. How many hyper missions am I going to have? How many depressed states am I going to have? What's going to happen when I have children? It's not nice to think what's going to happen in the future. Because I'm always going to have it, it's never going to go away. (P2)

The second main aspect of concern for the future was what would happen to the PEP when, or if, the family member could no longer provide support. This was particularly pertinent for the parent-child participants.

Some family members felt resentment towards formal services for not telling them what they should be doing to best help the PEP. Other relatives, who had had more experience, came to the conclusion that formal services may not have the answers themselves:

When I think of the psychiatrists we've seen, dozens of them, and they sit there and they listen to you talk...the fact that you go and talk and you voice your ideas of fears helps you, but you don't actually get any help because they don't know what to say do they? (F1, mother)

This realisation painfully underscored the incurable nature of psychosis: although it may not have a chronic course, there is no cure. This was illustrated by one husband:

I'd always believed myself that there's always an answer to everything. And at times when she was first ill, hallucinating, being very very ill...there didn't seem to be any answers to it and you know, when doctors tell you there's no cure for it, it's even worse. (F6, husband)

Several family members also expressed frustration at what they perceived as their exclusion from formal services. They did not feel heard and felt that confidentiality could be taken too far. As these parents described:

I rang the counsellor and I said 'I'm worried', and she said, 'all I can say is I hear what you say'. Because they don't talk to you, you know. It's all confidential. And I was a bit put out about that (F3, mother)

...it's very difficult for the people who are, on a daily basis, living with somebody like this and the counsellors just say, 'sorry, can't talk to you'. We really didn't know where we were going (F3, father)

Interestingly the son of this couple, along with other PEPs, also felt it would be helpful if families were to be included in the 'communication loop':

...it's important for the family because they don't know what's going on and [the doctor] can explain to a degree...he is a professional and he can translate what they're seeing, but they can't understand, into terms which they can understand. And that's important because the family do

take a big brunt of it...And so it's very important that they do get feedback. And that probably should happen more. (P3)

Powerlessness

In supporting the PEP, family members described a sense of powerlessness. They felt there was little they could do to actually help against the psychosis and that this was the role of formal services and medication. Instead, they viewed their role as providing the safe space in which the participant could recover.

...he was seeing [psychiatrist] on a weekly basis then...He's in good hands and what we're going to do is just provide him meals and be supportive and just be around. (F3, father)

Several participants viewed their offer of being there, continuing as normal, providing a safe environment and talking as all they could do: *"It's just being there, it's all you can do...That's how I help her, just to be there"* (F2, mother). This was frustrating for participants as they felt that 'all they could do' was not enough in the face of the illness: *"Don't know what to do. I mean what can I do really? I'm the sort of person to do something. I can't do anything, that's the thing"* (F9, sister). The sense of there being little family members could do to help was echoed by the PEPs:

I don't think there's anything anybody can do. Because it's all in here, it's all in my mind. And there's nothing anybody can say or do to stop...or do anything about it. (P8)

For one participant this felt vulnerable: “...just [my mother] against all these really bad horrible things isn’t enough” (P7). Despite their sense of powerlessness, the families in this study had remained involved with the PEP and continued to try to help:

I suppose sometimes you see my weaknesses or see me crumble occasionally. And that’s not good you see. She does need really strong support and a path of recovery you know. And to be able to provide that for her constantly, which I do, but I can only take it day by day though, this is the thing. To build a bigger, better, brighter future for us sometimes does seem a bit out of my grasp, but I do remain hopeful – don’t I darling? – that something will work out for us. (F7, mother)

Theme 7: Psychosis disrupts relationships

Perhaps unsurprisingly, both family members and the PEPs made several references to the disruption brought about by the psychosis. It put a strain on family relationships – between other family members as well as between the index family member and the PEP – and some even ended. The core experiences of psychosis – hallucinations, delusions and thought disorder – could contort both communication and support efforts. From both perspectives it sometimes felt hard to get through to the other person, even in a simple way: “...basic communication was getting a bit lost there” (F7, mother). For the family members it felt as if the PEP had become another person; someone who was unaware they were ill, who had become self absorbed and could be irritable. Most participants, however, also described positive changes in their family relationships. Together this all impacted upon the helping relationship, generally making it harder to offer support.

Psychosis disrupts helping

Psychosis affected the helping relationship, in part this was because, as the PEP relapsed, their views on what would be helpful changed. Although in hindsight they frequently concurred, at the time of relapse the PEPs and their family members described holding different views on how best to manage the problems. The main strategies of family members were, as already noted, getting formal services involved and persuading the PEP to take or increase their medication. However, as one father pointed out, if the PEPs were not aware they were relapsing, they would not see a need for formal services, but until they accessed formal services or medication, they would not know they were unwell – an impasse:

It's getting them insight as fast as possible so it's getting them on medicine as fast as possible really, isn't it? It's more about them understanding they're ill...The trouble is it's easy to say when you get him into the [clinic] but you can't force somebody to go to the [clinic] so you've got to persuade them they're ill before they, you know. So it's a catch-22 really. (F3, father)

Family members described frustration because it felt as if the PEP did not want help. Even when the PEPs were aware that something was 'wrong', what they wanted at the time was different from what their family members thought best, this could lead to conflict, particularly if the PEP experienced bipolar disorder:

I was very angry, very very angry at them... I was furious...when they turned up I was just like, leave me alone. Just get out of my face. I mean I just wanted my own space. I realised things had gone wrong but I just

wanted to deal with them myself. I just didn't want anyone else involved.

(P3)

Thus when family members did involve formal services it felt like betrayal to the PEPs, as if their families had turned against them, even if later they recognised the wisdom of their family member's actions:

It felt like betrayal a lot of the time but then you haven't got any choice have you? But I understand now that they would be doing what they thought was right, and normally they were doing what was right. (P1)

At times, particularly as they relapsed, it felt as if the PEP had become another person. This was commented on by both the PEPs and their family members, for example: "...at one time I lost my wife. I didn't know who this person was. It was a completely different person to what I knew or why we were married" (F6, husband).

The PEPs talked about the many things they had done when ill, such as vandalism, breaking into someone else's house, running down the street naked, wandering the streets and, above all, being withdrawn, incoherent, threatening or abusive:

I was completely different. Didn't want to go out, didn't relate any more, stopped reading, didn't want to watch television any more, didn't see my friends as much. (P8)

Many family members described being frightened of the PEP at these times. Inevitably this put great strain on family relationships.

Another way in which psychosis influenced the helping relationship was by contorting the family member's efforts to help. The PEPs' beliefs at the time could lead them to withdraw, so that family members could not get close enough to offer support: *"She wouldn't let anyone in that room. I couldn't go in there to do anything or even to talk to her or anything"* (F5, mother).

Some of the PEPs withdrew because their hallucinations told them that they were hurting their family in some way:

It helps [being with my family], but then I'm hearing voices telling me that what I'm going through is affecting everybody. That I'm affecting the people close to me and all this sort of thing. So after a while it becomes depressing, because I fear that my illness is affecting other people. (P9)

This was another dilemma: without family support their difficulties were unlikely to resolve themselves, but some PEPs feared that in allowing their family members close enough to support them, they could be harming their family. For other PEPs, their psychosis distorted their family member's support attempts. Even relatively straightforward gentle attempts to be encouraging or helpful could then become threatening, as this PEP and her mother described:

[family members] try and say, 'come on and be real', but I don't want to listen to them because it makes me feel like the voices are making them say something to me. It's not them, their actual heart, telling me that there's nothing to worry about. (P7)

But I feel I wasn't reaching her somehow...and what she's explained to me since is that some days, from me simply trying to encourage her

through my own agenda, like I want you to get up because you could be you know doing some artwork or doing something, it hasn't been helpful to her when she was really truly in the grip of the illness, because she'd find simply my voice would flow into the other voices and become, or even trigger, the other voices off, and so...she would feel that I was actually abusing her by trying to encourage her in the mornings. (F7, mother)

Although relatively stable, this PEP continued to experience disabling symptoms, one of which being difficulty in communicating. During the interview her mother helped her to express herself, but even this felt threatening for the PEP:

Mum seems to be able to know what I'm thinking and speak about it and I wonder how she can...pinpoint exactly what I'm thinking. Is it because she's heard the voices or is it because she is one of the voices? (P7)

What could be helpful at one point in time, such as empathy or affection, could become distinctly unhelpful at another point in time because of the influence of the PEP's psychosis: *"Most of the time it's really good that my mum is here and supportive but then there's times when I look at my mum and she isn't my mum"* (P7). This inconsistency made it even harder for family members to know how best to support the PEP.

Awareness

A pervasive theme for both family members and PEPs was the PEPs' lack of awareness when they were acutely unwell; as one participant put it: *"I wasn't particularly obviously in touch with reality. I had my own reality which was obviously*

an incorrect one but nevertheless was where I was at" (P4). So although, objectively, they were sharing the same experience, it did not hold the same meaning for family members and the PEPs. This made it hard for either side to understand the other's point of view, exacerbating the problems in the family's relationships. One participant felt that his lack of awareness was protective to some extent and that his psychosis must be more difficult for his family:

...it's very traumatic for the family, more so actually than the person who's enduring a psychosis because, you know, half the time you're not quite sure what's going on anyway. (P3)

Linked into this was the PEPs' apparent self-absorption. To the family members, the PEP seemed oblivious to societal norms and the way in which society might view them. Family members felt the PEP acted without consideration for others and became selfish because of their lack of awareness, as one father described:

...if the patient has some sort of insight and he's got some idea what effect his actions or words are having on other people. One of the characteristics of the worst face of it, is that you lose all that and don't have the slightest idea or are damn well interested in what anybody else's reaction might be. (F1, father)

Most family members questioned the extent of this lack of awareness. They wondered whether, 'somewhere inside', the PEP had some knowledge of what was happening: *"When he's had earlier episodes, he's been blithely unconscious the follow morning. Or apparently unconscious" (F1, father).* Family members' allusions to 'somewhere inside' may have reflected their continued efforts to see beyond the illness to the person. It could also have been because the family members had

difficulty switching between viewing the PEP as their rational son, partner or sibling and viewing them as irrational or unwell.

Some PEPs also suggested that, somewhere 'deep down', they had a degree of awareness which enabled them, on some level, to respond to what their family members were saying or doing:

[they were] trying to communicate with me, even though I probably didn't respond very effectively to it, I may have at a level...On a subliminal level, there may have been some response, at least some connection, even though consciously probably not. (P3)

However, this was not the case for all participants:

I think when you're at that depth of your illness, it's difficult to share anything...I mean other people being there when you're very ill is a support, but it's not something you're always aware of either...It's more when I'm recovering that I know what's going on and I can relate to what people are doing to help me and so on. (P9)

Positive aspects to support

Family members gave no sense of having actively chosen to remain involved with the PEP. Only one family member raised the possibility of not having involvement in future. Others seemed to view it as the default option; given their previous family relationships, they had not even considered not being involved. As this husband described:

...why did I ever be a carer?...I didn't really get much opportunity not to be one. I had a family and I had a wife who I cared quite a lot about and my family. I couldn't run out on my kids, I couldn't run out on my wife. There's plenty of people in hospital with [wife], especially middle-aged women and young women who've lost all their family over their illness. But I didn't really want to give in to that. (F6, husband)

Despite not having chosen their role as care giver, family members mentioned a number of positive aspects stemming from their experiences in this role. These did not counter the many difficulties they faced, but ran in parallel with them. Thus, as this participant described, she gained a sense of reward from even small steps in her daughter's recovery:

...for quite a long time it just felt exhausting and we wasn't getting any sort of feedback or anything positive from her – however much energy and love you put into her nothing was coming back. But now, as she's making progress, it feels really rewarding and it gives me a lot of joy to see her just getting her little self back together. So even the simplest things on her road to recovery become really, really pleasant. (F2, mother)

Other family members described personal qualities they felt that they had gained through their experience, such as patience, strength and tolerance:

...learned to be a bit more sympathetic towards people who obviously are ill...if you know somebody is ill you have a different attitude towards [ill people on the street], because you know that they're behaving as they might not normally have behaved. (F1, mother)

Both PEPs and their family members repeatedly commented that the experience of psychosis in the family had improved aspects of their relationship as well as causing disruption. In particular they felt that it had brought them closer together. In part, this was because they had had to relate on issues which may usually have been kept private. One participant described how his wife's experience of psychosis had resulted in them becoming friends: *"We've built a friendship up. But it wasn't always like that. And I think before she was mentally ill, it wasn't really like that at all"* (F6, husband).

For the PEPs, one of the positive aspects was a deeper appreciation of their family members (and friends). From their encounters with other people with severe mental illness whilst in hospital or through voluntary organisations, most had noted that ongoing family involvement was not always the case:

I think with care and support, I've always appreciated that I am privileged because I've got a lovely family and loads of friends and I've got that whole network. (F1)

CHAPTER 4: DISCUSSION

OVERVIEW

This qualitative study explored the experience of offering and receiving support in families where one person had experienced psychosis. Nine people who experienced repeated episodes of psychosis and a member of their family were interviewed. The interview enquired about the types of support provided, what was helpful or unhelpful from each person's perspective and the participants' respective experiences in the process of offering and receiving support. The resultant transcripts were analysed according to the principles of interpretative phenomenological analysis.

Seven themes captured the key elements of the participants' experiences; these were organised into two higher order domains. The first domain, 'Normal life', encompassed what was offered by family members and what the people who had experienced psychosis found helpful. It consisted of four main themes: 'Continuity', 'Sanctuary', 'Being there' and 'Protection and rescue'. 'Issues in help and support' was the second domain. This covered some of the difficulties, tensions and dilemmas which affected the families' experience of offering and receiving support. This domain incorporated three main themes: 'Independence, autonomy and beneficence', 'Trying to make sense' and 'Psychosis affects relationships'.

This chapter will first review the findings of the study and discuss them in the wider context of the existing literature. This will be followed by a section identifying the key methodological issues which must be considered when interpreting and drawing conclusions from the study. The chapter will conclude with an exploration of the potential implications this study holds for future research and clinical practice.

FINDINGS AND LITERATURE

Summary of findings

This study set out to explore the help and support experiences of families living with psychosis – both from the perspective of the people who had experienced psychosis and that of their family members. Those issues relating specifically to help and support will be discussed below. However, in order to fully understand the context of such support, an initial brief overview of the families' broader experiences of living with psychosis will first be provided.

Participants' accounts portrayed their experiences in vivid and moving detail. For the PEPs, psychosis impacted upon every aspect of their life: their intimate relationships, their wider social integration, their autonomy and their career. Subjectively they described: shame, stigma, loss of confidence, anxiety, depression and a sense of ongoing vulnerability. Family members described a sense both of sadness and respect for the person who had experienced psychosis. They were uncertain how to help, were unsure if they did help and often felt powerless. Sometimes their worry and continued support efforts felt physically and emotionally exhausting. At times they felt stigmatised or blamed by formal services and the wider society. Both the PEPs and their family members expressed fears for the future. They struggled to find ways to make sense of the psychosis – frequently in the absence of support or information from formal services.

Despite these difficulties, families were not just passive in the face of psychosis and most also identified positive aspects to living with psychosis. Together, the people who had experienced psychosis and their family members, described an active approach to managing and accommodating the difficulties imposed by the illness. What was offered by family members and what was perceived by the PEPs as

supportive can largely be subsumed under two broad areas: 'constancy' and 'asylum'. Participants, however, also highlighted a number of issues or dilemmas in each of these areas. The following sections will therefore address these two broad areas in turn and incorporate discussion of the tensions inherent in offering or receiving constancy and asylum. A brief discussion of the families' relationships with formal services will conclude this section.

Before continuing, it is important to note the phase-dependent dimension to these areas. Although family members were involved with every phase of the PEP's illness, their help and support was fundamental during relapse and recovery. Thus the discussion below predominantly relates to these two phases.

Constancy

Constancy was a pervasive thread unifying participants' accounts. It refers to the continuity through time in the way that family members related to the person who had experienced psychosis, the way in which families as a whole tried to continue as normal, and their aim of enabling the person who had experienced psychosis to lead as normal a life as possible.

The families were able to provide this constancy because their support occurred within the context of ongoing communal relationships (Clark, 1983). This enabled a long-term perspective to the interactions between the family members and the PEPs. Where possible, their interactions did not revolve around psychosis, and were able to assume elements of routine, ordinary interactions; such as in their reciprocity. Often, families did not describe specific incidences of support, instead they discussed general attitudes or provisions such as treating the PEP as the same or continuing as normal. This accords with the suggestion that communal

relationships "...tend to be a matter of ongoing mutual commitment and responsiveness and are not dependent of specific exchanges for their definition" (Coyne et al., p. 130).

Families did not deliberately set out to continue in the same way that they had always done. Instead, this constancy arose, in part, because of their uncertainty over how best to help. Initially, as the PEP first became unwell, neither they nor their family members knew what was happening. The major changes they saw in the PEP in conjunction with their lack of knowledge or information, left family members desperate to help but uncertain how best to do so. Their uncertainty resulted in families just 'going with the flow' in conducting family life and, as far as possible, relating to one another in a familiar, routine manner.

Uncertainty in family members does not appear to be well documented. However in a study exploring mothers of adult children with schizophrenia Vatri-Boydell (1996) concludes:

[They] are untrained, often without support, either formal or informal, and must accomplish their caregiving tasks in isolation. Consequently, they are at a loss as to the course of action to take. They live in a state of sustained uncertainty. (p. 180)

As evidenced in this study, families received little clarification from formal services, and, even years after the first psychotic episode, uncertainty was a ubiquitous theme in participants' accounts.

Providing care in interpersonal relationships can lead to 'dilemmas of helping' in which what benefits one person may be detrimental to the other or to their

relationship (Coyne et al., 1990). Uncertainty over how to help has been suggested as possibly exacerbating such interpersonal tensions (Coyne et al., 1990). However, in this study, family members' response to their uncertainty - continuing as before - appears to be the opposite of a dilemma of helping: it was an element of their support which was viewed as beneficial by, and to, both family members and the people who had experienced psychosis.

The importance of constancy

The importance of constancy in these families was, largely, a response to the total disruption caused by the psychosis in terms of the identity, behaviour and life-course of the PEP. These changes in their adult child, sibling or partner disrupted the family members' lives. The disruption in families where one person experiences psychosis has been well-documented in the literature (e.g. Cook et al., 1997; Stein & Wemmerus, 2001),

In a qualitative study on caring for people with severe mental illness, Rose (1998) found that a central element for family members was their need to see the PEP as a person, focus on aspects of the PEP unchanged by their illness and convey this 'essence' of the PEP to others. This study complements Rose's research by indicating what it may be that people who have experienced psychosis gain from their families viewing them as more than an illness: a sense of continuity.

Since Bleuler, researchers have recognised the break in the sense-of-self inherent within psychosis (e.g. Parnas & Handest, 2003). As Bentall (2003) notes:

...the self is the centre of narrative gravity, which, like the centre of gravity of a physical body, cannot be isolated and touched, but around

which our memories, the stories we tell about ourselves, and the decisions we make all revolve (Bentall, 2003, p. 199)

A break in the sense-of-self represents, therefore, the dis-continuity of conscious experience. Thus, for the PEPs, having their family members continue to treat them in the same manner may have counterbalanced the break in self-identity; providing them with a way of connecting with their 'self' before the psychotic episode. Even though they felt different, being treated as the same by those close to them helped the PEPs to feel that there may not have been a catastrophic irreversible change in their personality. Moreover, treating them as a person, gave the PEP a sense of continued value as a son, daughter, partner or sibling. This countered the sense imparted by formal services, of being nothing more than an illness. Together these were important because of the psychological and emotional sequelae of psychosis, such as the depression and loss of self-esteem described by the PEPs in this study and documented in the literature (Appelo et al., 1993).

Constancy in the family's daily structure, as evidenced in the theme of continuing as normal, also helped to provide a safe, comforting, routine experience for both the people who had experienced psychosis and their family members. For the PEPs, seeing their families able to continue as normal helped them to cope themselves: although their inner world may have been in turmoil, their families' ability to carry on gave them a sense of structure, stability and containment. It also reduced their sense of guilt at the disruption and 'burden' they had imposed on their families.

For families, continuity offered a way of stress management, paralleling 'stability zones' (e.g. Toffler, 1970). Toffler suggested that having an area – such as a relationship or a place – which is relatively stable within their lives, enables people to cope with frustration, change, uncertainty, pressure and complexity. Thus,

stability zones are 'grounding' and benefit all people, not just those experiencing, or providing care for, mental illness.

In their capacity to stay together and continue to offer care, families in this study displayed resilience – an ability to withstand the aversive disruption caused by the psychosis. Family resilience has been conceptualised as a combination of coherence (factors such as acceptance, trust and caring) and hardiness (a sense of meaningfulness and durability, McCubbin & McCubbin, 1988). It seems likely that for the families in this study, their constancy was associated with their resilience – either because the stability provided by their constancy facilitated resilience, or because it represented part of their resilience.

In their study on resilience amongst families coping with severe mental illness, Marsh and colleagues (1996) noted that resilience manifested itself in a number of dimensions including: personal growth and reinforcing family bonds (see also, Veltman et al., 2002). This capacity by care givers to gain awareness of their inner strengths has been referred to as "personal gain" (Pearlin, Mullan, Semple, & Skaff, 1990). Both of these factors were also conveyed in the description offered by this study's participants of the positive aspects to their experiences.

The families' description of their attempts to both create and maintain as normal a life as possible for the person who had experienced psychosis resonate with the notion of normalisation in its earliest, ideological, formulation:

...making available...patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society. (Nirje, 1969, p. 181, cited in Rapley, 1990)

Although normalisation (together with its subsequent reformulation as social role valorisation) has been most associated with the field of learning disabilities, it has also been applied in the field of mental health (e.g. Williams, 1999). The principles of normalisation were the main ideology behind the rehabilitation of long-stay patients during the closure of long stay hospitals in the UK (Holloway, Carson, & Davis, 2002). In the context of this study, providing the scaffolding for the PEPs to lead a normal life enabled them to maximise their abilities and, as they noted, gave them a sense of mastery in their achievements. This further helped to counter the loss of self-confidence and shame they experienced.

It has been argued that the ideology of normalisation “can be interpreted as denying the reality of the severe psychiatric disabilities experienced by former mental hospital patients” (Holloway et al., 2002, p. 629). However, there appears to be a cohort effect such that younger people with psychosis have higher expectations and more community integration than older cohorts (Cook et al., 1997). This may explain why the participants in this study, none of whom had been ‘institutionalised’, found notions of normalisation so beneficial.

Similarly, in the field of learning disabilities, there has been debate over the relevance of normalisation to people with profound learning disabilities; namely, it has been argued that this sets up a cycle of unrealistic expectations (Bartlett & Bunning, 1997). It seems that there may be a parallel argument in the applicability of normalisation to people with severe mental illness: it could be beneficial to people who are less disabled by their difficulties – as evidenced in this study – whilst being an unrealistic ideology for people who have more chronic, unremitting symptoms as suggested by Holloway and colleagues (2002).

Issues in providing constancy

One of the issues highlighted by the families was the disruption psychosis caused to both their relationships and their efforts to provide or receive support. Disrupted relationships have been well documented in the qualitative literature on families and psychosis (e.g. Saunders & Byrne, 2002; Tuck et al., 1997). Less attention has been paid to the difficulties imposed by psychotic symptoms on the provision of informal support. There were some commonalities in this study with the findings on informal support for depression, for example: a fear of getting it wrong and finding out what works through trial and error (Harris, 2002). However, participants also described psychosis-specific difficulties. For some PEPs, their auditory hallucinations and beliefs dissuaded them from seeking help from family members as well as contorting their relatives' support attempts. Further compounding these difficulties was the inability of the person who had experienced psychosis to explain that this was happening because they were unaware that there was something to explain, or their voices told them not to explain, or because they did not want to distress their relatives.

It has been suggested that informal helping works mainly at the 'bond' level of therapeutic alliance (Barker & Pistrang, 2002). There are two other components of therapeutic alliance, 'task' and 'goal' (Bordin, 1979). This study provides some evidence to suggest that commonalities in 'task' may also be relevant in families living with psychosis. Overall, family members and the people who had experienced psychosis shared the same broad goal of recovery. However, during relapses they diverged on how to achieve this recovery; that is on 'task'. During relapse, some PEPs wanted to be left alone whereas their family members wanted to involve formal services or increase the PEPs' medication. At the time, this conflict on task created a temporary rupture in the families' alliance which the PEPs described as a

sense of betrayal. Subsequently, after the PEPs had recovered some stability, they were grateful that their families had taken the necessary action.

Having to forget painful incidences which occurred during acute psychotic episodes, mentioned by the families, was a necessary step towards achieving constancy. This was a way of compartmentalising the more extreme manifestations of psychosis. As Rose (1998) suggested, this enabled family members to continue to relate to the 'essence' of the PEP as distinct from their illness. For the PEPs in this study, it enabled them to maintain a sense of continued identity. However the cost of this 'forgetting' was the potential loss of the families' shared narrative: the stories that families tell about themselves, their history and family self-perception (Morgan, 2000). A disruption in shared narrative has been noted by other researchers in reference to the capacity of affective disorders to influence family life (Beardslee, 2002, cited in Dew & Arnold, 2003). Little, if any, work has focussed on the shared narratives within families where one person experiences psychosis.

Psychotic episodes left family members and the people who had experienced psychosis with different memories and understandings. Family members described uncertainty over what the PEPs remembered of the incidents and were torn between reminding them and trying to disregard past events. PEPs felt their family members did not really understand what they had experienced. It is unclear from this study what effect this loss of shared narrative may have had on these families, but it seems likely that it may influence subsequent family cohesion and smooth family functioning.

Asylum

Participants' accounts of the process of support also coalesced into a second main thread; that of 'asylum'. Asylum relates to the refuge or space into which the people who had experienced psychosis could withdraw as they relapsed and, particularly, as they recovered. A space without pressure where the PEPs knew they would be loved and protected.

Again, family members did not deliberately set out to create a place of asylum for the PEPs, although they later became aware of its importance to the PEP. As before, it was partly motivated by uncertainty over how best to help. It was also viewed as all they could do. Family members recognised that they could not cure psychosis – to some extent they saw this as the role of formal services and medication. Instead they felt their role to be complementary, providing a safe, protective, space and environment in which this recovery could occur. The only 'rules' in this space were that the people who had experienced psychosis stay near and take their medication. In a sense, the recuperative space family members provided is suggestive of the original nineteenth century utopian vision for asylums: a protective environment in which 'gentleness and kindness' and 'humanity' can "work towards their restoration to sanity" (Scull, MacKenzie, & Hervey, 1996, p. 89).

The term asylum has had multiple applications in the literature (Montgomery, 2001). While it is frequently used in reference to a place – such as jail, hospital or home – "asylum can also be defined by its functions: provision of a peaceful environment; protection from harm and escape from pressure. 'Asylum' appears to have a social dimension that parallels sanctuary, haven and refuge." (Montgomery, 2001, p. 426). Although, participants' descriptions of what was offered, or received, somewhat related to a physical space (home), participants referred primarily to asylum's function as a safe, peaceful environment.

The importance of asylum

Unlike constancy which had direct benefits for both family members and the people who had experienced psychosis, the provision of asylum was most beneficial to the PEPs. They perceived recovery as a long, slow process which little could hasten, but such factors as pressure and conflict could disrupt. Following a psychotic episode, the PEPs described themselves as vulnerable. The literature documents this vulnerability as including: loss of hope, self-esteem and confidence; depression; anxiety; shame; and, problems in finding a new identity (Appelo et al., 1993). In addition, in the early stages of recovery, the PEPs needed support in the practical aspects of daily life, such as managing a house and decision-making. The family members provided a safe space for the PEP in which the pressures of daily living or social interactions were minimised, thereby facilitating recovery.

Most family members made it clear to the person who had experienced psychosis that the asylum provided was unconditional. This contrasted with the PEPs' perception of potential societal judgement. During their psychotic episode, most PEPs had displayed extreme behaviour, irritability or unusual beliefs. Although, at the time of their psychosis, most had little awareness of their actions, one of the difficulties they described was coming to terms with what they had done, as they recovered. Knowing that their family members were still 'there' for them, that they had not been rejected and remained part of the family affections, facilitated the PEPs own acceptance of their situation.

Social isolation, particularly regarding extra-familial contacts, is another consequence of their illness described by the PEPs. This conforms with other findings documented in the literature on psychosis such as, social isolation (Hirschberg, 1985; Huxley & Thornicroft, 2003), and restricted social networks (e.g.

Cohen & Sokolovsky, 1978; Cresswell et al., 1992; Meeks & Murrell, 1994; Romans & McPherson, 1992). The PEPs' social isolation therefore made family members' continued involvement even more important to the PEP.

Some of the PEPs' isolation was self-imposed: they had withdrawn from the outside world due to shame or because they found it stressful. On the other hand, some PEPs described how former friends, or even partners, had withdrawn from them. Seeking refuge in their family home could therefore be construed as an example of 'positive withdrawal', a deliberate 'at a distance' position from the environment which minimises the impact of societal rejection or marginalisation (Corin, 1990). In Corin's original formulation, this withdrawal mainly encompassed family members, she described how "patients perceive themselves as remaining in an intermediary position regarding their family: being neither too close nor too distant from their relatives, perceiving themselves as being moderately integrated within the family's life" (p. 169). It is possible that what she is describing is, therefore, a protective response against overinvolved, critical or hostile family members; that is, high expressed emotion (EE) families. The PEPs in this study did not appear to describe this same response to their family members, which perhaps is explained by the nature of their family relationships (this is further explored in the next section).

The people who had experienced psychosis frequently contrasted their experience of 'home' with a psychiatric ward. The major distinction being the PEPs' perception of threat in a ward – home felt safer. Once the PEPs began to emerge from their psychosis, the presence of other, very ill people was disturbing and threatening. This again suggests 'home' as an asylum. In fact, one of the earliest proponents of humane asylums argued that such institutions may not be the best place for people with severe mental illness:

...no one in his senses will believe, that a man whose mind is disordered is likely in any stage of his disorder to derive benefit from being surrounded by men whose mental faculties are obscured...and who present to him, in place of models of sound mind, in place of rational and kind associates, in place of reasonable and judicious conversation, every specimen of folly, of melancholy and of extravagant madness.

(Connolly, 1830, cited from Scull, 1996 p. 54)

Although Connolly's general argument was in favour of asylums, here he almost appears to be advocating for community care. Since the onset of community care, there has been debate within the literature over where asylum is now to be found. As Montgomery (2001) notes, "which – the community or the institution – is responsible for giving asylum to the mentally ill, which place is most suitable and what is the role and value of asylum in service delivery." (pp. 425-426). This study suggests a role for both home and institution, depending on the phase of the illness. For many of the people who had experienced psychosis, however, institutions lacked a sense of asylum.

Issues in providing asylum

Autonomy and asylum

As noted above, the function of asylum includes a gentle environment without pressure, as well as protection from harm (Montgomery, 2001). These two aspects can conflict, as was evident in the participants' accounts. Initially, as the people who had experienced psychosis were relapsing, their family members felt they needed to protect them and be proactive in contacting formal services. Later, as the PEPs were recovering, both they and their family members described a need for a responsive, stable, non-pressuring environment. Later still, the participants

described a gradual transfer of autonomy back to the PEP. Within this, both family members and the PEPs described difficulty both in discerning the transition points – when to do what – and in the actual process of relinquishing or regaining control.

Participants described what was, in essence, a complex balancing act between the autonomy of the person who had experienced psychosis and acting in their own best interest (beneficence). Both PEPs and family members had the common aim of recovery and independence for the PEP; although, whilst they were relapsing and acutely unwell, the PEPs generally did not want help. Hence, getting formal services involved felt like betrayal to both PEPs and their family members. In an interesting discourse on autonomy and paternalism during family caregiving for people with schizophrenia, Atkinson and Coia (1995) suggested that there is a “dilemma between short term desires and goals (and thus autonomous choices) and their potential damage to long-term choices (or autonomy).” (p. 206). Here too, family members appeared to protect the PEPs’ long term autonomy at the cost of short-term paternalism. Their dilemma is underscored by the wider discussion of the balance between autonomy and paternalism in formal service provisioning – as is evident in the current discussion over the new Mental Health Act.

It is not always the case that the interests of people who have experienced psychosis and their families coincide (Atkinson & Coia, 1995). In contacting formal services or increasing the PEPs’ medication, family members were acting not only in the PEPs’ best interest but also their own, since it became increasingly intolerable to have the PEP at home when they were that unwell. However, participants also described incidences where the best interests of the other subsumed their own needs. For example, family members described trying to conceal the impact that the PEPs’ illness was having on them, leaving them feeling isolated and potentially exacerbating their sense of burden. The PEPs also described risking their own

wellbeing with their reluctance to disclose the difficulties they were experiencing, because they did not want to burden their relative. These 'dilemmas of helping' represent further examples of the difficulty in coordinating individual needs in interdependent relationships (Coyne, et al., 1990).

Asylum and expressed emotion

It is possible that there is an association between asylum and aspects of low expressed emotion. The descriptions by both the PEPs and their family members of what was offered in the way of support, seem to suggest that – were they to be classified – most of the families involved would be viewed as low EE. These descriptions included: constant, stable atmosphere; overlooking or forgetting extreme behaviour; allowing the PEPs to get on with their own lives; and, no pressure or judgement. Some of these descriptions could be considered to map directly onto the three components of EE, for example: allowing the PEPs to get on with their own lives seems to be the antithesis of emotional overinvolvement. One of the criticisms of EE has been its lack of 'interactional underpinnings' (Birchwood & Cochrane, 1990); it has yet to be fully understood what underlying family factors are detected by EE (Kuipers, 1995). An in-depth interactional perspective, such as this study, complements the research trying to elucidate such factors.

The clarification that stems from such an interactional perspective is seen in the descriptions made by two of the participants in this study. One family member described trying to 'bully' her brother into finding employment. The sister was trying to help her brother, but perceived his inability to take action as if he was not trying to help himself. She wanted to help, but was unsure what would be helpful. In trying to understand his situation, she extrapolated from her own experience, noticing that when she was not busy she began to ruminate on problems. Thus she tried to apply the same solution she would adopt, to her brother's situation. Despite her good

intentions, her support efforts felt pressurising to her brother, which he described as unhelpful.

This example illustrates two points. First, that whilst the sister's behaviour could potentially be construed as high EE, the study goes beyond the simple label, and offers a description of the factors contributing to her behaviour: uncertainty, inability to understand, a desire to help, a need to take action and misinterpretation of her brother's difficulties as not trying to help himself. It also demonstrates that unrealistic expectations can feel pressurising to the PEP – as noted by Tolsdorf (1976) – which in turn may lead the PEP to withdraw from the relationship. The second point was that, as noted by the interactional social support literature, intentions and impact do not always coincide in support (Coyne et al., 1990; Lehman et al., 1986). Both these points suggest ways in which we can better help family members to help the person who had experienced psychosis.

Most of the participants' descriptions, however, seemed to epitomise low EE. Again, their descriptions go beyond a simple label on family environment and illustrate the interactional factors contributing to low EE: that is, how and why family members came to adopt their stance towards the PEP, and how it felt to the PEP – a safe, containing asylum.

Relationship with formal services

Almost all participants spontaneously discussed their relationship with formal services, despite not being explicitly asked. This illustrated the centrality of formal services to their experience; psychosis probably necessitates the involvement of formal services more than other mental health problems. In addition, it may perhaps have been influenced by their perception of the interviewer as an 'insider ear'. As

noted in Chapter Three, the participants' accounts incorporated many aspects of their relationship with formal services. Not all of these aspects will be discussed here, but the participants' views on their perception of collaboration with formal services will be further explored since it impacted directly on family informal helping.

Most family members felt that there should be a collaborative partnership between themselves and formal services. They frequently felt let down in this partnership. This has been a feature of several other qualitative studies of families living with psychosis (e.g. Johnson, 2000; Saunders & Byrne, 2002; Vatri-Boydell, 1996; Veltman et al., 2002) – it is important to note that this qualitative research was conducted in North America where service provision has a somewhat different structure. The families in this study echoed the issues raised by families in other research, namely: not being given information about psychosis or how to help; feeling that their contributions and insights were disregarded by professionals; and feeling excluded by confidentiality. They felt this significantly hampered their support efforts. This was echoed by some of the people who had experienced psychosis, who felt their best interest would be met by a closer alliance between their relatives and the system.

The recent National Service Framework for Mental Health (1999), 'Standard Six: Caring About Carers', begins:

Carers play a vital role in helping to look after service users of mental health services, particularly those with severe mental illness. Providing help, advice and services to carers can be one of the best ways of helping people with mental health problems. (p. 69)

It continues:

Carers of people with severe mental illness who provide substantial care on a regular basis [should]:

- have seen and had explained to them the care plan of the person for whom they provide care [given the service user's consent or best interest]
- understand the nature of their illness (p. 75)

As yet, it appears that these recommendations have not filtered into general practice – at least in the experience of most participants in this study.

METHODOLOGICAL ISSUES

In evaluating this study and reflecting on its implications, several methodological issues need to be considered. These include sample characteristics such as representativeness and heterogeneity, as well as issues relating to quality, validity and reflexivity.

Sample characteristics

Three broad characteristics of the sample will be considered below: representability, heterogeneity and quality of the interview data.

Representativeness of participants

This section will consider the extent to which the participants in this study may differ from, or have commonalities with, the full spectrum of families where one person experiences psychosis.

Recruitment sources

Potential participants – both family members and people who had experienced psychosis - were approached through various routes: their contact in the NHS, advertisements in mental health charity newsletters and voluntary group meetings. Given the varied tenets and geographical locations of the organisations involved, a wide range of potential participants were approached encompassing a range of socioeconomic and ethnic backgrounds. However, the nature of the recruitment process meant that it was not possible to know the characteristics of the people who were not interested in taking part, thereby precluding comparison of the two groups. Recruitment was hard and few people chose or were in a position to take part. The main reasons which were put forward in face to face or telephone contact with potential participants were: they were not in close contact with their families; the other person in the family (family member or PEP) or themselves were not interested in taking part; individuals within the family were too busy or were experiencing certain stressful life events; and/or the PEP was not in remission or stable – the latter two were specific exclusion criteria.

Self selection

One of the difficulties inherent in studies where participants are self-selected is that those who chose to take part may be unusual or atypical in certain respects. With respect to this study, it could be that: the families as a whole may have been more cohesive and/or had a more positive experience of family help and support; they may also have been more interested in reflecting on their experience – which in itself may imply that they were in a sufficiently stable family position to have the space to be reflective; they may also have felt better able to articulate their experiences, either because they were naturally more articulate or because they were less depressed or experiencing fewer residual symptoms (if a PEP).

Heterogeneity and homogeneity of sample

Although their accounts shared many commonalities, the families who took part in this study differed on a number of criteria: diagnosis (schizophrenia, bipolar or schizoaffective disorder); relationship with family member (parent, partner or sibling); and time since first onset. Interestingly a high proportion of both qualitative studies and family burden studies in this area also share these three methodological characteristics (e.g. Johnson, 2000; Reinhart & Horwitz, 1995; Rose, 1998; Solomon & Draine, 1995; Veltman et al., 2002). As far as possible, clarifications as to where these differences impacted on the participant accounts have been made in Chapter Three. Each of these criteria is considered below together with the relative ethnic homogeneity of the sample.

Diagnosis

As noted in Chapter Two, the stage of analysis involving collation of individual transcript themes to major themes was first done separately for those where the PEP experienced bipolar disorder or schizophrenia (and schizoaffective disorder). Close attention was paid to any differences in the emerging themes, however, there was a broad overlap on all of the themes and sub-themes. The key difference seemed to be around the level of irritability displayed by the people who had experienced psychosis as they relapsed: participants with bipolar disorder were generally characterised as more irritable by their family members.

It is unclear how the involvement of both affective and non-affective psychosis in this study affected the outcome. To the best of my knowledge, no qualitative study has explicitly explored family experiences with bipolar disorder. There have been, however, a few studies looking at families where one person experiences schizophrenia (e.g. Saunders & Byrne, 2002; Stein & Wemmerus, 2001; Tuck et al.,

1997; Vatri-Boydell, 1996). These studies appear consistent with the findings from this study.

Relationship between the PEP and family member

The views of family members were represented by one or two members of each family – generally including the primary care giver. Although this reflects the method employed in almost all studies examining the impact of mental illness on families, Harvey and Burns (2003) have criticised this approach on a number of points: (1) a confusion over ‘the family’ and ‘a family member’; (2) poor definition of primary care giver; (3) involvement of family members with mixed relationships to the PEP. It is worth considering each of these in turn in order to assess their potential impact on the study findings. The confusion between family and family member is a valid criticism. It is important to remember that, in this chapter, the term ‘family’ only refers to the family members who were interviewed (including the PEP). Although, primary care giver was self-defined in this study – by either the PEP or family member – in all cases the family member or members who were interviewed represented all the family involved on a daily basis during crisis. The two possible exceptions both talked about a parent who lived in another city and who had been involved during earlier episodes, but not recent ones. Finally, this study included parents, partners and a sibling. Their differing relationship to the PEP is likely to have influenced their experience of offering support. Research has found that the nature of the relationship influences: levels of involvement (e.g. Stein & Wemmerus, 2001); commitment (Jones, 1997); and interpretation of illness (e.g. Johnson, 2000).

Time since first episode

Clearly, families’ knowledge and experiences around psychosis evolve over time. Families where the person who had experienced psychosis was newly diagnosed were excluded since the evidence suggested these families face unique difficulties

(e.g. Tennakoon et al., 1997). However, duration of the PEPs illness has been also found to impact upon family experiences (e.g. Cook et al, 1994; Lefley, 1997b). For example, those families who have been living with psychosis for longer periods may have a clearer idea of what is and what is not helpful. They may also have needed to come to terms with the chronicity of the illness in a way that other families have not yet faced.

Ethnic diversity and gender

Although the participants were drawn from a wide range of socioeconomic backgrounds, in other sociodemographic areas, such as ethnicity and religion, they represented a relatively homogeneous group. One pair of participants described themselves as black British, the remainder viewed themselves as white British. All participants were either Christian or not religious. It is difficult to speculate on the impact of this sociodemographic homogeneity on the data, since there is little research available for comparison. That which does exist suggests that different factors, such as ethnicity, religiosity or socioeconomic status, influence people's experiences in highly specific ways, depending on the nature of the sociodemographic factor (Finley, 1998; Johnson, 2000). Thus it may be that families in this study shared certain beliefs about psychosis, stemming from their sociodemographic background, which influenced their style and level of involvement with both the person who had experienced psychosis and this study, but which distanced their experiences from that of other families. If this proves to be the case, the commonalities expressed by participants may not be representative of the experiences of any but similar families. It may also be that the themes found in this study are broadly representative, since the themes yielded by the accounts of the black British family were fully consistent with the themes in other participant accounts.

In terms of gender, the participants who experienced psychosis were fairly evenly balanced. Amongst family member participants, there were twice as many women as men. This bias is in fact marginally over-representative of the wider gender bias towards women in a caregiving role, which has been estimated as 58% female (H.M. Government, 1999).

Given the breadth of heterogeneity described above, it may be that the broad themes yielded by the participants' accounts are to some extent reflective of broad issues faced by families living with psychosis. Support for this is provided by the similarities between participant accounts in this study and in other qualitative studies of living with psychosis. However, the small sample size, self-selected nature, and primarily ethnic and religious homogeneity are likely to limit the applicability of these findings to other populations – at least without prior research. In addition, although there was strong support in most accounts for some themes, saturation may not have been reached since some of the later interviews did contribute a few new angles to some of the themes.

Quality of interview data

The majority of participants conveyed their experiences in clear, rich, articulate detail. A very few of the participants were less able to articulate their experiences. Two of the people who had experienced psychosis seemed to be more affected by ongoing residual difficulties, such as self doubt, voices and negative symptoms, which influenced either the quantity of their account or its clarity. This may have biased the analysis such that the contributions of these less articulate participants were underrepresented. In addition, if the PEP was experiencing residual difficulties, it is possible that this influenced the families' accounts of help and support. For

example, phase dependent differences were noted by both family members and the PEPs such as in stress levels and types of support described as beneficial.

Another factor which may have influenced the quality of the interview data was that expressed in the sub-theme of 'Remembering and forgetting'. Both family members and the people who had experienced psychosis were sometimes hazy about what had happened during the acute phases of the illness. They attributed this to both a deliberate act of forgetting the more painful periods as well as a passive process due to the nature of the illness (PEPs), or the stress at this time (family members). Given that this was also a retrospective study, it may well be that some of the detail from these acute episodes is lost, particularly over specific interactions. However, the alternative, interviewing families at the time of relapse or crisis, seems somewhat unfeasible and inappropriate. At these times, family members experience exacerbated stress and burden. They might lack the space and time for reflection (as was described by family members who declined involvement in this study). In addition, acute psychosis would have a major impact on the interviews of PEPs. Although it is possible to conduct interviews at this time (e.g. Chapman, 1966), an exploration of the perceptions of family support may well seem irrelevant to these people and could, perhaps, exacerbate their difficulties. Issues relating to informed consent are also likely to be pertinent at this time.

Whether the participants were interviewed together or separately might have influenced their accounts. It was initially intended to interview all participants separately. However, many families expressed a preference for a joint interview. It is difficult to tell if these families would have been more open or stated different ideas had they been interviewed separately. Certainly my initial reserve was that these families might find it harder to discuss the difficulties they encountered or unhelpful aspects of support. This might have been the case, particularly given the views

family members expressed in the theme of 'Concealing impact'. Despite this, participants did appear to be able to discuss some of the more negative aspects of their support experiences in front of the other family taking part. Interestingly, the decision to be interviewed separately appeared to be mainly based on geographical or temporal convenience.

Validity

Qualitative theorists have noted that the criteria used to evaluate quantitative research cannot be meaningfully applied to qualitative research in their current form (Willig, 2001). This has resulted in the publication of a number of good practice guidelines to ensure qualitative research is rigorously conducted and the interpretations and conclusions from such studies are "internally consistent, useful, robust, generalisable, or fruitful" (Stiles, 1993, p. 607; see also Elliott et al., 1999; Henwood & Pigeon, 1992).

While these guidelines are all somewhat different, most of their fundamental commonalities have already been addressed by this study. Thus, the sample was situated (Elliott et al., 1999) by description of the recruitment process and participant characteristics. In addition, the process of analysis has been detailed in Chapter Two and the interpretation and understanding developed from the analysis have been 'grounded in examples' (Elliott et al., 1999). Credibility checks on the preliminary codings and final framework were conducted by a second researcher, as described in Chapter Two. However, credibility would have been further improved by asking some of the participants to gauge whether the themes identified adequately reflected their experience (e.g. Willig, 2001).

Reflexivity

The process of qualitative research is inevitably influenced by researcher's own preconceptions, beliefs, values, experiences and interests. Since it is not possible to fully set aside one's perspective, issues of reflexivity have therefore been emphasised within guidelines for qualitative research (e.g. Elliott et al., 1999; Willig, 2001).

During recruitment, it is possible that my own presentation as a white middle class female may have influenced potential participants' perception of the study – particularly since some of the recruitment attempts took place in ethnically diverse or deprived locations. Different branches of Mind have different tenets, some are strongly anti-medical model or labelling. Whilst these are not the antithesis of my own position, when describing the study I may have represented such a model to the individuals I was addressing. These factors could well have influenced those who chose not to take part.

Within the interviews, I was aware of the possibility of interview bias and tried to be mindful of my own expectations and beliefs. To minimise the risk of imposing these upon the participants' accounts, I intervened as little as possible and conducted the interviews in a respectful and non-judgemental manner. However, it is likely that, on some level, my presentation, interests and beliefs did influence the direction and content of the interviews in, for example, my choice of what to follow-up, and when to reflect back or empathise.

Whilst participants' relationship with formal services was undoubtedly central to their experience, it may be that their perception of me as a 'professional' also influenced the content of the interviews. To the participants, I am likely to have represented an

'insider ear' with respect to formal services; someone who was not involved in their care, but who they could educate about some of the difficulties they had encountered with formal services. My interest in human rights and power issues may also have had a role in this aspect, since participants' descriptions of their struggles with formal services had strong resonance for me. This may have biased my subsequent analysis of participant accounts.

As noted, before the study I had anticipated that family members might express uncertainty and that there may be a phase-dependent element to what the people who had experienced psychosis found helpful. In addition, as the study progressed, my growing awareness of certain recurrent themes in the participant accounts, such as 'sanctuary' and 'more than an illness', may have subtly guided conduction of the later interviews. That these themes, ultimately, were present in the interpretation of the data may, in part, represent the influence of these expectations.

It is difficult to gauge how much these factors affected the direction of the interview and subsequent analysis and interpretation. However, their influence is likely to have been limited, to some extent, by the credibility checks provided by the second researcher. In addition, there were several unanticipated findings which refuted my initial position. For example, before the study I had expected there to be more conflict in these families and did not foresee that asylum would be so central to participants' experiences. Similarly, the themes around constancy ran counter to my original assumption that psychosis imposed considerable disruption to family life – I had not anticipated the active adaptations displayed by these families to the challenges they encountered.

FURTHER RESEARCH

Studies on living with psychosis from an informal helping framework appear to be absent from the literature. Yet this study showed it to be a potentially rich avenue for understanding these families experiences, and it could well be informative to follow up on some of the tentative findings.

First, but not foremost, some of the methodological considerations described above could be overcome by specific research into these areas. This could tease apart some of the heterogeneity. For example, the study could be replicated for families: from other ethnic backgrounds; living with bipolar disorder; and holding different relationships to the person who had experienced psychosis – such as siblings or partners. The development of some of these themes through time could be explored by specifically focussing on families with different durations of experience.

By adopting an interactional qualitative perspective and including the people who had experienced psychosis as well as family members, this study demonstrated that it was possible to complement and expand on the existing body of literature on expressed emotion. Future studies in this area could include triangulating participant accounts with a measure of EE and targeting the interview schedule more specifically at the components of EE. This could then give an understanding both of how such family response styles are perceived, experienced and reacted to by the PEP as well as what underlies the family members' unhelpful reactions.

As with most research, this study probably stimulates more questions than it answers and it would be interesting to further explore some of the themes highlighted by this study. One such theme was family members' sense of uncertainty over how to help. Both in this and other studies (e.g. Coyne et al., 1990;

Lehman et al., 1986), uncertainty seems to have influenced how people have tried to offer support. In families living with psychosis, it would be interesting to discover if or how uncertainty relates to family burden and whether the uncertainty is exacerbated by such factors as the understandability of their relative's difficulties.

Another area which bears further research is the notion of 'asylum' which emerged from these participants accounts. Does the existence of an 'asylum' influence relapse rates for the PEPs? What happens to those PEPs who do not have this sense of asylum connected to their home? Is 'asylum' important for other areas of physical and psychological wellbeing? Before investigating these questions, it would be necessary first to explore further what the PEPs' sense of asylum gives them, and what psychological components this maps onto. Following this, one could construct a measure of asylum, incorporating aspects of what it is and its function: a place, an environment, a subjective perception. By using this to explore individuals' sense of asylum for various places, such as wards, community homes and family homes, one may begin to elucidate how to introduce or enhance this sense of asylum across services.

Finally, although this study deliberately set out to study family support in psychosis, it is important to note that nearly half the people who experience psychosis do not have close involvement with their families (Department of Health, 1999). It is important therefore to explore whether such notions as constancy or asylum are relevant to such people and, if so, from which potential sources.

CLINICAL IMPLICATIONS

This study holds clinical implications on two levels: direct work with families who are living with psychosis; and indirectly, though service provision to people who experience psychosis and their families.

Direct work with families

One of the findings shown by this study appears to be that seemingly high EE behaviours, such as overprotectiveness and bullying, may stem from family members' keen desire to help but lack of information about how to do so; particularly their uncertainty and inability to understand. This suggests that it is crucial to provide all families with more information as early as possible in the course of their relative's illness. This should include information about the current understanding of psychosis (or specific diagnosis) and the vulnerability-stress model of onset and relapse as well as information on what research has shown to be more, or less, helpful. This, of course, is not a new suggestion and has been repeatedly stated both within the literature as well as in the recommendations provided by the World Schizophrenia Fellowship (World Schizophrenia Fellowship, 1998), the Schizophrenia Patient Outcomes Research Team (PORT, Lehman & Steinwachs, 1998), and the National Service Framework for Mental Health (1999).

This research further indicates that what appears to be helpful to the people who had experienced psychosis is not just the absence of high EE, but also the presence of constancy and asylum. Further research is obviously needed to confirm, refute or refine these themes before any clinical intervention could incorporate them. In general, the advice stemming from the EE literature tends to focus on what families should not be doing, It is likely that it would be extremely helpful to families if formal

services could also suggest positive things which they could be doing to help the PEP.

As shown above, despite the PEPs reporting their family support to be mostly beneficial, family members repeatedly expressed uncertainty about what they should be doing and whether they were helping. For some families, particularly those with low EE status, it may well be that they are already offering constancy and asylum, but are unaware that this could be beneficial. In this case, it is necessary to validate both what these families are already doing, and the issues or dilemmas that they may be facing; particularly in terms of relinquishing or taking control.

Finally, this study contributes to the growing literature on positive aspects of caregiving and family resilience. Whilst further research is needed in this area, it has been suggested that formal services “acknowledge the potential for family resilience; encourage resilient thinking and behavior among family members and reinforce resilience when it does occur” (Marsh et al., 1996, p. 11). Eliciting such positive aspects could help to empower families as well as countering the sense of blame some families perceive from formal services.

Implications for service provision

It seems vital that formal services adopt a more collaborative mode of working with families. This has been repeatedly recommended in the literature (e.g. Lehman & Steinwachs, 1998; WSF, 1998) and this study merely adds another voice to this suggestion. As noted above, this would involve the provision of more information. In addition, formal services should listen to families, particularly around the time of relapse. It has been suggested that families are in a good position to act as an ‘early warning system’ to the PEPs’ relapses and are frequently involved in connecting

formal services with the PEP at this time (Carpentier, Lesage, & White, 1999). Family members in this study repeatedly requested involvement in decisions which affect them, such as in planning around the PEPs' discharge from hospital. Again, this is already a recommendation in the National Service Framework for Mental Health (1999). Such a collaborative approach would not only be beneficial to families in reducing their sense of burden, but would also be helpful to the person experiences psychosis.

This study may also have implications for formal services when working directly with people who experience severe mental health problems. A greater awareness of the importance of constancy in service provision seems important. Families particularly commented that when staff moved on, they felt that personal knowledge of the PEP or family was lost, and that they had to start again with someone new. Although, it may be difficult to reduce staff turnover rates, it may be possible to have clear handover sessions – involving family members and the PEPs – in which information is shared between the new and old members of staff. Another recommendation stemming from the importance of constancy is for ongoing awareness in service providers that people who experience psychosis are 'more than an illness'. This surely already occurs in some areas of service provision, but apparently still needs emphasising.

Although, at times, the recollection of their experiences could be painful for some participants, most commented that it was both therapeutic and helpful to be given the space to reflect on their support during the interview. As they were talking, some participants were able to clarify for themselves some of the issues and tensions in family support. Having done so, some even came up with their own solutions. For example, one set of parents came up with the idea of a written plan, made with their son whilst he was stable, detailing what he wanted to happen if he relapsed. At the

end of the interview, questions participants raised regarding psychosis, service structure, sources of support, and support within families were addressed. In addition, their experiences were validated. Even a simple statement to the effect that this was an area which other participants had struggled with, seemed to have a powerful impact. The whole meeting rarely took longer than two hours.

How this may be adapted into a brief therapeutic intervention for families living with psychosis, therefore, seems worth considering. It may well be most beneficial to involve the person who has experienced psychosis in such an intervention. This would not be *in lieu* of a formal family psychoeducation group, but in the realistic acknowledgement that, given the staffing and budgetary limitations to most Community Mental Health Teams, families still hold a fairly low priority – despite government recommendations.

CONCLUSION

This study set out to explore informal helping in families living with psychosis. It identified a number of ways in which people who experience psychosis felt supported by their families. In addition it highlighted some of the issues and dilemmas involved in such support. Interviewing both the people who had experienced psychosis and their family members enabled a rich, detailed picture of family support efforts. This complemented and expanded the existing literature on family burden and expressed emotion. Although a sense of burden was evident in the participants' accounts, the study also demonstrated that families are not just passive in the face of psychosis, but actively adopt strategies to manage their own and their relatives' difficulties. In terms of expressed emotion, the study also provided preliminary insight into one way of understanding why family members may respond in the ways that they do. In addition, the study provided further support for

the notion that, what may be helpful in families is not just the absence of high EE responses. Therefore, in contrast to the generally negative findings in family burden and expressed emotion research, this study suggested modes of support which PEPs seemed to experience as helpful. As already acknowledged, many of the broader recommendations stemming from this study have already been repeatedly made in the literature. It seems that, as yet, their application remains sporadic.

REFERENCES

- Acuff, A. (2000). Commentary: Listening to the message. *Journal of Clinical Psychology, 56*, 1459-1465.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: American Psychiatric Association.
- Andreasson, S., Allebeck, P., Engstrom, A., & Rydberg, U. (1987). Cannabis and schizophrenia: A longitudinal study of Swedish conscripts. *Lancet, 26*, 1483-1486.
- Appelo, M. T., Slooff, C. J., Woonings, F. M. J., Carson, J., & Louwerens, J. W. (1993). Grief: It's significance for rehabilitation in schizophrenia. *Clinical Psychology and Psychotherapy, 1*, 53-59.
- Atkinson, J. M., & Coia, D. A. (1995). *Families coping with schizophrenia: A practitioner's guide to family groups*. Chichester: Wiley.
- Baier, M. (1995). Uncertainty of illness for persons with schizophrenia. *Issues in Mental Health Nursing, 16*, 201-212.
- Barker, C., & Pistrang, N. (2002). Psychotherapy and social support: Integrating research on psychological helping. *Clinical Psychology Review, 22*, 361-379.
- Barker, C., Pistrang, N., & Elliott, R. (1994). *Research methods in clinical and counselling psychology*. Chichester: Wiley.
- Barker, C., Pistrang, N., & Elliott, R. (2002). *Research methods in clinical psychology* (2nd ed.). Chichester: Wiley.
- Barker, C., Pistrang, N., Shapiro, D. A., & Shaw, I. (1990). Coping and help-seeking in the UK adult population. *British Journal of Clinical Psychology, 29*, 271-285.
- Baronet, A. M. (1999). Factors associated with caregiver burden in mental illness: A critical review of the research literature. *Clinical Psychology Review, 19*, 819-841.
- Barrera, M. (1986). Distinctions between social support concepts, measures, and models. *American Journal of Community Psychology, 14*, 413-445.

- Barrett, L., Dunbar, R., & Lycett, J. (2001). *Human evolutionary psychology*. London: Palgrave Macmillan.
- Barrowclough, C., Lobban, F., Hatton, C., & Quinn, J. (2001). An investigation of models of illness in carers of schizophrenia patients using the Illness Perception Questionnaire. *British Journal of Clinical Psychology, 40*, 371-385.
- Bartlett, C., & Bunning, K. (1997). The importance of communication partnerships: A study to investigate the communicative exchanges between staff and adults with learning disabilities. *British Journal of Learning Disabilities, 25*, 148-152.
- Bebbington, P. E., Brugha, T., Meltzer, H., Jenkins, R., Ceresa, C., Farrell, M., et al. (2000). Neurotic disorders and the receipt of psychiatric treatment. *Psychological Medicine, 30*, 1369-1376.
- Bentall, R. (2003). *Madness explained: Psychosis and human nature*. London: Allen Lane.
- Bentall, R. (Ed.). (1990). *Reconstructing schizophrenia*. London: Routledge.
- Billings, A. G., & Moos, R. H. (1984). Chronic and nonchronic unipolar depression: The differential role of environmental stressors and resources. *Journal of Nervous and Mental Disease, 172*, 65-75.
- Birchwood, M., & Cochrane, R. (1990). Families coping with schizophrenia: Coping styles, their origins and correlates. *Psychological Medicine, 20*, 857-865.
- Bordin, E. (1979). The generalizability of the psychoanalytic notion of the working alliance. *Psychotherapy, 16*, 252-260.
- Boyle, M. (1990). *Schizophrenia: A scientific delusion?* London: Routledge.
- Boyle, M. (1996). Schizophrenia: The fallacy of diagnosis. *Changes: An International Journal of Psychology and Psychotherapy, 14*, 5-13.
- Brown, G. W., Birley, J. L. T., & Wing, J. K. (1972). Influence of family life on the course of schizophrenic disorders: A replication. *British Journal of Psychiatry, 121*, 241-258.

- Brown, G. W., & Harris, T. (1978). *Social origins of depression: A study of psychiatric disorders in women*. New York: Free Press.
- Brugha, T. S. (1995). Social support and psychiatric disorder: Overview of evidence. In T. S. Brugha (Ed.), *Social support and psychiatric disorder: Research findings and guidelines for clinical practice* (pp. 1-38). Cambridge: Cambridge University Press.
- Brugha, T. S., Bebbington, P. E., Maccarthy, B., Potter, J., Sturt, E., & Wykes, T. (1987). Social networks, social support and the type of depressive illness. *Acta Psychiatrica Scandinavica*, 76, 664-673.
- Brugha, T. S., Wing, J. K., Brewin, C. R., Maccarthy, B., & Lesage, A. (1993). The relationship of social network deficits with deficits in social functioning in long-term psychiatric disorders. *Social Psychiatry and Psychiatric Epidemiology*, 28, 218-224.
- Burman, E. (1994). Interviewing. In P. Banister, E. Burman, I. Parker, M. Taylor & C. Tindall (Eds.), *Qualitative methods in psychology: A research guide* (pp. 48-71). Buckingham: Open University Press.
- Cannon, M., Jones, P., Gilvarry, C., Rifkin, L., McKenzie, K., Foerster, A., et al. (1997). Premorbid social functioning in schizophrenia and bipolar disorder: Similarities and differences. *American Journal of Psychiatry*, 154, 1544-1550.
- Carpentier, N., Lesage, A., & White, D. (1999). Family influence on the first stages of the trajectory of patients diagnosed with severe psychiatric disorders. *Family Relations: Interdisciplinary Journal of Applied Family Studies*, 48, 397-403.
- Cassel, J. (1976). The contribution of the social environment to host resistance. *American Journal of Epidemiology*, 104, 107-123.
- Chadwick, P. K. (1993). The stepladder to the impossible: A first hand phenomenological account of a schizoaffective psychotic crisis. *Journal of Mental Health*, 2, 239-250.

- Chadwick, P. K. (1997). Recovery from psychosis: Learning more from patients. *Journal of Mental Health, 6*, 577-588.
- Chadwick, P. K. (2001). Psychotic consciousness. *International Journal of Social Psychiatry, 47*.
- Chakrabarti, S., & Gill, S. (2002). Coping and its correlates among caregivers of patients with bipolar disorder: A preliminary study. *Bipolar Disorders, 4*, 50-60.
- Chapman, J. (1966). The early symptoms of schizophrenia. *British Journal of Psychiatry, 112*, 225-251.
- Chapman, L. J., Chapman, J. P., Kwapil, T. R., Eckblad, M., & Zinser, M. C. (1994). Putatively psychosis-prone subjects 10 years later. *Journal of Abnormal Psychology, 103*, 171-183.
- Christensen, A. J., Dornink, R., Ehlers, S. L., & Schultz, S. K. (1999). Social environment and longevity in schizophrenia. *Psychosomatic Medicine, 61*, 141-145.
- Chung, M. C., & Jenner, F. A. (1995). Understanding schizophrenia. *Changes: An International Journal of Psychology and Psychotherapy, 13*, 102-107.
- Cialdini, R. B., Schaller, M., Houlihan, D., Arps, K., Fultz, J., & Beaman, A. L. (1987). Empathy based helping: Is it selflessly or selfishly motivated. *Journal of Personality and Social Psychology, 52*, 749-758.
- Cinnirella, M., & Loewenthal, K. (1999). Religious and ethnic group influences on beliefs about mental illness: A qualitative interview study. *British Journal of Medical Psychology, 72*, 505-524.
- Claridge, G. (Ed.). (1997). *Schizotypy: Relations to illness and health*. Oxford: Oxford University Press.
- Clark, M. S. (1983). Some implications of close social bonds for help-seeking. In N. A. DePaulo B.M., Fisher J.D. (Ed.), *New directions in helping*. (Vol. 2: Help seeking, pp. 205-229). New York: Academic Press.

- Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine*, 38, 300-314.
- Cohen, C. I., & Sokolovsky, J. (1978). Schizophrenia and social networks: Ex-patients in the inner city. *Schizophrenia Bulletin*, 4, 546-560.
- Cohen, S., Doyle, W. J., Skoner, D. P., Rabin, B. S., & Gwaltney, J. M. (1997). Social ties and susceptibility to the common cold. *Journal of the American Medical Association*, 277, 1940-1944.
- Cohen, S., Underwood, L. G., & Gottlieb, B. H. (2000). *Social support measurement and intervention: A guide for health and social scientists*. Oxford: Oxford University Press.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98, 310-357.
- Cook, J. A., Cohler, B. J., Pickett, S. A., & Beeler, J. A. (1997). Life-course and severe mental illness: Implications for caregiving within the family of later life. *Family Relations*, 26, 427-436.
- Cook, J. A., Lefley, H. P., Pickett, S. A., & Cohler, B. J. (1994). Age and family burden among parents of offspring with severe mental illness. *American Journal of Orthopsychiatry*, 64, 435-447.
- Corin, E., & Lauzon, G. (1994). From symptoms to phenomena: The articulation of experience in schizophrenia. *Journal of Phenomenological Psychology*, 25, 3-50.
- Corin, E. E. (1990). Facts and meaning in psychiatry: An anthropological approach to the lifeworld of schizophrenics. *Culture, Medicine and Psychiatry*, 14, 153-188.
- Corrigan, P. W., & Penn, D. (1997). Disease and discrimination: Two paradigms that describe severe mental illness. *Journal of Mental Health*, 6, 355-366.
- Cowen, E. L. (1982). Help is where you find it: Four informal helping groups. *American Psychologist*, 37, 385-395.
- Coyne, J. C., & Bolger, N. (1990). Doing without social support as an explanatory concept. *Journal of Social and Clinical Psychology*, 9, 148-158.

- Coyne, J. C., & DeLongis, A. (1986). Going beyond social support: The role of social relationships in adaptation. *Journal of Consulting and Clinical Psychology, 54*, 454-460.
- Coyne, J. C., Ellard, J. H., & Smith, D. A. F. (1990). Social support, interdependence, and the dilemmas of helping. In B. R. Sarason, Sarason, I.G., Pierce, G.R. (Ed.), *Social support: An interactional view* (pp. 129-149). New York: John Wiley & Sons.
- Cresswell, C. M., Kuipers, L., & Power, M. J. (1992). Social networks and support in long-term psychiatric patients. *Psychological Medicine, 22*, 1019-1026.
- Crossley, M. L., & Crossley, N. (2001). 'Patient' voices, social movements and the habitus; how psychiatric survivors 'speak out'. *Social Science and Medicine, 52*, 1477-1489.
- Cuijpers, P. (1999). The effects of family interventions on relatives' burden: A meta-analysis. *Journal of Mental Health, 8*, 275-285.
- Dakof, G. A., & Taylor, S. E. (1990). Victims' perceptions of social support: What is helpful from whom? *Journal of Personality and Social Psychology, 58*, 80-89.
- Davidson, L. (2003). *Living outside mental illness: Qualitative studies of recovery in schizophrenia*. New York: New York Press.
- Department of Health. (1999). *The mental health national service framework*. London: Author.
- Dew, R., & Arnold, E. M. (2003). Out of the darkened room: When a parent is depressed: Protecting the children and strengthening the family. *Journal of the American Academy of Child and Adolescent Psychiatry, 42*, 1262-1263.
- Dixon, L. (1999). Providing services to families of persons with schizophrenia: Present and future. *The Journal of Mental Health Policy & Economics, 2*, 3-8.
- Dixon, L., Adams, C., & Lucksted, A. (2000). Update on family psychoeducation for schizophrenia. *Schizophrenia Bulletin, 26*, 5-20.

- Dixon, L., McFarlane, W. R., Lefley, H., Lucksted, A., Cohen, M., Falloon, I., et al. (2001). Evidence-based practices for services to families of people with psychiatric disabilities. *Psychiatric Services, 52*, 903-910.
- Doane, J. A., Falloon, I. R., Goldstein, M. J., & Mintz, J. (1985). Parental affective style and the treatment of schizophrenia: Predicting course of illness and social functioning. *Archives of General Psychiatry, 42*, 34-42.
- Eakes, G. G. (1995). Chronic sorrow: The lived experience of parents of chronically mentally ill individuals. *Archives of Psychiatric Nursing, 9*, 77-84.
- Ell, K., Nishimoto, R., Mediansky, L., Mantell, J., & Hamovitch, M. (1992). Social relations, social support and survival among patients with cancer. *Journal of Psychosomatic Research, 36*, 531-541.
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215-229.
- Erickson, D. H., Beiser, M., & Iacono, W. G. (1998). Social support predicts 5-year outcome in first-episode schizophrenia. *Journal of Abnormal Psychology, 107*, 681-685.
- Erickson, D. H., Beiser, M., Iacono, W. G., Fleming, J. A. E., & Lin, T. Y. (1989). The role of social relationships in the course of first-episode schizophrenia and affective psychosis. *American Journal of Psychiatry, 146*, 1456-1461.
- Fadden, G. (1998). Family intervention in psychosis. *Journal of Mental Health, 7*, 115-122.
- Fadden, G., Bebbington, P., & Kuipers, E. (1987a). The burden of care: The impact of functional psychiatric illness on the patient's family. *British Journal of Psychiatry, 150*, 285-292.
- Fadden, G., Bebbington, P., & Kuipers, E. (1987b). Caring and its burdens: A study of the spouses of depressed people. *British Journal of Psychiatry, 151*, 660-667.

- Finley, L. Y. (1998). The cultural context: Families coping with severe mental illness. *Psychiatric Rehabilitation Journal, 21*, 230-240.
- Fuller Torrey, E., & Miller, J. (2001). *The invisible plague*. London: Rutgers University Press.
- Gilbert, P. (1995). Attachment, cooperation and rank: The evolution of the need for status and social support. In T. S. Brugha (Ed.), *Social support and psychiatric disorder: Research findings and guidelines for clinical practice* (pp. 41-60). Cambridge: Cambridge University Press.
- Gore, S. (1978). The effect of social support in moderating the health consequences of unemployment. *Journal of Health and Social Behavior, 19*, 157-165.
- Gregor, K. (Producer) (2003). Manic Depression [Radio], *Between Ourselves*. UK: Radio 4.
- Gupta, R. D., & Guest, J. F. (2002). Annual cost of bipolar disorder to UK society. *British Journal of Psychiatry, 180*, 227-233.
- H.M. Government. (1999). *Caring about carers: A national strategy for carers*. London: HMSO.
- Haaga, D. A. F. (2000). Introduction to the special section on stepped care models in psychotherapy. *Journal of Consulting and Clinical Psychology, 68*, 547-548.
- Harris, T. J. R. (2002). *Partner support in depression*. Unpublished doctoral thesis, University College London, London.
- Harvey, K., & Burns, T. (2003). Relatives of patients with severe mental disorders: Unique traits and experiences of primary, nonprimary and lone caregivers. *American Journal of Orthopsychiatry, 73*, 324-333.
- Hatfield, A. B., Spaniol, L., & Zipple, A. M. (1987). Expressed emotion: A family perspective. *Schizophrenia Bulletin, 13*.
- Hayward, P., & Bright, J. A. (1997). Stigma and mental illness: A review and critique. *Journal of Mental Health, 6*, 345-354.

- Henwood, K. L., & Pidgeon, N. F. (1992). Psychological research and psychological theorising. *British Journal of Psychology*, *83*, 97-111.
- Hirschberg, W. (1985). Social isolation among schizophrenic out-patients. *Social Psychiatry*, *20*, 171-178.
- Hogan, B. E., Linden, W., & Najarian, B. (2002). Social support interventions: Do they work? *Clinical Psychology Review*, *22*, 381-440.
- Holloway, F., Carson, J., & Davis, S. (2002). Rehabilitation in the United Kingdom: Research, policy, and practice. *Canadian Journal of Psychiatry*, *47*, 628-634.
- Hooley, J. M., & Hiller, J. B. (2001). Family relationships and major mental disorder: Risk factors and preventive strategies. In B. R. Sarason & S. Duck (Eds.), *Personal relationships: Implications for clinical and community psychology* (pp. 61-87). Chichester: Wiley.
- Huxley, P., & Thornicroft, G. (2003). Social inclusion, social quality and mental illness. *British Journal of Psychiatry*, *182*, 289-290.
- Jamison, K. R. (1994). *Touched with fire: Manic-depressive illness and the artistic temperament*. New York: Free Press Paperbacks.
- Jamison, K. R. (1995). *An unquiet mind: A memoir of moods and madness*. London: Picador.
- Jenkins, R., Lewis, G., Bebbington, P., Brugha, T., & et al. (1997). The national psychiatric morbidity surveys of Great Britain: Initial findings from the household survey. *Psychological Medicine*, *27*, 775-789.
- Johnson, E. D. (2000). Differences among families coping with serious mental illness: A qualitative analysis. *American Journal of Orthopsychiatry*, *70*, 126-134.
- Johnson, L., Lundstrom, O., Aberg-Wistedt, A., & Mathe, A. A. (2003). Social support in bipolar disorder: Its relevance to remission and relapse. *Bipolar Disorders*, *5*, 129-137.

- Johnson, S. L., Meyer, B., Winett, C., & Small, J. (2000). Social support and self-esteem predict changes in bipolar depression but not mania. *Journal of Affective Disorders, 58*, 79-86.
- Johnson, S. L., & Roberts, J. E. (1995). Life events and bipolar disorder: Implications from biological theories. *Psychological Bulletin, 117*, 434-449.
- Johnson, S. L., Winett, C. A., Meyer, B., Greenhouse, W. J., & Miller, I. (1999). Social support and the course of bipolar disorder. *Journal of Abnormal Psychology, 108*, 558-566.
- Jones, S., Guy, A., & Ormrod, J. A. (2003). A Q-methodological study of hearing voices: A preliminary exploration of voice hearers' understanding of their experiences. *Psychology and Psychotherapy: Theory, Research and Practice, 76*, 189-209.
- Jones, S. L. (1997). Caregiver burden: The experience of parents, children, siblings and spouses of people with mental illness. *Psychiatric Rehabilitation Journal, 20*, 84-87.
- Joyce, J., Leese, M., Kuipers, E., Szmukler, G., Harris, T., & Staples, E. (2003). Evaluating a model of caregiving for people with psychosis. *Social Psychiatry and Psychiatric Epidemiology, 38*, 189-195.
- Kavanagh, D. J. (1992). Recent developments in expressed emotion and schizophrenia. *British Journal of Psychiatry, 160*, 601-620.
- Kinderman, P., & Cooke, A. (Eds.). (2000). *Understanding mental illness: Recent advances in understanding mental illness and psychotic experiences*. Leicester: British Psychological Society.
- King, S. (2000). Is expressed emotion cause or effect in the mothers of schizophrenic young adults? *Schizophrenia Research, 45*, 65-78.
- King, S., & Dixon, M. (1999). Expressed emotion and relapse in young schizophrenic outpatients. *Schizophrenia Research, 25*, 377-386.

- King, S., & Dixon, M. J. (1996). The influence of expressed emotion, family dynamics, and symptom type on the social adjustment of schizophrenic young adults. *Archives of General Psychiatry*, *53*, 1098-1104.
- Kirmayer, L. J., & Corin, E. (1998). Inside knowledge: Cultural constructions of insight in psychosis. In X. Amador & A. Davids (Eds.), *Insight in psychosis* (pp. 193-220). Oxford: Oxford University Press.
- Knapp, M. (1997). Costs of schizophrenia. *British Journal of Psychiatry*, *171*, 509-518.
- Kuipers, E. (1992). Expressed emotion research in Europe. *British Journal of Clinical Psychology*, *31*, 429-443.
- Kuipers, E. (1995). Expressed emotion: Measurement, intervention and training issues. In T. S. Brugha (Ed.), *Social support and psychiatric disorder: Research findings and guidelines for clinical practice* (pp. 257-276). Cambridge: Cambridge University Press.
- Lara, M. E., Leader, J., & Klein, D. N. (1997). The association between social support and course of depression: Is it confounded with personality? *Journal of Abnormal Psychology*, *106*, 478-482.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Lefley, H. P. (1992). Expressed emotion: Conceptual, clinical, and social policy issues. *Hospital and Community Psychiatry*, *43*, 591-598.
- Lefley, H. P. (1997a). The consumer recovery vision: Will it alleviate family burden? *American Journal of Orthopsychiatry*, *67*, 210-219.
- Lefley, H. P. (1997b). Synthesizing the family caregiving studies: Implications for service planning, social policy, and further research. *Family Relations*, *46*, 443-450.

- Lehman, A. F., & Steinwachs, D. M. (1998). *The Schizophrenia Patient Outcomes Research Team (PORT) Treatment Recommendations*. Retrieved 26 November, 2003, from <http://www.ahrq.gov/clinic/schzrec.htm>
- Lehman, D. R., Ellard, J. H., & Wortman, C. B. (1986). Social support for the bereaved: Recipients' and providers' perspectives on what is helpful. *Journal of Consulting & Clinical Psychology, 54*, 438-446.
- Liddle, P. (1987). The symptoms of chronic schizophrenia: A re-examination of the positive-negative dichotomy. *British Journal of Psychiatry, 151*, 145-151.
- Lloyd, C. (1995). Understanding social support within the context of theory and research on the relationship of life stress and mental health. In T. S. Brugha (Ed.), *Social support and psychiatric disorder: Research findings and guidelines for clinical practice* (pp. 41-60). Cambridge: Cambridge University Press.
- MacCarthy, B., Hemsley, D. R., Shrank-Fernandez, C., Kuipers, L., & Katz, R. (1986). Unpredictability as a correlate of expressed emotion in the relatives of schizophrenics. *British Journal of Psychiatry, 148*, 727-731.
- Macdonald, E. M., Hayes, R. L., & Baglioni, A. J. (2000). The quantity and quality of the social networks of young people with early psychosis compared with closely matched controls. *Schizophrenia Research, 46*, 25-30.
- Magliano, L., Fadden, G., Economou, M., Held, T., Xavier, M., Guarneri, M., et al. (2000). Family burden and coping strategies in schizophrenia: 1-year follow-up data from the BIOMED I study. *Social Psychiatry and Psychiatric Epidemiology, 35*, 109-115.
- Magliano, L., Marasco, C., Fiorillo, A., Malangone, C., Guarneri, M., & Maj, M. (2002). The impact of professional and social network support on the burden of families of patients with schizophrenia in Italy. *Acta Psychiatrica Scandinavica, 106*, 291-298.
- Mannion, E. (1996). Resilience and burden in spouses of people with mental illness. *Psychiatric Rehabilitation Journal, 20*, 13-23.

- Marsh, D. T., Lefley, H. P., Evans-Rhodes, D., Ansell, V. I., Doerzbacher, B. M., LaBarbera, L., et al. (1996). The family experience of mental illness: Evidence for resilience. *Psychiatric Rehabilitation Journal*, 20, 3-12.
- Maurin, J. T., & Boyd, C. B. (1990). Burden of mental illness on the family: A critical review. *Archives of Psychiatric Nursing*, 4, 99-107.
- McCreadie, R., & Phillips, K. (1988). The Nithsdale Schizophrenia Survey VII: Does relatives' high expressed emotion predict relapse? *British Journal of Psychiatry*, 152, 477-481.
- McCubbin, H. I., & McCubbin, M. A. (1988). Typologies of resilient families: Emerging roles of social class and ethnicity. *Family Relations*, 37, 247-254.
- McGlashan, T. H., & Carpenter, W. T. (1976). Post psychotic depression in schizophrenia. *Archives of General Psychiatry*, 33, 231-239.
- McKenna, P. (2003). Schizophrenia is a valid concept. In J. Van Os & P. McKenna (Eds.), *Does schizophrenia exist?* London: Maudesley.
- Meeks, S., & Murrell, S. A. (1994). Service providers in the social networks of clients with severe mental illness. *Schizophrenia Bulletin*, 20, 399-406.
- Miklowitz, D., Goldstein, M. J., Nuechterlein, K. H., Snyder, K. S., & Mintz, J. (1988). Family factors and the course of bipolar affective disorder. *Archives of General Psychiatry*, 45, 225-231.
- Miklowitz, D. J., Velligan, D. I., Goldstein, M. J., Nuechterlein, K. H., Gitlin, M. J., Ranlett, G., et al. (1991). Communication deviance in families of schizophrenic and manic patients. *Journal of Abnormal Psychology*, 100, 163-173.
- Millett, K. (1991). *The loony bin trip*. London: Virago.
- Monroe, S. M., & Johnson, S. L. (1992). Social support, depression, and other mental disorders: In retrospect and toward future prospects. In H. O. F. Veiel & U. Baumann (Eds.), *The meaning and measurement of social support* (pp. 93-105). London: Hemisphere.

- Monroe, S. M., & Steiner, S. C. (1986). Social support and psychopathology: Interrelations with preexisting disorder, stress, and personality. *Journal of Abnormal Psychology, 95*, 29-39.
- Montgomery, P. (2001). Shifting meaning of asylum. *Journal of Advanced Nursing, 33*, 425-431.
- Morgan, A. (2000). *What is Narrative Therapy?* Adelaide: Dulwich Centre Publications.
- Nadler, A. (1991). Help-seeking behavior: Psychological costs and instrumental benefits. In M. S. Clark (Ed.), *Review of personality and social psychology. Volume 12: Prosocial behavior* (pp. 290-311).
- National Health Service Executive. (1996). *Burden of disease*. Leeds: NHSE.
- O'Connell, R. A., Mayo, J. A., Eng, L. K., Jones, J. S., & Gabel, R. H. (1985). Social support and long-term lithium outcome. *British Journal of Psychiatry, 147*, 272-275.
- O'Connell, R. A., Mayo, J. A., Flatow, L., Cuthbertson, B., & O'Brien, B. E. (1991). Outcome of bipolar disorder on long-term treatment with lithium. *British Journal of Psychiatry, 159*, 123-129.
- Ohaeri, J. U. (2003). The burden of caregiving in families with a mental illness: A review of 2002. *Current Opinion in Psychiatry, 16*, 457-465.
- Osborn, M., & Smith, J. A. (1998). The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. *British Journal of Health Psychology, 65*-83.
- Pagel, M. D., Erdly, W. W., & Becker, J. (1987). Social networks: We get by with (and in spite of) a little help from our friends. *Journal of Personality and Social Psychology, 53*, 793-804.
- Parnas, J., & Handest, P. (2003). Phenomenology of anomalous self-experience in early schizophrenia. *Comprehensive Psychiatry, 44*, 121-134.

- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583-594.
- Perkins, R. (1999). My three psychiatric careers. In P. Barker, P. Campbell & B. Davidson (Eds.), *From the ashes of experience: Reflections on madness, survival and growth* (pp. 134-146). London: Whurr.
- Perkins, R. (2001). Rejecting the concept of 'carer'. *Openmind*, May/June.
- Phelan, J. C., Bromet, E. J., & Link, B. G. (1998). Psychiatric illness and family stigma. *Schizophrenia Bulletin*, 24, 115-126.
- Pickett, S. A., Cook, J. A., Cohler, B. J., & Solomon, M. L. (1995). Off-timedness as a contributor to subjective burden for parents of offspring with severe mental illness. *Family Relations*, 44, 195-201.
- Pistrang, N., & Barker, C. (1995). The partner relationship in psychological response to breast cancer. *Social Science and Medicine*, 40, 789-797.
- Pistrang, N., & Barker, C. (1998). Partners and fellow patients: Two sources of emotional support for women with breast cancer. *American Journal of Community Psychology*, 26, 439-456.
- Pistrang, N., Barker, C., & Rutter, C. (1997). Social support as conversation: Analysing breast cancer patients' interactions with their partners. *Social Science and Medicine*, 45, 773-782.
- Pistrang, N., Clare, L., & Baker, C. (1999). The helping process in couples during recovery from heart attack: A single case study. *British Journal of Medical Psychology*, 72, 227-237.
- Pistrang, N., Picciotto, A., & Barker, C. (2001). The communication of empathy in couples during the transition to parenthood. *Journal of Community Psychology*, 29, 615-636.

- Pitschel-Walz, G., Leucht, S., Baeuml, J., Kissling, W., & Engel, R. R. (2001). The effect of family interventions on relapse and rehospitalization in schizophrenia: A meta-analysis. *Schizophrenia Bulletin*, 27, 73-92.
- Post, R. M. (1992). Transduction of psychosocial stress into the neurobiology of recurrent affective disorder. *American Journal of Psychiatry*, 149, 999-1010.
- Rapley, M. (1990). Is normalisation a scientific theory? *Clinical Psychology Forum*, October, 16-20.
- Reinhart, S. C., & Horwitz, A. V. (1995). Caregiver burden: Differentiating the content and consequences of family caregiving. *Journal of Marriage and the Family*, 57, 741-751.
- Ridgway. (2001). ReStorying psychiatric disability: Learning from first person recovery narratives. *Psychiatric Rehabilitation Journal*, 24, 335-343.
- Rogers, C. R. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of Consulting Psychology*, 21, 95-103.
- Rogler, L. H., & Cortes, D. E. (1993). Help-seeking pathways: A unifying concept in mental health care. *American Journal of Psychiatry*, 150, 554-561.
- Romans, S. E., & McPherson, H. M. (1992). The social networks of bipolar affective disorder patients. *Journal of Affective Disorders*, 25, 221-228.
- Romme, M., & Escher, S. (Eds.). (1998). *Accepting Voices* (2nd ed.). London: Mind Publications.
- Rook, K. S. (1984). The negative side of social interaction. *Journal of Personality and Social Psychology*, 46, 1097-1108.
- Rook, K. S. (1990). Parallels in the study of social support and social strain. *Journal of Social and Clinical Psychology*, 9, 118-132.
- Rose, L., E. (1998). Gaining control: Family members relate to persons with severe mental illness. *Research in Nursing and Health*, 21, 363-373.
- Rudnick, A., & Kravetz, S. (2001). The relation of social support-seeking to quality of life in schizophrenia. *Journal of Nervous and Mental Disease*, 189, 258-262.

- Saunders, J. C., & Byrne, M. M. (2002). A thematic analysis of families living with schizophrenia. *Archives of Psychiatric Nursing*, 16, 217-223.
- Scazufca, M., & Kuipers, E. (1996). Links between EE and burden of care in relatives of patients with schizophrenia. *British Journal of Psychiatry*, 168, 580-587.
- Schiller, L., & Bennett, A. (1994). *The quiet room: A journey out of the torment of madness*. New York: Warner Books.
- Scull, A., MacKenzie, C., & Hervey, N. (1996). *Masters of bedlam: The transformation of the mad-doctoring trade*. Chichester: Princeton University Press.
- Scully, P. J., Owens, J. M., Kinsella, A., & Waddington, J. L. (2002). Dimensions of psychopathology in bipolar disorder versus other affective and non-affective psychoses among an epidemiologically complete population. *Bipolar Disorders*, 4, 43-44.
- Sheikh, S., & Furnham, A. (2000). A cross-cultural study of mental health beliefs and attitudes towards seeking professional help. *Social Psychiatry and Psychiatric Epidemiology*, 35, 326-334.
- Singleton, N., Robert, B., O'Brien, M., Lee, A., & Meltzer, H. (2000). *Psychiatric morbidity among adults living in private households: Summary report*. London: Office for National Statistics.
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11, 261-271.
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing Interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods*. (pp. 218-240). London: Sage.
- Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51-80). London: Sage.

- Solomon, P., & Draine, J. (1995). Subjective burden among family members of mentally ill adults: Relation to stress, coping and adaptation. *American Journal of Orthopsychiatry*, 65, 419-427.
- Staner, L., Tracy, A., Dramaix, M., Genevrois, C., Vanderelst, M., Vilane, A., et al. (1997). Clinical and psychosocial predictors of recurrence in recovered bipolar and unipolar depressives: A one-year controlled prospective study. *Psychiatry Research*, 69, 39-51.
- Stanton, B., & David, A. (2000). First-person accounts of delusions. *Psychiatric Bulletin*, 24, 333-336.
- Stein, C. H., & Wemmerus, V. A. (2001). Personal accounts of adults with schizophrenia, their parents and well-siblings. *American Journal of Community Psychology*, 29, 725-746.
- Stern, S., Doolan, M., Staples, E., Szmukler, G., & Eisler, I. (1999). Disruption and reconstruction: Narrative insights in to the experience of family members caring for a relative diagnosed with serious mental illness. *Family Process*, 38, 353-369.
- Stevens, A., & Price, J. (2000). *Evolutionary psychiatry: A new beginning (2nd ed.)*: (2000).
- Stiles, W. B. (1993). Quality control in qualitative research. *Clinical Psychology Review*, 13, 593-618.
- Stiles, W. B., Shapiro, D. A., & Elliott, R. (1986). Are all psychotherapies equivalent? *American Psychologist*, 41, 165-180.
- Strauss, J. S. (1989). Subjective experiences of schizophrenia: Toward a new dynamic psychiatry: II. *Schizophrenia Bulletin*, 15, 179-187.
- Strauss, J. S., Rakfeldt, J., Harding, C. M., & Liberman, R. P. (1989). Psychological and social aspects of negative symptoms. *British Journal of Psychiatry*, 155, 128-132.

- Stromwell, L. K., & Robinson, A. R. (1998). When a family member has a schizophrenic disorder: Practice issues across the family life cycle. *American Journal of Orthopsychiatry*, 68, 580-589.
- Subotnik, K. L., Goldstein, M. J., Nuechterlein, K. H., Woo, S. M., & Mintz, J. (2002). Are communication deviance and expressed emotion related to family history of psychiatric disorders in schizophrenia. *Schizophrenia Bulletin*, 28, 719-729.
- Sue, S. (2002). *Asian American mental health: What we know and what we don't know*. Retrieved 18 November 2003, from <http://www.wvu.edu/~culture>
- Summerfield, D. (1999). A critique of seven assumptions behind psychological trauma programmes in war-affected areas. *Social Science and Medicine*, 48, 1449-1462.
- Sutherland, S. (1995). *Breakdown: A personal crisis and a medical dilemma*. Oxford: Oxford University Press.
- Szmukler, G., Herrman, H., Colusa, S., Benson, A., & Bloch, S. (1996a). A controlled trial of a counselling intervention for caregivers of relatives with schizophrenia. *Social Psychiatry and Psychiatric Epidemiology*, 31, 149-155.
- Szmukler, G., Wykes, T., & Parkman, S. (1998). Care-giving and the impact on carers of a community mental health service. PRISM Psychosis Study. 6. *British Journal of Psychiatry*, 173, 399-403.
- Szmukler, G. I., Burgess, P., Herrman, H., Benson, A., Colusa, S., & Bloch, S. (1996b). Caring for relatives with serious mental illness: The development of the experience of caregiving inventory. *Social Psychiatry and Psychiatric Epidemiology*, 31, 137-148.
- Tennakoon, L., Fannon, D., Doku, V., O'Ceallaigh, S., Soni, W., Santamaria, M., et al. (2000). Experience of caregiving: Relatives of people experiencing a first episode of psychosis. *British Journal of Psychiatry*, 177, 529-533.
- The Sainsbury Centre for Mental Health. (2003). *The economic and social costs of mental illness (Policy Paper 3)*. London: Author.

- Thoits, P. A. (1986). Social support as coping assistance. *Journal of Consulting & Clinical Psychology, 54*, 416-423.
- Thornicroft, G., & Goldberg, D. (1998). Has community care failed? *Maudsley Discussion Paper, 5*.
- Toffler, A. (1970). *Future shock*. New York: Random House.
- Tolsdorf, C. C. (1976). Social networks, support, and coping: An exploratory study. *Family Process, 15*, 407-417.
- Tsuang, M. T., Stone, W. S., & Faraone, S. V. (2000). Toward reformulating the diagnosis of schizophrenia. *American Journal of Psychiatry, 157*, 1041-1050.
- Tuck, I., du Mont, P., Evans, G., & Shupe, J. (1997). The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing, 11*, 118-125.
- Uchino, B. N., Cacioppo, J. T., & Kiecolt-Glaser, J. K. (1996). The relationship between social support and physiological processes: A review with emphasis on underlying mechanisms and implications for health. *Psychological Bulletin, 119*, 488-531.
- Vatri-Boydell, K. M. (1997). *Mothering adult children with schizophrenia: The hidden realities of caring*. Unpublished doctoral thesis, York University, North York, Ontario.
- Vaughn, C., & Leff, J. (1976). The influence of family and social factors on the course of psychiatric illness: A comparison of schizophrenic and depressed neurotic patients. *British Journal of Psychiatry, 129*, 125-137.
- Veiel, H. O. (1985). Dimensions of social support: A conceptual framework for research. *Social Psychiatry, 20*, 156-162.
- Veiel, H. O. F., & Baumann, U. (Eds.). (1992). *The meaning and measurement of social support*. London: Hemisphere.
- Veltman, A., Cameron, J. I., & Stewart, D. E. (2002). The experience of providing care to relatives with chronic mental illness. *Journal of Nervous and Mental Disease, 190*, 108-114.

- Vilhjalmsson, R. (1993). Life stress, social support and clinical depression: A reanalysis of the literature. *Social Science & Medicine*, 37, 331-342.
- Webb, C., Pfeiffer, M., Mueser, K. T., Gladis, M., Mensch, E., DeGirolamo, J., et al. (1998). Burden and well-being of caregivers for the severely mentally ill: The role of coping style and social support. *Schizophrenia Research*, 34, 169-180.
- White, A. (1979). *Frost in May*. London: Virago.
- Williams, P. (1999). An exploration of the application of social role valorization in special hospitals. *Journal of Psychiatric and Mental Health Nursing*, 6, 225-232.
- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham: Open University Press.
- Wills, T. A. (1991). Social support and interpersonal relationships. In M. S. Clark (Ed.), *Prosocial behaviour*. London: Sage.
- Winefield, H. R. (1987). Psychotherapy and social support: Parallels and differences in the helping process. *Clinical Psychology Review*, 7, 631-644.
- World Schizophrenia Fellowship. (1998). *Families as partners in care: Goals and principles*. Retrieved 26 November, 2003, from www.world-schizophrenia.org/activities/fpc/principles.html
- Yen, C. F., Chen, C. S., Yeh, M. L., Yen, J. Y., Ker, J. H., & Yang, S. J. (2002). Comparison of insight in patients with schizophrenia and bipolar disorder in remission. *Journal of Nervous and Mental Disease*, 190, 847-849.
- Zubin, J., & Spring, B. (1977). Vulnerability: A new view of schizophrenia. *Journal of Abnormal Psychology*, 86, 103-126.